

The Legacy of Eugenic Discourses in the History of Hungarian Medicine

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Abstract

In my dissertation I explore the legacy of eugenics in the history of Hungarian medicine. In this project I analyze how gender, race/ethnicity, and class play role in shaping medical concerns. And how do medical sciences contribute to empowerment in different historical periods. I was initially interested in how geneticists are producing knowledge about Roma people within Europe and more specifically in Hungary. I started my work with one very narrow question in mind: whether these works contribute to the geneticization of race/ethnicity as Troy Duster, Jonathan Kahn, Dorothy Roberts, Carolyn M. Rouse and many other scholars claim, and if yes, in what ways they do. I was interested in contemporary medical genetic discussions but I was aware that this discourse has continuities with the medical genetic discussions of the socialist period. In order to explore the commonalities and differences between these two, I did 35 interviews with medical geneticists and biologists who take part in research, teaching, or genetic counseling. These were in-depth semi-structured interviews in which I asked about their specific fields, about the continuities that they see with socialist medical aims regarding reproduction, how they see the role of race/ethnicity, gender, and class in shaping genetic concerns, and how would they describe the social relevance of their work. In the interviews I inquired how they view their work in relation to eugenics and their replies pointed towards connections between their work and the eugenic arguments of the early twentieth century. Thus, I became interested in the comparative analysis of eugenic thinking in the Hungarian medical discourse in two historically distant periods. Specifically, the early 1900s and 1910s when eugenics entered the Hungarian medical discourse with the present medical genetic concerns closely connected with the socialist medical practice. Medical genetics as a discipline emerged in the 1960s as a result of biotechnological developments. In the Hungarian literature medical

genetic studies were first published around the end of the 60s. Institutions, that incorporated medical genetic knowledge to aid reproductive decision making such as genetic counseling institutes, were established in the 70s. Among the early concerns the degeneration of the population appeared similarly to the early eugenic discourse thus I think it is possible to establish connections between these two. In the early medical genetic publications of the 1970s the main concern was the possible transmission of 'bad' genes for the future generations and the role that medical genetics could play to avoid that outcome. Their focus was on the female body but explicitly racial or ethnic concerns were not present in genetic argumentation until the early 1980s, although ethnicity based medical studies have appeared in the 1960s and 70s. The aim of population genetic works is to compare the genetic structure of Roma and non-Roma Hungarians in order to design screening panels that would improve the management of their healthcare. I think regarding these medical efforts one of the question to look at is how genetic knowledge empowers people at the intersection of the social categories of gender, class, race/ethnicity? In what ways do geneticists molecularize these social categories? And what are the possible ethical consequences of this practice?

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Barna Szamosi

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Preface

“After a while I perceived the disadvantages of fetal diagnosis, that is, we destroy embryos in ever larger numbers that are anomalous and ill, and even those who could live a humane life with the help of medicine. This is why I use today the concept of modern Taygetus.”¹

Endre Czeizel (2009, p. 9)

To embark on comparative research on the legacy of eugenics in the history of Hungarian medicine such standpoints – quoted above – from medical geneticists like Endre Czeizel were important in guiding ideas during my work. Certainly, Czeizel is not the only person who addressed this issue, especially not the only researcher whom I interviewed, but I found it notable that he was perhaps among the few geneticists who publicly articulated his concerns about the medical genetic practices of the present. Eugenics is a controversial issue. In the first half of the twentieth century eugenics culminated in the practices of Nazi Germany. After the Second World War racially informed eugenic ideas were rejected but with the advances of genetic technology the knowledge gained was used for population management purposes – genetic counseling was one such field in this new phase of reproduction control. By analyzing the transformation of eugenic thought I will argue that the values of science, technology, and society are intertwined in all of these different but closely connected historical, political, social, and medical discourses.

Since the 1960s critical works in philosophy of science started to complicate the classic positivist standpoint that scientific knowledge is value-free. Perhaps the most influential philosopher from the first wave was Thomas S. Kuhn ([1962] 1970), who approached scientific

¹ If otherwise not indicated all translations are mine.

work from a historical perspective and suggested that the truth-value of scientific information depends on the accepted scientific paradigms. Paradigm shifts or scientific developments occur after rigorous debates over old and new approaches, thus he proposed a more sensitive view on the processes of producing objective scientific facts. The second wave of critical works started with the school of sociology of scientific knowledge (SSK) that provided social constructivist analyses about the production of scientific results, these studies were successful in pointing out that social values play a key role in scientific knowledge production. The charge against this school is that they opened up scientific knowledge to relativism, since they claim that epistemic communities integrate the social values of their environment into the knowledge acquired itself, which implies that the truth-value of scientific knowledge is relative to cultural contexts.

The science critiques that appeared in the third wave intended to move beyond the inherent relativism of SSK. These critical discussions were pioneered by the work of Bruno Latour and Steve Woolgar first published in 1979 who argue that the scientific, the technological, and human factors intertwine inextricably thus by proposing actor-network-theory (ANT) they posited that the truth-value of scientific facts depended on the complexity of human and non-human networks (Latour & Woolgar, 1986). This is why ANT can be regarded as a social theory that encompasses scientific discourses: these complex networks produce, enable, and legitimate scientific knowledge. This perspective implies, what Donna Haraway (1988) formulated differently: scientific knowledge is situated. By arguing that, even if one scrutinizes scientific facts rigorously, knowledge is situated, scholars do not devalue scientific knowledge; their aim is make scientific results explicitly grounded and transparent from the perspective of what factors drive its production and usage. STS scholars emphasize that conditions matter and both social and natural science researchers must attend to the complex web of networks that facilitate scientific knowledges. Critical works that have been written about eugenics and contemporary medicine in this light explore the dynamics of

discursive factors that shape the focus of scientific activity and enable the application of the results achieved.

In order to be able to analyze comparatively the historical discourses and the contemporary scientific narratives I relied on the methods of constructivist grounded theory. The sensitive and thorough methodology of GT makes it possible to consistently connect and investigate the interconnections of discourses with the scientific interpretations of contemporary researchers and clinicians of medical genetics. To prove the applicability of the methodology for my project I will overview the major developmental shifts in its history and explain what scholars mean by the constructivist turn regarding this originally positivist research tool. Here I will introduce and explain the concrete methodological techniques that I used for collecting, organizing, and interpreting my materials. In this section of the dissertation, I will introduce the sources used for my analysis, and I will also explain the methodology of conducting interviews for qualitative research. The fact that the sources used are characterized by thematic and historical continuity supports the justification of the comparative study that I completed.

In my view to make a historically plausible claim that eugenic thought in Hungarian medical discourse was transformed during the twentieth century, it is necessary to review how it entered into medical debates. Thus, in chapter 3 I will review the early discourse on eugenics, the tensions that social and natural scientists had regarding its scientific validity, and how eugenic ideology gradually became acceptable in shaping the public health discourse. I will analyze the medical discussion on reproduction control to show that the newly discovered laws of inheritance influenced by economic and eugenic values contributed to the acceptance of medical practices that subordinated individual rights to state interest, that is, to the interest of the Hungarian race. In this light, I will point out that risk groups were constructed along the social categories of class, and gender. Gynecologists and surgeons alike denied the reproductive

rights of women who suffered from tuberculosis and were identified as working class who supposedly could not restrain themselves sexually, thus risking their own lives, the birth of children with tuberculosis, and consequently bestowing an economic and public health burden on the state. I will not address the interwar period in detail because it is unquestionable that the exclusionary political climate of the era enabled racially motivated eugenic laws. The primary focus of my research is how were the less severe, but medically supported eugenic ideas of the democratic period were re-enabled in the 1950s and 1960s.

In Chapter 4, I will re-construct the medical discussions that surrounded the shift that took place in the 1950s. Vaccinations for contagious diseases became widely available for the population during the 1950s and this public health development shifted the focus of medical professionals towards congenital malformations. Congenital disorders were identified as the most significant factor that influenced adversely the newborn statistics and thus the general health standards of the population. With the newly discovered genetic knowledge of the 1950s that started to be integrated into Hungarian medical disciplines the focus of biopolitical control started to shift towards reproduction. In my view one of the key findings of my analysis is that eugenic ideas were uncritically integrated into the new medical techniques that became available for population control.

In what follows, in Chapter 5, I will discuss two important developments in the public health discourse of the first half of the socialist period regarding ethnic identity that remained central to public health concerns until the end of the 1980s. The first issue is that racial stereotypes that were accepted during the interwar period were integrated into the public health control of gypsy communities. One of these practices identified by critical scholars was forced-bathings that continued until the end of the socialist era. These healthcare activities were rationalized as crucial steps to ensure the general well-being of both the gypsy and non-gypsy population. Another direction that complemented the discussion introduced in Chapter 4 was

the birth results of gypsy communities. Clinicians and researchers observed that the newborn statistics of the country were ‘impaired’ by the reproductive results of gypsies. Researchers interpreted this as a significant economic burden on the Hungarian healthcare system. Hence, they argued that it was important to research gypsy communities and develop a better understanding of their social, economic, and health related habits if better results were to be achieved. It was understood by them that structural changes were necessary in healthcare if they wanted to elevate the health standards of Roma people.

In Chapter 6, I will explore the changes that took place in the medical discourse on genetic counseling from the 1970s to the 1990s. Genetic counseling was viewed by clinicians and researchers alike that it is the field where the scientific results of human genetics could be applied with the most success. I will analyze the slow shift that occurred during these twenty years that initially embraced old-eugenic ideas and this started to be replaced with new eugenic techniques. Although it is debated in the literature whether it is justified to define present medical genetic practices as ‘eugenic’, I share the position that perhaps the more important question is rather how these techniques privilege some and marginalize others when medical decision-making enters the realm of individual rights. In this part of the dissertation, I will discuss the way liberal democratic values influenced changes in medical ethics and by doing so, I will show that social values influenced the application of medical scientific results in these different political paradigms.

Population genetics as a field started to gain significance in Hungary in the 1980s. Studies were initiated by for example Endre Czeizel (1982), who argued that similarly to other countries where medical genetic technology was developed, population based studies should be conducted in order to map the genetic mutations of populations in order to design adequate medical responses. Thus, in Chapter 7, I will review the discussions that surrounded population based medical genetic studies and analyze the arguments put forward by clinicians and

researchers alike in favor of using ethnic/racial categories in delineating populations defined in terms of the present medical discourse. In my view this chapter contributes to the discourse about the social values that play a role in defining the target groups of medical sciences and investigates the issue how these values influence the success of medical treatments.

In Chapter 8, I approach racial/ethnic categorization from the perspective of constructivist science studies. My aim in this chapter is to discuss the arguments provided by genetic researchers, clinicians, and sociologists alike for using racial/ethnic categorization, and to explore the possible controversies that racial/ethnic categorization can cause in healthcare. In my view, the strongest argument is that race/ethnicity or more precisely racial/ethnic discrimination cause health disparities and thus biological differences in any racially stratified society. The best that healthcare professionals can do to provide identical healthcare is to take into account racial/ethnic differences and provide treatment on the basis of that knowledge. I think that this could work to the extent that gender works with various other categories in reproductive screenings, where gender is used with other medically relevant factors with the active involvement of the patients. In a similar vein, I argue that racial/ethnic categories, understood as context dependent social constructs, can work for the benefits of patients, if both clinicians and patients are aware of their limitations, and if patients are not coerced into accepting racially profiled medical treatments. If medical genetic knowledge is distributed to the members of Roma communities and they are made capable of making informed decisions regarding their own treatment based on the genetic information that they received their further marginalization could be lessened. In a society where racial discrimination is historically embedded and present in institutional practices it is important to make medical knowledge available to the Roma so that they will not be defenseless and can act on the basis of this knowledge.

In the present post-genomic discourse where liberal eugenic decision-making is naturalized, it is necessary to understand how social categories play a role in the molecularization of disorders, that is how diseases become understood as gender, race, ethnicity, or class based problems. Exploring the history of Hungarian medicine by focusing on the transformation of eugenic thought I contribute to the field of feminist science and technology studies by making a local case that the medical scientific discourse and the knowledge that scientists produce are always the results of complex networks of human and non-human actors and as such are never value-free. Thus, it is paramount for science and technology scholars to make the process of knowledge production transparent by articulating the diverse factors and values that played a role in shaping the discourse. By making the scientific process transparent, and by making its goals explicit researchers can assist the application of the produced medical knowledge by the members of the target groups, and thus facilitating identical healthcare for individuals at the diverse intersections of social identities.

1. Researching Medical Sciences with an Intersectional Lens: Approaching Eugenic Values in Contemporary Genetics

In my review, I draw on feminist intersectional research, critical race theory, biopolitical criticism, and science and technology studies to indicate the relevance of my research on the eugenic legacy in the history of Hungarian medicine. The first line of inquiry explores the relationship of social values and technology. It addresses issues related to the influence that social values, and in particular eugenic values, had and still has in medical processes. The second line of inquiry concerns the role that technological tools have played in the realization of political-medical goals. Regarding this problem, I think the most important is to look at processes that help us to understand how medical technology has been used to shape the public health standards of the population and find empirical examples about gender, racial/ethnic, or class based differentiation. The aim is to analyze these cases to find out whether there is any discrepancy between the aim of an egalitarian medical discourse and the actual outcome of its practitioner's activities. To make my analytical focus more sensitive I integrate the insights of intersectional research and critical race theory into my historical analysis of the Hungarian medical discourse because it helps us to understand that any racial discourse has historical continuities and people can experience multiple oppression given their social identities are devalued in a social context.

1.1. Feminist Engagements with Biological Sciences from the Perspective of Science and Technology Studies

Science and technology studies as a field emerged in the late 1980s after the publication of the work of Bruno Latour *Science in Action* (1987). The term itself refers to the intention of

philosophers of science to bridge the gap between the traditional view about the subjects of science and technology. In the conventional approach, it was thought that science deals with facts while technology deals with artifacts. The aim of researchers was to develop a new framework that is inclusive regarding the interrelatedness of the way facts and artifacts are produced. According to László Ropolyi (2013), who is a philosopher of science, Latour can be viewed as an empirical philosopher whose methodology and theoretical approach enables him to create hybrid entities through the interpretation of the interactions of scientific research, with various actors in such a research, and the social environment that surrounds any scientific activity. In addition to these, it accommodates both human and non-human actors, economic and political categories as well. With this approach the classic realist view, that scientific research is the way to discover *how things universally are* is displaced. Scientific knowledge is socially constructed through the dynamic networks of human and non-human elements and as such the knowledge produced is never value-neutral.

To paraphrase Sergio Sismondo (2008, p. 14), who is a historian and philosopher of science, a standard review of science and technology studies can plausibly start with a reflection on the classic and widely cited work of Thomas S. Kuhn originally published in 1962 entitled *The Structure of Scientific Revolutions*. In his work, Kuhn reveals three qualitatively important characteristics of scientific knowledge production: (1) epistemological communities are the basic elements, (2) the scientific knowledge that they produce is perspectival, and (3) scientific knowledge production is dynamic, active process where participants performatively engage in constructing scientific information. Kuhn's work was a capstone essay for sociologists of scientific knowledge whose aim was to draw on his insights and expose the myth of value neutrality in scientific knowledge structures. In the Anglo-Saxon academic world the field of science studies started to emerge centralized around the question: whether sociological or philosophical approaches are best suited to study scientific knowledge production. These early

science critiques, developed into the field of sociology of scientific knowledge (SSK) already successfully destabilizing the belief in conventionally understood objective science (Woolgar, 2004, p. 345). David Bloor (1976) and Barry Barnes (1974) in developing their theory, called the strong program, in the field of SSK used Kuhn's work as their starting point (cited in Sismondo 2008, p. 14). They began from the problem of naturalization of scientific knowledge to work out possible alternative explanations for its production. Their method was interested in going beyond the asymmetrical explanations of scientifically true and false knowledge. They have shown that cultural values enter into scientific knowledge production. Both traditional history and philosophy of science work with the assumption that only rational scientific knowledge is true which entails that a methodologically rigorous value-neutral scientific project will produce true universally applicable knowledge. This epistemological position implies that researchers pursuing scientific truth will also avoid the production of false scientific knowledge.

Early feminist science studies criticism focused on the place of women in science, sexism in scientific knowledge construction, and other gendered perspectives that shape the production of scientific knowledge. Initial historical works were soon followed by critical contributions to the field of sociology of scientific knowledge where scholars like Nancy Hartsock (1985), Sandra Harding (1986), Donna Haraway (1988), and Helen Longino (1990) were interested in working out theoretical frameworks that make possible the reconceptualization of traditional scientific ideas such as objectivity, value neutrality, and universality. Despite their explicit commitment to social constructionist frameworks that prioritize the discursive signifying practices of the epistemological communities, their aim was to retain some form of connection with materiality. Despite this commitment to avoid the exclusion of materiality, the initial ideas that can be traced back to the mid-1980s urge scholars to rethink human relationship to materiality; the material turn, in other words, the onto-

epistemological spin in feminist science and technology studies occurred only in the first years of the twenty-first century.

Feminist scholars were working in the field of SSK from the late 1970s and by introducing gender into the field, feminists extended the scope of research. By explaining the role of gender in science, they made it necessary to reflect on the gendered positions of the researchers that contributed to the incorporation of gender based perspectives in traditional scientific knowledge production (Hekman, 2008, p. 89). The concepts which are developed by feminist scholars in connection to SSK critique – and still used in some form in science studies – are strong objectivity, standpoint theory, and situated knowledges. Standpoint theory was developed by Dorothy Smith (1987), Donna Haraway (1988), Patricia Hill Collins (1991), and Sandra Harding (1993) as a response to the scientific relativism inherent in the strong program of the SSK. In their works, standpoint is a politically constructed position, only those agents have access to the political standpoint who participated constitutively in its formulation. In this sense, standpoints are necessarily interest-based positions. They are formulated from specific places in a social context, researchers experience and view the world from these particular positions. Developing this strand of theorizing further, Sandra Harding, who is a feminist philosopher of science, proposed the concept of strong objectivity in order to retain the values associated with objective scientific conduct, but also to avoid scientific relativism, that would emerge from the locatedness of standpoint theories. Harding argued for explicit integration of values and social positions into scientific research projects in order to maximize scientific objectivity. In relation to this argument, Donna Haraway (1988), who is a biologist by training, also proposed a related concept, situated knowledges, in order to describe the embodied, socially embedded, value-laden, and perspectival character of scientific knowledge production. Haraway proposed, similarly to Harding, that to do socially relevant, sensitive, and empowering science, scientists must not only avoid abstracting their work from the everyday experiences of

people but must produce applicable/useful non-universal, that is, local knowledges directly to them. Despite the extensive work of feminist science criticism which was largely written in the style of social constructivism, scholars could not convincingly move beyond the discursive, or linguistic turn that dominated science and technology studies after the 1970s in order to deconstruct the nature/culture divide, which was problematized in feminist scholarship from the 1950s.

The intention to include the material environment in the theorizing of scientific knowledge production appeared in the work of Bruno Latour and Steve Woolgar in the late 1970s. In their essay, *Laboratory Life* (1979), they used anthropological methods to explore the construction of scientific facts in the context of the lab. They designed their project in the hope of developing further the principle of reflexivity of the strong program and they worked out the methodologies here that later other science and technology scholars applied in their research (Kutrovacz, 2013). A significant change in the field of science and technology studies research occurred after the publication of Latour’s *Science in Action* (1987). In his work, Latour argues, that studying scientific research, the traditional subject-object dichotomy that is present in history and philosophy of science, and in the natural sciences, poses a crucial problem. According to him, the problem with the standard constructivist position is that it views things as independent material units, which are not constitutive elements in scientific knowledge production. Latour challenges this position by arguing that science studies scholars must see the networks of human and non-human actors as equally constitutive elements in scientific conduct, scholars must imagine things as imbued with values that in turn play role in the construction of scientific knowledge (Latour, 1987; Ropolyi, 2013; Kutrovacz, 2013). Parallel to the inclusion of things, Latour articulates the so-called actor-network-theory (ANT) which is capable of addressing and analyzing the role of human and non-human actors in the networks of knowledge production. Actor-network theory is later developed further by Latour himself

(1993, 1999) and by many other scholars, among these are John Law (1994), Annemarie Mol (2002), and Karen Barad (2007).

The original aim of Latour and Woolgar was to succeed in addressing scientific knowledge production in a novel way that SSK was incapable performing. Despite the close connection of the ANT to sociology of knowledge leading theorist of SSK heavily criticized their approach (Bloor, 1999; Collins & Yearly, 1992). Latour defending the achievements of ANT, claims “If ANT can be credited with something, it is to have developed a science studies that entirely bypasses the question of ‘social construction’ and the ‘realist/relativist debate” (Latour, 1999a, p. 22). In his words, “the collective scientific reality is a circulation of transformations,” which as he writes material, social, and narrative at once. With ANT science studies scholars are provided with a theoretical-methodological perspective to think through the interrelations of technology, science, and society. The term itself, technoscience, refers to the inextricable nature of technoscientific knowledge form the social sphere. Since the early 1990s the technoscientific approach has dominated the research field of science and technology studies, which is visible from the terminology used by scholars referring to the intermingled nature of their research: technomedicine, biotechnology, technopolitics, molecular biopolitics are such instances to name a few.

Woolgar emphasizes among the most significant contributions that STS deconstructed the boundary between the scientific and the social and between the social and the technological (Woolgar, 2004, p. 345). Then he argues that this contribution implies a crucial point: in contemporary STS discussions, the hardest possible case to address is politics. „STS told us that technology is politics by other means. [...] If politics is a latest hardest possible case, it means that an STS perspective on technology must be central to any analysis of political life” (Woolgar, 2004, p. 346). Woolgar’s standpoint positions biotechnologies as biopolitics, and argues that as such provides a crucial field for STS critical interventions.

Drawing on these theoretical insights I will show how social values shaped medical research in different historical periods in Hungary. In my analysis, I will point out the interdependent nature of scientific work with the social, economic, and political discourses. Approaching these discussions from the perspective of feminist science studies the central aim of my work is explore the naturalization of the medical knowledge produced in historically different social contexts and also to point out that biotechnological developments and the produced scientific knowledge dynamically shapes social values and attitudes regarding health.

1.2. Contemporary Molecular Governance of Technomedicine

Thomas Lemke differentiates two main strands in the reception and interpretation of Michel Foucault's concept of biopolitics. The first line of investigation concerns the ecological relationship of humans and their environment, and the second strand is related to biopolitics as technopolitics. The main interest of critical works in the first case is to defend the environment from technological expansion; the means through which this end is possible is the limitation of technology through biopolitical governance. On the other hand, the second line of reception since the 1960s has aimed at using biotechnological developments to redefine the boundaries of the natural-cultural divide, to use technology in an expansive manner, and to transform the social and the biological through technological innovations (Lemke, 2011, p. 3). In his groundbreaking work *Birth of the Clinic* (1976 [1963]), Foucault's intention was to explore the discourses which shaped the ways in which the data of medical scientific phenomena were obtained. In other words, Foucault's aim was to problematize, to think through how they came about, and point out how they were constructed and subsequently became naturalized. Hence, he was analyzing the material-discursive conditions that lead to the production of the normal, deviant, morbid, and sick. This is what he terms 'effective history' (Foucault, 1986; see Dean,

1994; cited in Philo, 2000) of the conditions of existence. In order to understand the process of medical construction, Foucault distinguished between three shifts, primary, secondary and tertiary spatialization of disease that contributed to the articulation of what he termed anatomico-clinical gaze².

Another but equally important side of transforming medical thought, that is emphasized by Michel Foucault, is related to social changes which are not always in immediate connection with medical practice. Nikolas Rose who is a sociologist of biotechnology, places emphasis in his interpretation of Foucault's essay, on the simultaneous entangled social processes concerning the circumstances, which allowed the emergence of the anatomico-clinical gaze, that still occupies a central place in the medical thinking about the human body. These processes "include changes in the laws and practices of assistance, shifts in the organization of medical profession and medical pedagogy, new forms of record-keeping in hospitals allowing the production of new types of statistics of morbidity and mortality, pathological anatomy of those, who died in hospitals and so forth" (Rose, 2007, p. 10). Beyond mapping the ways how diseases were grasped by medical practitioners, Foucault traced back the roots of modern medical

² In the first shift, called primary spatialization, Foucault described the practice of collecting, classifying, grouping, and hierarchizing diseases, during this mapping process, medical professionals of the eighteenth century placed diseases according to their appearance on the surface of the body. The secondary spatialization was explored by him through contrasting the writings of first phase with the writings of the nineteenth century medical professionals. As a result of the comparative work, he concluded that the second phase was concerned with placing diseases within the body, as a result of the shift in medical thinking, the focus of interest changed from imagining diseases as abstract categories, to exploring the processes how these medical problems were taking shape. From this time onwards, the medical professionals' work was to subject the patients' body to the technologically available most rigorous medical scrutiny, not only to look at the body, but to look into the body. The aim was to confront the embodied nature of disease by directly addressing the problems through getting as close as possible to the cause of suffering. This anatomico-clinical gaze wanted to grasp the dynamic changes that occurred in the body, the time-space configurations of the disease. And the third shift, called tertiary spatialization, is the process of diseases being divided, isolated, classified, distributed to hospitals. In this phase Foucault describes a whole set of medical practices and institutionalization processes, how hospitals become closed, privileged regions within a society, where people with medical problems were institutionalized thereby physically dividing the population into healthy and diseased cohorts. Christopher Philo, who is a medical geographer, argues that we should think of Foucault's work as an early example of medical geography as well. In this sense, Foucault's work can be read as successful investigations of material-discursive productions of diseases in different sites of the medical profession with exposing a prominent shift in the way how medical objects have been produced (for more see Philo 2000, 2012).

governmentality – the politics of medicine – to the transformations that occurred at the turn of the nineteenth century.

Molecular biology started to take shape as an independent research field in the 1930s and its stabilization lasted until the 1980s. This was the time when technological advancements made it possible to combine methods from the fields of physics, chemistry and biology (Rheinberger, 2009; Zallen, 1992). Doris T. Zallen in her article, shows the historical period when works towards the molecularization of biology started, and Lily E. Kay explores, how it became an established discipline within the biological sciences only later, in the 1950s and 60s (Kay, 1993). The central strand of molecular biological research was concerned with genetics and the application of that knowledge in medicine and contributed to the establishment of the field of medical genetics. Biotechnological advances that took place in and after the 1930s transformed the previously existing medical vision about life, health, and disease.

The problem that the literature emphasizes in critiquing Foucault's concept of biopolitics is that it focuses on bodies and populations. In contrast to the Foucauldian notion, contemporary biopolitics became molecular, in the sense that through technological developments the focus of governance is placed into the sphere of molecular biology. With the available biomedical technology the body is no longer seen as a whole entity. Thomas Lemke brings two examples to strengthen this position (Lemke 2011, p. 94): Michael Dillon and Julian Reid (2001) place emphasis on the immense possibilities of recombination of the biological as a result of molecularization and digitalization of the biological material. This 'recombinant biopolitics' extends beyond the molar level. Michael J. Fowler and Deborah Heath (1993) claims that the most important distinction between contemporary biopolitics and the Foucauldian notion is that the individual is located in the gene pool. In this molecular biopolitical perspective the body is theorized as the sum of its molecular parts, and importantly in this technological frame, instead of placing the individual body into a population, molecularized biopolitics

locates the individual in the governmentally relevant gene pool: its molecular elements are relevant for technomedical reasons to elevate the health standards of the population.

The theoretical position that contemporary biopolitics manages the population by focusing on the molecular level phenomena is a significant analytical perspective that helps establishing a critical position towards the molecularization of social categories such as race and ethnicity. Molecular level health management prioritizes on individual health problems and thus personalized genetic medicine would provide medical solutions to individual issues. This position is compatible with the theory that genetic variations (genetic markers) are shared across social groups, that is not only within one social group, but at the same time this position is critical of using genetic traits in a manner that would genetically homogenize the members of a community. Regarding the contemporary genetic research on Roma, my work contributes to the position developed by critical race scholars and bioethicists, that racial/ethnic classification of biological material could hinder precise medical diagnosis if individual factors are not taken into account.

1.3. Transformation of Eugenic Thought: From Purification to the Present Preventive Logic of Medical Governance

Eugenics is a term that was created by the English anthropologist Francis Galton (1883) in the second half of the nineteenth century; the discourse of eugenics rests on the Darwinian theory of evolution. Eugenicists wanted to oppose natural selection, and wanted to control the reproduction of the ‘degenerate’ members of the population. In the case of eugenics, the control meant primarily negative medical and political interventions such as sterilizations and segregation. According to this discourse the goal was to improve the quality of the race by not letting the unworthy reproduce. Advocates of eugenics wanted to introduce state control over

the improvement of the race and their aim was to control reproduction without the consent of the individuals; individual life was not significant for the interest of the race. The eugenic standards of the race were identified through phenotypes and the intervention took place on the molar level.

Both the discourse of eugenics and the movement of eugenics originated from nineteenth-century England but the cultural receptions of eugenics differed significantly in different parts of the world already in the early phase. Stepan (1991) argues in her book on the eugenic movements of Latin America, that the understanding of eugenics in these countries differed from the eugenics of the United States, Great Britain, or Germany. But she underscores that their difference does not mean that these Latin-American movements can be labeled as something *other* than eugenics. She argues that it rather helps us to see the cultural ‘constructedness’ of the sciences and the scientific arguments both of which emerge at the intersection of different political, scientific and social values. The argument of Stepan stands for the European development of eugenics as well. Historians of eugenic thought have pointed out the various ways that eugenic policies were enacted in different European countries (Brandhorst, 2003; Cassels, 1964; Cleminson, 2003; King & Hansen, 1999; Schneider, 1982; Sonn, 2005). Radical change occurred in the perception of eugenics after the Second World War, when the ‘scientific’ practices of the Nazi geneticists caused a major turning point in the health policy and genetic research of the US (Larson, 2010). The focus shifted towards genetic screening and counseling to control the reproductive decisions of the citizens. During this period we can see that the molecular level starts to dominate the medical discourse.

The critical analysis of the eugenic movements in the United States and in Western-Europe started to take place much earlier than the analyses of these movements within the Eastern part of Europe. For example, Daniel J. Kevles, who is an American historian, provided rich analyses on the history of eugenics and gave insights into the eugenic policies of the United

States that lasted well beyond the Second World War (Kevles, 1980, 1986, 1992, 1999). In Europe as well, eugenic policies were at work after the 1950s. Niels Lynøe (2007) discussed in his work how racial enhancement took place through involuntary sterilization until 1975 in Sweden. He estimates that roughly 63000 people were sterilized and most of them were women. He claims that similar practices were implemented into medical conduct in other Nordic countries as well. Critical studies on Nazi Germany (Weikart, 2004; Weindling, 1989b, 1989a, Weiss, 1987, 2010) shed light on the process of how racial science became a biopolitical driving force that resulted in a rationalization of biological racism supported and controlled by Nazi human geneticists. Daniel Kevles (cited by Asch & Geller, 1996, p. 321) notes that research in genetics before the 1950s “was often motivated by the desire to find negative information about already-stigmatized ethnic, racial, and class groups.” In other words, as Maria Bucur (2002) argues in relation to the Romanian interwar context, genetics offered a way to justify and institutionalize eugenic prejudices against particular minorities. Thus, eugenics was an important driving force in shaping the public health goals of the first half of the twentieth century.

It is debated in the literature whether eugenics is still a relevant discourse shaping medical decision making since the 1950s. Scholars, Nikolas Rose for example, argues that the contemporary medical practice is radically different from the eugenic discourses of the past. He claims that 'optimization' is the key concern in this medical paradigm (Rose, 2007, pp. 18–20). He suggests that the contemporary focus on susceptibility is an extension of two modes of thought: (1) predisposition and (2) risk. Both have a long history dating back to the 18th and 19th centuries. Predisposition was understood as an inherited flaw that would manifest itself in illness or pathology. In the 19th century all predispositions (social pathology and danger) were understood as degeneracy. It encompassed problems like: urban existence affecting the life quality of the working class and other city dwellers, for others it was about how migrants

contribute negatively to the nation's health standards, or how pathologies (such as tuberculosis, venereal diseases, mental illnesses) affect the quality of the offspring. Others said that the issue is rather about how these 'degenerates' are kept alive by the welfare state, so that they can pass down to their offspring their deteriorated genetic structure, thus contributing to a downward spiral of general health standards. The concerns of the biotechnological discourse over susceptibility are thus connected to these older beliefs. But according to Rose there is an important transformation in this new perspective in contrast to the earlier concerns. This accompanied by the results of epidemiological studies that explore various sectors of the population (divided by age, gender, race, class, weight, diet, family history etc.) suggest risk scales to assess an individual's susceptibility to develop a certain disease. This means, that the present discourse looks at individuals as pre-symptomatically ill. And the direction of biotechnological work is in that of the optimization of the life chances of the individual. This makes it radically different from eugenic discourses. Other social critics such as Allen Buchanan (Buchanan, 2011; Buchanan, Brock, Daniels, & Wikler, 2000), Dan W. Brock (1994), or John Harris (1998, 2007) similarly to Rose, see much more the positive contribution of genetic research to our societies and they think it should not be conflated with the eugenics of the past.

In contrast to this position, there are critical works that suggest eugenic policies are transformed and integrated into contemporary biotechnological research and medical thinking. Jürgen Habermas (2003) provides a very complex ethical frame concerning the questions related to genetic enhancement and liberal eugenics. He claims that genetic research and its applications are justified through biopolitical goals. Such goals are the improved health of the individual or prolonged lifespan and these goals tend to change radically since the aim of genetic engineering is not the clinical treatment of health problems but the genetic construction of the healthy individual. The central claim of Habermas is that the biotechnological

intervention decided by a third party, necessarily takes away the autonomy of the self. To set out his argument, he draws a parallel between our *lifeworld* and the Aristotelian meaning of the concept. He claims that we are still living in the same Aristotelian world. In its basic constitution it is the same and we still think about our life similarly. In our everyday practices, we intuitively distinguish between the organic and inorganic forms of nature. Aristotle makes a division between the technical and ethical attitudes of the individual. The technical attitude means that the person while producing different kinds of products intervenes into nature. On the other hand, the actor, who engages in a communicative action, performs in order to reach a mutual understanding with the other person in a given social context. The basic point that Habermas makes is that these performative communicative practices show respect to the dynamics that humans find in the natural world. Radical modification of the human genetic makeup blurs the line between the natural and the social in a way that in consequence of the biotechnological intervention, the intuitively distinguished line between the organic and inorganic or between *the grown* and *the made* will vanish (Habermas, 2003, 44–47). Genetic engineering is in contrast with the value of the autonomously conducted life. In contrast to socialization, designer children are determined by their parents and by a third person, who intervenes into their genetic structure. For Habermas this act would blur the line between the natural and the cultural sphere and would take away the autonomy of the self.

Contributing to this critical discourse, Michael J. Sandel (2007) similarly argues that not only negative eugenics are eugenics, not only the attempts to create a better race is eugenics, but the contemporary marketized genetics can be equated with eugenics because of its market strategy to sell designer babies according to the demands of the customers. Intervention into the genetic structure of humans and creating babies, which are desired by the customers, is just as eugenically motivated as the racial betterment of the population through the tools of eugenic policies. Sandel gives contemporary examples to justify his claim: it is common to reject the

charges of eugenics by claiming that a medical intervention is the choice of the client. When the rhetoric is based on the free will argument it implies that it is not possible to talk about eugenics since coercion does not apply in such a democratic context. Sandel gives a clear example to counter this claim: the Indonesian government pays for voluntary sterilization for those women whose education and income is low, and supposed to give birth to biologically inferior children. This example clearly shows the eugenically motivated biopolitical policy, based on class, and an ill-formulated argument that tries to justify voluntary sterilization in cases where women are vulnerable because of their social position. But according to him, it is also important to call attention to eugenic practices in other cases as well, when people want to have a designer baby that meets the norms of their social group, or even exceeds them. This is similarly eugenically motivated because in these cases babies deliberately designed and produced according to the values of the community.

It is not only the ideological part but the methodological is important as well for critical scholars. Troy Duster (2003) suggests that genetic screening as a method is akin to the dramatic technique of placing a gun on the wall, as Chekhov points it out: if one places it on the wall in the first scene, it means that it must be used by the third scene. In other words, the mapping of our genetic structure and connecting this to genetic counseling is like creating a tool for a certain purpose and the tool itself implies that it will be used against certain populations. Duster agrees with the liberal argument that when we can use the knowledge provided by our genetic counselors (like how to change our habits, eating, sport etc.) it can be very valuable. If this knowledge creates more possibility and the individual is capable of living with these opportunities that is good in itself. However, he pays attention in his analysis to variables such as class position, environmental issues, and racial identity as well. He suggests that an important task for social scientists is to identify how certain diseases become racial, how risk groups change according to the social factors that are constitutive of medical targets. It is imperative

to explore and make it explicit how genetic issues are framed as class, race, or gender problems. Not only genetic screens are significant in this discourse for Duster, but the hidden arguments within health policies and medical encounters. Because he claims that there is a conflict of interest regarding the use of the knowledge provided. Geneticists for example must justify their work towards the state economically and medically as well, hence it puts pressure on them to provide results for the state. One of the most obvious ways they can show results is by claiming that they have managed to screen and prevent the birth of those with serious health defects. The question is how the individual is manipulated in a decision making situation and whether they (the couple or the woman) would have the right to have their child with that health condition. Duster gives examples from the context of the United States. It was proposed by the Chicago Bar Association in the state of Illinois to change marriage laws: every couple who would like to get married must obtain a certificate that informs them about their genetic condition (Duster, 2003, p. 127, cited from Kevles, 1985). This is a clear example of hidden eugenic arguments at work. The rationale of the suggestion is that couples who know about their shared genetic problem and it is likely that they would pass it down to their offspring must choose a reproductive option that ensures the birth of a healthy child. Duster argues it is economically and medically justified that these different institutions (genetic research, genetic counseling etc.) support the public interest. Thus, he says „the elimination or prevention of the „defective fetus” is the most likely consequence and ultimate meaning of a genetic screen” (Duster, 2003, p. 130). In his view, liberal democratic states will not embrace eugenics directly, but inevitable he says that the real question is how target groups of genetic screens are identified, what the constitutive social factors are that play a role in circumscribing the targets. And thus, what is an acceptable public policy in cases when the condition is not life threatening, and how to ensure diverse understanding of what it means to be well-born.

With these analytical perspectives in mind, the aim of this dissertation is to work out an understanding about the transformation of eugenic thought in Hungary. Starting with the early public health discourse when eugenic thinking entered into medical discussions the goal is to characterize the type of eugenics of the first two decades of the twentieth century. In the chapters that focus on the socialist and post-socialist periods, the aim is to trace the heritage of the early eugenics and explore how eugenic argumentation sank to the deep structures of preventive medicine. Throughout these periods up until the contemporary discourse, the thesis focuses on the dynamics of the social, technological, and scientific spheres and explores how biotechnological results influenced social and scientific values and in turn how social values influenced scientific research and technological developments.

1.4. Critical Race Theory Concerning Health Equality

In the United States during the 1960s the civil rights movement arrived at a plateau, it was perceived by scholars and activists alike that the proposed racial reforms are not working and are not properly implemented to change institutional practice and give equal opportunity and equal results for every racial stratum of the society. A movement called critical race theory developed as a response to these problems. It started to emerge in the 1970s with the works of the legal scholars Derrick Bell and Alan Freeman. They were interested in developing a critical legal discourse that can address the complexities of racism; one that can take into account the everyday experiences of non-white Americans who suffer from the injustices of various institutions (Delgado & Stefancic, 2000, p. xvi). Civil rights activists such as Martin Luther King, Rosa Parks, or Malcom X inspired critical race theorists early on, and parallel to the effects of political activism they were also influenced by the works of critical legal theorists, feminists, and continental social and political philosophers.

Critical race theorists build their work on five basic tenets (Delgado & Stefancic, 2001, pp. 6–8) that concern racism, material determinism, conceptualization of race, racialization, and the thesis of unique voice of color. The most important starting point in their works is the thesis that racism is ordinary, by this they mean that racism is so engrained into the everyday practices of social life that it is hard to recognize every form of it especially if one tries to approach equality from a color-blind perspective. Addressing color-blindness means in this case that they try to move beyond formal conceptualizations of equality and integrate racialized experiences to point out what are the problems with neutrality in educational, legal, or a healthcare environment. The second feature is material determinism or ‘interest convergence’ – to use the concept of Derrick Bell. This states that racism works to advance the economic state of white elites, and it also advances the situation of the working class whose majority belongs to the white strata therefore they are interested in keeping the status quo unless their political and material interest dictates otherwise (Bell provides an example in the case of *Brown v. Board of Education*, see here Delgado & Stefancic, 2001, pp. 18–20). Another central theme in critical race theory is how to understand the concept of race. Although the movement places emphasis on materialism and the materialist consequences of racism, it would be a misunderstanding of the movement to view the term from a classical philosophical realist perspective. Critical race theory builds on sociological, historical, philosophical, and linguistic scholarship that understands race from a social constructivist position (Delgado & Stefancic, 2001, pp. 7–8; Byrd & Clayton, 2001; Haney López, 2005; López, 2010). By this critical race theorists mean that race and racial classification are social products, it is not possible to find biological structures that are objective equivalents of racial categories. Social discourses produce races and these categories are contextually, that is, historically and culturally varied. Certainly, critics do not argue that race is fluid in the sense that there is no possibility of finding biological similarities that make it possible to group people together; they rather want to take issue with a

very problematic understanding of social constructivism. In this understanding, there is no materiality to race, but this group of critical race theorists argues that there are real, material consequences of race – albeit these are operationalized differently in various social contexts – that we need to confront in our societies. People attach different stereotypical traits to the hierarchically understood racial types that fuels various forms of racial discrimination across all aspects of social life. The last tenet in when someone works from the framework of critical race theory is to give voice to the subordinated, racially silenced people. This is what critics term, voice-of-color thesis (Delgado & Stefancic, 2001, p. 9); and by contrast to an essentialist understanding they do not mean that people of color have a biologically unique voice that one can identify with that particular racial group, but this draws on their unique experiences as a racialized group. Because of their racialized ways of lives members of these communities have access to perspectives which are not available to people who belong to the privileged racial group. The thesis entails that these people of color are capable of authentically describing race and racism thus critical theorists seek to integrate their narratives into their institutional critiques, or when it is not possible to include their voices, to point out how, why, and where institutional practices omit their perspectives. They claim that without the views of the non-white population on institutional racism it is not possible to attain a racially just society.

Contemporary scholarship deals with issues of color-blindness that goes back to the era of the civil rights movement when Martin Luther King called for a social practice that would judge people based on their actions and not based on their skin color; a related issue today is to develop a language that deals with racial identity and how other social categories intersect with racialized micro-level experience. A similarly important theme is addressing how globalization affects the economic circumstances of domestic minorities and their Third World counterparts. Critical race theorists argue that the exploitation of both groups by the elite is an interconnected issue thus it should be addressed simultaneously. Another important development in the field

is that it has been open to feminist, queer, Latino/a issues and scholars successfully established these critical subdisciplines. With the insights of critical race theory scholars can address issues related to the intersections of race, gender, sexuality, and racial discrimination that directed towards people of color of non-African-American descent (see Delgado & Stefancic, 2001). As critical race theory expands into other disciplines it remains an important force that can direct social transformation. Below I will introduce its applications in the field of public health at the crossroads of gender, race/ethnicity, sexuality, and class.

In a society where different forms of racial oppression are still normal, critical race theorists find it important to bring to the forefront of social discussions the embedded racialized practices of different institutions. Medicine is no exception to that. In a society, such as the United States, where the health standards of African Americans are significantly lower than members of the white racial group scholars from various disciplines seek to address the structural barriers to race equality in health care. One of the most important steps that helps scholars, medical professionals, and everyday medical interactions is to acknowledge the historical roots of racial medical practice in any cultural context. One such example of the contemporary significance of this issue is the protest against the statue of J. Marion Sims, who was a gynecologist in the nineteenth century and he has statues in several places in the United States (Brown, 2017). Sims pioneered surgery for fistula, gallbladder problems, and also, he was the first gynecologist who performed the first successful artificial insemination. The problem with Sims, and his scientific feats, is the path that he took in order to develop successful methods to cure women. He practiced medicine in Alabama between 1835 and 1849 where it was possible for him to experiment with slaves raising important ethical issues. He performed surgeries without the consent of slave women, and because at the time anesthesia was only recently discovered it was not normally used during surgeries thus Sims operated on slave women without anesthesia. He held the belief that black women do not feel any pain. In a

contemporary analysis, Carolyn Moxley Rouse (2009) in her work on health care treatment of African American patients with sickle cell disease points out the long-lasting effect of this racial stereotype. Rouse discusses the culturally constructed nature of suffering regarding the racialized patient. “Culturally accepted notions of who is a victim, and who suffers are not stable across time. Conceptualizations of suffering are dependent on notions of causation, accountability, innocence, agency, rationality, and selfhood, all of which change relative to the age, race, wealth, gender, and assumed intelligence of the sufferer” (Rouse, 2009, p. 124). Sickle-cell anemia is a medical condition that describes the shape of the blood cells that basically block the capillaries thus obstructing blood flow and consequently withholding oxygen from bodily organs. This process causes immense pain on the one hand and irreversible organ damage on the other hand. Thus, it is crucial to treat the pain of the patient as quickly and efficiently as possible. Despite the protocols accepted by the physicians and hematologists working with SCD patients, Rouse points out how health professionals’ understanding of pain differs from each other’s understanding, and also from the actual experiences of African-American patients; thus, their treatment practices vary as well (Rouse, 2009, pp. 24–25). But it is not only the physical inaccessibility of the feeling that patients experience, it is also the vocabulary that patients and healthcare workers use that makes treatment racialized. In a story related to a patient called Max, Rouse explains that the description Max gave about his experience was simply incomprehensible to the medical staff. Max used cultural signifiers in his interactions which were meaningless for his caregivers, who instead of putting effort into precise cultural translation substituted his words with racist, classist, and gendered tropes (Rouse, 2009, p. 40). In the case that Rouse describes, she notes it, that she does not want to place emphasis on racism or on the racist practices of medical professionals in her account, rather she wants to describe the hidden dimensions of institutionalized racism in the medical sphere. Her aim is to show her readers, how racist beliefs are acted out unconsciously by

medical staff thereby perpetuating racial inequality in their profession. If the aim is to treat patients equally it is mandatory to bring practices of racialization to the foreground by for example, integrating the experiences of individuals such as Max into critical understandings of healthcare.

Critical race studies in the field of history of medicine such as the works of W. Michael Byrd and Linda A. Clayton (2000, 2002), both of whom are health policy researchers and trained physicians, are crucial contributions to the field that aims at reconfiguring healthcare. In their works, they explore the history of medical treatments that African American's have received since the foundation of American colonies. They claim that the institution of slavery laid down the groundwork for a dual health system that persists until the present. Byrd and Clayton start out their analysis from reviewing the works Western medical professionals from ancient times. Fundamentally, they argue that color based classification of races existed in some preliminary form as a result of the works of the Greek philosophers Plato and Aristotle who assigned inferior status to slaves indifferent of their racial ancestry. Later the works of the Roman physician Galen and the Moslem Avicenna also contributed to the ideology of racial hierarchy by teaching that blacks are physically and psychologically inferior types (Byrd & Clayton, 2001, p. 17). Medieval monks accepted and relied on the teachings of ancient philosophers and physicians. And by the time of the Fifteenth and Sixteenth Centuries Western physicians developed and widely accepted the thesis of 'separate and unequal creations' – which is attributed to the Swiss physician called Paracelcus – that was later used to justify racial separation and subordination of peoples who are different from whites (Byrd & Clayton, 2001, p. 17). Thus, the hierarchical understanding of races was a historically embedded ideology by the time of the Enlightenment when philosophers and naturalists tried to use reason to explore, classify, give explanation as to how and why things work the way they do in our human centered universe. In this endeavor the classification of races was a central concern for many naturalists.

For example, Carl Linnaeus, who is considered to be the father of biological classification, Johann Blumenbach, George Leclerc de Buffon, and George Cuvier all contributed to Western European imperialism by providing pseudo-scientific justification for the subordination of non-white people across the globe (Byrd & Clayton, 2001, p. 18). The knowledge that these naturalists produced was used to strengthen stereotypes such as the idea that poor health of black people is normal, they are biologically weaker in comparison to whites. Byrd and Clayton argue that the difference between the health standards of white and non-white Americans thus is a product of racialization and racism that was present in the American discourse since its beginning, but importantly, they claim that it has lasting effects in the twenty-first century.

Byrd and Clayton underscores (2001, p. 20) that the basic infrastructure of the health delivery system of the United States was ready by 1920 and it has changed little regarding its accessibility by marginalized citizens. Basically, it was developed into a racially segregated institution which is very inaccessible for people from lower socioeconomic classes. Unfortunately, the authors claim, this has changed little during the Twentieth century. Instructive examples from the first half of the twentieth century are the eugenics informed efforts to sterilize the socially subversive members of the population. Sterilization laws were enacted in the 1920s by a dozen states and these concerned people who were incarcerated, who were deemed mentally handicapped or mentally ill (Kevles, 1999, p. 436). Kevles claims that in California alone, more people were sterilized by 1933 than in the other states combined. And he makes an important distinction regarding the class based and racialized nature of the law: those who had private care were not subjected to the process. This also means that poor people, African Americans, and other minorities were much more often subjected to sterilization than Anglo-Saxon whites. Another shocking example for institutional racism by misusing medical power in the recent history of American public health that affected African Americans is the Tuskegee syphilis study that was conducted between 1932 and 1972 (Reverby, 2008, p. 478).

In this experiment, African American patients with late stage syphilis were deceived by the staff members of the Public Health Service who basically observed the progress of the disease by pretending to give free health care to those who took part in the clinical study. The time-span, its scale, and its institutionally organized nature makes the Tuskegee study still a prominent example of contemporary racism and makes understandable the distrust of African Americans towards the U.S. medical apparatus. The situation started to change in 1964 when the Civil Rights Act was enacted (Byrd & Clayton, 2001, p. 21). With the hospital desegregation ruling and the start of the health center movement the health of African Americans has gradually improved. Michael Byrd and Linda Clayton write that they had more access to healthcare because of the reforms, and efforts were made to improve minority access to medical education – though these latter efforts were very symbolic instances. They further claim, that the positive change that started in 1964 had stopped by the end of the 1970s and the health status of African Americans has deteriorated since that time. Byrd and Clayton claim: “until persistent institutional racism and racial discrimination in health policy, medical and health professions education, and health delivery are eradicated - all of which play significant roles in access, availability, and quality of care – African Americans will continue to experience poor health status and outcomes” (2001, p. 25). Without systematic transformations, it is not possible to reach an egalitarian healthcare system that can work according to a new non-racializing paradigm.

In the 1990s with the launch of the Human Genome project it seemed that geneticists will provide scientific knowledge for the world within the scope of ten years that settles the doubts that has still surround that the idea of race and racial difference. But instead of accomplishing this goal racial science takes new shape through genetic studies. Dorothy Roberts (2011, p. 57) claims, this is mainly because of two scientific developments: scientists wanted to abandon race and suggested a focus on statistical genomic similarities and an

alternative to this was the suggestion that geographic ancestry be used as a substitute that leaves behind the discriminative baggage of the concept. With this move scientists basically re-dressed the concept in genetic terms. Roberts argues, that race persists because it is politically useful thus she emphasizes that “racial science and politics are inseparable” (2011, p. 79). Because of these interconnections, Roberts finds it important to analyze the political function of race in its context and provide a thorough critique that justifies its rejection from the scientific discourse.

In my view, not only the history of eugenics but a contemporary focus on race/ethnicity necessitates the use of a critical framework that allows for the mapping of continuities in terms of racialization among different historical periods. Critical race theory will help the analysis by shedding light on the historical embeddedness of racial structures in the Hungarian society and how it is represented in medical discussions. The contemporary racial focus of medical genetics is rooted in reproductive discussions of the socialist period, while some of the arguments present in the socialist discourse can be traced back to the early eugenic concerns of the twentieth century as I will point this out in my analysis. Drawing on the insights of critical race theory in order to provide a well-founded critique of the racializing tendencies in the contemporary Hungarian medical genetic discourse it is instructive to analyze the historical background of how race and racialization took place at the turn of the twentieth century, after the second world war during socialism, and in the contemporary post-genomic discourse.

1.5. Intersectional Contributions to Critical Studies on Public Health

Intersectionality, defined as "analytic sensibility" (Cho, Crenshaw, & McCall, 2013, p. 795), became a widely deployed theoretical and methodological tool in feminist studies since its inception at the end of the 1980s. In an earlier work, McCall (2005) puts the definition in a more detailed manner: intersectionality addresses the multiple dimensions of social relations and their relevance to possible subjectivities that can be formed within the social worlds. This new approach was developed to shed light on the complex nature of discrimination that women experience depending on their class, race and gender. Feminist researchers are working with the concept in political science (Brah & Phoenix, 2004; Kimberle Crenshaw, 1991; Ferree, 2012; Hancock, 2007; hooks, 2000; Wekker, 2004), in philosophy (Barad, 2003; Braidotti, 2002; Harding, 1993; van der Tuin, 2009), in sociology (Mccall, 2001, 2005; Yuval-Davis, 2011), and in public health as well (Bowleg, 2012; Hankivsky, 2012). In the following review, I will discuss the contemporary directions suggested by feminist scholars with a focus on public health. I will lay out briefly (1) the main contribution of intersectionality to feminist debates, (2) the main criticism that it received, (3) the directions that it took, during these thirty years of research, and (4) some of the most important suggestions of scholars as to move beyond present problems.

The first critical works that pointed towards the direction of intersectional theorizing appeared in the late 1970s and early 1980s. These were works of black feminist scholars and activists whose aim was to call attention to the inherent inequalities within identity politics and to shed light on the deterministic/marginalizing nature of social categories that rather act as labels for those who are identified as others. In 1977 within the black liberationist movement feminists published a statement about the different experiences of black women, which can be

read as an early work towards intersectional thinking. In their work, titled *The Combahee River Collective Statement*, they argued that different kinds of oppressions construct their living conditions in the United States. They emphasized that their main aim was to “struggle against racial, sexual, heterosexual, and class oppression” (Combahee River Collective, 2000, p. 264, originally published in 1977). In a similar manner, bell hooks argued in her book, titled *Ain't I a Woman* (1981), that black women experience discrimination differently from white women, and therefore traditional identity politics is not solving their problems. These examples from early intersectionally-tuned works were calling theorists to develop new perspectives to fight multiple-discrimination. Intersectionality, developed in accordance with these problems, seemed to be a promising, sensitive, and open new framework.

It was the legal scholar, Kimberlé Crenshaw's article (Crenshaw, 1988), in which she first proposed the use of the term to address multiple discrimination of black women in court cases. In her work, she argues that the problem with traditional anti-discrimination movement and identity politics is that they are addressing only one axis of oppression that is either race or gender, when in fact oppression works on bodies from multiple directions. In her later work (Crenshaw, 1991), developing the concept further she proposed three different aspects for intersectional research, namely structural, political, and representational intersectionality. In this early paper, Crenshaw (1991, p. 1242) argues for a more precise approach that can correct the problems of identity politics. She says, that the problem with identity politics is not the often-mentioned idea that it fails to transcend difference, but its inherent force that identity categories homogenize groups and thus intra-group differences are silenced. In her essay, she starts out from structural problems such as racism and sexism and claims that these analytically and conceptually different discriminatory forces are readily intersect in the lives of ordinary people. Through legal cases, Crenshaw pointed out that battering and rape affect women of color differently. In this work I think one of the most important contributions of Crenshaw was

to underscore in these empirical cases that the boundaries of identity constructs are not neatly distinguishable from each other thus an intersectional analysis demands a careful look at various crossroads of subjective experiences where individuals try to negotiate their subject positions to avoid economic or political marginalization, stigmatization, or any other type of discrimination. By adopting an intersectional lens, social scientists are in a better position to address inequalities because they can rely on a multidimensional method that can handle the dynamics between multiple identities.

And perhaps the most important contribution of intersectionality to feminist theory is that it allowed addressing both the locational and structural inequalities that play a role in the marginalization of people's lives. An intersectional perspective in analyzing the production of oppressed, marginalized, and silenced subject positions allow for considering multiple dimensions of identities, so that it enables us to view subject positions as configurations of discursive power relations. In other words, by looking at the locational, that is individual or group level interactions, and interpreting the lived experience of subjects in relation to greater structural inequalities, an intersectional approach allows the incorporations of infinite variables (social categories) into its sociological investigation. The openness of intersectionality can be viewed both as its strength and its weakness and the stances researchers take in applauding or rejecting its usefulness sometimes hark back to this characteristic (see Davis, 2008; Geerts & Van der Tuin, 2013).

Early on intersectional studies addressed different forms of aggravated discrimination that were based on sex, sexuality, language, political opinion, religion, social origin etc. As is evident from recent studies cited above, that although intersectionality is a recent sociological development to study complex discriminatory mechanisms, it is notable that struggles for political recognition in the women's movement around the turn of the nineteenth and twentieth centuries implied the identity category of class and gender. Women's everyday experiences

were articulated from different social economic positions thus class positions led to the division of women because priorities were different and those in power, particularly middle-class women, silenced the voices of those who were economically marginalized (Kóczé & Popa, 2009, p. 18). This example is only one instance to suggest that the problem, that intersectional scholars address, namely that social identities like gender are not homogenous categories, but with the interaction of other social identities such as class and race, they create qualitatively different subjectivities.

It is possible to argue that in most feminist studies race, gender, and class work as the most influential social identities that shape research. These categories are treated in such analyses with equal importance; they are understood to be mutually constituting and reinforcing each other. Angéla Kóczé and Raluca Maria Popa (2009, p. 25) emphasize that it is necessary in Central Eastern Europe to accept that only with the recognition of class as a crucial element of inequality thus a vital element of social analysis, will we get sufficient understanding of the situation of Roma. We must recognize that class plays a key role in the dynamics of marginalization along with race and gender. Drawing on the works of intersectional scholars, Enikő Magyari-Vincze underscores (in Kóczé & Popa, 2009, p. 26) that studies can focus on the structural problems, namely how race, class, and gender work on the structural level and provide frames or limitations for subjectivities at the crossroads of power vectors. Patricia Hill Collins, who is a sociologist, termed these structural forces as matrix of domination (2000, p. 276). By this expression she means that oppressive social forces operate in four domains and can be visualized as a complex web of forces. These four interrelated domains are the structural, disciplinary, hegemonic, and interpersonal domains. Regarding this problem, Collins says that “the structural domain organizes oppression, whereas the disciplinary manages it. The hegemonic domain justifies oppression, and the interpersonal domain influences everyday lived experience and the individual consciousness that ensues.”

Those studies that focus on the personal level can explore and bring forward the personal everyday experiences of subjects whose lives are at stake because of the entanglements of social forces at the microlevel. This direction for example, is visible in the work of Dorte Staunæs (2003), a Danish educational psychologist, who analyzed the microlevel experiences of school children regarding their understanding of race/ethnicity and masculinity. In her paper, she demonstrates that already existing racial and gender categories intersect in the subjectification processes of children who have ethnic Danish and Turkish cultural backgrounds thus privilege some and marginalize others depending on the value that is socially attached to their identificatory categories. For the argument made throughout this dissertation, it is important to emphasize that my work looks at various cases which serve to explore the interrelatedness of race, class, and gender in public health as healthcare professionals discursively shape them. Thus, my work addresses structural, disciplinary, and interpersonal issues, how healthcare professionals contribute to a public health discourse that sets out the options for medically and politically privileged and non-privileged subjectivities.

Although intersectional perspectives are applied in various social science disciplines it is not true of studies that are within the broad field of public health. It is a new methodological framework as discussed above: it only started to become integrated into social science disciplines in the 1990s, and it is a tool that researchers have used only recently to address public health inequalities. Lisa Bowleg, who is a social psychologist, argues that intersectionality is beneficial for public health studies because it can be integrated with health equality goals (Bowleg, 2012). Intersectional studies are about social inequalities, their aims are exploring and exposing invisible obstructions to equal treatment and opportunity, thus as a perspective, it is compatible with critical works that address public health issues with the aim of leveling health standards among different social groups. According to Bowleg one of the main benefits of the perspective is its compatibility with a recent direction in public health that

also places emphasis on “social determinants of health, or ecosocial determinants, or social inequality” in this new approach an “ever-growing chorus of public health scholars have advocated for a greater focus on how social-structural factors beyond the level of the individual influence health” (2012, p. 1269). Bowleg further asserts (2012, p. 1272) that an intersectionally informed research starts out from the experiences of historically oppressed communities therefore it can assist the development and of well-targeted and cost-effective health promotion campaigns, medical interventions, or public health policies.

One of the most important problems in addition to single-category analyses is when a category is treated with a single focus such as in the case with gender when conflated with the category of women. This is problematic for various reasons. The first is that gender is not synonymous with the category of women, and, it is not a homogenous category, it should be further divided by taking sexuality, class, religion, and race/ethnicity, and other contextually relevant identity categories into account. But another crucial problem is that gender is often used interchangeably with women thus men and their equally diverse groups are left out of the analysis. This also means that their gender specific healthcare needs are not visible (Hankivsky, 2012, p. 1713). Without the integration of these perspectives it is not possible to move ahead in creating conditions for equal treatment in healthcare.

But also, Hankivsky notes (2012, p. 1714), we must move beyond the binaries such as interest in the health of men and women. The problem with such research designs is that it tries to answer questions which are formulated with a stereotypical gender bias in mind. To take an example, a question such as: do women and men have the same risk of getting cancer is problematic because it re-creates two seemingly homogenous groups based on the sex of the participants when there is evidence that women and men can both share certain genetic mutations that would make them similarly susceptible to cancer. Thus, research questions that focus on for example genetic traits which are linked to cancer are more beneficial for the public

health needs of both men and women and would help to create hybrid groups in which sex is only one social category among many others that complicates our understanding of susceptibility.

Intersectionality must not be understood as a prescriptive method. It rather contributes to scientific analyses by opening analytical frames and letting us bring in analytical categories that were – and perhaps still are – incompatible with each other in single dimensional methodological paradigms. It facilitates discussion by pointing out complexities that were previously glossed over because of insensitive methodological lenses. Thus, I think the most important contribution of my work lies in its aim of making visible intersectional elements in the medical discourse that thwart healthcare equality or perhaps even implicitly support discriminative practices in healthcare. I will use the perspective of intersectionality to explore the Hungarian medical discourse in order to point out that identities such as race/ethnicity, gender, and class work as structuring principles in organizing social hierarchies in the professional narratives. Clinicians, perhaps inadvertently, produce medically significant subject positions in their narratives along the lines of said identities, and by doing so, they reproduce distinct groups and fail to stress the shared genetic characteristics across groups.

1.6. Research Questions

In my dissertation, I address the issues that emerge from the literature on medicine that point to patterns of eugenic thinking. Critical works try to demarcate eugenics from genomics; however, there is no published research methodology that I found which investigates the continuities of these two scientific paradigms. There is no methodology yet for acting critically and effectively against such eugenic residue. Hence, my research questions are the following:

- (1) Is there any continuity that can be confirmed between the approaches of early eugenics and contemporary genetics?
- (2) Where is it possible to observe the effects of eugenic thinking in the present genetic logic? How can we amend this thinking in order to come up with a model for genetic research for the Roma community?
- (3) What patterns can be explored which point to the value-loaded characteristics of contemporary human genetic research?
- (4) Applying the methodology of postmodern constructivist grounded theory, what can we learn from scrutinizing genetic studies focusing on the biologization of social categories?
- (5) What are the emerging new directions as a result of the project to conduct biological research differently? Going beyond intersectional standpoint theory is key here. The assumption is that whereas the naturalization of knowledge seems to work perfectly on a discursive level, this picture might change when we look at genetics from a renewed empirical point of view. How do not only the Roma people resist social categorization but also the biological material resist scientific classification?

2. Qualitative Methods for Researching Eugenic Aspects in Medical Discourses³

2.1. Positioning: Researchers and Informants at the Intersections of Scientific Discourses

Norman K. Denzin stated that “self-reflection in ethnographic practice is no longer an option” (1996, p. 352 cited in Clarke, 2005, p. 12), by which he meant that after the ‘interpretive turn’ researchers have to position themselves as producers of knowledge, they have to reflect on several characteristics of their research: on the processes that lead to knowledge production, on their own context, on the context of their informants, and on the power dynamics which are at play in the analytical situation. After the ‘postmodern turn’ qualitative researchers have to position themselves so as to be held accountable for the consequences of their research. Adele E. Clarke, who developed grounded theory into a feminist methodology, also thinks reflexivity is crucial for applying constructivist grounded theory. For Clarke (2005, p. 12) it is necessary to establish who is the researcher, who/what is the researched material, what are the consequences of the research and for whom, who paid for the research and why, and who/what is placed at risk by this research and who/what is advantaged by it and how. And importantly, what knowledge counts to whom under what conditions.

In the following I will describe how I understand doing grounded theory research in feminist studies in science and technology. I will explain in detail how I order my material from the interviews that I collected during my empirical research. And I will explain constructivist perspective, which is still the underlying theoretical framework for onto-epistemological

³ A version of this chapter appeared in the Eger Journal of American Studies (Szamosi, 2018).

research, and why it views biological knowledge as necessarily partial, that is situated, local knowledge.

2.2. Constructivist Grounded Theory: A Method for Science and Technology Studies

I position my research within the framework of the constructivist version of grounded theory articulated by Kathy Charmaz (2003, 2006) and further developed by Adele E. Clarke (2005). Traditional grounded theory was developed by the sociologists Barney G. Glaser and Anselm L. Strauss and was introduced in 1967 through their book *The Discovery of Grounded Theory* (Glaser & Strauss, 1999). Although Glaser and Strauss worked together to articulate the original version of grounded theory, their views on how to conduct qualitative research within their originally proposed framework diverged and they developed their methodological theory further in separate directions. These directions had been consolidated by the 1990s and referred to as Glaserian-grounded theory and Straussian-grounded theory; the latter was developed by Strauss with the contribution of Juliet Corbin (Dey, 1999, Higginbottom & Lauridsen, 2014). The central difference in doing grounded theory research according to Glaser is to generate theory from the data – a classical positivist stance – while, according to the Straussian model, the grounded theory method is verificational (Charmaz, 2003, p. 255). In the following I will present the guidelines for doing traditional grounded theory (GT) research in order to distinguish it from the succeeding constructivist framework which I apply in my research.

The traditional GT method can be characterized as positivist for a number of reasons. It presupposes that an external reality exists and awaits the discovery of the researcher; it aims for objective – in the sense of value neutral – descriptions of the world; and its terms and concepts are deduced from the analysis of empirical work. In their original work Strauss and Glaser sought to work out a method which is applicable to discovering theories from systematically

conducted social research. To attain this goal they argued that social scientists have to start their research without predetermined hypotheses, by which they certainly did not mean that researchers should not enter the research process without any theoretically derived ideas about why it is promising to conduct a particular research study; their point is to keep these ideas flexible so that they will eventually allow the theory to emerge from the material. In other words research should not rest on preconceived theorizing; for grounded theorists, research is not theory-testing, instead theories must emerge from the empirical material (Bryant, 2007, p. 107). Bryant further argues that in traditional GT the emphasis is placed on the objectivist representation of the world; in this framework representation will not pose problems for the researcher once a neutral point of reference is established.

Although traditional GT method is endorsed by Glaser and Strauss, their ideas significantly diverged: Glaser's views are still in the positivist paradigm, while in the Straussian variation, we can see the roots of constructivism. In his article which was written as a response to Kathy Charmaz's (2003, originally published in 2000) elaboration of her constructivist grounded theory method in opposition to the methods of objectivist grounded theory (Glaser, 2012, [2002]), Glaser argues that the remodeling of GT by constructivism is not desirable. Whilst Glaser does not abandon the objectivist framework, Strauss (1987) and Strauss and Corbin's work (1990, 1998), opened up the original method for constructivist researchers. Jane Mills and her colleagues (Mills, Bonner, & Francis, 2006) argued that the roots of Charmaz's constructivist grounded theory method were already present in their work. They based their arguments on the explicit standpoints of Strauss and Corbin and how they think about the process of theorizing, about the researcher's role in grasping reality, and about the role of the researcher in this process. In their work Strauss and Corbin equate theorizing with construction itself, they claim that this process is the interpreting of different perspectives which are produced from the researched material (Mills et al., 2006, p. 4). "Strauss and Corbin clearly

stated that they do not believe in the existence of a “pre-existing reality ‘out there.’ To think otherwise is to take a positivistic position that ... we reject ... Our position is that truth is enacted”” (Strauss & Corbin, 1994, p. 279 cited in Mills et al., 2006, p. 3). Despite this explicitly articulated constructivist standpoint, Charmaz claims that Strauss and Corbin’s take on GT method is positioned in the postpositivist frame; they acknowledge the existence of objective external reality; they think that grounded theorists must aim at unbiased data collection and, according to their stance, truth claims about objective reality can be verified (Charmaz, 2003, p. 254). Besides the above critique, Charmaz acknowledges that Strauss and Corbin’s position moved out of the positivist frame towards postpositivist theorizing, inasmuch as they are proposing to give voice to their respondents. Their aim is to represent their interviewees as accurately as possible taking into account how their views of reality – their own and their respondents’ – differ from each other. Kathy Charmaz developed this strand of theorizing further by proposing to apply constructivist GT method which “assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meaning” (based on Guba & Lincoln, 1994; Schwandt, 1994, in Charmaz, 2003, p. 250). Her approach differs from the postpositivist leanings of Strauss and Corbin’s method in the sense that her aim is to transform GT so that it is more open-ended; for her the emphasis is much more on the emergent elements of the method.

For Charmaz the key to differentiating her constructivist method from the preceding variants is directly linked with the mutual interplay of the researcher and the researched material. Charmaz argues that the viewer is part of the viewed material, there is no breaking point within their interaction, and they mutually constitute each other. What is crucial for her is the process of interpretation versus discovery. For constructivists, or interpretivists, the material is open to the interpretation of the analysts; their engagement with the material creates

the data. As a result, CGT researchers see their analytical work as a process which is always shaped by their own socio-cultural contexts (Charmaz, 2003, p. 273). In other words, one side of the interpretive horizon is connected to the structural *locus* of the researcher, and the other to the way they think about causality. For constructivists, causality is “suggestive, incomplete, and indeterminate” (Charmaz, 2003, p. 273), which according to the rules of the framework, prompts the researcher to find conditional statements which are crucial in defining the realities of their informants.

Adele E. Clarke goes further than Charmaz in her work in arguing that grounded theory has always already been around the postmodern turn. While the goal of Charmaz is to work out a constructivist frame for grounded theorists, she also acknowledges constructivist leanings within the works of Anselm Strauss and Juliet Corbin. Clarke however claims that within grounded theory itself, attentive researchers can find characteristics which have been binding GT method to postmodernism since its inception. The characteristics that Clarke finds crucial are perspectives or situatedness, materialist social constructivism, deconstructive analytic interpretation through open coding, its focus on social processes and contingencies, a range of variation as a feature of difference, and the structuration of social worlds (2005, p. 6). These are the foundational elements for doing grounded theory which were incorporated into the traditional methodology itself and hence make the method compatible with postmodern perspectives.

The concept of perspective or situatedness is a key starting point for Clarke’s genealogy of grounded theory since she claims that the work of Margaret Mead underpinned the early Chicago school of sociology until the emergence of social constructivism with the work of Peter L. Berger and Thomas Luckmann entitled *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* (Berger & Luckmann, 1966). Clarke’s aim in pointing out the links between Mead and the social constructionist sociology is that interpretive interactionism was

grounded on these already existing and powerful theories in American sociology. Another crucial tenet of grounded theory, at least for Clarke, is its materialist social constructionism. She asserts that it is a misinterpretation of social constructionism that it is only interested in the symbolic world: for social constructionists the human and non-human elements are both key in theorizing; for constructionist theoreticians it is merely how we humans think about our access to the world that is different – our realities about the world are constructed through language and are available to us through a shared linguistic universe. Another important characteristic of grounded theory which pushes the method to the edge of positivism is its analytic tool of open coding. For Clarke this perspective within the method enables researchers to read their data along multiple logical lines of interpretation. For postmodern interpretive researchers there is no single essential interpretation of the material; instead they think that knowledge constructions are themselves historically and geographically situated. In the Straussian version of grounded theory method, Clarke sees a strong orientation towards an analytical process by which grounded theorists can point towards ruptures, turning points and trajectories. This is crucial for pointing out contingencies: that is, the analytic process highlights how things are and how they could have been otherwise. In other words, it points towards the contingent nature of our social realities; our social worlds become real through the constant intra-actions of human and non-human elements – hence the method's emphasis on context dependence. Difference is tied to this characteristic as well, since early grounded theorists were also looking for variations in human activity; Clarke aims to build on this characteristic in her methodological theory, by proposing to create situational maps. With the help of situational maps researchers are able to make visible non-dominant differences and make silences speak about unvoiced differences in a hegemonic discourse. The Straussian concept of social worlds/arenas serves as the starting point for Clarke to develop her situational approach, which is the core of her postmodern grounded theory. Clarke values this methodological tool in grounded theory since it provides

an open, fluid, and discourse-based approach to the analysis of different configurations of collective action (Clarke, 2005, pp. 6–10).

Clarke advocates applying six strategies for doing grounded theory. These are embodiment or the situatedness of the knowledge producer; using the situation itself for grounding the analysis; shifting the research focus on to complexities, differences, and heterogeneities; sensitizing concepts as an analytical strategy; doing situational maps during the research process; and using narrative, visual, and historical discourses to expand the domain of social life (Clarke, 2005, p. 19). By applying these six strategies, researchers can consolidate their work within the constructivist/postmodern framework. The most crucial move for doing grounded theory research is acknowledging the situatedness of our position as researchers and the situatedness of our informants (Clarke, 2005, pp. 20–21). With this move constructivists are able to produce knowledges which represent heterogeneous, contextually grounded perspectives that mirror the intersectional perspectives of knowledge producers. Postmodern constructivist scholars are aiming to counter the aperspectival knowledge claims of researchers whose position-taking is unvoiced and whose identities are rendered invisible through the methods of their positivist framework. The third tenet of Clarke's strategy is directly linked to situated knowledges. Here she places emphasis on situations, and on how researchers have to approach the study of situated research problems. The concept of situation refers to the broader relatedness of the studied phenomenon and relations among situations in the Straussian sense (for more on this see Clarke, 2005, p. 23). In addition, Clarke prompts researchers to design research questions which address situational problems, and as a consequence researchers must embrace the limitations of their work. For postmodern social scientists the situatedness or the explicit limitations of their research is considered one of the strengths of their method. From the limited nature of doing postmodern research it follows that analysts can focus on differences, complexities and multiplicities. Grounded theory method allows researchers to

fracture their data and as a consequence it allows for multiple interpretations which enable a researcher to focus on differences as opposed to the representations of normativity and homogeneity in traditional positivist sciences. Clarke argues that “we need to conceptually replace modernist unidimensional normal curves with postmodern multidimensional mappings in order to represent lived situations and the variety of positionalities and human and nonhuman activities and discourses within them. Otherwise we merely continue performing recursive classifications that ignore the empirical world” (2005, p. 25). What is crucial here is the focus on the heterogeneity of the world: researchers need to recognize normative conceptualizations in modernist knowledge structures and they have to de-reify them through empirical research. In other words, their central aim is to study specificities within particular situations, to attend to variation within their data and to explore how complexities, differences, and multiplicities manifest in their situated analysis. Instead of constructing theory from data, researchers should aim at theorizing through sensitized concepts constructed through interpretive analysis. Analysts should aim at writing thick analyses from their data, making situated analytic claims that allow them to avoid over-generalization and over-abstraction. In conjunction with the previous analytical strategy Clarke suggests that we make situational maps as a visual strategy that helps create connections among the elements of our research which in turn fosters relational analyses. The last strategy that Clarke proposes for pushing grounded theory around the postmodern turn, and consolidating it as postmodern/constructivist method, is to analyze discourses of three kinds: narrative, visual, and historical. These all facilitate the idea of expanding the domains of social life that our research addresses (Clarke, 2005, pp. 28–31). In my research I focused on narrative and historical discourses in conjunction but primarily through my interviewees’ accounts. Clarke understands discourse following Michel Foucault (1972), who defines discourse as “historically contingent cultural systems of knowledge, belief, and power” (Bucholtz, 2005, p. 45). In my research I was interested in the specifically

Hungarian ways of organizing medical genetic research and knowledge production, and for this reason narrative interviews serve as the primary method for collecting empirical data about the historical contingencies of the Hungarian medical genetic discourse.

2.3. Mapping, Coding and Memo-writing

During the analysis of the interview data, I followed most closely the methodological principles that were laid down by postmodern constructivist grounded theorists. Postmodern and constructivist principles are compatible with each other; in fact Adele E. Clarke argues, that her situational analysis method, which involves mapping strategies, is complementary to traditional grounded theory methods such as coding and memo-writing (Clarke, 2005). Coding and memo-writing are pre-requisites for making the analytical maps that Clarke advocates. But what does coding and memo-writing mean in a grounded theory framework?

Before moving on to describe the methods of coding and memo-writing, there is another important prerequisite for doing precise qualitative analytical work when using interview records as empirical materials. To do precise work, qualitative researchers have to transcribe their records and only when they have completed their transcriptions can they start the first analytical phase which is coding. In my analytical work I went through three phases of coding procedures with constant comparative methods (Charmaz, 2003, 2006). In the initial coding phase, a researcher can work his/her way through the text word-by-word, line-by-line, or incident-by-incident. In this initial phase, I applied these strategies interchangeably, but my main focus was on incidents. In my work I am looking at how certain medical realities are produced, and consequently in this phase my aim is to locate and compare these incidents with each other from different locations. In this phase I developed active short codes to describe the actions which are retailed by the interview participants. After this first step, I continued with

focused coding, which means that I returned to my initial codes and worked out new descriptions which I considered would best describe what was emerging from my work. At the final stage of the coding work I developed out of these two-phase codes theoretical codes which entered into the sphere of concepts which provided the skeleton of my analytical work. These codes are regarded as necessary for working out analytical perspectives, that is, these codes facilitate the fragmentation and re-structuring of the empirical material through the logic of the constructed concepts.

For Charmaz memo-writing is an intermediate step between coding our material and completing the first draft of our analytical work (2003, p. 261), while for Clarke, memo-writing is a crucial tool throughout the analytical procedures (2005). Clarke suggests writing memos as a part of the comparative work that we are doing while we are analyzing our material in every phase of the research, including in the phase of working out situational maps. Memo-writing facilitates thinking about our codes concerning relationships within our project, and as a result it allows us, to rethink our work while we are constantly engaged with our material. Charmaz suggests that during memo-writing we write detailed descriptions of the processes, assumptions, and actions which are implied by our codes. During coding, we have to come up with active codes, because active codes facilitate comparison between different research problems. Memo-writing is essentially a reflective work. It is used to help us in seeing connections between seemingly unrelated static research themes. During memo-writing researchers have to detail what they and their informants mean by the codes, what these codes designate in their field of research, and as a result researchers are better able to see how these diverse, but related elements fit into the larger picture (Charmaz, 2003, p. 261). In sum, Charmaz writes, “[M]emo writing helps researchers (a) to grapple with ideas about the data, (b) to set an analytic course, (c) to refine categories, (d) to define the relationships among various categories, (e) to gain a sense of confidence and competence in their ability to analyze data”

(2003, p. 263). Detailed coding and memo-writing lead the researcher to start his/her work with situational maps.

Three main types of situational maps and analyses are proposed by Clarke (2005, p. 86): these are (1) situational maps, (2) social worlds / arenas / discourses maps, and (3) positional maps. Developed by Clarke, these are intended to be used for opening up the raw data for analysis, and then to facilitate easier movement within the data which we are interrogating. Clarke considers the biggest advantage of creating maps for analytical purposes to be that they provide the researcher with “the big picture” (Clarke, 2005, p. 85). That is, maps are helpful in locating the project/situation in the world. Let me elaborate the differences between them below.

To make situational maps researchers have to locate all the human and nonhuman elements as they are framed by the informants and by the analyst; the main task here is to draw up a picture of the situation that we are interested in. Human elements are individuals, groups, organizations, institutions, subcultures which emerge in our situation, while nonhuman elements are those actors (nonhuman elements as agents) which unavoidably force human elements to deal with them. Their interrelationship within our situation is not the question at the time we complete our map; the question is the nature of their relationships. In other words, the first phase within this methodological strategy is rather descriptive, the most important thing is quite literally to have a situational map which answers the questions (1) who and what is in our situation of concern; (2) who and what matters; (3) and what elements make a difference. When a situational map is ready the researcher can move onto the next phase which is the relational analysis of the situational map through memo-writing. In this phase, researchers have to take all elements one-by-one and find out what other elements they are related to, and during their memo-writing they have to determine the quality of their relationship to each other

(Clarke, 2005, pp. 86–87). Once a situational map is completed, researchers can turn to construct their social worlds/arenas/discourses map.

Social worlds are quite simply universes of discourses in the Straussian sense – this fundamentally symbolic interactionist perspective, is applied in Clarke’s analysis (Clarke, 2005, pp. 109–110), because these are the worlds where social groups actively take part in knowledge construction and researchers can observe their collective actions toward shared or conflicting interests. During social worlds analysis researchers can interpret how the unequal distribution of power is altering the balance among the elements in the situation of concern. With these maps the researcher can explore the diverse social actions in which the members of different worlds and groups take part: these are actions through which humans become members of each world; through these actions they performatively create their social positions. Basically they do a kind of identity work, and they make their subjectivities meaningful for themselves and for others through these interactions. The stake in these interactions is how individuals express their belonging, their commitments, their values through their actions, and parallel to this, how discourses/social worlds play a role in defining their subjectivities – in other words, what individuals have to internalize and then display in order to become an acknowledged member of the collectivity. Two possible focuses are advocated by Clarke: (1) is on actions/processes as discussed above, and (2) is on units of actions, that is, the entities both human and nonhuman which are present in the analyzed situation. In sum, the analytical focus is on the processes that the elements enact collectively and, importantly, researchers can use this focus as a boundary-making tool to set distinctions among social worlds (Clarke, 2005, p. 113). The first analytical step in creating a social worlds map is the identification of different social worlds which come together in our situation. During the analysis, researchers have to look for patterns of collective commitment; that is, we have to identify sequences of actions which are performed in order to achieve a shared goal. Related to this analytical focus, we have

to interpret their perspectives so that we are able to identify their shared goal. It is necessary to characterize the human and nonhuman actors in each world with a special focus on the constraints, opportunities, and resources that they provide in that world (Clarke, 2005, p. 110). The following step in the analytical process is to create positional maps which are useful for mapping the positions which are taken in the data.

The biggest emphasis is placed on making a distinction between positions of individuals, groups or institutions versus positions in discourses. Clarke presses the importance of “moving beyond the knowing subject” in the Foucauldian sense, and warns researchers that they must focus on mapping the positions which are taken in the discourses in their analytical situation (2005, p. 126). Let me put it this way, these positions are not the positions expressed by individuals, or made explicit by groups, these positional maps are about the emerging positions within the analyzed situation. These positions are about those topics which emerge through our coding procedures. Clarke writes that the previously described processes, such as coding and situational mapping, are fracturing the data in such a manner that researchers are able to delineate positions and draw positional maps that adequately describe the major standpoints which are taken (2005, p. 128). In the process of constructing positional maps researchers have to look for “issues, positions on issues, absences of positions where they might be expected (sites of discursive silence), and differences in discursive positions central to the situation under study” (Clarke, 2005, p. 126). During positional mapping, researchers have to locate all the positions which are taken in the discourse, but by doing that, Clarke notes, positions are not valued equally; this interpretation would be a serious flaw in understanding the central tenet of relativism (2005, p. 127). By locating all positions researchers democratically represent the major standpoints in the situation of concern, but as Clarke emphasizes, this does not mean that all of the positions are valued equally by the researcher. In fact in postmodern grounded theory, the aim is to point out that values operate throughout any research, and in any kind of work,

which means that individuals and collectivities reach different valuations which it is then possible to problematize. With this move, researchers are able to point toward power inequalities and raise questions by interpreting silences or silenced positions. For Clarke (2005, p. 136), the most important aspect of making situational maps is locating those positions which are not taken in the data. Researchers are able to make these silences speak through positional mapping. Fundamentally, the aim is the democratic representation of heterogeneity and the comparative analysis of these positions relative to each other in the situation.

2.4. Forms of Empirical Data

To design my research I used a lecture series that had been organized at the Semmelweis Medical Science University in Budapest, where I could gather names and lecture titles that allowed me to narrow down the research interest of practising human geneticists. And in addition to this, I used the webpage of the Hungarian Genetic Society, to find contact information about researchers who are working in the area of my research interest. I organized the interviews based on this data and I asked all of my interviewees to suggest other researchers that they know who worked in the field of medical genetics. Since the interpretive turn interview-sampling is a valued empirical method in the social sciences (Denzin, 2003, Clarke, 2005, Charmaz, 2006). I chose in-depth interviewing as the primary method of my research to collect empirical data because it allows constant adjustments during the process of inquiry and this characteristic makes it compatible with constructivist grounded theory. I used the flexibility of this method constantly in my investigation. I started with a historical-conceptual approach that was reflected in my questions and as analytical themes emerged I gradually moved towards mining for processes within the narratives of researchers who gave insights into their work from different sites of medical genetics.

In the first phase of the research my aim was to interview population geneticists, but it turned out that there are not very many population geneticists in Hungary, and they are also working at the intersection of some other subfield of human genetics, therefore I started to include clinical geneticists in the research. My intention was to explore the narratives of human geneticists from these different sites and comparatively analyze their takes on the relevance of gender, class, and ethnicity for medical genetic research. From the spring of 2011, I conducted 30 core interviews; before 2011, I recorded four interviews as a part of my master's thesis (Szamosi, 2010), and I recorded six follow-up interviews after the core records had been written up. I organized these interviews in emails and I stated in my letter that I was looking for human geneticists who were willing to talk about historical aspects of medical genetics, because my research is a comparative historical analysis of genetic developments in Hungary. I decided to use the interview transcripts by paraphrasing my material so that the identity of my informants remained anonymous. This serves two goals, to protect my informants and also to place their views on the same footing because this way not only their names are hidden, but their positions as well. I coded the interviews according to the dates of recording them, thus I will refer to them in this way.

In designing the interview, I developed open-ended questions that allow the free floating of information right from the beginning of the interview. I found it useful to create an interview question guide which contained sub-questions to direct the discussion when it was necessary. Some of the interviewees were very open and covered most of the sub-questions without my actually having to pose them, but some of the interviewees tended to disclose more limited information, and in these cases the semi-structured interview guide proved useful. Interviewing is a directed conversation therefore I saw my task as an interviewer to ask for clarification or elaboration; but this was mainly in order to facilitate ongoing discussion as promising themes emerged. My intention was to avoid creating a situation where the interviewee would feel that

I was interrogating (Charmaz, 2006) first and foremost because interviewing is not a form of interrogation and secondly because it would have created an inconvenient atmosphere that would block the flow of information. I formulated my questions around three main themes, (1) institutionalization of medical genetics and genetic counseling, (2) population genetics, (3) personalized medical genetics. All these themes were directed towards the significance of class, gender, race/ethnicity for geneticists practicing in different sites towards different medical goals.

In addition to the interviews, I chose five well-recognized social science and medical journals that encompassed the periods from the early 1900s to the present medical genetic discussions. In the early public hygiene discourse when eugenic ideas were debated but slowly integrated into medical practice I reviewed the *Huszdik Század* (Twentieth Century, 1900-1919), *Magyar Társadalomtudományi Szemle* (The Hungarian Social Science Review 1908-1914), *Orvosi Hetilap* (Medical Weekly, 1857-), *Népegészségügy* (Public Health, 1920-), *Magyar Epidemiológia* (Hungarian Epidemiology, 2004-). In these journals I was looking for articles in which authors have shown continuity in problem identification, reasoning, and personal contribution to eugenic thinking.

2.5. Theoretical and Methodological Implications for the Empirical Analysis

It is possible to differentiate between two kinds of constructivist directions based on how they view science. The sociology of scientific knowledge school views science and scientific knowledge as passive and into which scientists incorporate social values. The followers of this approach view scientific knowledge from a relativist perspective: every cultural and subcultural context imprints its social values on the knowledge acquired, and thus their conclusions are necessarily relative. The more recent constructivist science philosophies driven by the ontological turn operate according to the principle developed by actor-network-theory philosophers that the social and scientific worlds are not distinct spheres and not only the social and scientific values, but human and nonhuman actors play a role in the production of knowledge. According to this approach, the values of a broader cultural and the narrower social contexts are integrated into the knowledge produced by scientific actors (classic SSK position) but they go further and extend the scope of possible factors that take part in this process. By taking this direction STS scholars argue that the relationship between the social, the scientific, and the technological is much more interconnected and they are a lot closer to each other than the school of sociology of scientific knowledge holds them to be.

To illuminate this point, the classic example that STS scholars use, is the case of biotechnology. By using biotechnology it is possible to point out that science and technology are embedded in social contexts to the extent that biotechnology gets transformed by interactively incorporating the needs of the society into its research goals and working mechanisms. This STS philosophy is perhaps best viewed as a type of social theory in which the constitutive factors of the social, the scientific, and the technological dynamically influence each other and thus produce qualitatively new interpretations of the world. In the following empirical analysis, this above described dynamic process will be examined through the shifts that took place in the medical discourse aiming at meeting the needs of public interest driven

by economic rationalization, the unacceptably high mortality rates of the population, and low health standards in comparison to the technologically developed countries. And the reflexivity of scientific and technological results, that is the dynamism between the spheres could be seen in the processes of integrating technoscientific insights into the application of medical genetic technologies for the betterment of public health.

The issue of eugenic legacy in the medical history of Hungary provides a case to analyze the transformation of moral values through the interaction of social, scientific, and technological discourses. Eugenics started out as a scientific discourse with the pretension of population management. It was articulated around public health and the accompanying social interests but it was burdened with harmful political values. Eugenics as a discourse is valuable for comparative study because in its various stages the fusion of moral values of a community with technological and scientific development becomes evident through the analysis of medical-scientific discourses. In the historical analysis the onto-epistemological principle, that the social, the scientific, and the technological values dynamically influence each other can be explored. One of the important cases that I will use to characterize this dynamism is the medical discourse around Down syndrome. I will point out that the Hungarian medical approach shifted from the early preventive attitude – that meant the termination of the pregnancy – to the present preventive attitude that means finding ways therapeutically to influence the condition of the fetus diagnosed with Down syndrome. In my view, the changes in genetic counseling principles, the practice of genetic counseling, and the developments of technological opportunities taken together provide grounds to analyze the co-construction of a qualitatively new medical discourse aiming at effective population management by using genomic data.

Population management is organized around social categories in modern societies. One of the main instruments of population control is the medical discourse. And the medical discourse similarly works with social categories; these act as signposts in a discourse and help

clinicians and researchers to orient themselves and treat their patients. However, the semantic fields of social categories are in a constant flux, they depend on historical and cultural contexts and also on the users interactions, and in contrast to this tendency, the medical discourse tends to apply social categories in a relatively rigid manner and establish its target groups along these categories. The medical discourse thus contributes to the materialization of such social constructs through the tools of its scientific discourse. Identity categories, such as gender, race, ethnicity, class, age, or religion, are all socially embedded, and although they are transmitted through historical periods and act seemingly independently from the preceding discourses, their meanings are interconnected. Thus, the way they evolve and achieve new meanings is a central analytical perspective in studying the interrelationships of science, technology, and society. It is easily traceable in the Hungarian medical discourse that accentuation is shifted regarding the organizing classificatory categories of gender, class, race, and ethnicity according to the dynamic changes that took place in those different but tightly connected contexts.

A concrete comparative example of such a shift from the empirical analysis regarding gender and class is from the early eugenically informed public health discourse where the reproductive rights of women were infringed. Lower class women, who suffered from tuberculosis were viewed by doctors to be reproductively dangerous for the public health and safety of the society. Doctors had the power to sterilize them by relying on stereotypes-as-arguments that these women could not control their sexuality, the disease itself and a possible accompanied pregnancy was dangerous for their health and for the fetus, and the children borne by these women would contribute to the sick population of the country. This strongly paternalist medical practice has changed and the present doctor-patient relationship is more on an equal footing; in this frame only the patient has the right to make a decision, clinicians can only facilitate decision making by interpreting the available scientific knowledge for their clients.

The discourse analysis of the historical contexts provide insight into the political, economic, and medical discussions that produce privileged and marginalized communities. In my view, the implications of critical race studies and intersectional research for the empirical work of the dissertation is that researchers must account for the material consequences that these discourses have on racial/ethnic, class, and gender based subject positions in medical contexts. Social science scholars must explore the ways structural forces such as sexism, racism, or class based discrimination act in medical discourses in favor of the privileged and / or dominant part of the population. Thus, in this regard, the stake for critical scholars is about deconstructing the structural barriers that obstruct people from getting equitable medical services and being able to live on similar health standards despite the differences that they have in terms of their cultural, religious, racial/ethnic, gender, or class based identities. Intersectional perspectives can provide tools to move beyond binary thinking of privileged or non-privileged, Roma and non-Roma, men and women in medical thinking. Intersectional analyses can reveal how racialization and gendering occur and what other social factors play a role in the establishment of social positions. Thus by exploring these constructions scholars can point towards their more complex and contingent –that is, their context dependent – nature.

Perhaps one of the strengths of doing a constructivist science study is that this approach mandates that researchers must situate themselves and their informants as knowledge producers in a broader context. The process of situating ourselves must be transparent; we must make explicit those values that we find paramount in designing and executing our research. By doing so we make explicit the values that drive our research, we imply perspectives that we use to address local questions relevant for a specific community in a well-defined historical and cultural context, and we also suggest ways to link these locally explored issues to general scientific problems. In order to write a sensitive critique that is capable of attending the complexities of local issues and avoids the positivist stance where analytic claims are presented

from a universal perspective I started my empirical work with Hungarian medical genetic research on Roma populations. Interviewing provides a method to initiate research by exploring the narratives of professionals regarding the values that underpin their work. By choosing interviewing as one of the methods, it is possible to acquire scientifically recent information and to observe through narrative analysis how geneticists structure their work along social categories such as race, ethnicity, class, or gender. And in addition to this, through such analysis it becomes evident that geneticists are not only using social categories but that, in fact, they construct these social realities through the language of genetics. Thus, medical knowledge is always the result of the interaction of social values, scientific conduct, and technological apparatus. But in order to ground the analysis of the present medical genetic discourse encumbered with eugenic ideas, it was necessary to explore the cultural embeddedness of those factors that play a role in the co-construction of medical genetic knowledge. Therefore, I comparatively analyzed how medical arguments were developed since eugenics entered the Hungarian health discourse and how target groups were constructed according to the values, beliefs, scientific results, and technological potentials of different social contexts.

3. The Appearance of Eugenics in the Hungarian Medical Discourse between 1900 to 1920

In this chapter I will reconstruct the medical discussion that took place in the first two decades of the twentieth century in which eugenic reasoning started to dominate the public health discourse. This study contributes to the discussion on liberal eugenics by claiming that the eugenic legacy of the present Hungarian discourse can be traced back to its first appearance in Hungarian medical thinking. This historical analysis is relevant for furthering the understanding about medical genetics as a field in which a deep-structure of eugenically informed decision making is present. In analyzing the relevant literature four concepts can be used to describe aspects that resonate with the present discourse. Degeneration and inheritance were connected as two sides of the same 'problem' hence it is possible, in the discussions around these, to apply the term transgenerational responsibility; this is an issue that was debated in the early discussions but it has relevance for present debates as well. In addition to this, moral considerations were important for population management in the way state responsibility was viewed; though this has shifted towards individual responsibility. Interpretations of disease and risk groups can also be used to compare the two historically distant medical discourses, thus I looked at how industrialization, poverty, class identity, and gender shaped the targets of medical intervention. And lastly I analyzed how reproductive rights had changed where identifying risk groups were concerned and how individual rights were subordinated to state interests. In this regard I looked at how the medical discussion had changed concerning tuberculous pregnancies.

In this work I do not analyze the institutionalization of eugenic values into various medical spheres, nor do I connect eugenic discussions to law-making; my main interest lies in

exploring how individuals with different professional backgrounds contributed to the consolidation of eugenic thinking in public health. This process is relevant for the present, because these arguments reappear in slightly different forms in the contemporary medical arguments presented by geneticists during the fieldwork interviews that I conducted during my fieldwork. I think one of the central questions that I have is how citizenship is shaped by medical actors who played a key role in defining which bodies were valuable from a medical-political perspective and how they should be influenced to become responsible citizens. Maria Björkman (Björkman, 2015, p. 491) suggests extending the use of the concept of biological citizenship – developed by Carlos Novas and Nikolas Rose (Novas & Rose, 2000) – by exploring how collective responsibility was influenced by eugenic and racial hygienic ideas in the past. In the discussions that took place in the first two decades medical professionals contributed to the articulation of a very repressive and exclusionary discourse that defined individual responsibility in terms of a racial future. Drawing on the work of Björkman, this development can be viewed as an early attempt to influence medically and biologically responsible decision making. Thus, the exploration of this question contributes to a historically more sensitive understanding of whether contemporary medical genetic studies and medical geneticists by their research bring about an emancipatory medical science or re-connect to a repressive biopolitical logic articulated at the turn of the century.

Critical scholarship has been published regarding the development of medical sciences around the 1900s. Kinga Szűcs for example studied the German medical influence on Hungarian medical thinking and practice (Szűcs, 2003). Marius Turda has published extensively on the developments of Hungarian eugenics and its fusion with a racialized nationalism (Turda, 2003, 2006a, 2007, 2010, 2013, 2014). Emese Lafferton has contributed to this discussion by pointing out the intertwinement of racial ideology with national politics in the disciplines of ethnography and physical anthropology (Lafferton, 2007, Buklijas &

Lafferton, 2007, Lafferton, 2016). In my understanding the dominant race concept in Hungary at the time was centered on the ethnographic view of race – it was culturally understood – but this perspective had biological and medical consequences as well, and thus the dominant understanding of race marginalized the ethnic others who exhibited various other cultural traits. Although explicitly racial discourse in this early period was not directed against other racial groups, the focus of public hygiene and eugenics was on the development of Hungarian health standards, hence implicitly marginalizing the health interest of other ethnic communities.

Studies were written regarding the continuities of eugenics between the pre-First World War and interwar periods as well (Farkas, 2012; Kund, 2012, 2016). And Gábor Szegedi (Szegedi, 2012, 2014) studied the development of the marriage counseling institution from the 1920s to the 1950s regarding the management of venereal diseases. Szegedi also pointed towards a eugenic logic that could be traced back to the pre-First World War medical discourse from the socialist period. Through this work, I contribute to this scholarship by exploring how eugenic reasoning became embedded in medical decision making by studying discussions of gynecologic practice. I chose to focus on gynecology, because through their work, obstetricians, gynecologists, and physicians acted as 'gate-keepers' whose medical gaze and consequently their decision making was shaped by what they internalized about gender, class, and race/ethnicity. They rationalized that their medical responsibility entailed revoking reproductive rights from those patients who were defined to be 'unfit' for further reproduction if they were placed in risk groups identified along the lines of gender, class, race, and degeneration.

In order to map the fusion of these discussions I relied on three journals. One of the social science journals of the period most referred to by historians interested in the Hungarian eugenic discourse is *Twentieth Century* [*Huszadik Század*] which was the journal of the progressive intelligentsia in which both left-wingers and conservatives published their views

about contemporary social problems. The journal was published by the Social Science Society [Társadalomtudományi Társaság] and appeared from 1900 to 1919. I started by reviewing the most important articles that addressed issues of public health and eugenics. To further explore the discussion I reviewed the *Hungarian Social Science Review* [*Magyar Társadalomtudományi Szemle*] that appeared between 1908 and 1914 and embraced more conservative-nationalistic values. And lastly, to connect the issues raised more closely to medical discussions, I reviewed the publications of the *Medical Weekly* [*Orvosi Hetilap*, published from 1857 to 2006] in the relevant 1900 to 1919 period. In all of the journals I was interested in the contributions were from medical professionals (people who were trained in medical universities) but sometimes I included the views of others when the discussion was still open (such was the case with the Debate on Eugenics [Eugenika Vita] published in *Twentieth Century*, or the reviews of the Hungarian public health statistics). This is because my aim was to trace the reasoning of medical professionals in viewing public health problems more and more as issues that needed answers approached from a eugenic point of view. I claim that by 1914 the dominant understandings of public health issues were eugenically informed and affected medical decision making. The most threatening problems such as tuberculosis, syphilis, and alcoholism were connected to reproduction through the dominant scientific understanding of inheritance. During the First World War discussions were about population losses and how the previously listed diseases could affect the quantity and quality of the future generations. The foundations for a race-hygienic discourse were laid and the interwar years were about the struggles to implement eugenic ideas into various medical institutions.

3.1. Personal Health Issues Getting Reframed as Racial Degeneration in the First Decade of the Twentieth Century

In the beginning of the twentieth century fertility rates provided important statistical data that helped professionals channel the discussion toward reproductive medicine and race-hygiene. In the reviews of the year 1904, birth rates of various ethnicities were compared with each other. The conclusion was that the natality rates of Serbs, Ruthenes, Slovaks, and Germans were the best (Széll, 1906b, p. 786). Death rates were reviewed in terms of their causes. Contagious diseases were the causes of 25.4 % of the total number. What was emphasized is the seriousness of tuberculosis because it accounted for more than half the deaths caused by contagious diseases. The medical and political focus was on the development of ethnic Hungarian birth rates because of the perceived threat that other ethnic minorities represented for Hungarian domination. Fertility rates provided assurance in quantity but it was also an indication for good health conditions of the society. The most important problems listed by Ignác Széll⁴ in his earlier review were communicable diseases such as typhoid fever and tuberculosis. The review had shown that one of the most urgent matters was to find public health responses for such widespread medical issues (Széll, 1902, p. 96). In 1904 the Ministry of Internal Affairs further supported the movement that was concerned with the development of public health standards to counter tuberculosis. The most important focus of the movement and the accompanying provisions were about the development of housing possibilities for the poor, the working class, and servants (Széll, 1906a, p. 755). The discourse on degeneration revolved around industrialization, bad environmental conditions, contagious diseases, and the inheritability of those negative changes that these factors *probably* caused in the human body.

⁴ Ignác Széll (1845-1914) was the minister of home affairs (Vas Megyei Levéltár, 2010).

This was emphasized by Gyula Donáth⁵ as well who thought that the primary cause of degeneration lies in the nature of modern states; societies can be characterized according to him as follows: unregulated working-hours, existential issues, poverty – a problem among the members of the lower classes – and narcotics (alcohol, morphine, cocaine); these last-mentioned present a problem for the members of the higher classes. Drawing on the works of Schallmayer⁶, he detailed the problems of alcoholism from the perspective of race-hygiene with a special focus on reproductive race-hygiene. According to Schallmayer the most important task of reproductive race-hygiene is to obstruct the reproduction of those whose germplasm had degenerated as a result of alcoholism, syphilis and other diseases; and on the other hand, race-hygiene must aid the reproduction of those with excellent biological characteristics (Donáth, 1906a, p. 677). Thus, Donáth suggested that alcohol consumption should be banned because it negatively influenced the biological future of the race. To assure his readers about the value of his anti-alcoholism position, he discussed the connection between alcohol consumption and tuberculosis (Donáth, 1906b). He drew on the works of English and French physicians who warned about the growing rates of tuberculosis with the spread of spirit production. He emphasized that tuberculosis was one of the most significant causes of death in the country, thus it would be useful to work out ways to counter alcohol consumption systematically.

Besides the fertility rate of the population and the premature death of newborn children was seen as a central health issue. This fertility discourse fused with eugenic ideas only got stronger during the First World War. But one of the directions that medical professionals and public health officials suggested early on was the improvement of mid-wifery. In this connection there were two important steps that they made: (1) institutions were established in order to train midwives certified as such by the end of their training and they had received

⁵ Gyula Donáth (1849-1944) was a neurologist and university professor. He was the chief-editor of the international *Epilepsia* journal (Kenyeres, 1994d).

⁶ Wilhelm Schallmayer (1857-1919) was a German race hygienist (Darwin, 1939).

grants on condition that they moved to locations where there were no midwives working previously. And (2) a directive was made to organize practical trainings in hospitals for auxiliary midwives who would be better trained than informally trained mid-wives⁷, but less well trained in comparison to certified midwives, whose training was organized in accordance with the medical knowledge of the time. Thus, they would be of crucial help, where there were no certified mid-wives and no physicians who could help in the process of pregnancy (Széll, 1902, p. 97). Structural changes both in training and in practice were understood to be necessary to get better results in newborn healthcare.

The wider professional public accepted the protection of newborns and the training of midwives but there was another side to this issue. For example, in gynecologist Gyula Pfeifer's view, unless mothers were protected it was impossible to obstruct the negative tendencies of depopulation (he linked the death-rates and birth-rates of the population together and emphasized the problem even more by doing so, but generally he contributed to the discussion on improving birth rate statistics). He understood the issue of protecting mothers to be of economic, social, national, and hygienic importance (Pfeifer, 1909a, p. 434). One of the class-based gender problems that hindered healthy reproduction was an issue that affected primarily unwed-mothers and working-class mothers who had to work until the day of childbirth for financial reasons. Thus, Pfeifer suggested that institutions (refuges) be established for mothers who could not afford to stay in hospital for the last months before giving birth. He argued that it would not only be beneficial for the mothers but also for the state since it was proven that the protection of the fetus while it was in the womb improves the quality of development of a newborn child. It was understood by international scholars that not only the amount of time that the fetus/child stays in the womb plays a crucial role but the quality of life that mothers can live

⁷ These mid-wives were referred in Hungarian as 'cédulás bába' to distinguish them from the medically trained ones.

improves the health of newborn children. Those mothers, Pfeifer reasoned, who worked until the last minute before giving birth in comparison to those who could stay in refuges, gave birth to children weighing 300 grams less on average (Pfeifer, 1909a, p. 435). This argumentation is important because public health discussion gives space to the interconnection of class interest, gender and race fused with eugenic thinking. In this frame mothers are the primary concern in the improvements of the health standards of the race and institutional responses are needed from the state in order to facilitate healthy reproduction. Thus, in Pfeifer's view, state response should focus on three areas: (1) establishing refuges following international examples (like the French practice, that he mentioned); (2) training nurses who take care of puerperal mothers in these institutions; (3) and improving the number of educated midwives since the lack of them is the primary reason why so many women die while giving birth.

Perhaps the most important early outcome of such discussions was the establishment of The National Association for the Protection of Mothers and Newborns in 1908 and it started its work in 1909 in Budapest (Pfeifer, 1909b, pp. 450–451). The aim of the association was to extend care work in the whole country with the intention of creating safe environments for women who were about to give birth (1-2 month pre-birth), or were at the time of giving birth or were in their puerperal period. What they wanted to ensure was the quality of the environment since they understood that this largely determines the development of the fetus. In addition to these refuges the association campaigned to ensure that working mothers could feed their newborns for 8-9 months. It was understood by them that the cause of protecting motherhood and newborns stands on common grounds: the maintenance of the reproduction of the race.

In the first decade of the twentieth century the dominant discursive position was that death statistics of the population were the best index of the health of a country. Jenő Barsi, who was a physician, in contrast to this previously stated dominant position suggested in his article that live birth statistics should be taken as the most important indicator, since death statistics

themselves are dependent on the rates of live-births per year. From this insight, he suggested, it follows that it is best to place emphasis on natural reproductive rates; so, he wrote that if there was a serious governmental intention to improve these statistics then the state should put more effort into controlling the live-births of the population. He further suggested that the idea of raising the number of live-births should be abandoned, and instead medical efforts should focus on reducing the ever-growing number of stillbirths (Barsi, 1909, p. 222). He strengthened his argument by drawing on statistical data showing the decreasing birth rates since the 1880s and claimed that in comparison to the ethnic Hungarian's reproductive statistics the birth rates of the Wallachian population showed a rising trend. His explanation was the following: (1) there was stagnation in the rate among the members of the reformed church, and (2) was the decreasing reproductive rate among city dwellers (Barsi, 1909, p. 223). He claimed that regarding the health standards of the cities, one part of the problem was that the health of the incoming population assimilated to the lower health standards of the city dwellers and these lower hygienic conditions obstructed reproduction; the other part was the hardships of life that placed a heavier burden on the shoulders of city dwelling women than on those of the rural women, so these environmental issues weakened them in their most important profession: motherhood.

Barsi was convinced that the reproductive domination of ethnic Hungarians must be secured because otherwise the reproductive rates of other ethnicities would overtake their numbers. In his understanding to develop the factors that improve the health standards – death rates and birth rates – it was necessary to manage two factors: (1) contagious diseases; and (2) child mortality rates. According to him, it was vital to increase the number of general practitioners in villages throughout Hungary in order to reverse the trend of child-mortality rates – accordingly to the statutes of the XIV. paragraph of the 1876 public health law (Barsi, 1909, pp. 223–224). (He further explained that there was a distrust of physicians on the part of

the rural population and it would not change unless regular free physical examinations were made available to these communities.) Thus, similarly to Pfeifer, he endorsed child and mother protection, and in addition suggested developing medical responses to contagious diseases. In Barsi's work, the most important lenses through which he saw the reproductive health problems of Hungary were gender, class, and ethnicity.

3.1.1. Eugenic Ideas Entered into Public Health Discussions

Regarding the explicit connection of individual health, inheritance, economic cost, and state interest in health management in the first years of the Twentieth Century already medical researchers presented arguments that were based on eugenic ideas. Here I will use three ideas and explain how they are connected to race. First alcoholism was addressed similarly to other European medical discourses, and roughly at the same time, using the same logic, diseases as such, were reframed as state issues, and by the end of the decade tuberculosis was attached to this racial discourse. In this eugenically informed medical discourse, Alcohol consumption was understood as a by-product of modernization and certain groups were particularly at risk of the negative effects of it. This risk came to be understood in this discussion as a racial risk for the citizens of the state, thus state measures should be introduced to tackle the accompanying problems. Ernő Moravcsik⁸, who was a psychiatrist and who was teaching at the medical university in Budapest, for example explained in what ways alcoholism was an increasing problem. His emphasis was on the idea that alcohol damages the individual but also it has negative effects on society. The individual (body) could be less resistant to alcohol abuse if there was an inherited disease, either mental or physical, which affected the person negatively,

⁸ Ernő Emil Moravcsik (1858-1924) was a professor of psychiatry. He became an expert psychiatrist of the Royal Courthouse of Budapest from 1887 (Kenyeres, 1994j).

or he added, the physical damage that the brain endures also contributes to less resistance to alcohol (Moravcsik, 1900b, p. 332). He claimed that alcoholism affects the progeny through inheritance so that they are less healthy both physically and mentally. He further claimed that among the descendants of alcoholics it was observed that there would be more who could become epileptic, hysteric, feeble-minded, insane, or at least, he added, they would give birth to less resistant, more vulnerable offsprings (Moravcsik, 1900b, p. 334). Moravcsik argued that the state has a responsibility to control alcohol abuse by prohibiting the sale of alcoholic drinks with a high amyl alcohol content such as spirits. Similarly, to this position, Lajos Hajós⁹ also argued that disease as such was not a personal issue but a social problem that demanded state action.

In his four-part piece Hajós set out an argument from the standpoint of psychology on the importance of health prevention for the benefits of the whole society (Hajós, 1901a, 1901c, 1901b, 1901d). He claimed that diseases were not only biological and individual problems, but they were pressing social issues. Diseases do not affect only individuals but they affect the whole society for a number of reasons: diseases do passive damage to the society in the sense that those individuals who are suffering from a disease cannot contribute to the well-being of the society, therefore their work, and even their healthcare is a 'burden' for others in the society. It was also noted by him that diseases are important from the perspective of inheritance, not only are contagious diseases dangerous for the population but inheritable health problems are a risk factor in the control of reproduction. As tackling diseases was crucial for the increase of the population, disease was seen by him as the precursor of death in the present, and it was a key factor that limited the quality and the length of the lives of future generations as well as their employability. The whole argument of Hajós revolved around the economic loss and

⁹ Lajos Hajós (1870-?) was a physician and university professor specialized in mental illnesses and psychiatry (P. T. Nagy, 2013).

burden that comes with diseases and around the problem of inheritance which was also linked to the economic productivity of future generations. Hajós on the one hand worked to improve the health of individuals and on the other hand advocated the regulation of public hygiene through education, religion, and directly through healthcare laws. For hygienists the most important environmental factor was poverty which was considered the cause of contagious diseases. The science of public hygiene urged the mitigation of those environmental factors which were the causes of diseases in most cases, in the expectation that a healthier environment would obstruct the outbreak of epidemics.

I want to highlight here that besides the epidemiological and transgenerational aspects of alcohol consumption, and in addition to the extension of the concept of disease from personal to socio-political concern, by the end of the first decade the medical gaze concerned with the health of the race zoomed on women's role regarding the management of tuberculosis especially in high at risk groups such as the economically poorest class. For example Dezső Okolicsányi-Kuthy¹⁰ had defined tuberculosis as one of the biggest threats to the population. He underscored that there were no barriers that might obstruct the spread of the disease but it was most prevalent in the poorest class. He called attention to the fact that if it was not treated then it could spread all through the population. He further wrote that Hungarian mothers were key in the struggle against tuberculosis because they could teach their children how to prevent the problem (Okolicsányi-Kuthy, 1909, p. 915). The risk factors that he mentioned were the following: acquired susceptibility that can be caused by other diseases, harmful professions (such as being a stonemason) or unhealthy habits (alcohol abuse), but it could be caused first and foremost by poverty (Okolicsányi-Kuthy, 1909, p. 917). He primarily pointed towards the actions that individuals could take: they must wash themselves regularly and their apartments

¹⁰ Dezső Okolicsányi-Kuthy (1869-1947) was a physician specialized in pulmonology. He became the head-physician of the dispensary at the János Hospital in Budapest from 1914 (Kenyeres, 1994k).

also, but among other things he suggested was that institutions be established which could take care of patients. Basically he argued, that women/or mothers could play a crucial role - besides the physicians - in the process of defending the nation from this dangerous and deadly disease. They would educate their children and keep their family homes clean so that their environment would not provide fertile ground for bacteria. Thus, in this understanding tuberculosis was viewed as a public health issue, it was underscored that the whole society's health is at stake, and women could contribute to health protection by managing the private sphere.

3.1.2. Science of Hygiene and Knowledge Dissemination: Issues of Race, Gender, and Class

Issues of race, gender and class were connected in the discussions that addressed methods of developing public hygienic conditions in the country. Regarding this problem, the lower classes were understood as the most vulnerable to health problems because of their lack of knowledge and economic resources to create a hygienic environment and women were viewed as primary actors in the struggle for better health conditions because they were responsible for their home and for the rearing of future generations. They not only took care of their closest environment but they could contribute to the dissemination of knowledge by teaching their children how to live hygienically. Thus, racial health depended on women's role in knowledge dissemination, their conscious reproductive decision making, and also on the state's role in the management of the lower classes.

Perhaps the most concise discussion that addressed public hygiene and knowledge dissemination took place at a Public Health Meeting of the Hungarian Social Science Association and the minutes were published in the *Hungarian Social Science Review* by Farkas

Heller¹¹, who was an economist and chairman of the association. The association was interested in inviting speakers from different walks of life like politics, science, and religion. During the first year these speakers contributed by their lectures to the shaping of the public perspective on public hygiene (Heller, 1912d, p. 430). These lectures were so popular among the elite that the audience always filled the lecture halls. The discussed issues were represented from a medical perspective by: Ödön Tuskai, László Detre, Dezső Okolicsányi Kuthy, Miksa Schacter, Zsigmond Gerlóczy, Adolf Havas, and Henrik Pach (Heller, 1912d, p. 432). In the following I will reconstruct the main arguments. In these edited written minutes of the talk the presenters placed emphasis on the role of women as primary practical hygienists of the state and suggested state interventions to raise the health standards of the poor and thus those of the whole society.

Emphasizing the need for a science of hygiene in Hungary and also for the dissemination of hygiene related knowledge was important for others as well. A legal scholar Jenő Gaal¹² made the point that without the right social mindset a society cannot practice hygiene adequately. But also, he pointed out, the right mindset meant an approach to each other, to our fellow citizens, that is based on love (Heller, 1912a, p. 155). It was not an argument, at least on his part, that would advocate coercive social-legal measures to enforce hygiene. On the subject of education, Gaal argued that, women need more education in the subject of hygiene because they are the primary hygienists of the society ('practical eugenicists' in his words). Education about hygiene must start in the family and women are at the center of the family regarding such issues, thus it is in the interest of the state to introduce programs that would ensure that they teach the right knowledge to their children. Another issue mentioned by him was the tension

¹¹ Farkas Heller (1877-1955) was an economist university professor at the Budapest University of Technology and Economics, and a member of the Hungarian Academy of Sciences (BME, 2018).

¹² Jenő Gaal (1846-1934) was a legal scholar, economist, and university professor. He was a member of the Hungarian Academy of Sciences (Kenyeres, 1994g).

between the classes regarding the insufficient education of the lower classes, and thus their incompetence in understanding the value of personal and public hygiene. Gaal thought that the task of disseminating knowledge and resources must be the responsibility of the higher classes who could afford to deal with such issues and have a good understanding of social and health problems resulting from inadequate healthcare (Heller, 1912a, p. 156). He also touched on the issue of governance as there is no development without systemic change regarding the legal and public administration activities of the state. In the discussion, Gaal said, that there was no difference among human beings in the Hungarian state regardless of their language or race, but he stated that it was important to aid the development of the Hungarian race first and foremost (Heller, 1912a, p. 159). He did not see any conflict in putting Hungarian health interest first by framing it as the most important racial need of the society.

In general the directions suggested by Gaal were supported by the speakers, Leó Liebermann¹³ for example agreed with Gaal in the following issues: he thought similarly that hygiene was a class problem, (educated members could recognize the importance of hygiene and be proactive whilst uneducated people from the lower classes were busy with other things in life and they did not have economic resources to be proactive). He also agreed with Gaal on the question of the education of women regarding hygiene. He argued that women should be scientifically trained for their profession (Heller, 1912a, p. 160). Lajos Ilosvay, who was a chemist, agreed with the previous presenters, that hygiene was primarily a class issue. It was not much of a problem where people had economic resources to act in a way that conformed to the science of hygiene (Heller, 1912a, p. 164). He also stressed solidarity as the basis for any future action that would have supported the will to create standards in public hygiene. He also

¹³ Leó Liebermann (1852-1926), physician, chemist, and hygienist. He was the first scholar, who started research in the field of biochemistry in Hungary. He worked as a public health professor at the Medical University of Budapest between 1902-1926 (Bakos et al., 2018).

thought that women were the primary elements in a system where hygiene based actions was to be preferred.

Educational reforms regarding distribution of information about hygienic practices were supported by other discussants; György Lukács¹⁴ even suggested that this should start early in the primary schools. For this, to achieve any result, it was necessary to educate primary and secondary teachers in the course of their university studies so that they could educate children when they worked in their schools. In addition to this, he suggested establishing a general network of school physicians who could monitor the well-being of children (Heller, 1912a, p. 167). Regarding the problem of the education of women, Lukács agreed with the previous speakers on their role in enhancing the health standards of the population, he distinguished three sub-problems: (1) general health information, which can be distributed in schools for women too; (2) the hygiene of women and mothers; (3) the hygiene of newborns and the hygiene of childrearing. In the latter two, Lukács noted problems regarding information dissemination. He thought that the problem was gender related: female physicians should take part in the education because the subject itself makes women uncomfortable in discussing sex related issues with male physicians. But this would have answered only a small part of the problem therefore he suggested the distribution of information in other ways as well. For example, he said that health trainings should be organized following the example of the National Public Health Institute that organized this training in Budapest, Lukács thought that this should be regularly organized in the countryside as well. He especially emphasized the impact that education in hygienic practices regarding newborns and children could make in the overall health standards of the nation, therefore these should be organized in hospitals, orphanages, and in midwifery schools (Heller, 1912a, p. 169). Augusztá Rosenberg¹⁵ also supported the intention to work out methods

¹⁴ György Lukács (1865-1950) was a legal scholar and a member of parliament (DKA, 2010).

¹⁵ Augusztá Rosenberg (1859-1946) teacher, feminist activist and vice-president of the Hungarian Women's Association [Magyarországi Nőegyesületek Szövetsége] (Szapor, 2017).

that would help women to learn about issues of personal and public hygiene. She also believed that educated women could play a key role in decreasing newborn mortality rates and in order to achieve that they should be educated not only about public health but also about how to avoid any contagious disease and how to recognize and aid the treatment of tuberculosis patients (Heller, 1912b, p. 246). In addition to these directions, she also said, that it would be desirable to introduce legal measures that would make it mandatory for couples who are about to marry to get themselves tested for venereal diseases and to obtain a certificate of their health status. This was considered by her to be highly important for the future of the family and the race (Heller, 1912b, p. 247). Individual interests were subordinated to racial/ethnic interests and it was emphasized by the presenters that state regulation and systematic responses were necessary for any positive change.

Legal measures were understood in this discussion as central in controlling the health of the population. Ernő Deutsch closed his talk with the claim that modern health meetings must take into account the scientific advances in modern biology and make the enhancement of the race a priority of the state's social hygiene policy. Race hygiene must be central in these social-political efforts (Heller, 1912c, p. 341). Ottó Pértik, who was a university professor, stated that the success of public health efforts to lessen the impacts of tuberculosis and sexual promiscuity without state sanctions is impossible, therefore he said, it is necessary to limit personal freedom in order to achieve progress in this field. An example of such an eugenic sanction would be to make it mandatory to obtain a health certificate for every couple who is about to marry (Heller, 1912c, p. 350). Dezső Okolicsányi Kuthy supported the standpoint that matters of hygiene should not be left to individual will, but should be managed by the state (Heller, 1912c, p. 357). Adolf Havas¹⁶ suggested that society should treat the willing infection of another person with

¹⁶ Adolf Havas (1854-1917) was a physician and university professor specialized in dermatology and venereal diseases (Kenyeres, 1994i).

venereal disease as a criminal offense, and also he thought that it would be very useful to introduce mandatory screenings before marriage. He said that it is mistaken to see venereal diseases as private problems thus individuals must recognize that their disease is potentially a public health issue and manage it consciously to avoid further infection (Heller, 1912c, p. 359). Heller saw the issue of public hygiene as a problem that is class related. The bad living conditions of the lower classes affect the members of the higher classes therefore it is vital that health issues be dealt with in a broader social context. Unless the social economic situation and the education of the lower classes changed there would be no progress in the question of hygiene (Heller, 1912c, pp. 361–362). Henrik Pach, who was a physician, also suggested that public health could only be advanced with social provisions.

In the following year in 1913 Ödön Tuskai¹⁷ contributed to this discussion with more explicitly eugenic arguments. He started out from the idea that culture or cultural development is the root cause of many health issues (tuberculosis, eye problems, venereal diseases, nicotine addiction, arteriosclerosis¹⁸ etc.). He made the claim, that it was perhaps true to argue that healing sciences work against natural selection, but it is not true in the case of hygiene. Hygiene was understood by him as the science of prevention, thus he thought that hygiene was compatible with eugenics because it could aid state efforts to avoid the 'degeneration' of the population (Tuskai, 1913, p. 57). He further elaborated his standpoint about the relationship of eugenics, hygiene, and the state in a way that made education and the integration of knowledge about hygiene the most important task of the scientifically and technologically developed state. He argued that instead of choosing a negative eugenic path – such as sterilizing the 'unfit' criminal and sick elements of the society – the state should be able to integrate the ideology of hygiene into its various institutions so that it could serve as a 'model of natural eugenics'.

¹⁷ Ödön Tuskai (1863-1945) was an obstetrician and gynecologist (Gracza, 2016).

¹⁸ Arteriosclerosis: "a chronic disease characterized by abnormal thickening and hardening of the arterial walls with resulting loss of elasticity" (Merriam-Webster).

3.2. Diversity in the Interpretations of Eugenics in the 1910s

Marius Turda explains the establishment of various societies which were concerned with the application of the results of eugenics to Hungarian society. In this process, the first step was the Debate on Eugenics [Eugenika Vita] in 1911. As a result of the coming years to 1914 and the beginning of a shift to the right-wing political ideology, the Committee for Racial Hygiene [Egyesületközi Fajegészségügyi Bizottság] was established. According to István Apáthy¹⁹ the establishment of the committee was advocated by the Royal Medical Association of Budapest [Budapesti Királyi Orvosegyesület] and the Association of Public Health. The committee extended its profile and changed its name in 1917 to Hungarian Society for Racial Hygiene and Population Policy [Magyar Fajegészségügyi és Népesedéspolitikai Társaság] (Turda, 2006a, 2007). The physicians actively took part in the formulation of eugenic ideology and its fusion with public-health policy. The fact that the physicians played a major role in setting the agenda of the eugenic movement makes it necessary to explore their professional contribution to the ideology of Hungarian racial hygiene. Furthermore, by exploring the heterogeneous views of medical professionals on eugenic ideas we will get a more nuanced picture of how eugenic values were integrated into medical practices.

In his article published in 1910 József Madzsar²⁰ presented an interpretation of eugenics that was in contrast to conservative-humanist discourse that saw the direction of social developments in technological advancements, public hygiene, education, and in positive economic changes. He argued, contrary to these directions, that the scientific knowledge on

¹⁹ István Apáthy (1863-1922), zoologist, university professor, corresponding member of the Hungarian Academy of Sciences (EMEK, 2011).

²⁰ József Madzsar (1876-1940), trained physician, who later in his life became a left-wing radical activist and politician. Active member of the anti-alcohol movement. He was the chairman of the Social Science Society (DKA, 2015).

inheritance proved that changes in the environment or education would not advance the well-being of the Hungarian race. He claimed that it was proved that certain diseases were inherited with the germplasm therefore there was no room for change in the lifetime of the progeny. Although Madzsar did not see selection of the ‘unfit’ as a viable option in his own time, he urged that at least the sterilization of the ‘unfit’ should be institutionalized with the positive assistance being given to the ‘fit’ to reproduce (Madzsar, 1910, pp. 115–116). Zsigmond Fülöp²¹ introduced the „new science of eugenics” for the Hungarian readers of *Huszdik Század* in a later issue but in the same year (Fülöp, 1910). He set out the goals of eugenic thinking, and he explained in this piece the biological knowledge that eugenicists relied on at the turn of the century. He briefly noted that this science was relatively new, it was introduced in Britain for the first time by Francis Galton approximately ten years before the appearance of Fülöp’s article. He used a couple of definitions to identify the main tenets of eugenics but he found the most useful the definition of Erich Becher, a German philosopher and psychologist, who claimed that eugenics is the science which aids humanity to become physically stronger, to gain outstanding mental capacities and in general to be born with better characteristics (Fülöp, 1910, p. 161). Fülöp contrasted the importance of quantitative data with qualitative data and argued that ‘eugenetics’ was crucial for future generations because the population increased as a result of cultural development, but this also pointed towards qualitative problems regarding the genetic stock of the population. He interpreted this as a simple result of human control over natural selection (the weaker can survive as a result of medical intervention), but he also noted that this must be replaced by artificial selection to improve the quality of the population. The amount of empirical evidence, argued Fülöp, supported the introduction of ‘eugenetically’ motivated social politics. Eugenics was posited as a social ‘necessity’ because of the large-scale industrialization of societies and also because of the degenerative effects of contagious diseases

²¹ Zsigmond Fülöp (1882-1948), translator, editor, professor, and natural science writer (Kenyeres, 1994f).

such as tuberculosis and venereal diseases, thus the focus was more on negative measures not enhancements.

International examples (from France and Switzerland) were used to prove the increasing numbers of degenerates in those countries and to argue that those same problems would appear in Hungary as well – it was only a matter of the development of the welfare state. For him, the problem lay within the political ideology of the welfare state. He claimed that as modern states developed, they transcended the process of natural selection, but the problem Madzsar wrote, was that modern social structures did not introduce artificial selection mechanisms to improve the health standards of the population (Madzsar, 1911). Thus, for him it was necessary to acknowledge that both social and health problems are inheritable problems – he discussed criminals, the mentally handicapped, alcoholics, hemophiliacs, and patients with diabetes and tuberculosis from the same perspective. Which meant that improvements could be achieved only after the acceptance of such a common stance.

By 1914 eugenics and hygiene were somewhat conflated by the contributors, but perhaps Géza Hoffmann's²² suggestion stands out. He proposed, following Apáthy, to use the German Rassenhygiene as the starting point in understanding the science of eugenics and he suggested the use of race hygiene [fajegészségügy] as the Hungarian equivalent of the term. In this understanding, it was the business of race hygiene to understand, locate, and take social-hygienic measures against those who were deemed 'unfit' or 'unworthy' for reproduction from the perspective of the health of the race (Hoffmann, 1914, p. 97). It was basically its task to select out the bad elements and help the reproduction of the good, and because of this aim the fertility rates of a society were necessarily linked with the practices of eugenics.

²² Géza Hoffmann (1885-1921), internationally acknowledged expert of eugenics, Austro-Hungarian Vice-Consulate to the United States (Turda, 2006b, p. 109).

In order to give public space for eugenic discussion and articulate a common eugenically informed stance on health problems, the Race-hygiene (eugenic) Branch of the Hungarian Association of Social Sciences was established on the 24th of January 1914. Their first meeting was held in joint collaboration with the National Public Health Association on the same day. The opening speech was given by Apáthy, who in his this talk, repeated his position on the most important direction that racially conscious hygienists could suggest to improve the future generation: to control reproduction as closely as possible. One direction in his understanding was to select those who can reproduce and prohibit the reproduction of those who are biologically harmful for the race. So he divided the steps that the state should take in the following way: (1) help medically those who want to reproduce by protecting their reproductive health, (2) detect those signs that help medical professionals in understanding the reproductive fitness of individuals, (3) prohibit the reproduction of those who were deemed 'unfit' (Apáthy, 1914, pp. 165–166).

Before the previously discussed common ground was reached the Hungarian Academy of Sciences had organized a debate on eugenics a few years earlier in 1911. In the debate leading health professionals and social scientists of Hungary presented their views on eugenics. The new 'scientific' claims of eugenics were questioned by a significant number of contributors and their doubts were articulated from the perspective of public hygiene and the laws of inheritance. These lectures were published in article format in the journal *Huszadik Század*. In the following I will reconstruct the main arguments regarding inheritance and degeneration, because this will provide a lens that will make epistemological problems of their time explicit, and thus will provide a frame for understanding how tuberculosis was tied to reproductive decision making in a medical environment.

3.3. Competing Views of Degeneration and Inheritance in the 1910s

Perhaps one of the most influential natural scientists in the eugenic discourse was István Apáthy. He defined eugenics in his lecture as racial hygiene and claimed that public hygiene and racial hygiene have much in common. The improvement of public hygiene standards is a form of eugenics; other methods are negative and positive measures to improve the quality of the population through reproduction. He placed emphasis on the number of children as a crucial aspect of eugenics serving the interest of the race because this improves the chances of giving birth to a greater number of good quality descendants (Apáthy, 1911, pp. 700–701). He argued that societies must intervene to provide equally favorable living conditions for everyone. He placed emphasis on good public health, good accommodation, nutrition, and equal possibilities for physical and mental development because in his view these factors could improve the quality of descendants through reproduction. Thus, Apáthy viewed the question of inheritance as paramount in raising the standards of racial hygiene, viewing eugenics from a Galtonian perspective.

Although Apáthy's view was strong, there were other scholars who questioned the dominant position on inheritance and its relationship to reproduction. For example, Sándor Doktor²³ discussed the scarce knowledge that scientists then had about the rules of inheritance. He argued that acquired characteristics cannot be transmitted to the next generations – therefore the Galtonian school of eugenics was wrong to place all the emphasis on inheritance (Doktor, 1911, p. 694). László Detre²⁴ also argued in his lecture that scientific knowledge is scarce on the questions of inheritance therefore it is best not to intervene since scientists are at the very beginning of their work. He argued, through numerous examples, how racial characteristics

²³ Sándor Doktor (1864-1945), obstetrician and gynecologist, between 1901-1914 he was the head professor of the Midwife-training Institute of Pécs (KÉL, 2018).

²⁴ László Detre (1874-1939) was a physician and microbiologist (E. Alexander, 2011).

disappear and transform over generations²⁵. Thus, according to him the questions of eugenics were rather class based economic issues (Detre, 1911, p. 699). László Epstein²⁶ also protested against the negative eugenic attitude towards psychiatric institutions present in the speech of Lajos Dienes²⁷, Madzsar and others. Epstein claimed that psychiatric institutions contribute to the well-being of the society since they do release healthy patients after their treatments who will become contributing members of society (Epstein, 1911, pp. 36–37). Besides this, he criticized the eugenic emphasis on inheritance, since the processes were not completely known, therefore he thought it would have been a mistake to introduce negative eugenic measures based on the scarce scientific data. Consequently, the discussion on clarifying the relationship between inheritance and degeneration was very lively in the debate because they viewed that this understanding would contribute to the articulation of the ‘right’ social-medical attitude.

In her talk for example, René Berkovits²⁸ defined degeneration in the following way: “inherited and consequently further inheritable mutations or the sum of divergences from racial types, which make the individual less valued from the perspective of the race” (Berkovits, 1911, pp. 41–42). She also questioned the recent theories about rapid and widespread racial degeneration. She argued that there are data for only two generations, and she claimed that most probably the reason behind the growing number of ‘degenerates’ was the growing population (Berkovits, 1911, pp. 43–44). She thought ‘real’ eugenic work must aim at devising ways to manage inherited biological problems and the only viable method to reach this aim in her view was selection. Berkovits claimed that social philanthropy has detrimental effects for the future

²⁵ He used examples from the United States: described through his personal experiences with American born Polish Jews whose appearance changed, just as the appearance of Hungarian peasants changed and they completely resembled American cowboys. He argued through these examples that acquired characteristics are crucial in determining the racial characteristics of a population.

²⁶ László Epstein (1865-1923), physician and psychiatrist, who worked at the mental hospital of Angyalföld, and later at the Institute at Lipótmező, both in Budapest (Fried, 2016; Turda, 2007).

²⁷ Lajos Dienes (1885-1974) was a biologist and biometrician (Turda, 2007).

²⁸ René Berkovits (1882-1944), physician and neurologist. She was a central figure in the progressive movement of Nagyvárad (Oradea) (Kenyeres, 1994a).

of the race therefore it was necessary to introduce negative eugenic measures to select and prohibit the reproduction of people perceived as ‘degenerates.’ Zoltán Rónai²⁹ provided an argument against the one-sided take on the role of germ-plasm in the processes of inheritance. He argued that research up to that time was insufficient to exclude the role of the environment. He argued in detail that biometric studies were very unreliable for predicting both physical and mental characteristics (Rónai, 1911, pp. 160–162). Rónai placed emphasis in his discussion on the role of germ poison that affects both the parents and their fetus. He regarded syphilis and alcohol as the most important germ-poisons frustrating the Hungarian eugenic efforts (Rónai, 1911, pp. 163–165). It was important for him to separate the issues of hygiene and racial degeneration because he thought that racial degeneration was caused by inheritable factors while public hygiene elevated the general health standards of the population and indirectly contributed to the racial improvement of the population. Doktor also debated the scientific truthfulness of degeneration: He argued that it was not proven that racial degeneration was an ongoing process. Furthermore, on the question of whether to intervene at the state level in order to improve the racial qualities of the population or work on the development of eugenic morals, Doktor took the latter stance. He thought that the development of eugenic morals was an ongoing process therefore the professional apparatus must work to further it. Dezső Buday³⁰ gave a conservative but supportive lecture on eugenics during the debate. He thought that the question of degeneration was not scientifically proven, but he noted that a very important aspect for eugenics was to control the spread and inheritance of syphilis (and other contagious diseases). He explained that although the disease was not among the most serious, he still

²⁹ Zoltán Rónai (1880-1940), lawyer, university professor, and politician. His works mostly appeared in the *Népszava* daily newspaper and *Szocializmus* journal (Kenyeres, 1994).

³⁰ Dezső Buday (1879-1919), jurist and legal professor first at the University of Kolozsvár (today Cluj-Napoca) between 1906-1913, then at the Legal Academy of the Reformed Church of Kecskemét (1913-1919) (Kenyeres, 1994b).

considered it a disease that needed to be tackled medically because it was still considered dangerous for the descendants (Buday, 1911, p. 32).

Those voices were present in the debate as well, who embraced racial improvement as a national goal - understood race as nation/ethnicity – but were dismissive towards eugenic laws. Leó Liebermann for example argued in his talk against every kind of eugenic measure. He discussed through the examples of Australia and the United States that criminal behavior is not inheritable, therefore it would be a grave mistake to sterilize those who do not conform to the morals of the state. On the contrary, he argued that developments in public hygiene would contribute to the elevation of health standards which would result in racial improvement (Liebermann, 1911, pp. 322–324). Dezső Hahn, who was an epidemiologist, premised his argumentation on the idea that it was in every parent's and every society's best interest to have the healthiest citizens possible. He held this position in common with most eugenicists, but in the rest of his talk he criticized eugenics as a young science which did not collect sufficient scientific data to justify a new health policy. He wanted to elevate the health standards of the society but by using the insights of public hygiene not the dubious science of eugenics (Hahn, 1911, pp. 326–327). Hahn also criticized the position of eugenicists on the idea of degeneration: the eugenic standpoint entails that as a result of cultural developments and public hygiene natural selection was not working therefore the number of degenerates who survived despite their weaknesses was growing. He thought that this was a misinterpretation of social and biological processes. He claimed that perhaps the death rates were decreasing but not in a manner which would have been acceptable. To underscore his statement, he used various examples on the effects of environment (comparative statistics on the relation of working conditions and death rates in different professions) and on the effects of germ poisons such as alcoholism and syphilis (Hahn, 1911, pp. 330–331). He explained that it was critical from a eugenic perspective to tackle germ-poisons as these affect the germ-plasm which causes infant

mortality and morbidity rates. He placed emphasis on syphilis since at that time that was the main cause of infant mortality (28 in 100 syphilitic women had miscarriages). In sum, Hahn argued that it was not practically possible to influence marriages, and also, it was not sufficiently theoretically grounded; he rather suggested that attention be turned towards germ-poisons which could practically contribute to the goal of racial improvement. That is, he supported a conservative public health approach to elevate general health standards.

3.4. Ethical Directions Regarding Population Management

For the development of eugenic morals the ideas of Apáthy shared during the first meeting of the race-hygiene society in 1914 were a culmination of the discussions that eugenicists had during the previous years starting with the Eugenic Debate. Apáthy considered it to be the most important task of society to create a social / or racial morality that would help achieve eugenic goals because racial morality should be understood as the equivalent of ethical eugenics. This ethical perspective viewed the biological and social development of the race as the most important value. In this frame the individual subjects himself/herself to the interest of the race (Apáthy, 1914, p. 166). Thus, Apáthy divided the most important tasks into five groups (Apáthy, 1914, pp. 169–170): (1) the foundation of social ethics that helps the integration of eugenic ideals into individual identities; (2) institutionalization of preventive eugenics; (3) diagnostics from the perspective of racial health; (4) prohibition of reproduction in those deemed 'unfit;' (this he classified as normative eugenics, and it entailed marriage counseling, sterilization, prostitution, and immigration control); (5) understanding the relationship of 'ethnic races' living in Hungary and governing their mixture from an eugenically informed perspective.

In the first group ideas such as education according to eugenic values already appeared in the Eugenic Debate in 1911. One early example for such a stance was Doktor's view regarding the question of state intervention in order to improve the racial qualities of the population or work on the development of eugenic morals (Doktor, 1911). He thought that the development of eugenic morals was an ongoing process therefore the professional apparatus (medical, sociological, political, and educational) must work to further this procedure. Vilma Glücklich³¹ who worked towards the protection of women and children, noted in her talk the importance of education for eugenic goals. She emphasized the role of sexual education for the health of future generations (Glücklich, 1911, pp. 324–326). She was against any state intervention into the private lives of citizens; she only supported educational methods to convince people to lead a eugenically informed and conscious way of life. I think marriage reforms and women's rights can also be grouped under the first of Apáthy's headings. László Detre noted that the most successful 'race' of all was unquestionably the American people and he argued that the reason must be their marriage policy (Detre, 1911). In the United States marriages were based on love as opposed to European traditions where dowry was a must. In the US couples decided on marriage if they were attracted to each other and loved their partner. For Detre this was one of the key aspects in the racial development of a society. Apáthy also suggested re-thinking the institution of marriage in order to provide room in the future for racial improvement (Apáthy, 1911, pp. 706–707). Péterfi argued that the success of feminist movements would also contribute to the greater number and better quality of descendants (Péterfi, 1911, p. 158). He thought that those families would be better placed to bring up their children where both of the parents were breadwinners, and when arranged marriages were a thing of the past. In contrast to this feminist position, the psychologist Epstein provided a

³¹ Vilma Glücklich (1872-1927) was a teacher and feminist activist. She was the first Hungarian woman who earned a liberal arts degree in philosophy. She was a founding member of the Feminists Association [Feministák Egyeslete] which was established in 1904 and acted as its chair. She was one of the leading figures of the bourgeois feminist movement of Hungary (Kenyeres, 1994h).

detailed argument against gender equality. He feared that with the advance of feminism and with the goals of gender equality, a similar physical burden would manifest itself on both males and females therefore he did not see this as advantageous from the perspective of racial development (Epstein, 1911, pp. 38–39). He saw the solution in social developments which would have made it unnecessary for females to take a share in public life.

By institutionalization of preventive eugenics and diagnostics Apáthy meant the integration of eugenic values into medical decision making. For this direction the discourse on tuberculosis and pregnancy serve as a good example and I will discuss it in detail in the subsequent subchapter. But before moving on to that issue it is useful to review the development of the discussion on negative eugenic measures. One of the first detailed explanations of positive and negative eugenic measures was given by Zsigmond Fülöp in 1910; he was sure that by applying sanctions a biologically enhanced population could be created.

The negative method for him was to prohibit any kind of practice that would negatively affect reproduction. And the positive method that he described was to aid the reproduction of the fittest by various institutions. The negative elements, or as he called them, the anti-selection elements, that work against natural selection, should be banned from social practice. Anti-selection elements are conscription, as in the army, and the wars that take away the strongest and fittest males from the society. It not only thwarts their reproduction, it also kills and disables many of them. He also argued against psychiatric institutions, because he blamed these medical institutions for letting the mentally ill return to society and reproduce. And he also advocated the abolition of celibacy in the Catholic Church, and mentioned the possibility of the prohibition of marriages (thus controlling reproduction) of the ‘degenerates.’ Somewhat differently from Fülöp, Imre Káldor, who was a physician, was convinced that positive measures for racial improvement were not scientifically grounded therefore they could not be applied; however, he thought that negative measures are much more applicable hence they need to be introduced in

extreme cases (Káldor, 1911, p. 158). Such cases were the eugenic management of born criminals or psychotic patients and his proposed ‘solution’ was sterilization.

Later during the First World War the discussion on positive and negative eugenic measures and their integration into social health policy became more explicit. Ernő Deutsch³² for example suggested that both positive and negative eugenic measures should be embraced (positive: help and support the reproduction of the ‘valuable’; and negative: prohibit the reproduction of the ‘unfit’). To underscore his point, he discussed how problematic it was that humanist cultures preserve those elements of the society who are worthless (he implied the blind, the deaf-mute, and the mentally and physically handicapped). Deutsch agreed wholeheartedly with Géza Hoffmann, who suggested that those who are ‘sub-standard’ should be tolerated, but that they should be prevented from reproducing in the interests of the race (Deutsch, 1917a, pp. 452–453). Deutsch thought that institutional changes were necessary to develop the society from a race-hygienic perspective after the population losses of the war. From his suggestions, I think the most important were the abolition of celibacy, and the abolition of the military officer’s bond system. He further suggested that the age threshold of marriage should be lowered because it would help the struggle against prostitution and venereal disease. In relation to the problem of marriage, Deutsch further proposed that the practice of convenience marriages should be abolished, because these marriages resulted in less valuable progeny than those of love-relationships (Deutsch, 1917b, p. 466). He compared the eugenically motivated practices of the United States – such as sterilization and internment – to Hungarian discussions about the problems addressed. Deutsch approached the issue of racial degeneration from an economic perspective and suggested that internment be adopted because of the burden that the ‘unfit’ represented for society, this way they would live according to their mental and

³² Ernő Deutsch (1872-1944) was a pediatrician. He was the head-physician of the Bródy Adél Children’s Hospital in Budapest (Kenyeres, 1994c).

physical capabilities in asylums and society would be ‘saved’ from their degenerate progeny (Deutsch, 1917c, pp. 489–490). Sterilization is the most radical way of eugenic prevention. Deutsch had explained that the previous practices that mutilated the body by removing parts of the sex organs by the time his article appeared were considered scientifically inappropriate because it affected the whole body by feminizing man and masculinizing women who were sterilized in that way. This is why Deutsch suggested that a more humane surgical method should be embraced that would not affect the health of the organism: for men vasectomy was the most scientifically advanced method and strong x-ray treatments were suggested for women.

Regarding marriage reforms, Deutsch raised the question whether coercive state regulation or eugenic education would be the most beneficial in the long term for the society. But he was in favor of giving eugenic education to state officials and priests who were involved in marriages. He thought that with the eugenic knowledge they would have they could influence the decisions making of couples in cases where they had one of the diseases which would have made their marriages dangerous. Thus, these officials would have directed young couples to get medical certificates about their health status and only with this medical certificate would have their marriage requests be accepted (Deutsch, 1917c, p. 490). He thought that societies already sanctioned marriages thus a eugenically motivated measure such as accepting marriage requests only with medical certificates would ensure the qualitative developments of the population.

3.5. Subordinating Individual Rights to Racial Interest in the Medical Discourse on Tuberculosis

In this part I will to point out how Hungarian state interest was understood as racial interest that was endangered by the possibility of the transmission of tuberculosis through reproduction therefore medical professionals articulated a response that focused on population management

at the intersections of gender, class, and the – implicitly understood – anthropological concept of race. Despite this common frame, tuberculosis was a problem that affected medical professionals differently depending on their specialization. I chose to discuss how tuberculosis affected pregnancy because the discourse conducted by gynecologists and physicians represents an aspect of the shift that took place from inclusive public hygiene to a more radical public healthcare where eugenic ideas were integrated into the decision making processes - at least at the micro-level – by the middle years of the second decade of the twentieth century. In the research articles that I reviewed social categories of gender, class, and race were implicitly integrated into the concerns of practitioners. What I want to show is how these categories were tacitly used in medical thinking to locate problematic groups and formulate procedures that deprived women of reproductive agency by reason of economic hardship supported by a stereotypical view of their uncontrollable promiscuity. Finally, I seek to show, how state interests were included in the argumentation. Some medical practitioners argued for responsible decision making by connecting individual problems to national economic and health interests.

3.5.1. Changing Scientific Views on the Inheritability of Tuberculosis

The question of how pregnancy influences tuberculosis and how tuberculosis influences pregnancy were among the hottest problems around the 1910s. Both Géza Királyfi, who was a gynecologist and József Frigyesi³³ were interested in exploring the relationship of these two processes regarding the situation of the mother who suffers from tuberculosis, and also of the fetus that might contract the disease in utero. They discussed the issue from three various

³³ József Frigyesi (1875-1967) was a gynecologist and university professor. He started his career at the II. Women's Clinic, then in 1929 he became the director of the I. Women's Clinic both in Budapest. He was a corresponding-member of the Hungarian Academy of Sciences from 1946 and in 1949 he became an advisory member (Kenyeres, 1994e).

perspectives: (1) whether it is important to intervene into the normal process of pregnancy; (2) if intervention is needed, when one should do that; (3) what kind of intervention is necessary (Királyfi & Frigyesi, 1911a, pp. 699–700). By 1911, they explained, the view that tuberculosis is a risk factor in pregnancy was generally accepted, and this is especially the case during the puerperium. Because of this existing knowledge, gynecologists and physicians advised the termination of the pregnancy on the grounds of protecting the lives of mothers (Királyfi & Frigyesi, 1911a, pp. 700–701). At the time of the publication of Királyfi and Frigyesi's article in 1911, there was a debate about whether the disease itself affects the pregnancy.

Already in 1905 Géza Királyfi had published a research article regarding the origins of congenital tuberculosis. In 1905 at the time of writing it was still being debated whether newborn children inherit tuberculosis congenitally or if they inherit only the susceptibility to the disease. According to Királyfi, perhaps the first research on this issue appeared in 1891 written by Birch-Hirschfeld and Schmörl; this supported the theory that the fetus got infected with the disease in the womb through the placenta therefore the mother gave birth to a child who was already infected with tuberculosis. They were successful in proving from the organs of the dead fetus that it had tuberculosis already within its mother's womb (Királyfi, 1905, p. 568). Királyfi contributed to this strand of research and proved the theory with similar success;³⁴ he claimed that it cannot be doubted that the bacteria that infect the fetus enters the body of the fetus from the body of its mother through the placenta. This original research is valuable for two reasons: (1) they were interested in the management of birth in the case of a serious disease such as tuberculosis that contributed in large numbers to the country's death rates; (2) and in this case, in Hungary, Királyfi managed to prove the transmission of the disease of the mother to her child. This study helped to develop a medical position that justified the indication of

³⁴ Királyfi injected guinea pigs with an emulsion created from the liver and spleen of the deceased child and observed the development of the disease and eventually the death of guinea pigs (Királyfi, 1905).

abortion in similarly serious cases. Although this was the first study published in the *Medical Weekly* about the transmission of the disease the validity of Királyfi's work was debated for another decade.

By 1914 the scientific standpoint about the inheritability of tuberculosis and syphilis was settled. Berkovits claimed that concepts such as 'inherited tuberculosis' or 'syphilis hereditaria' were outdated ideas without any scientific grounding and with recent experimental results Berkovits wrote that the decade long discussion about the inheritability of these diseases was closed. The dominant scientific view among pathologists, was that tuberculosis and syphilis were congenitally transmitted to the child by the mother (Berkovits, 1914a, p. 431). The only remaining question for her was about the disposition of newborns towards syphilis and tuberculosis. She argued that it was accepted that the alcoholism of parents or their syphilis exposed their prospective child to various health problems (such as mental disorders in the case of alcohol consumption). She was convinced that it was a similar issue in the case of tuberculosis as well; these are acquired diseases in the case of newborns even if they become apparent only years later. The only question regarding these problems was whether every child inherits the disposition, or in other words how could science explain the visible difference in children who develop and who does not develop a certain disease. Berkovits thought that the answer resides in genes (Berkovits, 1914a, p. 432). Those children who receive dominant mutations from both of their parents inherit susceptibility towards these problems while those who do not they will be healthy.

3.5.2. Conflicting Interests in the Medical Indication of Abortion

The interest of the mother was the most important reason to advise abortion in the case of pregnancy because it was observed that a woman's health quickly deteriorates in severe cases,

thus endangering her life. This logic was complemented by eugenic and paternal reasons; physicians and gynecologists argued it is in the interest of the mother and the state to effect the termination of the pregnancy in such cases because doctors were reckoned to be responsible – and thus to be in a decision making position – to control the spread of tuberculosis. I emphasize below that gender and class played crucial roles in formulating the 'right' medical procedure.

Different observations indicated that tuberculosis would result in premature birth or even in spontaneous abortion. Regarding the question of intervention, the camp of gynecologists and physicians was divided: there were those who suggested that the artificial termination of the pregnancy is best for the mother; and there were those who opposed abortion on principle (they thought that the fetus was unaffected by the mother's pregnancy and thus a completely healthy life would be terminated); and there were those who sought a middle-ground by trying to establish criteria for when the pregnancy itself endangers the life of the mother (most gynecologists considered the first half of the pregnancy to be the best time for the mother, and a radical group of gynecologists not only terminated pregnancy but also sterilized the woman) (Királyfi & Frigyesi, 1911a, p. 702). These last argued that an abortion itself is very dangerous for the life of the mother so a mother who suffers from tuberculosis must be protected from further risks. However, there were those, who thought that because people were recovering from tuberculosis, it was a grave mistake to take away the right of the woman to get pregnant and give birth later when her health would allow it.

Based on the review of international literature and their own observations, Királyfi and Frigyesi formulated a position that supported abortion only in the first half of the pregnancy – stating that in the third trimester it should only happen if the woman's life was in danger. What they added to this middle-position is how they viewed the economic factor in medical decision making (Királyfi & Frigyesi, 1911b, p. 726). They stated that even in milder cases of tuberculosis bad social environments could influence the recovery of women for the worse, so

they viewed lower social economic status as a vital indicator for the termination of pregnancy. And they also stated that in some cases when tuberculosis was severe the right of the women to abortion was more restricted because gynecologists and physicians must take care of the life of the child, since the women's lives could not be saved.

The standpoint that women's rights must be subordinated to racial interest was not shared by everyone. If we take a closer look at the stance of Vilmos Müller – who was a surgeon and the head of a tuberculosis sanatorium – this becomes evident. He stated that gynecologists must abide by the principle to protect the life of the woman when they were in a position to choose between the life of the woman or her fetus. (He cited an interesting example: he explained a situation in which the husband of the pregnant woman pressured him to try to save the life of his child when the life of the woman was in danger – Müller said that even in such cases when a man views *his own* wife solely as a 'childbearing medium' (his words) gynecologists must resist this type of objectification and protect the life of the woman) (Müller, 1913a, p. 119). He further added that the legitimacy of abortion - while the pregnant woman suffered from tuberculosis – arose because it was not scientifically settled whether the mother transmitted the disease or not. This was relevant for him, because of the quality of life that the child could live as a result of the congenitally received diseases. This explanation is an embodiment of eugenic values that was slowly integrated into the reasoning of medical professionals. After Müller had thoroughly analyzed twenty-two cases he concluded that the process of tuberculosis affected the pregnancy only in very severe cases when the symptoms of the disease suggested deterioration. He thought it was possible to establish connections between a miscarriage and the disease only in these cases and abortion could only be indicated in such circumstances (Müller, 1913b, pp. 143–144). He was convinced that with long enough treatments in sanitariums tuberculous patients with mild or average symptoms would recover, thus the medical termination of their pregnancies could not be justified on scientific grounds.

Contrary to the previous ethical directions Jenő Konrád placed emphasis on the health risks to the women and on the death rates of children born with tuberculosis. He presented the latest findings and latest medical views on the transmission of tuberculosis through intrauterine processes to the fetus. He reviewed the international literature that contributed to the understanding of the process. He argued not only that most of the professionals accepted the transmission of tuberculosis as a fact, but most gynecologists and physicians favored the most radical intervention when they were confronted with tuberculous pregnancies – they supported sterilization primarily in the interest of the women. They reasoned that women who suffered from tuberculosis were likely to die after giving birth because of the deterioration of their situation (Konrád, 1914a, pp. 641–642). He emphasized the life-prospects of children born with tuberculosis: (1) he wrote that 70 percent of children died in their first year of life, (2) and only 12-15 percent of those remaining lived up to their twentieth birthdays or thereabouts. Thus, Konrád proposed that the medical decision regarding the termination of the pregnancy and the sterilization of women should be guided by eugenic ideas and prevention. He framed his proposition as a eugenic and preventive measure because abortion and sterilization would protect the population from further infection, and thus would contribute to better health standards. The question he posed was threefold: (1) is it in the best interests of the race to prevent the birth of children with such a serious disease; or (2) should gynecologists only terminate each pregnancy without sterilization; (3) or should not they intervene at all?

Basically, he started the elaboration of his position from the shared standpoint of physicians and gynecologists: doctors working in each of these medical professions supported the termination of the pregnancy to protect the mother and avoid the ‘burden’ of further tuberculous individuals. They were divided however on the issue of sterilization. Most of the physicians were against the sterilization of the women because they observed complete recovery from tuberculosis, hence they would not have taken away the women’s reproductive

right. And this is the point where Konrád's view added a new layer to the discussion (Konrád, 1914b, p. 661). He would have sterilized all women who were from the lower classes since they would not have had the economic means to relocate themselves into healthy environments and afford healthy food thus would have never recovered from tuberculosis. Besides he added that 'these' men and women had less self-discipline in comparison with middle-class people thus their libido would have put them at in risk of termination of further dangerous pregnancies. He based his arguments on statistical data; he described the ratio of valuable lives to non-valuable lives as 10 to 90 per 100 births affected by tuberculosis. Thus, he claimed that with sterilization it was not only good for the woman (because they had the chance to recover, or at least not to die from tuberculosis) but it was beneficial for the society as well since the practice would have prevented the spread of further infection. Konrád was convinced that until major economic developments were reached, and the environmental circumstances of the poor were sufficiently developed, this radical measure was the only viable option to prevent the spread of tuberculosis.

3.5. Conclusion

One of the points that came out early on from the analysis, is the idea that eugenics was not perceived as bad at all, but was viewed very skeptically. New 'science,' new and radical ideas fused with heated nationalism and racialization and the struggle for economic and military domination over others in Hungary had been accommodated well to the progressive sentiments of the age, the only problem most scientists, sociologists, jurists, and politicians had with the 'science' was its practical applications. But eventually they had managed to link conservative public health interests with eugenic ideas by integrating them into a preventive discourse that laid the grounds for further institutionalization later in the interwar period.

Medical professionals integrated eugenic ideas into public health discussions by initially connecting individual health problems to shared health issues such as contagious diseases like tuberculosis and then used economic arguments that those who were sick represented a burden to the healthy part of society. In addition to this, they drew on nationalist/racial sentiments to the effect that those who were sick passed on biological disadvantages to their progeny, who because they would have become sick could spread disease in the society while they lived. All of this was interpreted as biological causes negatively influencing the genetic future of the Hungarian race. Thus, they suggested measures to counter these tendencies by, for example, medically indicating the termination of tuberculous pregnancies. At the same time they advocated the sterilization of working class women who suffered from tuberculosis in order to save them from themselves – from their sexual promiscuity and misguided decision making – as well as to save the rest of the society from further tuberculous patients incapable of work and a burden on the state budget.

Social scientists, politicians, and natural scientists took part in formulating the ideas that allowed a medical discourse about women from the lower economic classes ignorant of the most developed scientific knowledge about personal and public hygiene, and therefore in need of decision-making on their behalf. The backbone of this logic was eugenic thinking about racial enhancement by avoiding racial degeneration in the present. With this logic it was possible to subordinate individual interests to state (or racial) interests and allow a type of medical practice that violated the autonomy of these women. This type of thinking provoked the sensitization of citizens toward their own biological heritage and in this discourse their interest was directly subordinated to state interest. It was understood that citizens were responsible for their health in view of their common interest in the enhancement of their race.

Another significant development of this early discourse was the wish to create a eugenic morality in citizens capable of making eugenically informed decisions because they would be

able to understand that their personal interests overlapped with state interests. They would be able to make medical decisions for themselves which would advance the well-being of the 'race'. With education and structural changes eugenicists saw a future society in which citizens would 'naturally' select the best possible offspring as a result of the internalized preventive approach. In my view marriage counseling in the interwar period followed up this direction. And later in the 1970s family planning programs, and genetic counseling institutions were suffused with this eugenic logic though from a less-repressive perspective.

4. Eugenic Matters of Public Health between 1948 to the 1970s: From Contagious Diseases to Congenital Disorders

In this chapter I will look at the medical discussions concerned with public health issues from the 1950s until the 1970s. In the 1950s the most important problem was the threat that contagious diseases represented for the population therefore the aim of healthcare professionals was to significantly reduce the morbidity and mortality rates resulting from these diseases. With the introduction of vaccinations, these previously lethal diseases ceased to represent any serious public health issue for the majority of Hungarians and this was visible in the statistical data. As the genetic turn reached Hungary in the 1960s clinicians recognized the new methods of genetics can be used to understand the causes of mortality and morbidity rates resulting from reproduction. Because accompanying the success of curbing contagious diseases health statistics have shown an increase in congenital disorders and thus the focus shifted towards finding ways to develop these healthcare results. Thus, reproduction became a central concern in the 1960s and 1970s for clinicians. In the following, I will map out the shift that took place during this period to show that eugenic thinking was present in these public health discussions, and were uncritically integrated later into the medical genetic discussions regarding reproduction.

4.1. Developing Public Health Institutions After the Second World War

I want to underscore two fields that Hungarian medical professionals emphasized as central for the elevation of health standards early in in the 1950s: (1) mother and infant protections, and (2) institutional foundations of public health. Although Hungary had excellent, internationally

acknowledged medical researchers and clinicians but the country's general health statistics were among the last in Europe taking into account the country's data regarding tuberculosis death rates, infant mortality rates, or typhoid fever. István Simonovits³⁵ claimed that this situation fundamentally changed after the Second World War. He listed changes in various fields such as general healing and preventive medicine, where the system of general practitioners was changed in order to function better. The GP system radically changed between the years of 1950 and 1954 because they centralized the city, city district, village, and panel-doctor system. These changes made medical services much more accessible to everyone (Simonovits, 1955, pp. 88–89). It is important to note that Simonovits said that the preventive approach, inherited from the interwar period, was compatible with the socialist values therefore the centralization of public healthcare were executed with the aim of making healthcare accessible to everyone. The difference in the socialist approach to prevention in comparison to the capitalist approach, according to Simonovits, was that it included environmental issues as well such as the workers' working and living conditions. The socialist preventive method entailed work that encompassed public health and epidemiology, mother and child protection, but in addition to these issues it sought to develop the working and living conditions of the working class. The reason for this lies in the acknowledgement that without improving these factors long lasting change in public health standards would not happen (Simonovits, 1957, p. 308).

Simonovits recalled that the first sign of state intention to centralize healthcare occurred in the nineteenth century. The 1876. XIV. statute first paragraph stated that "public health belongs to the sphere of state governmentality" (Simonovits, 1957, p. 306). So he said that although it is true that efforts to centralize healthcare started more than eighty years ago it was

³⁵ Simonovits, István (1907-1985), physician, hematologist, university professor, undersecretary, and a member of the Hungarian Academy of Sciences.

not completed for various reasons (the capitalist approach of the Dualist period, still different approach in the interwar period, the Second World War) but in the fifties stronger efforts were made to complete the process. For example epidemiological work strongly improved because as Simonovits wrote, until the end of the Second World War there was only one institution that dealt with public health³⁶. After the war the National Institution of Workhealth (OMI) was organized, but at the same time the National Food Safety Institute was also established (OÉTTI). In relation to epidemiology the most important development was the organization of KÖJÁL³⁷ across the country in 1954. This meant that a network of epidemiological stations was established in every county of the country (basically these stations were situated in county towns) (Simonovits, 1957, p. 310). These institutes were organized around issues such as contagious diseases, food bacteriology, parasitology, water chemistry, and work health issues (Vilmon, 1955, p. 113). It was an important legal change in that previously physicians had the power only to give recommendations, in the new, socialist structure they had the right to take measures and to penalize citizens or institutions³⁸.

4.1.1. Mother and Infant Protection

Mother and child protection became one of the central medical priorities by the mid-1950s. In these debates on how to develop the institutional network that would help mothers and infants the role that the state and medical workers must play in protecting mothers and their infants was very much emphasized (Drexler, 1953). Two directions were outlined by Imre Lóránt that would contribute to better reproductive results. The first one was the law that made abortion

³⁶ This was the OKI, National Institution of Public Health [Országos Közegészségügyi Intézet].

³⁷ Translates to Public Health and Epidemiological Station.

³⁸ This is an important change that affected Roma people throughout the Socialist period as I will show it in Chapter 6.

illegal³⁹, it was understood as a crime that endangers the life of the mother and kills the fetus. In medical cases⁴⁰, when the life of the mother was in danger, abortion remained a legal option. But every miscarriage and in-utero intervention was required by ministerial statute to be reported (Lóránt, 1953, p. 71). Another important direction was to reduce the infant mortality rates in the country. To achieve this goal, the state supported the establishment of infant-care facilities. In hospitals, divisions for prematurely born children were established to support the already existing child departments. The state also wanted to achieve by 1954 the presence of nurses in every part of the country (Lóránt, 1953, p. 72)⁴¹. Thus monitoring and helping every mother and newborn child.

As a result of the regulation that the health ministry made – it extended mother protection by integrating midwives into the system of prenatal care and made it compulsory to report every pregnancy – the number of those women who appeared in pregnant counseling

³⁹ Imre Ozsváth and Sándor Radó reviewed the developments that occurred since the 1953 law that prohibited abortion (Ozsváth & Radó, 1961, p. 124). They emphasized that the law itself placed so much burden on maternity wards and hospitals that it was softened immediately in 1954 and gradually it was changed in 1956. The 1956 law (1047/1956 M.T. statute) basically relegated this right to the sphere of individuals; it was argued that women could decide best for themselves whether they want the child or not (Ozsváth & Radó, 1961, p. 121). But they also placed emphasis on the fact that the number of abortions increased as a result of the relaxed law and also because of the social and eugenic perspectives that direct the decision making of parents, and thus they argued abortion became a public health issue by the 1960s. The solution they proposed was systematically offered sexual instruction for teenagers; they agreed with the law that abortion is a basic personal right, but they also saw that women who opted for abortion were not familiar with the methods of sexual protection or they used various ineffective methods (such as irrigation with water after sexual intercourse), thus the primary task for Ozsváth and Radó was to work out methods for information distribution.

⁴⁰ Gyula Nyitray and János Asbot discussed the lack of regulation regarding abortion until 1952 June that would have helped to save the life of women in case of any health danger. They wrote that this was an issue that was up to scientific and moral convictions of doctors to decide when they consider the case dangerous to recommend and perform abortion (Nyitray & Asbot, 1953, pp. 82-83). Another problematic issue that they mentioned is the lack of clarification regarding the quality of the health problem. This practice was very problematic because in several cases women who really needed medical intervention could not get adequate help, they were forced by this chaotic system to find someone who understood their problem and perhaps similarly saw the necessity to terminate the pregnancy, and there were cases in which women ran out of time during this process and were forced to give birth. In 1952 the Health Ministry issued a statute that regulated procured abortion (81/34/1952). The statute stated that procured abortions could only be performed in institutions, it established and regulated statewide the first and second-degree committees who opinionated and allowed procured abortions. It also defined the diseases that accompanying pregnancies indicate abortions. It also allowed to the second-degree committees to decide in cases when the disease that affect the pregnant woman is not listed in the statute. In most cases tuberculosis served as the indication of procured abortions for both first and second degree committees (Nyitray & Asbot, 1953, p. 84).

⁴¹ Compared to 1938 the number of nurses more than quadrupled (from 344 to 1709) which was crucial since they help the work of physicians in ensuring the healthy process of pregnancy. It was their specific task to take care of the prematurely born, endangered infants and pregnant women. Because they worked closely with their panel-doctors (GPs) the statistics of infant mortality rates were significantly developed (Lóránt, 1955).

services grew rapidly. By 1954 more than one million women took part in these counseling services which in comparison to the 33000 women of the 1938 data is huge. The number of beds in obstetrical wards and in maternity hospitals also grew. And all of these changes resulted in a closer monitoring of pregnant women and the process of pregnancy itself, thus by 1954 the death of mothers per birth reduced to 5.3 percent per 10000 occasions (in 1945 this was 15.8 percent) (Lóránt, 1955, pp. 107–108). In a later publication, Lóránt placed emphasis on the further development of nurse system in Hungary (Lóránt, 1956, p. 114). He suggested that it would be beneficial to extend its capacity in a manner that every village doctor would have a nurse accompanying him/her to closely monitor pregnancies and infant health.

4.1.2. Institutional Foundations of Public Health and Its Results

The most important task after the Second World War was to stop the spread of contagious diseases, thus one key area of health work concentrated on issues of public health and contagious diseases (Közegészségügy-járványügy). The stations of KÖJÁL were started to be established state-wide from 1954 and by 1955 there were 24 stations across the country. In 1957 the organization of local groups that dealt with epidemiological issues was started in various districts in Budapest and at the same time in county towns (these groups were known as (Public Health and Epidemiological Service [Közegészségügyi és Járványügyi Szolgálat, KJSz]). These groups were responsible for controlling local epidemiological problems. An important structural change took place in 1968 regarding the organization when its name was changed from Állami Közegészségügyi Felügyelet to Állami Közegészségügyi-Járványügyi Felügyelet. In this new framework the duties were more precisely separated: (1) authority related and (2) other public health tasks (Kátay, 1970, pp. 86–87). The results of epidemiological work from the 1950s until the end of the 1960s were remarkable: traditional epidemiological problems

were reduced greatly in their significance. Important examples to underscore this success are the following: there was a serious outbreak of typhoid fever in 1954 which affected 158 people, but it ceased to be a serious problem after 1958 (there was no other recorded typhoid fever case after that time). Child-paralysis decreased from 1000 instances in the 1950s to 1-7 occurrences in the years of 1961-1968 as a result of systematic polio vaccinations (Kátay, 1970, p. 89). Kátay emphasized that the results were in general thanks to systematic vaccinations (polio, BCG) but also to the results of the work of KÖJÁL that encompassed activities from information distribution to environmental control.

Besides the obvious structural benefits for public health the functioning of KÖJÁL had its drawbacks as well. One of the most important negative aspects was the following: (1) they could not develop the quality of enlightening work regarding health issues, a problem that Gyula Vilmon⁴² emphasized was that the institution did not use the help of the radio, the press, and other public institutions; and (2) they did not develop the antiseptic system in the villages. This latter one would contribute greatly to the cause of public hygiene (Vilmon, 1956, p. 87). Aladár Kátay, who was a pediatrician, similarly emphasized the interconnection between epidemiology and antiseptic work. Epidemiology without the latter is not efficient. He wrote that the training of occasional antiseptic workers was completed in all counties; the problem is that their knowledge is not applied when it should have been. He further placed emphasis on one preventive method of epidemiology and this was the protection against lice. Kátay explained, that it is a very important field because without efficient antiseptic action against lice the infection of typhus would always be a constant problem (Kátay, 1956, pp. 94–95). He underscored his point by giving an example: from Budapest and Zala county where the

⁴² Vilmon, Gyula (1897-1966), physician, undersecretary of healthcare.

combined action of KÖJÁL with the police, Red Cross, and the relevant state authorities achieved good results.

In addition to these introduced structural changes, the state introduced vaccination to control contagious diseases in the 1950s. These vaccinations were against contagious child paralysis, typhoid fever, diphtheria, and tuberculosis (Simonovits, 1957, pp. 310–311). Although the introduction of BCG vaccination was a significant step in the struggle against tuberculosis, but in Hungary it remained a serious problem in the foresighted future. Dénes Mosolygó noted (Mosolygó, 1957, p. 314) that it was known at that time that because of the organized preventive work and the introduction of BCG vaccinations, in the Scandinavian countries tuberculosis started to lose its epidemiological character. The first vaccinations were carried out in 1923 and it was used only sporadically until the late 1940s. In 1947 and 1949, the state carried out a campaign in which 1.5 million people were vaccinated. The most significant development was the ministerial statute of 60/1953 in which it was mandated to vaccinate every newborn child.

Since 1949, according to Mosolygó (1957), a slow but steady development can be observed. The obstacles that he listed were in relation to mistrust by citizens towards the vaccination. This was the primary reason why the statute was enacted: it was argued by physicians that further development in the issue of tuberculosis was not possible unless vaccinations were mandatory for everyone. And another related problem was the issue of re-vaccination. He explained that mistrust and lack of medical staff was the cause of bad results in re-vaccination. He stated that to develop the medical control of tuberculosis⁴³ it was necessary

⁴³ Tibor Németh and his colleagues claimed that the public health work that aimed at finding defense mechanisms against tuberculosis could be divided into two phases: the first seventy years were characterized by passive protection, and the last thirty years were characterized by active measure such as vaccination (Németh, Nyárádi, & Vadász, 1983, p. 1309). They claimed that by 1983 with the method active protection the number of newly infected patients decreased to a yearly 5000 incidents. Ottó Schweiger similarly stated that the BCG vaccinations introduced in the early 1950s worked for children from their birth until their 15th birthday (Schweiger, 1983). After fifteen years the vaccination started to lose its effectiveness, thus revaccination was necessary. This meant that the age group between 15-50 years were considered high risk population thus their public health care were

to organize more closely the work of general practitioners, nurses, creche-, pre-school-, and school doctors, pediatricians, epidemiological medical officers, and obstetrical wards.

In a ten years' time-period significant developments were visible. Tibor Bakács⁴⁴, by reviewing the statistical results regarding the mortality rates of contagious diseases, stated that roughly 60 to 80 percent decrease could be measured in comparison to the statistics of 1953. So he concluded that the systematic developments since the end of the Second World War placed Hungary into a circle of European countries whose health statistics regarding contagious diseases could be seen as average (previously Hungary was among the least successful countries in struggling with these health issues). He also underscored that one of the best results that Hungary managed to achieve was the decrease of tuberculous mortality rates thus tuberculosis ceased to be a lethal epidemiological disease by 1965 (Bakács, 1965, pp. 385–386). As a result of these efforts, Bakács suggested, medical and economic resources could be used to tackle other important issues that had recently emerged such as elderly tuberculosis infection, and malignant tumors. And other clinicians and researchers suggested a focus on the rising numbers of congenital malformations and their possible medical management.

4.2. The Direction of Standardizing and Managing Developmental Abnormalities

As early as the end of the 1950s discussions around congenital malformations began. Alfréd Berndorfer was among the first clinicians who urged his fellow colleagues to find common ground in understanding this matter. He wrote that there are three medical aims in tackling

considered to be of high priority. They added that poverty and harmful habits such as alcohol consumption could contribute to ineffective containment of the disease. They also said that tuberculosis remained largely the problem of the elderly who were above 50 years, and mostly the new incidents of infection appeared in this group. At the same time they argued that in the recent years tuberculosis ceased to be considered by medical professionals as an everyday health issue, thus they unfortunately often misinterpret the reappearing symptoms on patients, which made it harder to eradicate the problem entirely from the population but that was their long term goal.

⁴⁴ Bakács, Tibor (1912-1977), physician, university professor.

congenital malformations: researching the cause of the disease, treating the disease, and preventing the disease (Berndorfer, 1958, p. 637). In order to become successful in tackling this issue, it was necessary to set up a department that only dealt with congenital malformations to treat, research and contribute to the prevention of these disorders (Berndorfer, 1958, p. 639). This discussion only became much more acknowledged and thus influential in the 1960s with the advances of molecular biology.

The breakthrough that the molecular level of inheritance meant for medicine was enormous. With molecular understandings the issue of inheritable diseases was placed onto biochemical grounds. György Szemere⁴⁵ distinguished three causes that could result in genetic harms: (1) mutagenic agents, (2) the pairings of recessive mutants, and (3) the change of the genetic code for some unknown reason (Szemere, 1964). Basically, he argued that all struggles that aimed at preventing inheritable genetic diseases must focus on studying these causes. Studies should focus on for example radiation (see Czeizel, 1964), or on the interaction of the human body with other chemical agents. And when pairings were at stake, genetic counseling was the adequate answer to prevent genetic disorders. And lastly, extensive studies were needed for the third issue: to understand more about the changes of the genetic code.

One of the key areas in the light of the above was the mortality rates of infants. The statistical results of Hungary were very poor in comparison to other European countries. The main problem that researchers such as Márius Hancsók and Endre Czeizel identified was fetal impairment. And they could only see development in this problem if research was focused on the different factors that could affect fetal development. The factors that they identified were microbiological causes (such as virus infections, bacterial infections, parasitological causes), alcohol consumption (they found out that coffee consumption was not harmful), smoking, AB0

⁴⁵ Szemere, György (1931-2016), medical geneticist, university professor. He founded the first genetic counseling office outside of Budapest in 1964 and he was among the first clinicians who applied the results of cytogenetic analysis in genetic counseling (see Raskó & Horváth, 2017).

blood group incompatibility, the time of conception, and pathospermia. They claimed that the knowledge produced regarding these causes could help design modern preventive measures (Hancsók & Czeizel, 1966). The development of infant mortality statistics, according to them, was only possible with extensive research regarding these factors in order to design educational and medical measures that would contribute to prevention. Sziráki and his colleagues contributed to this discussion by similarly analyzing possible causes of perinatal mortality rates. Based on the data of the Central Statistical Agency (Központi Statisztikai Hivatal) they argued that congenital malformations had a significant role. They compared their data with international statistics in which congenital developmental malformations were identified as the third most important cause of perinatal mortality rates. Thus, they claimed, that to decrease mortality rates in Hungary, it was necessary to study the various different causes of the most relevant malformations (Sziráki, Bodnár, & Szabó, 1969, p. 899). One of their key results was that they managed to consolidate the acceptance of other research results, for example, that among the various factors, the age of the mother plays an important role in the development of Down syndrome. More specifically, they claimed that after the age of 27 the incidence of Down-syndrome increases and the number triples in every 5 years (Sziráki et al., 1969, p. 901). These studies, they suggested, could be important contributions to the accepted 'modern' preventive medical principles in which the main aim was to prevent developmental malformations in utero.

4.3. Biotechnological Developments in the Management of Reproduction

Development of the field of cytogenetics started in 1963. Scholars began to appreciate the role that it could play in clinical medicine. Sándor Nagy for example emphasized that this was a new field (only three years old at the time of the publication of his article) and has relatively few contributions to make, but one of them was the discovery of trisomy 21, the tripled 21

chromosome that indicates Down syndrome⁴⁶. Nagy noted that although it was very complicated at the time to do chromosome analysis it was still a promising method for diagnostics because if systematically applied it would contribute to the detection of chromosomal anomalies (Nagy, 1963, p. 1166).

Important breakthroughs were necessary in order to accept cytogenetics as a method to help clinical diagnostics and prevention, and thus become a key tool in genetic counseling. According to Tamás Fleischmann (Fleischmann, 1967) the following breakthroughs were paramount. In 1956 Tijo and Levan discovered that the normal chromosome number in a human being is 46. In 1959, the cause of Down-syndrome was pointed out by Lejeune and his colleagues; and because previous studies managed to explain the differences regarding the role of Barr sex chromatin in various (Turner-, Klinefelter-) syndromes, following this lead cytogeneticists primarily wanted to clarify the role that pathological sexual chromosomes play in various disorders. The most important contribution of Fleischmann's review is that he spelled out the clinical consequences of the latest cytogenetic studies for clinical practice. Clinical cytogenetic studies were the most important and most rapidly developing subfield of medical genetics in the 1960s. These analytical works aimed at mapping the boundaries of 'normal human chromosomes'⁴⁷ in order to facilitate easier and quicker identification processes (Fleischmann, 1971, p. 1623). Fleischmann emphasized the significance of population based cytogenetic studies that gather data in order to help automatization and shape the focus of medical concerns in designing screening procedures.

⁴⁶ This result was published by Lejeune, Gautier and Turpin in 1959 (Nagy, 1963, p. 1162). In their own research results they analyzed cases for Klinefelter syndrome, leukemia, and polycythemia-leukemia.

⁴⁷ One of the most researched field is the comparative aspects of sexual chromosomes. Studies conducted in this field for example in the 1960s focused on the 'XYY syndrome' because knowledge regarding this problem could significantly contribute to clinical diagnosis. The theory was that tall aggressive criminals share this karyotype, so the basic question is whether these people are indictable because of their genetic predetermination towards these crimes. Most of the geneticists thought that they were not punishable precisely because of this genetic predisposition (Fleischmann, 1971).

As a result of rapid developments of genetics in the 1950s and 60s medical genetics applied its insights in many spheres of medicine, thus by the end of the 1960s it was unimaginable to have modern gynecological assistance without cytogenetic laboratory (Papp, Gardó, Herpay, & Árvay, 1969, p. 1911). Cytogenetic studies pointed out that at least one fifth of miscarriages had some kind of abnormal genetic structure. This abnormal structure can be differentiated into two larger groups: (1) gene mutations, which are molecular differences from the norm; (2) chromosome-mutations; these mutations could be the parts of chromosomes or whole chromosome mutations. The problem with these genetic mutations, they claimed was that these embryos can survive intra uterine life and can live for a short period. “These chromosome-aberrations which are compatible with life for a short period of time play role in prae- and perinatal-mortality” (Papp et al., 1969, p. 1911). The most frequent problems are autosomal trisomies with 45 percent; these are Edwards-syndrome, Down-syndrome, and Patau-syndrome. And they also refer to the problem of sex-chromosome anomalies, when their excess number (XXY, XXX) or the lack of them (X0) enables the development of abnormal variants. And sometimes sex-chromosomes develop into forms which are incapable of living (Y0). All of these could be detected researchers argued in prenatal testing thus could be prevented by abortion. In their studies Papp and his colleagues (1969, p. 1914), emphasized that newborn retardation could be caused by chromosomal anomalies, therefore they suggested that prenatal genetic diagnostics could help in screening those problems. At the same time, they emphasized the significance of pre-conception and prenatal care of mothers in order to ensure the birth of children.

The field of population based cytogenetic⁴⁸ research was not only interested in Down-syndrome but they were looking for other relatively frequent chromosomal variations as well.

⁴⁸ The strand of research called population cytogenetics that studies chromosome abnormalities according to geographical location and age groups emerged in the 1960s (Méhes, 1973, p. 2211).

One of the general criticism of cytogenetics was that it deals with 'clinical rarities' (Méhes, 1973, p. 2212). According to this standpoint, chromosomal deficiencies are not epidemiological issues. To temper this position Károly Méhes⁴⁹ reviewed the recent global statistical data and pointed out that roughly 0.5 to 0.6 percent of live births show chromosome issues, from this amount, 0.2 percent are those mutations known as Down-, Patau-, and Edwards-syndrome. Méhes compared the mean value of global literature to that of Baranya county and stated that with minimal differences (Down syndrome, and Patau syndrome were more frequent for example, while Edwards syndrome was less frequent) they had similar results, thus similar epidemiological consequences could be inferred. He emphasized here, that these results make explicit that child-mortality rates are affected but also the occurrence of these diseases place burden (though not stated explicitly, but precisely because of this, it could be a burden both economic and personal) on healthcare institutions that take care of people with disabilities (Méhes, 1973, p. 2212). He infers two conclusions as to how the results of cytogenetic studies could be used: (1) family planning should direct couples to aim at having children before the women reached the age of 32 to 35. To justify this suggestion, he drew on the literature that emphasized the significance of the age of the mother regarding Down syndrome at least since 1933 when Penrose published his findings but Méhes claimed that this is the case with other chromosome abnormalities as well. And (2) the new technology of prenatal diagnostics seemed promising to him in the work of preventing the occurrence of genetic disorders but in his time the economic and technological constraints of the society made it important to identify precisely the risk groups where amniocentesis would work best. (Méhes, among other clinicians, placed

⁴⁹ Méhes, Károly (1936-2007), pediatrician, medical geneticists, university professor, member of the Hungarian Academy of Sciences.

emphasis on the technique of amniocentesis⁵⁰ in order to ensure precise diagnosis that aids medical efforts to find inheritable anomalies with cytogenetic analysis.)

It is also important that he acknowledged the fact that cytogenetics reaches beyond the medical sphere by affecting family planning and love relationships by ‘perhaps’ influencing choices (Méhes, 1973, p. 2212). In this claim, it was entailed that this eugenic technique of the state influences citizenship understanding thus it affects how individuals view their personal contribution to the society and what they also expect from their partners as conscious biological citizens who take into account the interest of their people.

⁵⁰ New ways of fetal diagnostics also contributed to the improvement of fetal health statistics which was among the most urgent public health matters of the 1960s. Fetal death during pregnancy considerably decreased by the end of the 60s, but during the perinatal period death results were significant just as in utero and puerperal death statistics. In order to facilitate improvements in these regards it was necessary to focus on factors such as isoimmunisation, toxemia, diabetes, over-carrying, infections, and other pregnancy related diseases – the same causes were linked by doctors to infant mortality rates as well. Ferenc Szontágh emphasized in these cases that to improve the related health statistics the best method was prevention. So he listed and explained the contemporary methods that could contribute to the goals of this preventive perspective. These methods are: endocrinology, amniocentesis, amnioscopy, fetal electrocardiography, microanalysis of fetal blood, Apgar-score, ultrasound diagnostics. Within endocrinology he discussed the quantitative definition of HCG (helps in the prognosis of miscarriage and judging whether an abortion was completely carried out), the measurement of steroid release (gives information about the placenta’s functionality and helps interpreting any danger regarding the status of the fetus), and oxytocin-sensitivity test (helps defining the time of birth-giving). Regarding amniocentesis he emphasized that the amniotic fluid with precise analysis could be used for diagnostics or therapeutic purposes (and that it was relatively safe for both mothers and fetuses). Amnioscopy was an entirely safe method to diagnose asphyxia in utero. Fetal ECG was developed in 1906 to detect heart functionality and healthcare professionals integrated the method widely since then. The microanalysis of blood sample from the fetus is an important method to diagnose fetal metabolic disorders. The Apgar-score was developed to get a better understanding about the health status of infants. And lastly ultrasound diagnostics was a key development in exchanging x-ray tests to follow the different stages of fetal development. All of these methods were used in the Hungarian obstetrics practice and their most important contribution was in their possibility to improve fetal results both quantitatively and qualitatively. Thus, these methods contributed to negative eugenic aims by for example diagnosing fetal issues and justifying the medical indication of the termination of a pregnancy. But on the other hand these methods improved the health standards of those fetuses who for example were diagnosed with PKU and helped these infants to immediate access to therapeutic procedures, thus these methods function as important indicators to start a necessary healing procedure (based on Szontágh, 1968).

4.3.1. Target Groups of Medical Genetics in the 1960s and 1970s

4.3.1.1. People With Mental Disorders

Mental retardation became an epidemiologically relevant issue because 3 to 4 percent of the population was affected. This is the reason why more and more studies appeared concerning congenital mental retardation. From the various different chromosomal anomalies, the most frequent were the Down-syndrome, Klinefelter-syndrome, and Turner-syndrome (Cholnoky, Méhes, Sulyok, Farkas, & Major, 1968, p. 809). In addition to these issues, researchers were aware of the frequency of metabolic problems as well that could affect mental health (i.e. PKU or galactosemia).

In order to define more precisely the frequency of these above mentioned disorders in the Hungarian population Péter Cholnoky and his colleagues used a closed, small population sample of 140 children, boys and girls, aged between 4 to 14, who lived in a mental health asylum in Bóly, Baranya county. They concluded that in comparison to the average population, among the mentally retarded there were more intersex individuals, they also claimed that regarding other chromosome anomalies, the Turner-, and Klinefelter-syndromes were significant, but the Down-syndrome was the most frequent in their sample group. They stated that „in these cases the proof of the diagnosis is important solely regarding the patients and the families prognosis,” and they also added that the health state of those who suffer from these chromosome anomalies could also be improved, so early diagnosis could be used to help them attain a better quality of life. The scientific contribution that has epidemiological consequences was that they managed to prove that in most cases mental disorders are genetically caused thus their results indicate the introduction of statewide screening programs for both newborns and

infants (Cholnoky et. al., 1968, p. 814). They claimed that ethical and economic considerations also underscore their suggestion.

In a similar vein, László Szabó and his colleagues tried to raise attention to the genetic background of mental disabilities. They wrote that because of the increasing number of mentally disabled people their sheer number puts more strain on the country's economy thus it would be beneficial to find out what the genetic mutations were which were most prevalent in the Hungarian population and develop screening programs to help prevent mental disorders. They found chromosome-abnormalities that are directly connected to mental disability. The most frequent chromosome disorders that they mentioned were similarly Down, Turner, and Klinefelter-syndrome. In addition to these genetic disorders they claimed that by 1970 roughly 100 metabolic disorders were identified and in these diverse problems the most frequently shared symptom was mental disability (Szabó et al., 1970, p. 25). Mapping the frequency of these disorders would contribute to better results in genetic counseling. They also argued that by introducing newborn screening programs that target metabolic disorders genetic diagnostics could contribute to the prevention of mental problems.

4.3.1.2. The Body of Pregnant Women

There were numerous articles published in international medical journals about the effects of smoking on the fetus and on pregnancy in general but for Hungarian researchers it was only in the late 1960s that the effects of smoking became a focal point. Influenced by these works, László Makay and Jenő Vincze drew on these studies to compare smokers with non-smokers and concluded that among smokers more women gave birth prematurely and to newborns with less weight in general, but they also presupposed that smoking could play role in miscarriages and in other developmental malformations (Makay & Vincze, 1968). They also noted that scholars published results in the international literature that analyzed the effects of passive

smoking, such as the effects of smoking fathers on their pregnant wives, and the effects of smoking on spermatogenesis as well.

In addition to environmental effects and behavioral factors such as smoking other variables like the age of the mother were studied as well. It was widely known that the age of the mother was connected to Down syndrome as early as the first decade of the twentieth century. Lóránt Bodnár used this information as a starting point for their observations with his colleagues; they managed to prove that the age of the mother affected the appearance of congenital abnormalities. The population of mothers was divided according to their age groups and they observed that below the age of 20 the frequency of congenital abnormalities was less than 0,01 percent, while after the age of 40 the number of congenital disorders rapidly rose; but a steady growth was pointed out by them between these age groups (Bodnár, 1970, p. 625). Bodnár claimed that based on the data that they collected from 1958 to 1967 they found that most frequently abnormalities occurred in first pregnancies, after several pregnancies, and above the age of 40. In addition to the age of pregnant women the age of their grandmothers became important. Papp and his colleagues for example discussed the significance of the age of grandmothers in the case of Down-syndrome (Papp, Váradi, & Szabó, 1975). They argued that because high numbers of children born with Down syndrome were borne by young mothers so their age could not be the reason why their child had the disorder. This is why Papp and his colleagues argued that the age of the grandmother could be an important factor because she could have developed a form of mozaicism that she may have transmitted to her daughter (both of them asymptomatic) and her daughter may have given birth to a child with Down syndrome for this reason. They also posited that the role of paternal grandmother's age and the possible mosaicism from that lineage could be more significant than was previously supposed.

4.3.1.3. Focus on Male Infertility

Of studies that started out from a focus on pregnant women, more precisely, how their habitual miscarriages happen, some shifted the focus to men, or more specifically to sperm analysis. In a study for example, Czeizel and his colleagues started out from the scientific claim that a significant amount of childless marriages were the result of male infertility and they also pointed towards the possible interrelationship of pathospermia to fetal impairments. So they suggested that the focus should be much more on the variables of fatherhood, and how this plays out in the process of conception. They claimed that “although the teratoid forms (of sperms) are infertile, their increased presence indicates pathological spermatogenesis. In the case of pathological spermatogenesis one must take into account microscopically invisible biochemical abnormalities that manifest themselves during fetal development and could result in the impairment of the fetus” (Czeizel, Hancsók, & Viczián, 1967, p. 1595). This remained an important direction in medical genetic research.

As is evident in a later published article by András Tóth and his colleagues in the 1980s it was an epidemiological issue since 10 to 15 percent of marriages had this problem. In their research, Tóth and his team focused on male infertility because they claimed that men were responsible in 30 percent of infertile marriages and they contributed to infertility in 20 percent of the cases. They drew on international literature and claimed that studies linked infertility to chromosomal abnormalities, thus they used the classification introduced in 1963 by Lionel S. Penrose to differentiate between infertile men. The first group included those who suffered from a lethal disorder and died before their reproductive age; the second group consisted of those who had a mental or somatic disorder and were incapable of normal heterosexual relationship (i.e. people with Down syndrome); and the third group of people whose general health condition was fine but who suffered from some kind of chromosome problem that decreased their capability for fertility (Tóth, Gaál, & László, 1982, p. 1723). The most important contribution

of their study was that they pointed towards a relatively new gender aspect of genetic counseling, namely to suggest chromosome analysis for couples who visited counselors because of infertility problems (Tóth et. al. 1982, p. 1728). This chromosome test could significantly reduce the number of further examinations and could open the way for alternative solutions such as in vitro fertilization or perhaps adoption.

4.3.1.4. From Major to Minor Anomalies

Ilona Pazonyi and her colleagues discussed a shift in the focus of mapping diseases. In previous medical practices of anamnesis the focus was on major anomalies. Clinicians wanted to register every major physical anomaly because it was the sign of serious disorder. This started to change during the mid-1960s when researchers started to point towards the significance of minor anomalies as possible indicators of serious invisible disorders. Minor anomalies are defined as physical signs, unusual morphological markers that do not have direct medical consequences; their significance is that they can indicate serious problems and they can be the signs of syndromes that could help clinicians in recognizing a disorder (Pazonyi et al., 1975, p. 3). An example that they gave for such a minor anomaly was the so called 'single palmar crease'⁵¹ that is linked to Down syndrome, but researcher contemplated other morphological variations such as ear shape, head shape, and facial variations. They pointed out that the difficulty of using data collected about these differences lay in understanding them as minor anomalies or simple phenotype variations (Pazonyi et al., 1975, p. 6). Minor anomalies are important mainly for recognizing multiplex disorders that point toward congenital diseases, thus they urged their

⁵¹ In the article the term simian crease (majombarázda) was used, but it is not used anymore because it conveys negative meaning, thus I chose to refer to this phenomenon by the contemporary terminology.

colleagues to examine routinely such differences because these could help the early recognition of disorders and hence the therapeutic work could be started earlier.

4.4. Conclusion

In this chapter I wanted to trace the reasoning that occurred in the public health discussion concerning raising the health standards and health statistics of the country. This is important because it preceded genetic counseling that started in the late 1960s early 1970s. In this period, from the '50s to the '70s, the dominant concern in medicine was the threat of contagious diseases. To successfully control these problems class issues such as environmental problems were placed at the forefront of discussions. Access to vaccinations again was approached from the perspective of class as the aim was to give equal protection to every citizen since this was in the interest of the society as well. This discussion was within an already defined preventive approach and I think this preventive approach had implicit eugenic values already incorporated into its mechanisms which were extended towards the management of reproduction. This is crucial because in the medical genetic period that started to take shape from the 1970s clinicians took for granted eugenic values that were already at work in the system. In this new phase, where clinicians were concerned with the management of healthy reproduction gender perspectives were taking shape. In this discourse women were positioned as the primary responsible parents whose body came under closer medical surveillance. It is important that the accumulated medical knowledge was intended to enhance decision making on the part of women, but this decision making process was already burdened with eugenic expectations. This is what I will show in the chapter that looks at the discourse on genetic counseling. I will focus on the reasoning and values explicitly stated by clinicians about the contribution of their work to the society.

5. Eugenic Concerns Structured by Race/Ethnicity and Class in Public Health Discussions Focusing on Reproduction

The public health discourse of the 1950s prioritized on contagious diseases and its main interest lay in finding ways to control these problems but *the* priority was on the majority perspective. In addition to this healthcare professionals did articulate these problems in connection to gypsy groups as well, there were certain state supported practices such as forced bathings – that researchers traced back to the interwar period – that primarily targeted gypsy communities. In this chapter, I will describe the way medical professionals of the socialist period integrated interwar public hygiene practices into the health management of gypsies from the perspective of public health. In these practices, ethnic/racial stereotypes shaped public health action. Public-health officials justified these actions on the basis of their fear that gypsy people would spread diseases if their hygienic issues were not controlled. Thus, the issue of ensuring good public-health standards was connected to environmental problems, class issues, and also to ethnic identity. The aim was to develop the general public health conditions of the Roma, but these methods were not enabling but rather constraining and discriminatory practices. A further development occurred in this discourse when gypsy ethnic identity came to be recognized as an important statistical variable in determining healthy birth rates. Regarding this question, I will show that ethnic identity as a variable, appeared in the medical discourse on how to develop the overall reproductive statistics of the state. It was discovered that gypsy reproductive statistics offset regional and national results, thus in order to relieve the burden that these bad results meant for the national healthcare system a better understanding about Roma reproductive processes was needed. Here as well, the intention was to help Roma people to healthier reproductive results and this was justified from an economic perspective.

5.1. Interwar Antecedents of Public Health Discourse on Roma

As a result of the unsuccessful attempts to assimilate the Roma and the growing influence of Nazi race theory, medical professionals started a discussion on public-health issues. Csaba Dupcsik reviewed the debate that took place in the *Népegészségügy (Public Health)* journal between 1939 and 1944. This particular journal is key to the understanding of the official state relation to the ‘gypsy question’ since it was the journal of the Ministry of Labour and Social Affairs until 1932 when it became the journal of the Ministry of Home Affairs. In the pages of this journal health professionals aligned their views with the official state position on this question (Dupcsik, 2009, p. 119). I will organize this short review around the issues analyzed by Dupcsik but place emphasis mainly on narratives of public-health risks and on reproduction.

During the 1920s the negative feelings towards wandering gypsies grew stronger. Perhaps as a result of the general racism towards gypsies the minister of internal affairs enacted a law in 1928 (257000/1928) that in each year the gendarmerie had to conduct raids in which they rounded-up wandering gypsies to curb the danger that these people presented to the general public. Dupcsik in his work highlights (2009, p. 103) that the usual punishments were interning them for hard labor, forced relocation, and also public disinfection. The practice of public disinfection shows that the general sentiment towards the health standards of Roma was very negative. Hungarian health professionals believed that these groups of people carried dangerous infectious diseases that must be controlled regularly. This idea to control their diseases in a separate and radical way came back into practice during the socialist period as I will elaborate later.

But it is also notable that these ideas that Roma carry different diseases that are dangerous for non-Roma people also contributed to the resistance that non-Roma felt and expressed when

it came to living together. However not only these imagined health problems but the ideas that Roma people are racially subordinated to non-Roma Hungarians was widely shared by the health professionals who contributed to the discussion of the gypsy-question on the pages of *Népegészségügy* (Dupcsik, 2009, pp. 123–124). They shared the belief that assimilation was not viable therefore it was not desired to foster the cohabitation of gypsy and non-gypsy Hungarians because that would inevitably lead to the degeneration of non-gypsy people, and hence contribute to the degeneration of the Hungarian race.

The theme of degeneration surfaces more strongly in relation to the number of gypsy and non-gypsy descendants. The narrative, how reproduction is linked to gypsy behavior, fits neatly into an exclusionary discourse. It was argued that Roma, because of their unproductive, lazy lifestyle are more sexually promiscuous; since they are not working in any socially productive sphere their only goal and pleasure in life is their sexuality. The difference between the reproductive growth of gypsy and non-gypsy communities, is explained by this previously described practice. According to Andor Olay (cited in Dupcsik, 2009, p. 121) their racial characteristics predestine gypsy people to such a way of life, therefore social assimilation is not a possible direction to solve the “gypsy-question”. Instead of assimilation, helped by reproductive interventions, healthcare professionals promoted the exact opposite.

They wanted to make sure that gypsy and non-gypsy people stay segregated because they believed that Roma present a serious biological threat to the Hungarian race. They approached the “gypsy-question” similarly to the “Jewish-question”. Their aim was to handle these racial issues alike. For example, Ferenc Orsós, who was a physician and university professor, suggested prohibiting mixed marriages between Roma and non-Roma couples just as the third Jewish-law prohibited mixed marriages between Jewish and non-Jewish couples in 1941. Orsós differentiated between the two “questions” in terms of danger and class: he argued that while mixed Jewish marriages are dangerous biologically and politically for the upper classes, mixed

gypsy marriages presented a danger to the working classes (Dupcsik, 2009, pp. 93–94). In addition to these measures, the discussion was directed towards more radical control of the population.

In order to strengthen their standpoint, healthcare professionals who took part in the debate drew on utilitarian ideas: they claimed that Roma people are not economically useful elements of the body politic therefore their medical attendance is pure loss without any profit. They sketched two directions to address the above issue. Similarly to their German counterparts, Hungarian race-theorists supported the forced relocation of Hungarian gypsy people to Eastern territories. They believed that the expulsion of gypsies from Hungary and from Europe would solve the health problems presented. Another method that was suggested by the contributors was forced sterilization on the condition that relocation could not be achieved. From the authors of 16 articles – which was the complete *Népegészségügy*-debate – 5 endorsed forced sterilizations, and the authors of 12 articles agreed that either relocation or internment to forced labor camps was the solution (Dupcsik, 2009, p. 127). From these positions it is evident that health professionals embraced and endorsed the radical segregation of Roma from non-Roma for reproductive reasons and also the proposal to stop their reproduction through sterilization.

It is needless to mention that neither of the above suggested reproductive interventions took place, but the contribution, that is, the aim of healthcare professionals to shape the political discourse from their racially biased position that is based on stereotypes, is clearly visible from the debate. In this late eugenic era healthcare professionals – such as physicians, head physicians, nurses, researchers, and research assistants – actively took part in shaping the discussion on how to improve the biological material of the Hungarian race. Their suggestions consisted in primarily negative eugenic interventions, along the lines of race, class, and gender, where gender meant the underlying principle in the control of heterosexual reproduction. In the

following I will analyze the changes that took place during the socialist era in contrast to the events of the interwar period.

5.2. Racial/ethnic Stereotypes that Shaped Public Health Discussions and Public Health Practices after 1948

Perhaps one of the most important developments of the socialist era in contrast to the interwar period is that explicit racial discrimination became politically unacceptable from 1948. Or at least one can say that in the official state discourse problems related to education, criminal behavior, or public health were not explained through the language of biological essentialism which would explicitly support racial bias. However, there are plenty of cases to draw on to explain how racial/ethnic discrimination worked in the socialist Hungarian state.

5.2.1. Legal Segregation: Black Identity Cards

On 26 August 1953 the Political Committee of the Hungarian Workers Party decided to equip all Hungarian citizens with identity cards. Their reasons for introducing IDs were the following: (1) the Hungarian population would need fewer documents yearly; (2) authorities would have less work; (3) it would frustrate class conflicts, and the goals of ‘imperial’ agents and criminals; (4) it would make the work of authorities easier in controlling border territories and cities (Purcsi, 2001). In addition to the previously described decree, on 26 June 1955 the Ministry of Home Affairs issued a supplement: those who could not prove their permanent address for two years and were not in work for at least six months must be categorized as people who maintained a wandering and work-avoiding lifestyle. These people must be provided with black identity cards on an annual basis. This law was not explicitly named as such, but this can be called the first racial regulation of the socialist period in which the aim was to control wandering gypsies.

In 1952 the Public Order Policing Department requested the Criminal Investigation Department to prepare a plan to settle and force wandering gypsies to work (Purcsi, 2001). The starting point of their argument was the stereotype that many gypsy people were not taking part in productive work. It is important to note that there were no precise numbers but only exaggerations were used to justify the regulation. The image of the culturally backward, thuggish gypsy was used to rationalize government action. Gypsy people were viewed as criminals who were not afraid to rob and kill settled working citizens. It was argued that they lived in shanty-towns during the winter but they left these places when spring arrived and they started roaming the country. It was added that they were not only dangerous from a law enforcement perspective but that they represented a danger to the public health and safety of the majority population: they might carry and spread different infectious diseases.

The idea that this was a racially discriminatory regulation is supported by Purcsi (2001) by citing statements from the law that regulated the introduction of identity cards. ‘Wanderer’ was used as a synonym for gypsy people and the idea to introduce black identity cards served the purpose of racial segregation. In the beginning of the socialist era since 1948 it was debated whether it was justified to legally acknowledge gypsy as a nationality. But it became a clearly established position by 1961 that in view of their *essential* difference from Hungarians they could not be acknowledged as a part of the Hungarian nation, therefore it was decided to abolish the Cultural Association of Hungarian Gypsy People. Furthermore, the Hungarian Socialist Workers Party categorized gypsy people as not belonging to any state (or nation) and as being incapable of further development. Race as a terminology never appears in the official documents but with one exception. By 1961 it was decided – perhaps because of the objections from gypsy activist László Mária and members of administrative bodies (Executive Committee of Pest County), and police officers for its racially discriminative nature – that identity cards must be distributed uniformly to all Hungarian citizens and black identity cards must be

withdrawn. With this act the unconstitutional racial discrimination of Hungarian gypsies ended at the official state level. However racial discrimination continued in the health discourse: it was argued that gypsies represented serious health dangers to non-gypsies because of their undeveloped living places and because of their wandering lifestyle. In the following I will take up the line of debate that continued in *Népegészségügy* after the Second World War.

5.2.2. Racial Discrimination of Gypsies in the Public Health Discourse

The tone and themes that were described above on the pages of *Népegészségügy* continued after the war and discriminative practices were common towards Roma during the decades of socialism. I want to start with the debate on the ‘gypsy-question’ that took place in the articles of József Galambos, János Heicinger and Ferenc Fellner – all of whom were physicians (Dupcsik, 2009, pp. 143–144). In these articles, the authors discussed the health threat that Roma people were thought to represent for the majority population after the war. The primary reasons on which they built their position were the sheer numbers of wandering gypsies and the numbers of those who were already settled within villages and cities because of the probability that they would house wandering gypsy families who could spread diseases. The attitude of healthcare professionals and police towards gypsy people can be demonstrated in the case of Hajdúhadház (Dupcsik, 2009, p. 145) – a village in Central-Eastern Hungary. Gypsy people had been living on the border of the village in shanty-towns since the 1940s. In 1947 the village was quarantined because it was suspected that typhus infected its inhabitants; later they found out that it was not typhus but malaria. First it was suspected by physicians that gypsies spread typhus, but when they realized that it was malaria they burned down the surrounding environment to kill mosquitoes and their larvae. Despite this action the majority population objected to leaving gypsies and their shanty-towns intact – they believed that they were still

potentially dangerous to their health so they relocated the gypsy families (331 people) and demolished their huts under the supervision of authorities.

Another significant practice that was indicated as an urgent public health need was the continuous forced bathing of gypsy people living in settlements on the borders of towns and villages during socialism. It is significant because more than half of the gypsy population of Hungary was forced to take part in these bathings. Practically it was introduced in the 1940s⁵² but it became widespread during the 1950s and it was continued until the end of the 1980s (Bernáth & Polyák, 2001, Dupcsik, 2009). Forced bathing meant that health officers regularly inspected settlements. And with the help of the police, soldiers and gypsy leaders, health officers forced gypsies into big tents where they were forced to shower with cresol soap and they were powdered with DDT both of which were used for disinfection against lice and typhus which was spread mostly – as they argued – through lice living on the human body. Health officials usually surrounded and quarantined settlements, set up an army tent, and methodically forced the inhabitants into the showering place. In these tents, healthcare officials could bath a hundred individuals per hour. Not only were these practices humiliating but both of the previously mentioned detergents are harmful and DDT was banned accordingly in 1968 by the United Nations Food and Agricultural Organization (FAO); Hungary was among the first countries to sign the treaty. The process of disinfection was more about the exertion of power over the gypsy ethnic minority by the authorities (and those majority Hungarians who helped in this process); in addition to this, health troopers usually depilated the body hair of everyone

⁵² The continuity of atrocities against Roma can be traced back to 1940 as Péter Bernát and Laura Polyák (2001) shows through the interview that they conducted with the physician abbreviated as K.P. and what is evident from their account is that the practices that were coated as public health measures eased off during the socialist period. The drastic actions that were taken against gypsies can be shown through the interview with doctor K.P. He tells a story about a village in Transylvania where he worked as a military physician after the annexation in 1940. It was thought that typhus was spread to the soldiers from a village and particularly from the settlement of gypsies. It was ordered to relocate everybody from the shanty-town but before that it was mandatory to depilate all of the inhabitants and disinfect them. As a final act of the public health measures that needed to be taken – he claimed – they burned down the huts of Roma and forced them to move out from the village to an uninhabited territory between villages.

that just added to their humiliation. These practices were far from medical urgencies as those gypsies were also forced to take part who had not got any medically justifiable problems and, importantly, no non-gypsy Hungarians were checked for lice or any other medical issue and none of the majority Hungarians were forced to take part in communal bathing. What Bernáth and Polyák aptly pointed out is the change in the rhetoric and somewhat in the practice, but the general racially biased attitude remained during the socialist period and continued after the transition as well⁵³.

5.3. Gypsy People at the Center of Socio-political Interest

Gypsy people came into the forefront of socio-political interest in the 1960s. To underscore this point two state statutes can be referenced (1961 and 1979) that defined the fields that would have helped the improvement of the living standards of gypsies and thus their integration into the society. The fields that these statutes named to work on were educational, employment, housing, and hygienic conditions. Mária Komlósi and her colleagues (Komlósi, Knáb, Szikszay, & Tényi, 1985a, 1985b) discussed the significant improvements that took place regarding the living standards (especially regarding their living conditions and their health) of Roma, in the period between 1960 and 1985; but their average life standards were far below the average non-gypsy standards. For example, as they refer to the sociologist István Kemény, the practice in Baranya County was not consistent with central ideas about integration, but rather it worked out in a way that new gypsy slums emerged as gypsies moved into smaller villages from their illegal settlements (Komlósi et al., 1985a, p. 305). Though this was the case in general, researchers recognized that gypsies are not a homogenous mass, but a layered

⁵³ A recent example that they gave is racial segregation in schools. In 1997 in Tiszavasvári – a town in North East Hungary – the school-leaving ceremony was separately held for Roma and non-Roma children because of public health reasons. The school was sued and the court fined the municipality. The municipality had to pay every Roma family for racial discrimination (Bernát & Polyák, 2001).

community; its layers are defined by social economic status, educational background, geographical location, gender, and their ethnic identities.

5.4. Ethnicity as a Factor that Affects Birth Rates

Ethnic identity as a variable for reproductive results became relevant for medical reasons in the 1960s and 1970s. Initially, researchers were looking for various factors that affected negatively the outcome of pregnancy. They listed factors, such as “the alcoholism of the pregnant woman, the size of the womb, four or more miscarriages” but in addition to these problems, factors such as “lower educational level, unhealthy living conditions, gypsy status, and bad social circumstances” were also connected to premature birth (Kóbor, Bédi, Thán, & Tényi, 1972, p. 282). József Kóbor and his colleagues argued that the most important factors that influenced premature birth were “nutritional possibilities, direct antecedents of birth, hygienic conditions, social-cultural environment, age and familial status, nurturing, and general health.”

Their study is important because it is one of the earliest public health studies (focusing on birth statistics) that shifts concerns from various factors onto two overlapping differences. Researchers found that certain characteristics go together thus they decided to exclude certain factors and focus on those that seemed to reflect multiple problems at once. Such factors were for example ‘bad social circumstances;’ researchers understood that these regularly go together with bad nutritional possibilities, bad housing conditions and thus result in bad health standards for the members of the group. They similarly noticed that being gypsy (or in their words “gypsy status”) also goes together with other factors. They termed these “encompassing factors” and started to analyze how these encompassing factors affect birth results. They found that being gypsy resulted in a high percentage of premature births (when they took out the gypsy results from their sample they noticed 2 percent fewer premature births in comparison to average). In

addition to this, they further took out the category of smokers and together with the gypsy category the number of premature births fell to the half of the average (Kóbor et al., 1972, pp. 285–286). In sum, they concluded that by taking out factors such as gypsy, smoker, hygienic housing conditions, and abortion, only 6.7 percent of the remaining mothers gave birth prematurely which was interpreted by them as favorable result even in comparison to international standards. Thus, they argued that it is important to further analyze the complex nature of these social, economic and biological factors that contribute to these results.

5.4.1. Statistical Figures on Pregnancy and Birth among Gypsies

When discussing gypsy pregnancies scholars highlighted those factors that influenced the birth rates of gypsy pregnancies (Horváth, Piszér, & Nagy, 1972). For example, they emphasized bad housing conditions, bad hygienic conditions, effects of smoking, inaccessibility to pregnant care because of geographical distances (there were no healthcare workers in the settlements or in the sample villages). Also unfavorable nutritional possibilities, high number of abortions, frequent medical conditions (hypotonia, anaemia, cystopyelitis, helminthiasis), many and frequent pregnancies per woman, and growing numbers of young mothers. As a possible solution, Mihály Horváth and his colleagues suggested distributing more information about personal healthcare and also about contraceptive methods, but at the same time they emphasized the need for institutional developments in the region. Without considerable developments regarding medical offices and medical staff, and without the conditions to access hospitals the health statistics of Roma people would not change.

Others started out from the observation that the number of live-births increased as a consequence of the enactments of population policy decrees. New contraceptive technologies were introduced and thus the traditional form of birth control (they meant abortion) started to

decrease. However healthcare workers recognized that these new technologies unfortunately were not accessible to people living in economically and socially marginalized communities (Bodnár, 1980, pp. 175–176). Bodnár for example analyzed the situation of gypsies in Szabolcs-Szatmár counties because researchers discovered that the gypsy population offset the live-birth statistics in this part of the country. Bodnár explained that the rate of gypsies to the majority population was 6.9 percent but in Szabolcs-Szatmár 18 percent of every 5th born (and above) children died. This was explained by the low-income, low-education, low-level of healthcare conduct, and bad living conditions of gypsies – although their housing conditions started to change in the 1960s their reproductive health results did not follow rapidly.

Researchers compared large families (with four or more children) of gypsy and non-gypsy backgrounds and found that those who were educated used some form of contraception while this was less and less true of those who had limited education. They found in their comparative study that most gypsy families (62 percent) used some form of contraception (pills and IUE⁵⁴). In 1960 there were 11041 large families and this number decreased to 4919 by 1977 which was interpreted as good progress. However, regarding these results, Bodnár (1980, p. 177) also placed emphasis on the fact that the practices of people who belonged to the lowest economic strata did not change, thus it prompted healthcare professionals to find ways that would help their reproductive decisions making. One of the examples that Bodnár gave was the regulation of IUEs (officially regulated by the 6/1977 Health Ministry decree): the placement of IUEs is the right and responsibility of healthcare institutions. He argued that perhaps it would have been more efficient to allow the placement of IUEs in other places as well, because of those gypsy and non-gypsy women who had large families and lived in very inaccessible settlements or villages. These women perhaps would opt for this contraceptive method if they could have access to it in their villages – but they would not travel 30 to 50 kilometers to get

⁵⁴ Intrauterine loop.

this technology (Bodnár, 1980, pp. 177–178). Thus, it was underscored that helping large families and the gypsy population should be one of society's priorities.

Similar results were found in succeeding studies. When Bodnár and his colleagues discussed newborn rates in Szabolcs-Szatmár county they came to the conclusion in their analysis that the gypsy population – although they were 7.3 percent of the population – accounted for 14 percent of live births and 25 percent of stillbirths (Bodnár, Babosi, Batári, Páll, & Szalivasán, 1981, p. 30). They emphasized that "the unfavorable characteristics of gypsy pregnant women and newborns aggravating the difficulties of the healthcare system to function effectively, they need special tasks and special provisions," in addition they pointed towards constant health education, and the need for cooperation among authorities (social, economic, cultural) in order to execute care work. In my view it is an important historical fact that healthcare workers have tracked mortality rates of gypsy newborns since 1962 (Bodnár et al., 1981, p. 32). Bodnár and his colleagues explained that it was possible to understand that gypsy newborn mortality rates were always higher than non-gypsy newborn mortality rates. From these records they inferred that the trend was downwards – in the early 60s it was 7-8 percent above the non-gypsy results while by the 80s this became only 1.5 percent – but it remained one of the key problems that the county had to face. Ethnic categorization from a medical perspective was an important tool that enabled researchers to understand health related differences between Roma and non-Roma communities, which was an important step towards overcoming health inequality.

It was pointed out that with these statistics they could understand how gypsy and other "undeveloped" strata held back healthcare institutions from delivering good results. And they also emphasized that their reproductive rates were higher than the average thus healthcare workers would have to face further issues; it was not only the question of infant mortality, but the frequently sick and underdeveloped children who represented further problems (Bodnár et

al., 1981, pp. 32–33). They suggested that not only biological causes were important in understanding mental backwardness but social-environmental factors as well – they meant that many of these children were raised in environments where they hardly had enough stimuli to help their developments. This in turn would make their education and social integration very difficult. They basically concluded that the cultural level of gypsy people determined their social opportunities; their cultural habits, their big families, their lack of education, their environmental factors – all contributed to reproducing their present detrimental situation. Thus they argued that medical professionals by exploring the field of infant health could contribute to the much needed change that would help gypsy communities to better healthcare.

5.4.2. Comparing the Biological Characteristics of Gypsy and Non-gypsy Mothers and Infants

In my view, one of the significant starting points in the comparative work of Roma and non-Roma biological characteristics is the articulation of racial difference: “undoubtedly, within the country’s population gypsy people belong to a sub-racial category” (Bodnár, 1981b, p. 308). Bodnár further explained that newborn data proved that there was material ground for differences that were understood to be the consequences of their racial difference, and to their socio-economic situation. The idea that gypsy women have different biological determinants in comparison to non-gypsy women and thus these biological factors would decisively influence their birth results was compatible with the view on racial difference. Although in their study, Bodnár and his colleagues rejected the idea that there are essential biological differences, they maintained that the biological condition of gypsy mothers influenced their births results. This biological condition however was determined by their socio-environmental conditions and thus the unfavorable birth results (premature birth, low-birth weight, early and late infant mortality rates) had been explained by their socially and economically marginalized situation in the

society (Bodnár, Babosi, Batári, & Páll, 1981, pp. 42–43). In addition to these problems they stressed the problem of short rest periods between pregnancies, miscarriages as factors that also influenced the growth of their infant mortalities. Infant mortality rates are considered to be important markers for understanding the economic standards of a society (Bodnár, 1981b, p. 308).

Bodnár highlighted that after the analysis of the comparative data, he discovered that those gypsy mothers who were living in good socio-economic conditions gave birth to infants whose biological characteristics came close to the average non-gypsy birth results (1981b, pp. 310–312). He came to the conclusion after a brief theoretical experiment, in which he presupposed better conditions for gypsy parents, and found that if they were living in better conditions (they would have jobs for both parents for example) their infant mortality rate could drop by 20 percent. But at the same time he maintained that there are genetic factors – understood as racial difference – that could play a role in determining their birth weights, or their more frequent premature birth rates. However, Bodnár maintained that unless all of the socio-economic factors were equalized it was pointless to presuppose that birth results are solely genetically determined. Bodnár shared the position of the WHO – published in 1965 – that questioned the idea that the birth weight of newborns is solely racially/ethnically determined. Bodnár summarized the WHO statement that sided with the idea that there are differences in birth statistics within one ethnic/racial group. Socio-economic status influences these results greatly thus what I can infer from their results is that there are ethnic/racial differences observed, but these were observed in unequal circumstances and if socio-economic differences are not eliminated biological differences cannot be linked to races. Hence I think Bodnár implied, it is important to track birth results more sensitively: not only race/ethnicity, but SES, environmental factors, stress factors, lifestyle factors, and even epigenetic factors are important in categorization.

Other researchers contributed to this strand of comparative health research on gypsy populations located in other geographical areas. Raffael Szabó and his colleagues for example studied the population of Ráckeve in Pest county (R. Szabó, Raffay, & Rex Kiss, 1984). They noted that most of the studies appeared regarding the gypsy populations of Szabolcs-Szatmár counties and Baranya counties; this is why they researched gypsies in the area of Pest. They recorded gypsy birth statistics after 1966; and from this data they analyzed live birth rates, still-birth rates, perinatal and infant mortality rates, birth weight, and sex ratio. They observed that gypsy women gave birth to 2 to 3 times more children in comparison to non-gypsies. In addition to this they noticed that the average birth weight of gypsy newborns were 300 grams less in comparison to non-gypsy infants. Based on these data, the dominant understanding was – for a long time – that a large percentage of gypsy newborns were born with low-birth weight. The average birth weight of non-gypsy newborns was used as the standard comparative point. It was only later recognized, that biological differences between gypsy and non-gypsy mothers played a defining role in the birth-weight of their children. Szabó and his colleagues recalled that studies were compared in which results underscored the fact that those mothers whose weight was lower gave birth to children with lower birth-weight. They found it important to point out that the average weight and height of gypsy mothers in comparison to non-gypsy mothers is lower thus it was a mistake to consider gypsy newborns less mature than non-gypsies. It was argued that mothers decisively influence the weight of newborns – the weight of fathers was not considered important at this point – and also exogenic factors such as environment, workplace, lifestyle etc. play a crucial role. Thus their standpoint was that the maturity of gypsy newborns must be defined from the perspective of *their* average height and weight ratio, this could help healthcare professionals (gynecologists, obstetricians, pediatricians) to identify a more precise dividing line (than the arbitrarily identified 2500 grams) between low-risk and high-risk newborns (Szabó et al., 1984, p. 27). Their suggestion to identify the threshold for

gypsy newborns at 2300 grams was based on the WHO directive that advised a lower threshold for Indian and Chinese newborns because of the racial difference in comparison to Caucasians. In line with the above standpoint, Szabó and Rex Kiss compared 3473 non-gypsy and 300 gypsy mother-infant weight data and concluded that there is a relationship between the weight of the mothers and the weight of the newborns (Szabó & Rex Kiss, 1984, p. 307). According to them ethnic characteristics (general biological difference of gypsies from non-gypsies) are the primary reason why gypsy mothers give birth to lower weight newborns.

Other researchers in contribution to this discussion, added to the average weight of gypsy women in comparison to non-gypsy women the importance of environmental factors. By comparing gypsy mothers and their newborns according to their housing conditions Lóránt Bodnár and Gabriella Bodnárné Pálosi concluded that those gypsy mothers who lived in slums had a lower weight on average than those living in normal conditions. Thus mothers from the slums gave birth to lower weight newborns. What they also added was the fact that weight gain during pregnancy favorably influenced the birth rates of newborns – however this was rarely the case (it simply did not occur that often) in the situation of slum dwellers (Bodnár & Bodnárné Pálosi, 1985, pp. 26–27). This information is medically significant since it was understood that these factors influence the birth weight of gypsies and thus put them at risk. And it was also pointed out that the rate of mental retardation is four times higher in those populations where the weight of the mother and the weight gain of the mother during pregnancy is inadequate. Thus their conclusion was that to change these statistics it was crucial to understand and also to influence their the lifestyle habits in a positive direction that could favorably influence the general health of Roma people.

5.5. Conclusion

Public health measures that had been taken by the state were initiated by the racial fear that gypsy settlements spread diseases that will affect non-gypsy citizens. This fear was articulated primarily along the lines of class and ethnic identity. It was understood by healthcare professionals and officials that gypsy people represented a health risk for those working class citizens who were in contact with them by nature of their living environments or workplaces. Thus it was suggested that their living environment be changed; so the state started to forcefully relocate gypsy communities into cities during the 1960s. Another important albeit racially discriminatory action that continued throughout the socialist period was the forced bathings of gypsy settlements. These had long lasting psychological and health impact on gypsy citizens because they had to endure these communal bathings in which they were not only humiliated but exposed to carcinogenic detergents that could have caused long lasting healthcare problems. The state did not compensate the members of gypsy communities until now.

The other central public health question, after handling the issue of contagious diseases, was the problem of birth rates. It was discovered that birth rates were negatively affected by the low health standards of gypsy people (bad living environment, inadequate diet, unemployment), and thus structural changes were necessary to reach better birth rates in the country. Research that focused on gypsy birth rates and birth results pointed out that the initial comparative standards (comparing birth weights of newborns to the average of non-gypsy newborns for example) did not work, but produced imprecise data. Many factors contributed to birth weight differences, and thus the introduction of an ethnic variable was interpreted as a useful category that helps healthcare workers in establishing precise databases about newborns. Thus this knowledge was not only useful for the medical staff, but it would have been important to gypsy

parents as well, in order to control the development of their children. Hence, it was suggested that ways be found to distribute information for the members of these communities so that they would be able to control the health of their newborns. In these types of state supported healthcare work, arguably the values of eugenics can be seen. While in the case of the management of contagious diseases, with forced bathings and forced relocation, the state aimed at controlling the members of the majority non-gypsy population. The goal was to ensure safe public spaces from a public health perspective that would contribute to better living standards and thus would help reproduction. In the discussion centered on reproduction the main focus was on healthy newborns and making sure that fewer children would be born with any kind of handicap. I understand this also to be a eugenic discussion, because the primary motivation to control these processes was coming from a utilitarian economic perspective that was at the heart of early eugenic discussions as well. In the following chapter I will map out how new technomedical practices helped to develop this reproductive discourse.

6. Representations of Eugenic Thinking in the Development of Genetic Counseling from the 1970s to the Early 1990s

The previous chapter was important because I wanted to show that racial concerns were tied to class, ethnic, and eugenic issues, hence healthcare actions followed these identified problems. After the technological discoveries that took place in the 1950s regarding the structure of human DNA and the possible analysis of chromosome differences the medical discourse started to use these insights in the 1960s and 1970s in Hungary. One of the central fields of these applications was in reproductive medicine and more precisely in genetic counseling. In this chapter I will discuss how mechanisms in genetic counseling initially were visibly organized uncritically according to eugenic values. This started to change in the 1980s and especially in the 1990s as a result of the democratic transition and the integration of Western European medical values. Although this process started in the 1980s genetic counseling is a very complex procedure, and problems do exist in our present as well that show how hard it is to keep genetic counseling neutral in which clients decide without any professional influence about their offspring's future. Thus, I will explore in this chapter the eugenic values that were present in the articulation of the rules of genetic counseling.

Genetic counseling as a practice is often referred to by geneticists as a tool that helps any society economically because it allows for medical intervention when it is deemed necessary. But the semantic field of *medical necessity* changes according to the values of different historical contexts, thus I will show below, what values played a key role in identifying disorders that had priority in this preventive medical discourse. In order to lay out my argument, I will start with the historical context that enabled and necessitated genetic counseling and then I will describe the early forms of genetic counseling. I will show through the case of screening

for Down syndrome, how medical professionals handled information distribution and how they classified disorders such as Down syndrome; and then I will show that the strongly eugenically influenced thinking and medical care regarding DS have changed. This slow shift implies larger structural changes in the client-patient interaction within a genetic counseling situation that is mostly the result of the integration of democratic values into medical conduct. Thus, here I will show how the heritage of eugenic thinking changed in this period of medical discourse and I argue that eugenic values have sunk to a deeper-structural level and have more radically opened up to individual decision making.

6.1. Articulating the Need for Genetic Counseling to Help Reproductive Decision Making

By the second half of the twentieth century monogenic and multifactorial genetic disorders were among the ten most important causes of deaths. Regarding infant mortality rates, Czeizel emphasized that death rates from genetic disorders were three times more than deaths from all contagious diseases together (Czeizel, 1973, p. 2401). What is important for him in this issue is the technological development that took place during this period that contributed to better public hygiene and that managed contagious diseases well thus genetic disorders came to the forefront of health problems. Czeizel discussed various possibilities to manage congenital disorders (Czeizel, 1973, p. 2402): he listed congenital hip dislocation as a positive example, because with early examinations these problems can be treated and thus be reduced in the overall population. He also mentioned spina bifida as a serious disorder that can be treated and noted that in England only 30 percent of children died because of surgical interventions; and he raised attention toward metabolic-disorders by claiming that it would be medically right and

economically beneficial to screen for such problems (like PKU) since screenings would cost a fragment in comparison to the savings that early diagnosis could make to the state⁵⁵.

In my view eugenically informed fears were to the fore in these discussions. This fear was identified by Czeizel as the "disruption of genetic equilibrium" (Czeizel, 1973, p. 2402). I find it important that the explanation for 'disruption' was given by Czeizel in bookkeeping terminology. There is the income or genetic mutations on the 'positive' side, while there is expenditure or genetic selection on the 'negative' side. In this argument, he stated that this biological equilibrium is in danger because on the one hand (income side) environmental changes such as x-ray and other radiations affect the human body, the use of nuclear energy, the increasing amount of prescription drug use, the use of food-additives, and the wider use of pesticides. All of these contribute to the growing number of medically significant mutations, while when we look at the other side of the coin, according to his elaboration, it was evident that medicine managed to treat various fatal problems. The result of this technomedical 'contraselection' is twofold, on the one hand he acknowledged these as medical, technological and ethical developments, but at the same time, Czeizel raised awareness of the problem that I termed in this discourse transgenerational biological responsibility, because individuals transmit genetic mutations with the help of medical technology. Thus these processes are important for him because „[t]he disruption of genetic equilibrium is a serious threat because in this case two forces predominate in the events that head into the same direction. The increasing genetic contamination of mankind above a certain threshold could launch a chain reaction that would not be indifferent for the fate of future generations" (Czeizel, 1973, p. 2403).

Czeizel also emphasized genetic counseling and prenatal diagnostics as the main techniques for the management of reproduction. He used a strong case, the story of L. J. who

⁵⁵ His calculations were the following: screenings would cost 350 thousand Forints per year while the manifested disorder would cost 9 million per individual; and lastly the diagnosed problem when treated medically would cost 1 million to the state (Czeizel, 1973, p. 2402).

gave birth to four children in her first marriage, all of her children were born with serious fatal disorders (the boy born in 1957 had multiplex disorder, and the girls born in 1959, 1962, and 1963 had occipital spina bifida) – all of them died very soon. When she remarried in the mid-1960s she gave birth to another child in her second marriage this time with a different fatal disorder diagnosed as Arnold – Chiari syndrome – this child also died very early on. This was the time when Czeizel and his colleagues received her case and tested her and her husband for various chromosomal disorders. They found a disorder called C group reciprocal translocation. This type of problem means that the individual has no phenotypical symptoms, but it also entails that the transmission of the mutations could cause genetic disorder in the offspring with a chance of 50 percent. Czeizel and his colleagues thus advised the woman to refrain from further pregnancies. However she became pregnant again in 1969 but as the geneticist suggested she requested the termination of her pregnancy. The sad lesson that Czeizel emphasized was that this last child was healthy. If they had had access to a technique such as amniocentesis they would have been able to confidently predict the health status of the child. He also emphasized that this new technological tool was available only from 1972 when Zoltán Papp and his colleagues “were capable of preventing the birth of a child with Down-syndrome,” thus, Czeizel made a case for „the use of prenatal diagnostics as the most effective method of genetic prevention” (Czeizel, 1973, p. 2407).

Czeizel pointed out that congenital anomalies were estimated to be between 6 and 15 percent around the time of birth. This he explained by reference to technological developments (more problems could be diagnosed), less selection around the time of birth, and with the extension of screening programs – that is prenatal and postnatal prevention programs contributed to this. He emphasized the various levels of prevention regarding congenital anomalies: (1) mapping mutagenic and teratogenic changes (these are about various chemical and human interactions; teratogenic studies are about the possible harms that the fetus receives

in utero); (2) modern pregnant care (to prevent teratogenic harms, or to suggest genetic counseling in order to prevent a disorder); (4) the registration of congenital anomalies to locate geographical and temporal frequency; (5) the screening of newborns for various disorders (PKU, galactosemia, hip displasia, hypothyreosis) to facilitate therapeutic care, or screening pregnant mothers (AFP-screening) to make sure that their child will not be born with spina-bifida (Czeizel, 1978, p. 2492). He placed emphasis on the role of physicians/clinicians/geneticists in this process to ensure the healthy birth of the new generation thereby contributing to a healthier society. In a later published article, Mária Bod and Endre Czeizel stressed that in 1975 three times more children died as a result of congenital malformations (CMs) than from contagious diseases. Since the 70s it is recorded that CMs were within the ten most significant causes of deaths. They made the claim that it was important to map the biological characteristics of all of the relevant congenital malformations because that would help to prevent such disorders. And they suggested that the "only optimal solution" was the prevention of the birth of these children because they cannot offer treatment for their problems (Bod & Czeizel, 1979, p. 1313).

6.2. Institutionalization of Genetic Counseling

Czeizel stated in this article that family planning became one of the key principles in the 20th century. He claimed that it is understandable that various birth control techniques ensure better economic and cultural circumstances. It was a development of this biological discourse, as Czeizel underscored here, that all families aim for ensuring better mental and physical capacities for their offspring (Czeizel, 1976, p. 1743). I want to underline the fact that here he discussed the internalization of positive eugenic values by families and embraced a basic idea of eugenic enhancement. He put this in a different way: Hungarian demographics did not

develop in an optimal manner, thus 'quality family planning' was emphasized by Czeizel as a key area that could help the reproductive statistics of the state.

A key pillar of the above-described direction was the institution of Family and Women Protection Councils (Család és Nővédelmi Tanácsadók or CsNT). Specializing in reproductive decision-making these were founded to check the health of prospective mothers whose near future plan was to get married and get pregnant. One of the priorities was to establish some sort of connection between counseling before marriages and before conception (Bognár, 1976, pp. 22–23). The central issue for a successful pre-marital counseling was how to ensure healthy conception and help women throughout their pregnancies. The data that healthcare workers collected during pre-marital counseling would provide the grounds for future pregnancy care. Some of the researchers, like Zoltán Bognár was convinced that the right thing would be "if every woman would go through a suitability test" before their pregnancies that would check their health status. But as this proposal was not feasible because of the structural inadequacies of the healthcare system, the focus in his analysis shifted toward the more realistic approach that would prioritize the screening and examination of those who were identified among those at risk. Through the analysis of data of a Budapest based institution, Bognár concluded that the work that would focus on preconception care should be developed in the future. This is the direction that was soon adopted.

An important antecedent to the changes that took place after the mid-70s regarding genetic counseling was the fact that from January 1. 1974 new reproductive policies were enacted in order to help reproductive statistics. The following key points of the law that significantly influenced reproductive results were emphasized by Endre Czeizel (1976, p. 1743): "(1) provisions to influence the social attitude positively (here the focus was to emphasize the significance of the family and children for human happiness and on the other hand their significance for social economic interests). And (2) economic support of families,

(3) the state introduced restrictions on abortions, (4) introduction of compulsory medical counseling before marriage, but counseling was introduced regarding family and women's safety, (5) plus state wide establishment of genetic counseling institutions". Czeizel made it explicit that better results were already visible in 1974 after the enactment of the law.

On January 1 1976 the country wide genetic counseling network was established. This was one of the results of the population/reproductive political statutes. As a consequence, Czeizel and his colleagues reviewed the main issues in the practice of genetic counseling that they encountered in Budapest. He emphasized that in 1976 'family-planners' requested advice regarding blood-related marriages, whether they can choose the sex of the child, and making sure that their child is healthy (Czeizel, Osztovcics, & Kiss, 1976, p. 2655). In the city of Győr, Western Hungary, state organized genetic counseling was introduced officially on October 1 1974 (but previously to this date there were privately initiated counseling sessions). Their results were different from the Budapest based study discussed by Czeizel. For example, their facilities were used by mainly patients (65 percent) who were advised by physicians to request genetic counseling. Regarding the class identity and mental capabilities of the patients genetic counseling is highly important from an epidemiological perspective (Méhés, 1977, p. 1653). Méhés emphasized the need for further collaboration among various physicians for preventive and therapeutic reasons, and he also noted that the continuous use of standardized principles must be ensured. And because of the different experiences that they had in various places, he suggested systematic comparison of their results from time to time.

The legal framework made it mandatory in every major city to establish genetic counseling offices, in addition to these offices the institution of Family and Women Protection Council intended to ensure regular healthcare check-ups among those women who planned their marriages. Comparative statistical works also helped the standardization of counseling practices thus they ensured quality feedback towards their patients and towards their colleagues. In order

to understand the change that took place within the institution of genetic counseling it is useful to analyze the self-reflexive professional discussions of medical geneticists about the positive and negative sides of counseling.

6.2.1. Evaluation of Genetic Counseling

The main problems that were listed regarding the success-rates of genetic counseling, were class inequality, by this it was understood that lower-class families from a deprived educational and economic background rarely requested advice. The problem that Czeizel and his colleagues wanted to emphasize regarding this issue is the statistical data, that the 10-20 percent of the population that produced 80-90 percent of genetic abnormalities had least opportunity for social mobility. They further noted that in their sample (1040 Budapest related people) they only had one 'familial' retardation and only two 'gypsy' families (Czeizel et al., 1976). And they pointed out that in order to develop health statistics it was necessary to take steps to contribute to the inclusion of those who were the most at risk population but at the same time lacking the knowledge and economic resources to do anything that would improve their reproductive health standards.

They further stressed the problem that many families only requested advice after they had already gone through an unsuccessful pregnancy (Czeizel et al., 1976, pp. 2658–2659). Furthermore, they placed emphasis on putting more efforts into changing these tendencies. They discussed the main benefits of genetic counseling and noted that a thorough analysis was not yet available because of the recent introduction of these services. Nevertheless, they pointed towards international statistics in which it was claimed that roughly 70 percent of family-planners accept the advice of genetic counselors, which is beneficial for the family and for the child – and if it facilitates treatment, also for society.

In a publication, which appeared in 1980, Czeizel and his colleagues gave an analysis of the effectiveness of genetic counseling from 1973 to 1977 based on the genetic counseling activity of the OKI (National Public Health Institute) II. Women's Clinic. In this discussion they argued that 91.5 percent of the clients understood the advice given by their counselors. From the whole sample, 95 percent of those who it was suggested might have children wanted to accept their advice while only 62 percent of those who it was suggested should refrain from having children wanted to accept their suggestion. The best measure, they claimed, to see the effectiveness of their work was the live birth rates from this sample. Czeizel and his colleagues argued that from those couples who it was suggested might have children only 4 percent had genetic disorders, while from those 62 percent who accidentally had children 70 percent of the offsprings had the expected disorder (Czeizel, Métényi, Osztovcics, & Pázy, 1980, p. 937). I think this also suggests that the success of genetic counseling boils down to two important strands: the optimization of life prospects and the prevention of the birth of those children who are incapable of individual life.

Social benefits were important for other researchers as well in stressing the possible positive outcomes of genetic counseling. For example the premise that „the most effective contemporary strategy to avoid congenital malformations is to prevent its occurrence and to prevent its recurrence” was widely accepted by medical geneticists (Halmai & Kosztolányi, 1985, p. 845). The practice of genetic counseling could contribute to this goal by analyzing various cases and providing information about the risks that family planners were facing; that is, in advising whether to undertake a pregnancy or to avoid getting pregnant. Geneticists understood counseling as a professional interaction in which the counselors distribute, analyze, and explain genetic information to couples in order to help them in decision-making. Help in these cases meant that counselors must respect the liberties of parents, thus their final decision. They could only facilitate the interpretation of the information. It is important to note that Mária

Halmai and György Kosztolányi understood genetic counseling as a practice that did not interfere with personal values and liberties however they still had an understanding of genetic counseling work as successful only if they managed to prevent congenital disorders by effective and precise counseling.

Halmai and Kosztolányi were working in Pécs, a city located in the South of Hungary in Baranya county, and contributed to the evaluation of genetic counseling practice by sharing the results – from 1976 to 1980 – of their genetic counseling center (Halmai & Kosztolányi, 1985, p. 847). They claimed that their results were good, because they managed to screen 226 fetuses and they advised giving birth to 208 children, from this number they diagnosed 6 children with some form of congenital abnormality. This is 2.9 percent which was in harmony with the general statistics for the whole population (3-5 %) but they suggested that their results were good compared to that as well, since they focused on an at risk population.

In later published contribution clinicians reviewed the period from 1978 to 1985. János László and his colleagues acknowledged that preventive work developed significantly during the recent decade: „more and more malformations can be diagnosed during the early phase of the pregnancy” (László, Fantoli, & Ibránszky, 1987, p. 1079). They argued that genetic counseling facilities (and practice) could contribute to quality family planning that in turn would help decrease the bad infant mortality statistics by preventing congenital developmental disorders. By preventing the birth of infants with genetic disorders, genetic counseling could raise the ratio of healthy newborns. They emphasized the responsibility of pregnant care workers regarding their role in the preventive process and claimed that for example „they know more than one fetus who born with Down-syndrome as a result of omitted screening tests” (László et al., 1987, p. 1084). Pregnancy care must be executed in a manner that would ensure that pregnant women visit genetic counseling facilities when they are above 40. In these cases they must approach counselors before the 11th week so that they can be screened and diagnosed

if necessary for various genetic disorders. A complex care work that focuses on the prevention of newborns with genetic disorders would contribute to better infant mortality statistics.

In addition to defining more specifically those groups who could benefit the most from genetic counseling and family planning services, Czeizel and his colleagues distinguished between two groups of people. Those couples belong to the first group who have a higher risk of the occurrence of a genetic disorder, usually they are already familiar with certain problems and they approach the counselor with their specific problem in mind. And in the second group, accounting for 90 percent of the population, couples still have a general risk, and family planning facilities could help them as well in managing their preparation for pregnancy (Czeizel, Fritz, & Pataki, 1986, p. 99). They argued that this is especially important regarding the statistical fact that 80 percent of congenital abnormalities result from healthy couples. They discussed three methods that would help this group of people: (1) general suitability test for prospective parents; (2) a three-month preparation period for conception (for example pregnancy multivitamin); and (3) ensuring early-pregnant care. For all of this to happen pressure mounted for the revision of methods of information distribution.

In connection to this issue, the first important debate that tried to modify the population policy decree of 1973 happened in 1986 during a parliamentary discussion of the new family law. The aim was to work out ways that would contribute to better reproduction statistics and to the more conscious use of genetic counseling offices by the citizens. To sum up the discussion shortly, perhaps it is useful to recall that the infant mortality rates of the 1960s drove the attention of researchers to the problems of family planning. The lack of sexual and reproductive knowledge negatively influenced pregnancy rates and birth results. The interrelationships of these processes were examined and researchers scientifically underpinned the introduction of the 1040/1973 state decree that defined the population policy of the 1970s and 1980s (Pintér & Czeizel, 1988, pp. 331–332). Attila Pintér and Endre Czeizel argued the law was outdated by

the end of the 1980s. In 1973 it became mandatory to go through premarital counseling but as they explained in reality these did not work. Engaged couples had to visit a physician who worked in one of the offices for the counseling and protection of women and families. The state wanted to make sure that couples received the right scientific information that would help them in the reproductive future – but these were not successful. Based on this information they suggested repealing that part of the law that made premarital counseling mandatory. Instead they suggested working out more complex means of information distribution right from primary schools up until adulthood. They were convinced that a more liberal approach to knowledge dissemination and the involvement of the population could deliver better results.

6.2.2. Some Methodological Developments that Contributed to Better Results

By the 1980s the method of genetic amniocentesis became a staple way of learning about the genetic status of the fetus (Papp, 1983, p. 2099). It was a relatively short time-period in which it became a routine diagnostic method that could be applied to clarify genetic disorders in utero. The first publication about amniotic fluid appeared in 1877; these interventions were introduced to treat hydramnios to deplete amniotic fluid in order to avoid any congenital abnormality – this was the regular practice until the 1930s. It was only in the 1950s when the amniotic fluid was tested for Rh-incompatibility – similarly, to avoid congenital issues – and these works opened the way for a more progressive approach towards the diagnostic possibilities present in its analysis. Thus by the 1980s amniocentesis for genetic diagnostic purposes before the 20th week of the pregnancy was deemed to be a relatively safe procedure in comparison to the risk of the disorder that it was devoted to diagnose.

Amniocentesis could only be justified medically in cases of chromosome mutations that lead to severe mental retardations, metabolic-disorders, or other serious disorder that is

incompatible with life. In these cases amniocentesis is a medically accepted method to find out whether the fetus was affected and it is the right of the parents to request medical assistance for the termination of the pregnancy (Papp, 1983, p. 2100). Papp argued that prenatal testing is valuable in cases when the parent can be reassured that her fetus is healthy, or when the diagnosis could confirm the suspicion and can help parents to request abortion. Basically, Papp argued that prenatal tests were designed to be carried out in cases when the risk for the appearance of a disorder is higher than 1 percent (as the risk of losing the fetus by amniocentesis is also 1 percent). Originally, the criteria for high-risk pregnancies were designed for Down syndrome diagnosis. But Papp argued that roughly 5 percent of women in a given population are in the high risk group – they give birth to the 20 percent of all children with genetic disorders. In this article, Papp claimed that it was not possible in the near future to screen for all of those problems, thus, the only rational and viable direction was mapping more risk groups in order to manage their pregnancies within the accepted preventive paradigm (Papp, 1983, p. 2106). Regarding the problem of risk group identification, the indication of Down-diagnostics was based on the population data that suggested screening above the age of 35 but at the same time noted high prevalence above 30 as well (Papp, 1983, p. 2108). Risk identification is an important tool in the production of the legal framework⁵⁶ that regulated abortion.

The paradigm change that took place in human genetics during the 1980s as a result of recombinant DNA technique medical fields became more focused on the molecular level (Falus, 1987, p. 1289). With the wider availability of this technology geneticists could isolate various genes⁵⁷ which meant for prenatal and presymptomatic diagnostics that it speeded up the

⁵⁶ In the 1980s as it was described by Papp (1983), pregnancies could be terminated until the 12th week if the risk of the fetus was higher than 10 percent; if the risk of a disorder was between 50 to 100 percent abortion was allowed until the 20th week. After the 20th week abortion was allowed only in cases when the fetus was incapable of postnatal life. And even after the 28th week if there was a medical indication registered by the obstetrician in the medical records of the patient the women could request abortion during this last period.

⁵⁷ In 1981 geneticists isolated 16 genes and by 1985 they have isolated 249 genes and from these isolates roughly 150 genes were localized (Falus, 1987).

process by allowing diagnostics when only a small amount of protein was available for testing. This entails faster and more precise diagnostic procedure that allows for prevention that is more efficient. Zoltán Papp also discussed the role that genetic studies played in the development of modern preventive methods, but he also emphasized the role that obstetricians must play at these various stages. He further added that the paradigm shift that took place in the second half of the 1970s, when geneticists shifted the focus to the molecular level and made more precise diagnostics possible, medical genetic prevention became even less risky. He listed and explained how various problems could be diagnosed prenatally with molecular methods such as cystic fibrosis, located on the short arm of chromosome 7, or Huntington chorea, located on chromosome 4, or type A and B haemophilia, that are sex chromosome linked problems (Papp, 1988, pp. 2179–2180). These examples are important because they already pointed toward a future in which more and more genetic disorders could be located prenatally and thus, if deemed incompatible with life, be prevented by abortion. Thus, the possibilities of negative eugenics were considerably extending.

As a result of technological advancements screening practices changed since the 1970s. They were first introduced in the following way: (1) in this early period the focus was on mothers above the age of 35 (high risk group for Down syndrome) and it was institutionally offered to these women to get tested with amniocentesis during their second trimester. Following this phase, (2) this practice changed in the 1980s when it was possible to offer general screening tests (AFP, hCG, and free estriol value) in which the pregnant women's blood samples were used to locate biomarkers that would indicate the presence of the disorder. This triadic screening practice that takes into account the age of the mother was generally applied in genetic laboratories by the end of the 1980s (Tóth & Szabó, 2000, pp. 2293–2294). This practice once more changed in light of technological developments in the 1990s when ultrasound-screening tests became suitable in detecting Down-related differences.

Another important milestone in Hungary was the introduction of the method called fluorescent in situ hybridization (FISH) in 1996. The benefits of this new technology for cytogenetic screenings in comparison to classic cytogenetic screenings were that this is less time consuming and it is possible to analyze cells in their initial developmental phase (there's no need for cell breeding in this case) (P. Tardy, Tóth, Hajdú, Gombos, & László, 1996, p. 523). Erika P. Tardy and her colleagues used the case of Down syndrome to argue that FISH technique could help to reduce economic costs and at the same time increase the capacity of laboratories to screen more patients for Down syndrome. They underlined that although Down-screening is state supported, it is state supported only above the age of 38 but most children (80 percent) with Down are given birth by mothers below the age of 38 (P. Tardy et al., 1996, p. 525). Thus, FISH was viewed as a technique that allows for a fast and more precise diagnosis and it also allows for an economically conscious approach that extends the focus of risk group to prevent the occurrence of Down syndrome.

6.3. Guidelines in Genetic Counseling Concerning Reproductive Decision Making

The early understanding of prevention in genetic counseling was very much informed by eugenic ideas. Let me start with one of the first arguments provided by Méhes and his colleagues who supported the termination of pregnancies in cases when it is sure or even when it is uncertain that the fetus is affected. They understood that the goal of prenatal diagnostics that take place between week 12 to 18 by amniocentesis is to find out whether the fetus has any genetic disorder or not, because that way genetic counselors can advise women to terminate or continue their pregnancy (Méhes, Pejtsik, & Kosztolányi, 1974, p. 1455). In their study they described the successful collaboration among various medical actors who helped an affected family to have a healthy child. Méhes and his colleagues emphasized that "correct prenatal diagnosis and the right guidance of the mother" by genetic counselors helped that family to

have a healthy child (Méhés et al., 1974, p. 1456). Others such as Czeizel, regarding the practice of giving advice, pointed out that besides the task of interpreting the results "it is not always an easy task to induce the right family planning behavior." He suggested to place emphasis on the Galtonian principle that stated "a physician only enlightens or gives advice, the right and responsibility to make a decision always belong to the clients" (Czeizel et al., 1976, pp. 2655–2656). From these quotes it is clear that although Czeizel understood counseling as a site where only advice is given, he had a eugenically informed hierarchical understanding of the best decision that parents could make. Still, in this framework, already in the 1970s there was no place for explicitly pressuring parents into a decision.

"The goal of medical genetics is to prevent the genetically determined diseases in part or entirely. At the moment the most important application of this is genetic counseling. We can employ two strategies during this process. One of these is called negative eugenics. This means to decreasing the number of offspring at significant risk, achieved by restraints at birth or by abortion after the recognition of disorders with prenatal diagnostics. [...] ⁵⁸ The other strategy is eugenics which is the conscious manipulation of environmental factors to avoid the manifestation of genetic predisposition" (Czeizel, 1988, p. 1411). Thus, Czeizel suggested that negative eugenics is primarily the responsibility of genetic counselors because in these cases Mendelian and chromosomal problems could be diagnosed and consequently prevented. But in other epidemiological issues – such as hypertension – eugenic prevention is the responsibility of those healthcare workers (GPs, factory doctors) who provide basic health provision (Czeizel, 1988, p. 1412). These healthcare workers could track patients, could disclose information about hereditary risks, and they could also suggest lifestyle practices that would avoid the manifestation of the disease.

⁵⁸ Czeizel discussed that in the case of hypertension negative eugenics was not an option because of ethical reasons. But he added that there were no known genetic markers at the time to diagnose hypertension in utero (1988, p. 1411).

Four different types of preventive measures were distinguished in the medical genetic discourse that aimed at reducing genetic harms. The first is that genetic counseling is directed at informing individuals how not to transmit their genetic problems. The second is to avoid the genetic harm of the zygote during pregnancy and to avoid any harm that could be caused to the female and male gamete (this entails preconception and environmental care as well). And the third is when the aim is to cure or treat the fetus (diagnostics, screenings, therapy). And lastly, if all attempts to cure the problem are in vain the last option is to medically indicate abortion (Papp, 1988, p. 2175). But this was acceptable only in cases of serious genetic disorders⁵⁹.

6.4. Changes of Medical Reasoning in Genetic Counseling Regarding Down-syndrome

6.4.1. Making Sense of Genetic Counseling: Individual and Social Benefits

Genetic counseling is important for both individuals and society at the same time. And the most important tasks of genetic counseling – as it was understood in the 1980s – can be summarized in the following manner: the primary focus is to ”ensure quality family planning,” and to do as genetic counselors inform, examine, and give advice to patients. It was considered by Czeizel to be of equal importance that clinicians medically intervene if it was considered necessary. For example if it was proved that the fetus is at risk they try to help, or if it was proved that the fetus had a genetic disorder, then their role is to prevent the birth of the fetus if parents consider this direction to be the best solution (Czeizel, 1980, p. 619). Czeizel stated that it is important to

⁵⁹ I think it is useful to recapture how geneticists delineated categories regarding the ’seriousness’ of a disorder (Czeizel, 1988). They created seven categories but the first three categories were those which were considered serious, incompatible with life therefore they constituted the grounds for medical indication of abortion. The (1.) category was defined according to incapability for independent social activity (here they listed Down-, and Martin-Bell syndrome and similar others); under the (2.) category they listed lethal disorders (anencephaly, Werdnig-Hoffmann syndrome); and in the (3.) they considered those that are seriously life threatening or make social integration hard. Based on these principles the method of genetic counseling is as follows.

bear in mind that medical geneticists who do the counseling primarily inform their clients. But it was debated whether actually they can give advice at all. The professional discussion was divided regarding this issue. Some medical geneticists argued that they can only inform their clients about risks and perhaps possible medical steps to ensure the health of their child. But others argued that this is not enough. According to their position, medical geneticists must work in a manner that with their interaction they "manipulate their clients decision making according to the interest of the society" (Czeizel, 1980, p. 620). Czeizel took a middle-stance in this debate. He thought that in certain questions it is good to give advice that advances the health of the child or helps the family and the society but it is not acceptable to influence directly their clients' decision. However, at the same time, it was acceptable to him to argue from a rational and humanist perspective for a standpoint that would keep the interest of the society in the first place (Czeizel, 1980, p. 620). These aims are ensured by "tactical principles" that aim to make genetic counseling as effective as possible.

According to the accepted routine the advices could be divided into five groups: (1) when risk is negligible and prospective parents can have children; (2) it is possible to have children but they need some therapies beforehand; (3) again, it is possible to have children but risk is above 2-3 percent therefore they must have genetic diagnostic in utero; (4) it is suggested that refraining from getting pregnant is advisable; (5) it is right or best to avoid getting pregnant (Czeizel, 1980, p. 620). Thus, I think it is important to review the strategies by which decision-making is pre-structured for prospective parents during a genetic counseling visit. The first step in the strategy is to decide the risk group of the clients and their offspring. If a disorder is likely to occur, genetic counselors have to suggest different steps for their clients according to the severity of the problem. This is divided into seven types: (1) minor problems, with no serious consequences, (2) major anomalies with good prognosis of that being corrected (problems like hip dysplasia); (3) disorders that thwart social integration (blindness, deafness, physical

disability, moderate mental disability etc.); (4) disorders that lead to death in a higher percentage of cases despite all medical efforts; (5) life threatening disorders that endanger social integration as well (example: spina bifida); (6) fatal genetic problems that mean incapability for a healthy child; (7) genetic disorders that make offspring incapable of individual social life (example: serious mental disabilities such as Down syndrome). Czeizel described a shift in the strategy regarding the last three options. These were considered serious problems primarily for two reasons: firstly, because these are fatal or life threatening issues and its risk type for occurrence is above twenty percent, and secondly, because these disorders represent an economic burden for the society. Thus, the suggested strategy for genetic counselors is to advise for refraining from pregnancy as this option is deemed the right one from a medical perspective (Czeizel, 1980, pp. 621–622). And this intertwines with the economic perspective as well, thus influencing the decision making process.

It is important that in the discussion of the various strategies Czeizel noted that the social economic standing of the parents or the mother was an important factor in the decision making process. Genetic counselors should inquire about the parents' cultural and economic background in order to design a strategy that would enable the right decision to be made. For example, he referred to the Budapest study, in which the studies' results suggested that there were families in which "the parents who completed auxiliary schools had on average six children and half of their children similarly to them had to attend auxiliary schools", this is termed by him "familiar" mental disability and stated that the genetic risk of the recurrence of these conditions is higher in people who already have such disorder. Thus, Czeizel argued, that despite the strong social support, because of their low income and large families it is not possible to ensure the good integration of their children into the society (Czeizel, 1980, p. 624).

He did not suggest restrictions, but I also think that he implied that genetic counselors in these cases should advise couples to refrain from having children.⁶⁰

This position is well elaborated in a later published article of Czeizel's. In this paper he defined the task of genetic counseling as the way to help families avoid genetic disorders (Czeizel, 1990). Basically he delineated three areas in this process. Firstly, the priority is to help families by enlightening them; secondly to contribute to a better and more efficient healthcare system by screening and diagnosing problems and thus allowing for an early start of medical therapy (here Czeizel included the choice of abortion in case of serious disorders). And lastly he emphasized the prevention of genetic disorders in serious cases. Here he primarily meant that the medical geneticist is right to take into account the interest of the society, but also emphasized that they must prioritize on the interest of the individual or couple⁶¹.

It is important to note that Czeizel's explanation – elaborated in 1990 – on the practice of genetic counseling signifies a shift in the discourse. Before the transition the dominant form of counseling was directive – largely explained by Czeizel by the fact that the physician did not consider patients as equal partners in the process of healing but directed them what to do in order to get healed – this was the norm in genetic counseling as well (Czeizel, 1990). But in Western countries, where Czeizel learned the skills of his profession, the accepted form was non-directive counseling, which largely meant that medical geneticists (as counselors) distribute information to their clients and they never give advice. That would mean influencing the client according to the medical policy of this paradigm. Czeizel developed a semi-

⁶⁰ It is important to look at various critical works regarding the Budapest research, in which ethnicity, class, and genetic preconditions are enmeshed in the argumentation in a way that made sociologists worry about racial / or even racist/ connotations. See for example Dupcsik (2009) for review of this question.

⁶¹ It is useful to recapture how geneticists delineated categories regarding the 'seriousness' of a disorder (see Czeizel, 1990). They created seven categories but the first three categories were those which were considered serious, incompatible with life therefore they constituted the grounds for medical indication of abortion. The (1.) category was defined according to incapability for independent social activity (here they listed Down-, and Martin-Bell syndrome and similar others); under the (2.) category they listed lethal disorders (anencephaly, Werdnig-Hoffmann syndrome); and in the (3.) they considered those that are seriously life threatening or make social integration hard.

directional method based on his theoretical knowledge and practical challenges that he had to face during his counseling sessions. He was confronted by the inadequacy of the non-directive method for the Hungarian clientele several times during his practice. One key moment that he recalled is when a miner from Tatabánya asked him "what he would do if he was in their shoes". The miner assured him that they would decide on their own, but they needed more direction than the simple handing over of information. For Czeizel this suggested that the non-directive practice dominant in Western democracies was simply not adaptable to the Hungarian medical context. But his long-term goal was to conform to the Western non-directive paradigm however he thought that in 1990 this was not possible since the population was socialized according to an entirely different doctor-patient relationship model. The principles regarding professional conduct during medical genetic counseling started to change in the 1990s.

One of the key arguments that suggested transformation in the broader sense of doctor-patient interaction was the work of Ilona Jenei (1996). She approached public health from a multidisciplinary perspective focusing on ethical principles and gave an argument to transform the paternalist doctor-patient relationship into a more patient oriented, open relationship where patient autonomy takes center stage. Jenei explained by reference to historical-sociological processes that the paternalist perspective had dominated the medical discourse since the 19th century and as a result of the development of the modern state the ethos of healing was interconnected with the duty of keeping the population healthy (Jenei, 1994, p. 72). As a result of these changes, Jenei noted, "doctors became public officers who practiced medical power [over the population]⁶²". From the perspective of medical ethics, Jenei characterized this discourse, as one that focused on actual diseases, in which patients are treated as subjects, and medical professionals were less likely to share their professional knowledge with their patients.

⁶² My translation from Jenei, 1994, p. 72.

In comparison to this paradigm, in Hungary during the 1990s medical professionals started to embrace an approach that placed emphasis on patient autonomy, Jenei argued that this should dominate the public health discourse in the future. She characterized this approach as follows: in addition to the classical medical values patient autonomy is regarded as one of the central features of modern medical ethics. "In this case health protection and prevention means informing, convincing, and cooperating with the population" (Jenei, 1994, p. 72). In this approach medical ethics prioritizes on the autonomous decision making of patients and aims at finding ways to make this possible in a medical encounter. This resulted in the transformation of doctor-patient relationship to that of expert-client relationship where the experts' knowledge is used to enhance the decision making of their clients. When one compares the previous medical ethical paradigm to that of the patient centered one, Jenei argued, it was easier - ethically speaking - to communicate with patients for example in the case of contagious diseases. In the new framework the idea that medical science will solve every medical problem single-handedly is abandoned, instead it is acknowledged that other fields should be involved or even civil organizations should work with medical professionals in order to find cures for diseases. In this case, communication is rather about "lifestyles, habits, and cultures" as possible risk factors. And in these cases, individuals are rather reluctant to embrace and even dispute medical suggestions. Jenei emphasized that "it is harder and harder from a medico-ethical perspective to establish and preserve trustworthiness" (Jenei, 1994, p. 73) nevertheless in present societies the most beneficial approach is to involve patients in the decision making process by widening medical responsibility in the direction of information distribution towards the clientele. Informed decision-making is compatible with the three ethical principles of modern bioethics (1) autonomy, (2) benevolence, and (3) justice because all of these values are taken into account in the process of articulating a decision.

6.4.2. Changes in Reasoning: Down-syndrome

In this part of the chapter I want to show the changes that took place regarding medical reasoning concerning the method of counselling in the case of serious genetic disorders. I will do this by looking at the developments that took place regarding Down syndrome. I will start again from the early 70s and look at how clinicians viewed the best options in handling parents whose child was diagnosed with Down syndrome. In of the early accounts for example, Júlia Métneki and Endre Czeizel emphasized the scientific significance the disorder, since they highlighted that it was the first chromosome disorder located in 1958 hence knowledge has accumulated on this problem the most. They argued that this is the most frequent chromosome disorder in (all) human populations – this means that every 600th birth is affected. In addition to these, they emphasized that this is perhaps the most significant form of mental retardation; and importantly, the age of the mother was recognized to be a contributing factor. And it has relevance for understanding the interrelations of carcinogenesis and chromosome abnormalities as well (Métneki & Czeizel, 1973, p. 1744). In their work, they argued that Down syndrome could serve as a case study to understand more about the frequencies of chromosome mutations, and furthering possibilities in genetic counseling, thus studying Down-frequency and screening statistics could contribute to better prevention results.

One of the direction that Métneki and Czeizel suggested – regarding better results in Down syndrome diagnostics – was amniocentesis because it is harmless for the mother and the risk of losing the fetus in case of complications is below one percent. They considered this an important technological development in preventive medicine because during the weeks of 12 to 14 the pregnancy could be aborted if a chromosome disorder was detected. Preventive medicine was largely understood – regarding at least serious genetic disorders – as genetic counseling and this medical apparatus helps society to avoid the birth of children with disorders. The aim was to perfect the biotechnological apparatus that ensures better results. Here, Métneki

and Czeizel argued that the economic benefits are important in weighing the values of prenatal diagnostics. They compared the costs of laboratory diagnostics in the case of preventing the birth of 4 children with Down syndrome with the annual medical costs of care work needed for 4 children with Down syndrome. From the comparison – because the cost is the same – they concluded that besides the doubtless economic value it should be considered as a possible direction in preventive medicine. They placed emphasis on the population of Budapest and advised that this preventive method is worthy of consideration perhaps with a stricter focus on 'older' pregnant women (Métneki & Czeizel, 1973, p. 1746).

I find it important to draw attention to further parallels that we can see here regarding explicit eugenic argumentation. They claim that because of the medical developments of the last decades more and more people with Down syndrome live up to their school years and even into their later years (before antibiotics were introduced 85 percent of them died before their 7th birthday). This means, that despite their serious biological disadvantages, contemporary medical technology can help them to live out their lives. In other words, they claim that the growing frequency of people with Down syndrome represents a triple burden: „psychological, ethical, and economic burden for the family, society, and the whole humanity. Solution could only be hoped from genetic prevention and for the sake of the cause effective healthcare-organizational measures are necessary (such as the extension of prenatal diagnostics)” (Métneki & Czeizel, 1973, pp. 1746–1747).

Zoltán Papp and his colleagues listed the four most important reasons that made Down syndrome one of the key disorders for geneticists (Papp et al., 1976). The first reason is that it occurs frequently. Secondly, individuals with Down syndrome represent 3-4 percent of the population with mental disorders and as a result of technological and medical developments their numbers are increasing thus they will become a bigger 'burden' for the family and the society. The third reason is that prevention is already worked out to a certain extent (prenatal

tests of women above the age 40), it was proven that the available biotechnological apparatus could manage the occurrence of the disorder. Lastly, because diagnostics are relatively easy this genetic problem lends itself to further research regarding the question of parental transmission. In their review article, they explored the various factors that contributed to the transmission of Down syndrome. They concluded that it was necessary to conduct further research in order to understand the causes of 21 trisomy, thus contributing to "better genetic counseling and diagnostics in order to prevent the birth of fetuses with Down syndrome" (Papp et al., 1976, p. 1078).

In an earlier article, Papp already made a case for prenatal diagnostics as the best available tool that safely contributes to the prevention of Down syndrome. In order to maximize its success, he emphasized the need for institutional developments throughout the country: more cytogenetic laboratories were necessary for the introduction of complex diagnostic programs, genetic counseling institutions were needed country wide, and the development of prenatal genetic methods. Here he also stated that "if these conditions are settled applying the guidelines he outlined in his article, the birth of those affected with chromosome-aberrations, primarily with Down syndrome, could be reduced significantly, if our efforts meet the requests and approval of parents" (Papp, 1974, p. 1106). In my view, he almost explicitly positions himself and the medical genetic profession as the responsible agents of the state whose primary goal is the prevention of the birth of children with genetic disorders. "Their aim and the parents' approval" in this context entails that the dominant medical position is the termination of pregnancies but also entails freedom on the side of parents, however this free decision-making is structured from this value laden professional position where scientific knowledge and technology intertwines with state interest.

The medical genetic stance on the value of prenatal screening and diagnostics and the accompanied genetic counseling changed after the transition as I explained the previous sub-

chapter. But explicit arguments regarding Down syndrome were published later. For example Tóth and Szabó argued in 2000 that the aim of genetic screening and diagnostics was "to widen the self-determination (or autonomy) and decision making options of mothers and parents by informing them" (2000, p. 2294). Medicine in general and medical genetics in particular makes informed decision making possible, but it does not interfere with individual values – it is the parents right to make any decision. Because the primary goal of genetic counseling is to inform parents (mothers) about the health status of their fetus in order to help their decision making with medical information (and not to prevent the birth of disabled children), they argued that "prevention cannot be marked as the primary aim of medical help" (Tóth & Szabó, 2000, p. 2297). This signifies an important shift away from the previous eugenically informed aim of genetic screening, diagnostics, and counseling.

In their article they explicitly dealt with the rejection of criticism that suggested prenatal screenings are eugenic practices. Tóth and Szabó started out by defining eugenics as an ideology introduced by Galton in 1883 – for Galton it meant the enhancement of human race (Tóth & Szabó, 2000, p. 2294). The authors argued that eugenic movements were organized worldwide between 1883 to 1945 but after the Second World War scientists and societies started to distance themselves from the politically corrupted ideology. They emphasized that presently eugenics is regarded as negative and because of the multiple but primarily negative interpretations, professionals who work in the field of medical ethics suggest abandoning the term. They listed the various eugenic charges against prenatal screening: (1) genetic based selection; (2) endangering reproductive autonomy through open or refined social constraints; (3) individual interest subordinated to community interest (here racial and economic interests are stressed); (4) it conveys social prejudice. They rejected systematically these charges by arguing that screening programs are voluntary thus these are not serving social interests. These screening programs and medical geneticists embrace the goals of information distribution and

the idea to widen the autonomy of citizens, but they reject the idea that these programs serve the interest of defending the healthy gene pool of the society. Genetic counseling practices must conform to international standards and must stay neutral (non-directive). According to them counselors must distribute information without actually influencing their clients in their decision-making. But they stated that in actual practice "it is very hard to keep counselling neutral" (Tóth & Szabó, 2000, p. 2295).

The relation towards pregnancy changed after the 1970s. In the early years of prenatal testing because it was expensive and took long time, it was important to connect the test itself to the acceptance of abortion by the parents. I think that this is important, because it explicitly suggests that eugenic values were at work in this reasoning. Of course ensuring the healthy birth of the child was considered the most important, but the way it was embraced, it implied eugenic ideas. Socio-economic interests intertwined with medical technological information distribution which was connected to the acceptance of abortion in case of negative diagnosis. This suggests that hidden-values were structuring these medical genetic processes. But what Tóth and Szabó argued is crucial here: this initial attitude changed because of the technological advances. It was transformed into a process that treated the value of prenatal testing more openly. This new approach embraced non-directive information distribution that would lead parents to evaluate the received information about their pregnancies in the following ways: (1) healthy fetus, no need for any further concern; (2) diagnosed health problem, thus parents can choose abortion; (3) diagnosed health problem, thus parents can prepare how to respond to this situation according to their personal values (Tóth & Szabó, 2000, p. 2295). They found it important to emphasize that genetic screening programs should not discriminate against disabilities. The medical stance toward any disorder is to help the decision making of parents, and if they decide to keep their fetus with a disorder, clinicians should help them by researching

the disease (to find treatments or to avoid the development of the problem in utero) and with the treatment of the child born with the disorder.

In their analysis, Tóth and Szabó (2000, p. 2296) addressed an important problem regarding accessibility to genetic screening. They argued that the principle of social justice can only be ensured by making screening accessible to every citizen. In the case of Down syndrome – the example that they used to underscore their point – a general screening program would work best. By general screening they understood a program to which everyone from all social strata has access. Research suggests that if this is not the case then those who are in better economic positions and more educated would use these programs more. Thus, the state would inadvertently put people living in the lower strata into worse situation by making access to screening economically hard and by putting the economic burden of raising their children with disability on them. And also it would be important to provide access to people from all age groups, because they claim that although Down-screening is accessible to those women who are above the age of 37, but 70 to 80 percent of children with Down are given birth by mothers below this threshold.

It is commonly accepted that the present discourse on what is the significance of Down-screening is divided into two camps (although this is maybe a simplification of the discourse it is useful to understand the key principles that clinicians find important regarding their work). The first perspective can be termed as the epidemiological approach, it sees the significance of Down-screening in the possibility of reducing the prevalence of the disorder in the society (preventive by abortion). The other camp (medical geneticists, gynecologists-obstetricians, and pediatricians) values genetic screening because it opens up more possibilities for individuals (and couples, families) and thus strengthens their autonomy. They think that genetic screens and diagnostics are important because they give medically relevant information to parents about their fetus – so it helps their decision-making. They argue that this approach is important

because it allows medical professionals involved in screenings to reject the charges of eugenics (Tóth & Szabó, 2005, pp. 259–260). Based in these tenets, they argued that information distribution in the case of Down-screening is important because of the modern principles of medicine (for example the principle of informed consent). These principles were integrated into the Hungarian legal system by the enactment of the 1997 healthcare law that ensures that these modern medical principles are to be applied in medical practice. In addition to this, Tóth and Szabó underscored that the significance of Down-screening lies in the present status of the disorder: it is not possible to offer medical treatment only the termination of the pregnancy.

By discussing the case of Down-screening Tóth and Szabó reflect on the turn in genetic counseling that took place in international practice. It is described by them that the dominant form of counseling was non-directive information distribution since at least from the 1970s, but "the success of this neutral method was gradually questioned by clinicians. They wrote that today it is expected that geneticists interpret the genetic information according to the educational level of parents and also that they explore and explain the values that a play role in the direction of counseling" (Tóth & Szabó, 2005, p. 261). Today the paradigm defines genetic counseling as an interaction in which both patient (or client) and doctor takes part with their whole personalities. This is understood to contribute to real autonomous decision making. According to this perspective it is crucial to reflect on one's own prejudice on both sides (patients and clinicians as well). Clinicians must overcome their age focused prejudice that only elderly mothers should be offered the test for Down-syndrome (Tóth & Szabó, 2005, p. 262). They must act self-reflexively (that this was a professional bias) and offer it for young mothers as well, because Down-syndrome occurs in their pregnancies as well, moreover it is acknowledged by the profession that most children with Down-syndrome are given birth by younger mothers who are not directed by medical professionals to go through genetic screenings. In addition to these values, the quality of information distribution expanded into the

direction of recounting experiences of raising children with Down syndrome (Tóth & Szabó, 2005, p. 262). This is an important aspect, because the previous medically accepted practice was to inform parents about the negative aspects of the disorder (all the problems, negative life prospects). In contrast to this approach, there was a shift in the international medical discourse and in Hungary as well: it became professionally accepted and perhaps ethically right to discuss the positive things as well that parents (or families) experience when raising their child with Down syndrome.

6.5. Conclusion

Economic and preventive reasons were connected and justified with a fear derived from the eugenic discourse: researchers anticipated the degeneration of the population. At the early stage of genetic counseling, the best solution deemed to be the prevention of the birth of children with serious inherited disorders. In order to facilitate this preventive direction family planning institutions were established resembling to the earlier interwar eugenic institutions explicitly aimed at ensuring parental fitness.

What we could observe is the legal-political support of this preventive ideology from the 1970s that aimed at ensuring better newborn statistics. The culmination was the 1973 state decree that made premarital counseling mandatory, but as this did not work in real life, clinicians suggested transforming it in the 1980s and finding ways to distribute information so that citizens would be willing to use genetic screening facilities voluntarily. In this discourse, clinical geneticists were concerned with the possible extension of screening programs to the relevant risk groups. This intention was driven by class and gender based concerns: most people could not allow for paying for prenatal tests, and this made it important to introduce free screening opportunities first for women above the age of 35, and after the technological

developments, when it was possible, offer general screening tests for every pregnant woman. As I have shown this move was eugenically motivated and economically justified.

According to the established guidelines, genetic counselors on the one hand distributed information to parents, primarily through the medical control of pregnant women, and on the other hand they understood their role on the basis of state interest. They were concerned with the health of the society as a whole and the economic problems that failed screenings could cause for both parents and for the people. Thus, decision-making or the options to choose from were pre-structured and prospective parents were 'guided' in accordance with the values of the established groupings. This process was based on the paternalist model of doctor-patient relationship and the transformation of this model started in the 1990s. In the new understanding of medical conduct, the most important value is the autonomy of the client. By prioritizing on autonomous decision-making this model shifts eugenically informed choices into the sphere of parental values and responsibility, but at the same time allows for choices in which diverse values can be seen represented.

7. Hidden Narratives of Eugenic Thinking: Roma Populations in the Focus of Genetic Research

In 1982, Endre Czeizel published an article that discussed population genetics and its relevance to medicine, history, and national identity. He defined population genetics as „the study of a population whose individual members belong to the same species” (Czeizel, 1982, p. 2271). He accepted the racial differentiation of Bernier proposed in 1684. Czeizel understood race as human types, but importantly, he underscored that it must not be confused with cultural and political categories such as nation or ethnicity. Population genetics as a discipline was not a field of study yet, but there were important contributions that population geneticists made to medicine and genetic history thus, he thought, it could be worthwhile pursuing studies in this direction in Hungary as well.

At this time in the history of Hungarian population genetics, Czeizel was interested in finding out whether there was some kind of genetic feature that could be identified as uniquely Hungarian. He started out from the works of anthropologists, such as Lajos Bartucz, and described the Hungarian population as a mixed one, but primarily characterized by Turkish-Hungarian (türkös-magyar) or Turáni racial type. This type is described as follows: „face is wide and flat, eyes are small and narrow – these refer to East-Asian origins – but the moderately big nose with developed nostrils that stands out from the face points toward European racial origins. Mouth is relatively small and narrow, body hair is dark, and slightly thick” (Czeizel, 1982, p. 2274). However, he held that despite the statistical significance of these phenotypical features these cannot be accepted as unique Hungarian physical-anthropological characteristics.

He understood the social benefits of population genetics primarily from a medical perspective, and for the purpose of my analysis this is also the most important aspect. He explained that it was widely accepted by geneticists that different populations (characterized by

race or ethnicity) have different disease spectrums because of their long history of endogamous marriages. Thus, he argued that it would be beneficial to explore the specific disease frequencies in the Hungarian population in order to manage diseases with the tools of medical genetics (Czeizel, 1982, p. 2276). During the 1980s, studies appeared that compared the prevalence of various mutations in ethnic communities. One such early example is the study of Flatz and his colleagues that focused on Hungarian ethnic communities from the perspective of lactose-intolerance and concluded that in general there were no large distinctions between groups except for Roma communities. They managed to point out that among Roma lactose-intolerance was 56 percent in comparison to the general Hungarian sample which was 37 percent (Flatz, Czeizel, & Flatz, 1984, p. 147). Another early direction was the mapping of cystic fibrosis (CF) mutations within Hungary (K. Németh, Holics, Újhelyi, Váradi, & Fekete, 1996). During the first half of the 1990s five CF mutations were found, which were considered the most prevalent causes of the disease in Europe. Researchers concluded that the Hungarian case (regarding $\Delta F 508$ with its 64 percent) resembles most closely to that of Poland and Finland. They found in their study that the other four mutations (G542X, G551D, R553X, and N1303K) were less prevalent causes of CF disorders than in the other neighboring countries.

In this chapter I will discuss how ethnic identity as a variable entered the medical genetic discourse. Just as with establishing risk groups within the population of Hungarian women as I described in the previous chapter, the idea to delineate racial groups within the whole Hungarian population was understood as a move that would help the creation of better diagnostic panels and thus would enable better reproductive healthcare in general for the Roma population. And in addition to these goals, it was understood that it would be economically beneficial for the state.

7.1. The Human Genome Project and Its Epidemiological Consequences

With the results of the Human Genome Project, scholars like, György Kosztolányi, suggested that with the technological advancements that made mapping the human genome possible 'real preventive' medicine would take shape. By this he meant that with genetic analysis it became possible to detect genetic mutations that put individuals into risk groups for developing various disorders. Thus, medicine would be capable of offering information for clients/patients on how to change their lifestyle that would help them avoid the development of the disorder. This is what he meant by real prevention: medical genetics would be capable of detecting a mutation and directing patients in a way to stay healthy (Kosztolányi, 2000, p. 2423). Another crucial paradigm shift crystallized with the results of HGP: medical genetics was a field with a primary focus on the individual / families. It was interested and had tools to diagnose diseases transmitted through inheritance and thus offering various options once diagnosed; this frame is transformed with the results of HGP because the findings of the project made it possible to shift the medical focus onto disorders that are of epidemiological significance. Examples of such problems are asthma, heart and cardiovascular diseases, tumors etc. These problems are important because medicine can make prognoses whether someone is susceptible to develop these health problems. Thus, Kosztolányi emphasized medical genetics became a field of medicine that plays a key role in the preservation of life quality and health of the population.

After the completion of the Human Genome Project, the genetic information gained became interesting and potentially useful for epidemiological reasons. In their study Szilvia Fialat and Róza Ádány started out from the premise that there are more and more disease associated genes that researchers discover and this means that such genes play a crucial role in the development of given diseases that make individuals susceptible to various health problems. The detection of such mutations can provide grounds for targeted phenotype prevention

programs therefore in order to design such programs they argued that it was necessary to map the most prevalent mutations in the Hungarian population. The best approach to achieve such goals is to study genetic variations epidemiologically, which means to map the prevalence of genetic variations in a population, explore gene-phenotype correlations, gene-gene interactions, and gene-environment interactions (Fiatal & Ádány, 2009, pp. 185–186). In distinct ethnic populations the prevalence of genetic mutations are different therefore they found it important to study the most prevalent mutations in Hungary. They concluded that Hungarians, similarly to other Caucasian populations, have mutations that make them susceptible to cardiovascular diseases (FV-Leiden mutation MTHFR-C677T), diabetes, and mental disorders for example, but they also stated that without reference results their findings could not be verified.

7.2. Public Health Standards of Roma and Non-Roma after the Transition

After 1989 it was widely recognized by researchers that there is a huge gap between the health standards of Roma and non-Roma Hungarians. For example in their study, the sociologist György Gyukits and his colleagues underscored that the Roma population suffered the biggest losses during the transition (Gyukits, Ürmös, Csoboth, & Purebl, 2000). Unemployment rates were very high among Roma, it was estimated to be around 45 percent thus their social economic situation largely determined their health standards. In their study, they explored the causes of very low participation rates of Roma women in lung screening programs. They claimed that in order to understand how effective prevention programs are the state must know about the various groups' activity using those preventive programs. They claimed that their results suggested that prevention programs and campaigns that target Roma people should be worked out in order to distribute information and help preserve their health. They further identified a problem that they could not answer: there was a big difference between Roma and

non-Roma Hungarians even if they were similarly from lower educated groups. Their initial hypothesis was that education could play a key role in using various healthcare facilities, but they found a contradictory result. This is relevant in view of racial/ethnic discrimination toward Roma people in healthcare services.

Other researchers, similarly focusing on environmental factors pointed out that the health of Roma people living in slums is much worse than that of those living in average circumstances (Z. Kósa et al., 2008). In addition to their detrimental social situation, they have to endure high rates of discrimination when they want to use healthcare services. In this study, Zoltán Kósa and his colleagues, compared the 45-64 age group, and found that Roma people view their own health status in a worse light than those who live in a similar economic stratum in the society but not in slums. They argued that the health status of Roma must be developed through multisectorial programs that are designed to target these communities (such as health education). Without structural changes, their health status will remain well under the average standards.

7.2.1. Elevating the Health of Minorities as a Criterion for Joining the European Union

Hungary's intention to join the European Union initiated numerous epidemiological studies. It is because Hungary had to meet the Copenhagen Criteria that "requires the respect and the protection of minorities through the stability of institutions that would ensure that" (K. Kósa, Lénárt, & Ádány, 2002, p. 2419). Consequently, a governmental program dealt with the issues of Roma minorities, and researchers such as Karolina Kósa and her colleagues contributed with their study to the health focus of the program by analyzing the general health standards of Roma. Because in order to facilitate measures that would improve their health conditions it was necessary to survey their demographic situation, their morbidity and mortality rates, their

genetic specificities, and their health behavior. According to Kósa and her team (2002, p. 2424), only those genetic factors should be examined that significantly influence life quality (such as inheritable disorders and epidemiologically relevant genetic factors). The point in these studies would be to identify those genetic factors that pose high risk and with the knowledge at hand, it would be possible to design screening programs that would boost the effectiveness of prevention. They also acknowledged that the data suggest that their detrimental health situation is the result of their marginalized social-economic positions – „their ethnicity is only epidemiologically important as a confounding factor” (K. Kósa et al., 2002, p. 2424). They also noted that any study interested in the mapping of health status must take into consideration the data protection law of 1992⁶³ that makes the use of racial, ethnic, or national identity in medical context dependent on the consent of the individual or dependent on legal approval. Importantly this was not prohibited in the socialist period and there was an institutionalized practice around this phenomenon as I showed it in Chapter 5. They argued that the new law made it hard to collect precise information on the health standards of Roma, but on the other hand they praised this law as a progressive measure that places ethnic/racial identification in the sphere of personal autonomy.

Genetic studies point towards the need to focus on mutations that are perhaps more frequent in Roma populations because of their cultural isolation (K. Kósa et al., 2002, p. 2422). Geneticists found that most of the Roma choose partners from within their Roma communities and also geneticists found that relative marriages are much more common among Roma which makes the prevalence of mutations and thus certain genetic disorders more frequent in these communities. Furthermore, healthcare studies pointed out that Roma people have an increased susceptibility to heart and cardiovascular diseases. For example the Leiden mutation is much more frequent in Roma living in East Hungary (12.2 percent of them carry the mutation in its

⁶³ The LXIII. law of 1992 about data protection of personal information and the accessibility of public data.

homo- or heterozygous form, against only 9.8 percent of non-Roma Hungarians) that makes people susceptible to thrombosis. Others like Kiss and his colleagues compared Hungarian Roma (Vlachian gypsies) with non-Roma Hungarian populations. They focused their studies on allelpolimorphisms that decisively influence tumor development and thus mortality rates in Hungary. They argued that studies are already published in which scholars have pointed out the higher rates of congenital glaucoma, galactokinase deficiency, and polycystic kidney disease in Roma people. They have argued that the studies of allelpolimorphisms are vital in order to design targeted preventive strategies (Kiss, Béres, Orsós, Sándor, & Ember, 2004, p. 69). And they found out by comparing their results to literary results about Indian and Caucasian populations that Hungarian Roma people differed from non-Roma Hungarians regarding the prevalence of GSTM1 and p53 genes and also they found that regarding the NAT2 gene the Hungarian Roma is in between the non-Roma Hungarian and Indian populations (Kiss et al., 2004, p. 72). And because of these findings they argued that a part of the Hungarian Roma population, the Vlachian gypsies, are more susceptible to developing certain tumors than members of non-Roma and other Roma populations. And I think this is important because it implies that targeted knowledge distribution would be crucial in tackling the related diseases. And thus, targeted screening programs could be developed that people who identify as members of these groups and might carry these genes could use.

Kósa recalls that in the European Union a complex public health program between 2003 and 2008 was working on health equality; accompanied by a study that suggested looking for structural inequalities that hinder equality in health status among various populations. The European Committee issued a statement in 2009 to start a complex program that would address these problems (K. Kósa, 2009, p. 334). The WHO started to research this topic already in 2005 and their results were published in 2008. Karolina Kósa summarized their most important findings on how to reduce inequality: (1) improve living conditions; (2) reduce the inequality

in the distribution of power and economic resources; and (3) targeted healthcare interventions. She argued that although it is the declared goal of Hungarian public health programs to reduce health inequality it will not work out that way. This goal was explicitly stated in the National Public Health Program accepted in 2003 the program aimed at helping Roma, handicapped, and homeless people to get access to healthcare. But she thought that this direction was a serious mistake because it did not correspond to the suggestions of the European Committee. The problem that she emphasized is related to structural inequality because the program did not address social and economic factors that determine the health of the marginalized groups. Contrary to that, Karolína Kósa argued that in itself access to health services would not solve health inequality in the long term. In my view, one of the key arguments put forward in order to enhance the well-being of Roma people in Hungary is the inclusion of Roma perspectives in shaping and executing local policies (Fésüs, McKee, & Ádány, 2010, p. 317). A more efficient contribution from Roma people – in which they can explain how they experience health issues, and other relevant social issues, – would help healthcare professionals, social scientists, and political decision makers to design programs that would include their needs and thus prioritize economic and human resources in order to develop their living conditions, working possibilities, and ultimately their health standards.

One of the key starting points of the discussion is the European Union's Roma integration plan drafted in 2011; in this plan one of the key pillars of integration was understood to be healthcare. From the various problems related to healthcare, the plan emphasized the need to improve access to health services, decrease infant mortality rates among Roma children, and improve the visibility of Roma issues in healthcare data (Balázs, Foley, Greczner, & Rákóczi, 2011, p. 68). Balázs and his colleagues drew on the work of Marc Lalonde – who was the Canadian minister of health – in arguing that ethnic classification of healthcare data could advance the well-being of minorities. In his work that appeared in 1974 (*A new perspective on*

the health of Canadians), Lalonde stated that it is important to acknowledge that humans are biological and social beings, and thus ethnic specificities should not be left out from epidemiological programs, otherwise important information is lost for healthcare services. In this light, Balázs and his colleagues argued for the integration of ethnic classification into medical research and service.

In their analysis, they emphasized that since 1989 there was still no healthcare database that would have collected health statistical data about Roma people in Hungary. To place more weight on this issue, they cite the relevant public policy statute enacted in 2003⁶⁴: “we don’t know exactly the relationships between the Roma population and the healthcare system’s specific institutions (general practitioners, clinics); and we don’t know completely how biased the attitude of healthcare workers towards Roma is, (and vice versa: what types of fears or biases Roma people have towards healthcare institutions or its workers). Based on the data it is possible to point out the effect that communicational issues have within doctor-patient relationship on judging disease behavior. It is an even more significant question, that in light of the data, general practitioners do not know the precise health condition of Roma people, their mortality rates, hence it is not probable that they would pay greater attention to their Roma patients” (Balázs et al., 2011, p. 72). Based on this problem, Balázs and his colleagues raised a very important question: “What would happen if the attitude of general practitioners changed? What kind of Roma population data would they be able to use?” In conclusion, they suggested that epidemiological studies are about the mapping of real health problems of various populations within a society, and at the same time providing data on which primary and secondary preventive programs could be based. They argued that if it were accepted that the identity category of Roma as a variable could help healthcare professionals in their work to

⁶⁴ 46/2003 (IV. 16.) Parliament declaration about the Epidemiological Program of the Decade of Health.

achieve epidemiological goals in the interest of Roma people⁶⁵, then it would be a mistake to refrain from using the tool of ethnic classification for securing healthcare information.

7.3. Indicating Genetic Studies of Roma in Hungary

There is a strong tendency to defend the standpoint that the genetic research that tries to map molecular biological differences between ethnic communities is apolitical. It is argued, for example, by István Raskó and Tibor Kalmár (2003), that the mapping of the distance of various ethnic communities from each other is an objective scientific method that can help connecting genetic traits with genetic diseases. In a similar manner, Judit Béres who is a population geneticist in Hungary focusing on the genetic structure of the Roma people, claims that there are genetic diseases which put primarily the Roma people of Hungary at risk. The genetic screening of Roma people is justified by human geneticists by reference to the large number of genetic diseases within the communities and their culturally-accepted endogamous practices (Béres, 2003). It is argued that because of the present geographical and social marginalization of Roma it is in their best interest to map their disease so that healthcare professionals can help them with their genetic problems. This strategy fits into the international medical genetic literature that studies populations classified by race and ethnicity.

Although the focus in the frame of contemporary medical genetics is on the individual, the aim is to help individuals, and couples with genetic disorders to be able to have healthy children, or to help them lead a life that allows them to avoid genetic diseases, or to tackle epidemiologically significant genetic disorders by helping individual patients. Various factors, such as socioeconomic status, race/ethnicity, age, or gender help the diagnostic processes in

⁶⁵ On page 69 in this article the authors explicitly stated that ethnic classification can only be used in medical data collection if it is treated as highly sensitive information and the person cannot be identified later (Balázs et al., 2011).

locating the cause of the disorder. The positive goals of genetic-screening programs are to find out what are the genetic diseases within the targeted population. Inheritance played a major role in driving the examinations because the familial ties through the diseases were transmitted to younger generations. This is how ethnicity became important in genetic screening. These early screening programs, just as the contemporary ones, are pro-natalist programs. The medical genetic programs which are connected to these screenings consist of genetic counseling programs which deal with the individuals' genetic diseases and give advice on reproductive decisions for individuals or couples.

Genetic screening for Tay-Sachs and β -Thalassemia are examples of successful programs. The first individuals who were examined with Tay-Sachs disease (TSD) were members of the American Ashkenazi Jewish community. Ruth Schwartz Cowan claims, that the TSD screenings were successful because it was organized, funded, and the knowledge was distributed by and to the Ashkenazi Jewish community. Another aspect of their success was that the workers of the screening programs were volunteers, and the people who were tested were also volunteers. And not the least importantly the church supported the screening programs for TSD within the community. Another successful, church-supported, state-organized example is the screening for β -Thalassemia in Cyprus where as a result of the voluntary screening programs across the country this type of genetic disease has been successfully reduced within the population (Cowan, 2008). These examples signal an important process within these communities in which individuals if they wish can benefit from genetic screening given that they identify as Ashkenazi Jews or Cypriots who think of themselves as at risk of transmitting the disorder.

A counter example for medical services related to epidemiologically significant genetic disorder is the sickle-cell anemia in the United States. This is a genetically-transmitted disease which was examined for the first time within the communities of African-Americans. This

disease is just as lethal as Tay-Sachs or β -Thalassemia, but the screening programs were unsuccessful primarily for two reasons: (1) it was organized from outside of the African-American community, (2) and the long-standing racism towards the African-Americans from the majority population left the community skeptical towards the white community (Rouse, 2009). In my view these cases, both the successful and the unsuccessful screenings, show what are the most important problems with genetic screenings that are organized from top to bottom without integrating into the process the needs of the members of the community and without being reflexive towards long-standing racial discrimination in a given society.

7.3.1. Making Distinctions Between Roma and non-Roma Communities

In the early works, geneticists were interested in finding out what are the genetic structures that make Hungarians Hungarian. For this reason, they wanted to compare different ethnicities but mainly they wanted to follow the lead of cultural anthropologists who suggested that people in the Órség region might be the ancestors of ancient Hungarians since they kept their separateness throughout the centuries. But this lead failed and they concluded that it is not possible to differentiate ethnic Hungarians from other white Europeans – which information is relevant in the rationalization of disease mapping.

In researching the genetic structure of the original Hungarian settlers they found out that the genetic structure is a mixture. There is no real difference between different ethnicities if they take away the Jewish and gypsy samples. They concluded that in Central-Eastern Europe the present populations are genetically kin populations, which is good for the society, because there is no Hungarian genetic disease. It is well-known that there are Jewish diseases, gypsy diseases, and Celtic, and even French-Canadian diseases, and researchers know about Finnish diseases as well. Basically, from the perspective of genetics the more mixed a population the better it is (PI 20121031).

Let me start with perhaps one of the most easily observable directions in the interviews: the distinctiveness of Roma and Jewish samples from the majority. The explanation is connected to international literature, implicitly stating that this is an accepted narrative in the international medical genetic discourse. Certain ethnic communities within a society keep their isolation; and it is even more understandable when the explanation is that geographical barriers stop people from mixing with other ethnic communities such as the case with Finland, and the so called Finnish diseases. And the separation of majority Hungarians from Roma and Jewish Hungarians is primarily explained through historical narratives as we can see in the following excerpt:

In Hungary one can distinguish between three ethnic groups of Roma: Vlachian, Romungro, and Beasi gypsies. It is clearly visible, that they joined the Hungarians later and hence they lived in isolations. This is like the Jewish case, firstly there is a religious law which prescribes that a Jewish woman can only bear a child to a Jewish man; and secondly in 1096 King Szent László sanctioned that Christians can only marry Christians, so he also restricted the choices of Jewish individuals, hence they chose partners from their small communities. As there were not so many individuals in these communities, certain kinds of inbred genetic characteristics were developed. If we live in inbred communities, for example where cousin marriages are very frequent, which is very typical for both gypsies and Jews, then because we inherit a flawed gene from our common ancestor, it is much more probable that these genes meet. For example, we know that there are Jewish-only diseases - there are seven such diseases -, which is interesting because in Israel all of the newborn babies are screened for these diseases. Our research confirmed that there are similar gypsy diseases. The congenital glaucoma, the buphthalmos is such an example; it is much more prevalent in their communities. Of course, this has advantages as well: there is no sclerosis-multiplex in gypsies. So it emerged, when we analyzed these gene signals, it was verifiable that they came from elsewhere, they lived as isolates, in inbred communities. But this was similarly verifiable regarding Jews (PI 20121031).

This explanation can be layered further with the other types of classifications that exist about Roma only within Hungary. For example the sociological literature differentiates among diverse Roma groups according to their occupational, linguistic, and geographical differences as well (see Dupcsik, 2009). The unfortunate outcome of the above cited narrow or simplified

ethnic classification is the homogenization of differences which are both social and biological and do affect reproductive choices that in turn contribute to health differences.

In another discussion that contributes to a stronger differentiation because it happens on the molecular level, when I inquired about the differences between Roma and non-Roma patients and their significance in diagnostics one of my informant told me that s/he thinks that it is possible to measure genetically who is Roma, and who is non-Roma:

During a medical interview, one can see roughly up to 80 percent who is Roma. There are certain phenotypical characteristics that differentiate them. I think one could measure these with anthropometric data. Of course not in a clinical genetic counseling setting – there is no time for that during a counseling session (PI 20140207).

This position not only underscores the belief in genetic differences but also re-creates the dividing line between racial/ethnic populations on a biological level. It is critiqued by several geneticists, and also by numerous social scientists because it paves the way for molecularization of race in genetics⁶⁶. Also in my view, the attitude of the researchers in the question about individual and group differences is decisive. They not only descriptively list differences, but by listing differences and grounding them with the linguistic and non-linguistic tools of genetics they re-inscribe race. Moreover, using reproductive practices is a one-sided and hence insufficient explanation and seemingly shifts the responsibility onto Roma by saying that they are unwilling to open their communities and mix with non-Roma because of their ethnic traditions. This perspective contributes to the masking of everyday racism of non-Roma Hungarians toward Roma, since it normalizes their separateness by using the strategy of simply defending their way of life. From this perspective, it seems rational and logical, and more importantly medically responsible to handle the genetic problems that these people face – but it will not contribute to the reconstruction of equality in healthcare.

⁶⁶ I will return to this topic in the last chapter.

7.3.2. The Problem of Isolated Populations

Knowledge about different disease frequencies in populations is produced with the methods of population genetics. The information that is gained through its techniques is applied in two main fields of medicine: in clinical diagnosis and in genetic counseling. The central organizing concept of population genetics is the Hardy-Weinberg equilibrium which allows researchers to predict the ratio of gene frequencies in different ideal and real populations. The main benefit of this principle is that researchers can predict that disease frequencies will be more or less the same in a given population on the condition that (1) it is large and mating is random, (2) there is no observable mutation so allele frequencies remain the same. In other words, there is no selection against any genotype and there is no significant allele frequency that has been contributed by immigrants to the endogenous population (Nussbaum, McInnes, & Willard, 2007, pp. 192–193). Population geneticists identified three factors that disturb the Hardy-Weinberg equilibrium (Nussbaum et al., 2007, pp. 195–196): (1) stratification of a population which means that subgroups of a large population remained genetically distinct from each other during the last centuries (this definition is focused on race/ethnicity (2) assortative mating means that individuals tend to choose partners with similar characteristics (from the perspective of medical genetics this contributes to the suspension of the Hardy-Weinberg law since mating partners possess similar traits), and lastly (3) inbreeding similarly to the previous two factors effectuates an increase in autosomal recessive diseases.

In the literature, the medical significance of isolates is explained by examples such as the colorblindness on the Pingelap Atoll; this problem is very frequent there and the mutation that causes the phenotype can be traced back to the same individual. The history of this mutation is connected to an environmental disaster – a typhoon killed most of the inhabitants on the atoll around 1775 – and from those who survived one person carried this genotype and passed it on

to the next generations. Another similar example is the shared asthma disease of the inhabitants of Tristan de Cunha, which is an island in the middle of the Atlantic Ocean. It was found out in 1961 that more than half of its 300 inhabitants carried the gene for the same asthmatic problem. Researchers comparatively analyzed the samples and they found out that the mutation can be traced back to the same person (see Raskó, 2015). These examples are medically significant in pointing out that genetic mutations accumulate in small populations which are closed from genetic inflow. These problems are relevant in any mainland as well. One of the classic examples for genetic analysis is the Ellis van Creweld syndrome that was first identified in Amish populations in the United States in the 1960s by Victor McKusick (2000). But there are several other examples of other social isolates as well: the beta-thalassemia in several at-risk populations in the Mediterranean (Cao & Galanello, 2010), or Tay-Sachs in Askhenazi Jewish communities in the US (Nussbaum et al., 2007). Therefore, it was important to inquire about the significance of this medical genetic knowledge for Hungarian populations. To emphasize its relevance one of my informants started out with Finland and pointed out that because of generational immobility of Hungarians a couple of decades ago, perhaps similar problems could be detected.

A good example can be Finland for this question, because around the Arctic Circle obviously there are some villages with a couple of thousand inhabitants who married to each other hence there was no big mixture. In these cases, those genes were accumulated which characterized those populations. Or when a genetic disease occurs its incidence is much higher in such an isolated population than in a population where the choice is wider. However there are isolates in the mainland as well, it is enough to think about small villages in a few decades earlier whose inhabitants could only reach the next villages to choose a partner. Thus, geography is one, but ethnicity is another factor, because there are ethnicities who choose partners only from their own ethnic community (PI 20130321).

In this explanation, besides the geographical determining factors, racial/ethnic stratification plays a significant role. Although it is widely accepted that members of ethnic communities

tend to choose partners from the same ethnicity it must be noted that these are not only determined by internal forces (such as community tradition/pressure) but also external forces such as xenophobia, racism, classism, linguistic discrimination play a key role in shaping individual reproductive choices.

Although other researchers whom I interviewed acknowledge its medical usefulness as well, not all of them considered the question of closed population easily explicable. They do think that it is indispensable to have this term and work along its tenets, but on the other hand they also shed light on its obscure nature. It is not possible to take hold of a closed population in a finite manner since they are constantly changing in reality.

It is hard to define. In reality, I think, there are no closed populations because external relationships always occur in any community. The question is rather their frequency (PI 20130214).

I wanted to know more about the methods and actual practices whereby geneticists choose homogenous populations, and how hard it is to find such isolates, especially Roma isolates, in Hungary. For this inquiry, I received the following answer:

We targeted Vlachian communities. We chose villages where the ratio of the population was more than fifty percent Vlachian gypsy. So to a certain extent homogenous population (PI 20131119).

This underscores that this endeavor is not easy. And it relates back to PI 20130214's position, in which it is stated that there are no homogenous populations in reality. It is rather how researchers think about homogeneity and how they construct (or circumscribe) the boundaries of a population, take samples and find a common, shared problem on which the members of the group are linked together, as is evident from another excerpt:

When individuals choose partners from within the same group there is no inflow and outflow of genes. Hence on a given genetic trait everybody is in genetic kinship relation with everybody (PI 20100527).

Here I think in the explanation it is glossed over that inbreeding is similar in effect to consanguineous marriages but not equal to this cultural custom. Inbreeding is rather the result

of an unfortunate social-geographical isolation from the majority population and hence the inflow and outflow of genes is minimal. In Roma communities, all the above mentioned three factors disturb to a certain extent the Hardy-Weinberg law which has medical consequences that must be addressed. In the following I will analyze how inbreeding and the problem of founder effect plays a role in designing population management goals.

7.3.3. Inbreeding and the Problem of Founder Effect

It is accepted within the field of human genetics that on a theoretical level humans are all in consanguineous relationship with each other since it is possible to trace back our ancestors to a common man and woman, but consanguinity is an important factor in determining the occurrence of medical problems. Taking this standpoint into account medical geneticists consider the problem of inbreeding to be relevant only in groups where closely related consanguineous marriages occur. Knowledge about inbred populations is important in calculating the F coefficient factor that helps in the prognosis of the occurrence of any genetic effect that is already accumulated in the studied population (Tóth & Hegyesi, 2007, pp. 144–145). The F inbreeding coefficient factor is the half of a first-grade familial relationship that means fifty percent genetic similarity and in the case of inbreeding it means twenty-five percent genetic similarity. This shows why it is hard to talk about genetically homogenous populations, on the one hand, but it also shows, that there are populations where genetic similarity among its members on given traits can lead to the accumulation of genetic disorders.

It is very difficult to talk about homogenous groups. It is only possible to talk about homogenous groups approximately. It was revealed by molecular genetic methods that even if I take a group to be homogenous according to their diagnosis they won't be homogenous genetically. This means that the same disease can be generated by different mutations, different genes or even different mutations of genes (PI 20140307).

There are inbred groups, whose members marry each other in these cases certain rare genes are accumulated. These founder effects influence the genetic characteristic of a population or a race in a given geographical area, because it is obviously true that the Roma population is endogamous decisively. But it is not the fault of the Roma, similarly as it is not the fault of the Ashkenazi Jews that Tay-Sachs is more frequent in their communities (PI 20140307).

As it is emphasized in the above quote in population genetic studies founder mutations are significant factors. We can understand them as two kinds. There is one kind that occurs only in the same population or same group of people, and there is another kind that can be traced back to its origin in two different populations. An example of this can be a mutation which was found on the Iberian Peninsula in a Roma individual in South Portugal, and at the same time this type of mutation was found in Spain in a non-Roma individual, but these two individuals had nothing in common, and researchers could prove through the analysis of their respective BCKDHA genes that they did not share common roots, they developed the mutation in separate historical and geographical contexts (Quental et al., 2009). There are individuals described by these researchers, who do not have anything in common. One identifies ethnically to be Roma and the other is non-Roma, they both carry the c.117delC- α mutation, but it has developed separately in space and time. These can be termed parallel founder mutations. The concept entails that the same mutation can develop as a response to environmental factors and then can be passed on to descendants and it means that retrospectively researchers can trace back the same genetic disorder to separate groups of people, and to ethnically and geographically independent individuals. A similar example was given in one of the interviews:

In Szeged a similar mutation was described. Researchers found a mutation for a very rare multiplex dermatological disease, - tumors appear in diverse locations on the patients' bodies – and within the same gene, the same type of mutation was described in England, in English families, thus it is impossible that one founder mutation spread from here to there or vice versa. This is a very rare event, but it can happen independently from each other. But there are founder mutations which are typical of populations. Let's take an example: cystic fibrosis, the most common mutation of this is the lack of phenylalanine, in an

enzyme, in a protein. This mutation is prevalent in the 85 percent of Danish patients, while in Hungarian and other South European patients this type is only 40 percent. In these populations there are other types as well which cause the disease (PI 20130328).

In this example, as well, cystic fibrosis is used as a genetic disorder that is ethnically/racially typical of certain populations, but it is not excluded by the interviewee that racially different groups, or members of those groups, carry the same mutation, though it is less likely. Hence to develop state funded programs targeting those communities for an atypical disorder seems hard to justify but I think that would mean a much more inclusive perspective.

7.3.4. Concerns over the Reproductive Practices of Roma

Making concerns explicit over the over-reproduction of the *other* is a characteristic of the welfare state since the nineteenth century. At the height of the industrial revolution concerns over reproduction were about the working class in comparison to the morality and rationality of the middle-class. This classist reproductive discourse started to change, but eugenic ideas stayed within the parlance; they became complemented with ethnicized ideas of reproduction since the 1920s. This trend to divide reproduction to good and bad types for the state and reason from ethnic/racial perspective can be traced throughout the twentieth century in Hungary, where the ethnicized other group is the Roma community; as I reviewed above the medical community is not exempt from this reproductive thinking that overemphasizes the theme of racial imbalance in the reproductive future of the country. The following quote underscores this issue:

Here in Hungary, I must say, Roma has this almost respectable family tradition, namely: to bear many children, which means that the given genetic characteristics which are typical of Roma are accumulated in the given population and now, consequently in the Hungarian population, because the newborn rate in the Hungarian population is very low. I know about a study in which it was stated that 39 percent of the newborns are Roma, now we can imagine that this rate obviously will only grow. This is not a positive

note that I will make now, but there are unemployed families - we can see that; Roma families; and they live on state benefits. They give birth to children one after the other because with the growing number of children the amount of state benefit will grow. Thus, I think that in ethnicities – and this is obviously a racial characteristic as well – because of endogamous marriages certain gene structures are accumulated. This is also true for geographically closed populations. And this is not positive or negative this just how it is (PI 20140307).

I find this quote important for the following reason: the suggested direction in how to handle health problems is envisioned in a Roma – non-Roma medical binary. The reproductive rates of Roma and their economically unproductive lifestyle contributes in this argument to the idea of designing screenings that allows for closer monitoring of Roma populations, because their reproductive rates are higher in some Hungarian regions consequently their disease rates contribute to a higher overall ratio which means more medical duties and medical expenses for the state. The presence of this ethnic-racial thinking in the contemporary medical profession suggests that racial or ethnic categorization is partly supported by arguments that rest on a seemingly benign exclusionary thinking.

Race and ethnicity works here as well, as a theory of kinship. “It is a system of classification in which complex relationships of biology (procreation) and law (marriage) are organized into a coherent framework” (Marks, 2008, p. 25). A theory of kinship provides a basic understanding of who we are, to which community we belong, and how should we orient ourselves when making decisions on procreation and marriage. Jonathan Marks explains that these decisions are important because new forms of marriage and new forms of procreation appear and they can be perceived as threats to the existence of the community. Thus, kinship theories help to rationalize thinking and decision making in our identity formations. Race/ethnicity is only one aspect of this identity formation, disease, nationality, gender, class, are other aspects that direct the individual in different social encounters.

In the above detailed quote, the informant gives a rather descriptive account of the perceived differences of procreation and marriage customs of Roma communities as opposed to the customs of non-Roma citizens of Hungary. In medical encounters a normalized theory of racial/ethnic kinship works, medical professionals act on these tacit notions and take part in the management of the population without challenging the existing racial/ethnic social order.

7.3.5. Intersecting Explanations of Class and Race/Ethnicity Regarding Obesity and Malnutrition

The intersections of class and race/ethnicity with ideas of healthy body image is widely analyzed in the social science literature. Studies have shown that the interplay of gender, class, and race relations in a social structure are defining in terms of health standards (Bowleg, 2012; Connell, 2012; Hankivsky, 2012). In the literature, regarding the relationship among age, class, race/ethnicity, sex, obesity, and malnutrition a classic and often cited example is the study of Mexican Pima Indians in the United States (Schulz et al., 2006). Research comparing Mexican Pima Indians with Pima Indians living in the United States suggests that their differences in obesity are a result of unfavorable environmental conditions and not their genetic predisposition. Schultz and his colleagues claim that this is a well-documented finding in other social contexts as well. For example, in the Nauru people of Australia where obesity also reaches epidemic proportions, the explanation for their condition is their lifestyle paired with environmental factors that contribute to the development of the disease. There are studies that analyze the interrelationships among class, ethnicity, age, and sex regarding European Roma (Iba, Rebato, & Poveda, 2014; Petrásová et al., 2014). Poveda and her colleagues claim that the differences between Roma and non-Roma obesity statistics can be explained by the inability of Roma to see themselves as obese (Iba et al., 2014, p. 428). They claim that the desired body image is different in traditional societies where being overweight means social success, beauty,

and health. We can see reference to this problem in the Hungarian medical genetic context regarding health problems that affect birth rate statistics between Roma and non-Roma members of the population. Here is one example from one of my respondents:

Their marginalized position in the society is a contributing factor to their health statistics – premature births, retarded newborns, high blood pressure are much more frequent in their populations. But in this question, another factor is their behavior, primarily I'm thinking of their austere dieting habits, because of their obesity, because they are either very obese or very skinny and this is the result of their eating habits. I think their obesity is a problem that is similar to their malnutrition and can be traced back to their frugality. Thus, they do not mind the money for food, and they eat lots of fat. Their bad dieting habits are just as problematic as when they do not eat (PI 20130123).

In Hungary, the situation of Roma is comparable to the above cited examples. They are socially and geographically marginalized and their lifestyle has changed in the recent decades. Unemployment rates are disproportionately high among Roma in comparison to non-Roma Hungarians that means inadequate access to diverse and healthy diet and low emphasis on leisure activities that would positively contribute to their health. Thus, in the case of Hungarian Roma, their obesity is a health problem that emerges at the intersection of class, race/ethnicity, age, and gender. I wanted to inquire about the possibility of any genetic predisposition known in Roma communities, but my informant explained this phenomenon largely in terms of their socialization:

So if you think that there are obese and sick gypsies because their parents or grandparents had bad dieting habits or they were underfed – then the question is much more complicated. Fundamentally it is not the reason. They get what they want, how shall I put it, fundamentally they could not afford those food items for themselves but they spend much more money on eating than on their health. They eat the wrong amount and quality of food that causes their obesity with every other consequence. It is a known fact that usually we suffer from our grandparents' bad dieting habits. This is true for everyone. But besides this, wrong socialization and wrong thinking plays into this problem. They don't do sports, they buy bad things, eat bad things, eat big amount of food etc. (PI 20130123).

It is argued by Sára Tóth and István Raskó (2015, p. 119) that obesity is a modern-day epidemic that affects adults and children similarly. It is pointed out that there are gene variations that affect individual susceptibility to obesity. György Paragh for example claims that roughly in 40 to 70 percent the genetic factors that individuals have are responsible for the differences in population body mass indices (BMIs) (Paragh, 2013, p. 151). He further states that it is accepted in the medical literature that modern lifestyle and modern nutritional habits create obesogenic environments but it is a simplification to put emphasis only on one side of the problem: both environmental and genetic factors play a decisive role in the development of obesity. Ethnicity as an explanatory factor is inadequate and perhaps glosses over finer details such as class, gender, geographical location, and social discrimination.

7.4. Conclusion

One of the turning points in medical genetic studies was the completion of the Human Genome Project. With its results, it changed the thinking about the possible applications of genetic knowledge in medicine. One of the key fields where it had a significant impact was epidemiology. The knowledge gained made it possible and ethically necessary to address population based health problems with the tools of genetics. Thus, partially, ethnically identified populations became the focus of such studies, in order to provide equal healthcare for everyone. In this frame, it became widely accepted that in order to provide equal healthcare, it was necessary to map population differences in any social context. This approach embraced the idea, that economic marginalization, racial discrimination, or gender inequality contribute to diverse health issues and unequal access to healthcare. Thus, it became mandatory to find ways that can tackle these empirical problems.

After the transition, the possibility of joining to the European Union opened up for Hungary and in 2004 the country successfully met the required criteria. As part of the requirement, it was mandatory to develop the rights and protection of minorities in Hungary. The health protection of Roma was one of the key priorities and among the most important goals sociologists and healthcare professionals identified were the improvement of housing possibilities, access to employment, and access to healthcare services. Medical geneticists contributed to this discussion with their own expertise by claiming that to improve the health standards of Roma it is important to map the most prevalent inheritable genetic disorders in their communities, and also the epidemiologically relevant genetic markers that make them at risk for diseases.

One of the conclusions that was drawn from the early epidemiologically important genetic studies is the fact that ethnic identity is important only because it mixes up the biological causes with the social factors and thus it is useful for better diagnosis and better healthcare service. By this they acknowledged on the one hand biological differences that can be important for both patients and clinicians, the socially marginalized situation of Roma that should be taken into account during medical interviews, and also the everyday racism that they have to endure during healthcare services that must be taken into account when healthcare statistics are evaluated. Researchers stressed the need for thorough structural changes regarding the situation of Roma and also the need for the inclusion of their perspectives into programs designed to ameliorate their well-being.

From the empirical work that I conducted the most important conclusions that I can draw are along the following issues: isolation and inbreeding connected to reproductive ideas about Roma, and about the slippage of what causes a medical status. In the interviews, medical geneticists on the one hand explained and stressed the isolation of Roma communities within the Hungarian state, and consequently the problem of transmitting genes within their relatively

closed groups. In this description geneticists implied that both racism and ethnic customs play a role in reproductive decision making thus affecting birth results. In addition to these problems, the idea that a mutation develops in only one group – although it occurs rarely, it does happen – makes a simplified ethnic focus medically problematic.

It became evident that racial bias and eugenic ideas were at work when I asked about Roma reproduction and obesity. Some of the perspectives of medical geneticists on these epidemiological issues show that racial bias could be at work in the medical genetic discourse that could lead medical understanding astray. These findings stress the idea that genetic knowledge about ethnic groups must be distributed in a manner that members of these groups could voluntarily use the produced medical information and medical professionals must be sensitized about their possible biases. Thus, minimizing discrimination in medical decision-making and medical services.

8. Implications of Racial/ethnic Classification in the Post-Genomic Medical Discourse

By using constructivist grounded theory, I managed to trace the presence of eugenic values in the history of Hungarian medicine from the present until the first decade of the twentieth century. In that early discourse the medical standpoint on the contributions that eugenics could make to healthcare was far from homogenous but clinicians managed to establish a common ground by fusing public health with eugenic arguments. Eugenic control over the population was evident regarding the acceptance of sterilization of women who suffered from tuberculosis since it was understood that the virus responsible for the disease was transmissible through the placenta. The reasoning was based on economic and healthcare grounds, in this practice those lower class women who suffered from tuberculosis had little power to assert their self-interest and often they were subjected to the decision of gynecologists and surgeons who regarded individual rights as less important than the interests of the political community. The female body remained in the focus of reproductive control during the socialist period. Biotechnological developments made it possible to diagnose disorders early on and intervene if it was deemed medically necessary. It was recognized from the 1960s that members of Roma communities were in such an economically marginalized situation and subject to further racial discrimination that their reproductive health standards were far below the national average.

I have shown that during this period medical and sociological research was aimed at working out ways to ameliorate their living conditions but because of the systematic racial/ethnic discrimination research results were not put to use efficiently. In the literature that deals with the applications of genetic results to improve health disparities it is possible to delineate two directions. The first approach understands connecting genetic patterns to race/ethnicity to be a scientific error, while the second approach embraces racial/ethnic classification of biological materials because it is argued, that this technique speeds up and

therefore helps medical diagnosis. I find it important to acknowledge that voluntary requests of genetic tests by patients to check genetic patterns for carrier status could be beneficial. But in societies where systematic racial/ethnic discrimination takes place and it is hard for patients and clients to assert their health interests, the medical consultations could contribute to the deepening and widening of the health gap.

In the following I will show that critical constructivist approaches can accommodate the context dependent interpretation of racial/ethnic identities in connection to the way their cultural environments generate meaning for the users of the concepts, but at the same time it gives a critical view on the essentializing tendencies of the genetic discourse and its possible drawbacks. As the Hungarian medical discourse places the interpretation of diseases significant for the population on genetic grounds – as do other contemporary modern medical scientific discourses – it follows that the disorders that weigh on the individual are interconnected with racial/ethnic identities in scientific reasoning. That is, with group membership identification, human geneticists inadvertently place racial differentiation on determinist grounds. However, as I will point out in my argument, this direction has many questionable elements and possibly controversial outcomes.

Thus, in this chapter I will briefly review the major frameworks regarding the conceptualization of race during the twentieth century and connect it to contemporary epistemological discussions. My aim in this part of my work is to provide theoretical underpinnings to my argument that an essentialist understanding of race in medical sciences could prove to be very dangerous in a society where racial minorities are structurally marginalized and discriminated against. The post-Human Genome Project genomic discourse entails some forms of liberal eugenic decision-making; in this discourse, marginalized groups, such as Hungarian Roma, and especially Hungarian Roma women, might be further oppressed if medical practitioners have undue regard to their racial/ethnic identity.

In order to support my claim I will analyze the arguments for using racial classification in medical genetics. The strongest arguments are, in my view, that we live in a racially stratified society and in our present it is not possible and not desirable to get rid of racial categorization because it would seriously damage medical understanding and thus equality in healthcare (Rose, 2007). Another reason is connected to this last problem if a society wants to give identical care for its citizens, it must take into account various identity categories, from class, gender, to race/ethnicity (Risch, Burchard, Ziv, & Tang, 2002). In my view, these issues are interconnected and the suggested avenue is to tackle health problems with the present vocabulary and already established racial framework.

My intention is to show the existing empirical problems of establishing and applying racial/ethnic categories in the Hungarian medical discourse. To achieve this I will comparatively analyze critical works published by scholars regarding this issue with the interviews that I conducted during my fieldwork. From this analysis, I draw the conclusion that medical geneticists do not accept unanimously and uncritically racial categorization in genetics; and there are geneticists who also suggest that a focus on individual genetic make-up will provide better information for establishing a diagnosis and thus providing identical healthcare.

8.1. Major Changes in the Conceptualization of Race during the Twentieth Century

There are three major approaches to theorizing about race in philosophy of science, these are called biological realism, social constructivism, and eliminativism (Haslanger, 2008; Ludwig, 2017). The most important distinction among these approaches is how theorists working within these paradigms regard race: the eliminativists for example consider race as something that is non-existent, therefore it is counterproductive to even discuss its relevance to any medical

discourse. Their approach was criticized by many scholars for turning a blind eye towards skin color; this approach they claimed will not solve the very real problems of everyday racism that people face in various societies. Social constructivists think that race is real in the sense that it is a social construct, and although it is imbued with different values in different social and historical contexts, it has very real consequences for people experiencing discrimination or privilege because of a racial discourse. Biological realism holds that there are races that correspond to biological differences. This strand of theorizing is revitalized as a result of molecular genetic studies. After the completion of Human Genome Project it is argued that within the differences mapped it is possible to find the reason for racial diversity that corresponds to racial subgroups which in turn, if recognized, contributes to health equality. In the following, I will overview very briefly the main shifts that took place in the scientific thinking about race.

During the Enlightenment the work of Johann Friedrich Blumenbach entitled *On the Innate Variety of Mankind*, published in 1775 defined the direction of racial studies for the coming 150 years and it had a long lasting impact on the twentieth century (Smith, 2015, p. 253; Raskó, 2015, p. 147). Blumenbach described four geographical varieties in his 1775 edition, then changed it slightly to five varieties in 1781 when he reworked his thesis, and finally concluded with five generic varieties classified as Caucasians, Mongolians, Ethiopians, Americans, and Malays in the final re-edition of his thesis in 1795 (Bhopal, 2007, p. 1308). Justin E. H. Smith argues in his book that although Blumenbach was hesitant to claim that there is a biological reality according to which clear racial divisions can be made, he still maintained, through statistical measures of human skulls that it is legitimate to support the racial classification of peoples into the racial taxonomic system that he proposed (Smith, 2015, pp. 259–260). This is why Smith claims that Blumenbach was a "statistical racial realist" and his

work lent itself easily to succeeding theorists whose aim was to establish accounts for the biological reality of race.

The view that there are essential racial types started to become more and more incompatible with developments in biological research. First Charles Darwin's evolutionary theory questioned whether it was possible to pinpoint toward racial types and then later Mendelian genetics provided rational arguments in favor of abandoning the essentialist approach. By the early twentieth century, the essentialist concept of race was supplanted by a geographical concept that divided races into subdivisions according to their geographic origin. For example William Z. Ripley in his work published in 1899 divided the people of Europe according to three different geographical regions: Alpine, Mediterranean, and Nordic (Marks, 2008, pp. 22–23). A series of works appeared in this paradigm from which perhaps the work of Theodozius Dobzhansky's was the most significant in 1937 entitled *Genetics and the Origin of Species*. Although the Second World War had an important impact on the reconceptualization of race, it is needless to say that the "Unesco Statement on Race" written by Ashley Montagu in 1950, described three major races European, Asian, and African and an unspecified number of subdivisions, which still adhered to the geographical type paradigm; this understanding dominated scientific thinking until the 1960s.

The civil rights movement in the 1960s pushed the theorization about race into a new paradigm. In 1962 Frank Livingstone argued that it is best to understand racial difference in terms of clines which are "geographical gradients of features in natural populations" (Marks, 2008, p. 24). In a similar manner Richard Lewontin quantitatively compared populations from a genetic perspective, he concluded that intra group differences are larger than in-between group differences thus deconstructing the race-as-geographical-type concept. Lewontin still holds that despite the developments in molecular genetic studies, abandonment of the biological race concept in medical research was well-supported. Marcus Feldman and Richard Lewontin (2008,

p. 90) state that if medical professionals understand race/ethnicity as a social construct they can gain important knowledge about the social-environmental factors that determine the health status of patients. In particular, knowledge about race/ethnicity can be informative in order to fight discrimination on the micro-, meso-, and macro-levels of society.

The third and perhaps most radical shift occurred during the 1990s when researchers started to problematize the idea that roughly seven percent of our molecular genetic difference can be racially relevant (see Sesardic, 2010, pp. 148–149). Researchers suggested that perhaps a more thorough understanding of this part of the human genome can contribute to make sense of human racial differences. The process through which race is projected onto the molecular level is called the molecularization of race (Duster, 2006; Fullwiley, 2008; Kahn, 2008, 2012). It would be a misunderstanding to see the present process of racialization as unreflective of racism - it is the opposite; scientists apply race in genomics as a biosocial reality but at the same time they are working towards the genetic explanations and rebuttals of any kind of racism; this is called the biosocial paradox of race (Bliss, 2011, p. 1019). The primary aim of racial classification that is advanced by scientists who work with genomic level data is to overcome health inequality that is caused by different factors of structural racism. And the main problem with this trend is that it plays into the re-inscription of race onto the molecular level, that is positing it to be biologically real, when it is widely accepted to be a social construct.

8.2. Arguments for Classifying Genetic Material According to Racial/Ethnic Identity

Although it is widely acknowledged by scientists that it is hard to define what race/ethnicity means in biomedical research, at the beginning of the twenty-first century, Nikolas Rose argues that it is inescapable for researchers working in the field of biomedicine to categorize through racial/ethnic identity (Rose, 2007, p. 172). Skin color is one of the markers (besides hair texture,

and bone structure) that define racial belonging following the work of modern naturalists. Although it is pointed out by numerous scholars that skin color or bone structure cannot be used to group people together for medical genetic purposes because it is a very arbitrary marker (Gould, 1981), it is still viewed by others as a medically valid factor to categorize. It is claimed that folk racial/ethnic categorization is useful because it shows that members of such groups share medically relevant genetic history. It is emphasized in the following quote, that skin color indicates deeper medical relevance than superficial racial resemblance.

Skin color is not only a superficial marker that accidentally helps, obviously, Caucasians or white people resemble to each other more than white people to black people. But within the white population, or black or Asian a Japanese is utterly different – not fundamentally of course – but represents a significant genetic difference in contrast to an Indian or Nepalese. This is because of the migratory routes of different populations. Those who lived together for a long enough time developed genetically unique characteristics (PI 20130311).

I do not interpret the above claim to be in tension with the medical genetic knowledge that within-group differences can be bigger than differences between groups. This position rather entails that, although there are no fundamental differences among human beings, there is medically useful information that can be teased out with the use of racial/ethnic categories.

In the Hungarian social context numerous ethnicities were analyzed by geneticists (see Béres, 2003). From these groups in most interviews Caucasians were viewed as the medically most significant ethnic group, and besides them Roma and Jewish groups were highlighted. In the excerpt below, it is noted that superficial racial/ethnic characteristics are not helpful in directing the caregiving process because in some cases they are not visible, or they do not diverge from the dominant outlook of individuals in the country. In these cases, self-defined ethnicity is understood to be crucial.

In Hungary the most significant ethnic group is the Caucasian, and there are a few Roma and Jewish groups. But I only inquire about ethnicity in the case of concrete diseases, when those are more prevalent

in certain ethnic groups; because I can't recognize always from the appearance of the patients which race they belong to (PI 20121207).

To put it differently medical genetic knowledge cannot be applied by clinicians in cases when there is no knowledge about ethnic belonging, but only a medical hypothesis exists about a possible diagnosis based on the medical interview and examination of the patient. And this medical hypothesis rests on an already existing racial stratification of people. Thus, self-defined race/ethnicity is viewed as a very good marker for medical understanding of the health status of the patient (Risch, Burchard, Ziv, & Tang, 2002). Risch and his colleagues argue that most of the research that addressed the genetic and epidemiological validity of race is not objective hence these studies, they claim, cannot contribute to the scientifically grounded reformation of healthcare. They acknowledge that because of the past and present racial/ethnic discourse of the United States racial/ethnic minorities are disadvantaged and their disadvantageous social position largely defines their health standards; they say besides the genetic structure, - about which they claim as empirically provable that racial/ethnic communities resemble to their members more than to non-members -, it is needless to take into account the environmental factors (overall health, education, lifestyle, support system, and socioeconomic status); these together define the genetically understood health needs of an individual. Therefore, they claim that it is vital to consider the self-defined racial/ethnic identity of patients in order to provide them with identical – though not equal – healthcare, because human beings are different.

I think this perspective can be sensitized even more with additional information if we take an actual problem. In the case of Hungarian ethnic groups for example, the homogenous racial/ethnic identity category of 'Caucasian' does not address not certain problems. The distribution of the cystic fibrosis gene $\Delta F 508$ is such an example. In the study conducted by scientists in Debrecen, the authors claim that the F508del mutation is the most significant variant in Hungary with 61.2 percent and it shows a decreasing north-to-south gradient in its

distribution in the country (Ivády et al., 2015, p. 50). It means that other mutations are also prevalent in the population and the diagnoses would be helped with further knowledge about the geographical ancestry of the individual.

In addition to this, it must be noted that population genetic studies that aim at mapping the diversity of certain diseases within various populations is very useful on a local level to shorten the time that is needed for diagnosing a given problem. Let's look at the following argumentation that points out differences between Roma, non-Roma, Hungarian, and non-Hungarian Caucasian populations to the West of Hungary regarding the above detailed cystic fibrosis disease. What I want to emphasize from the quote below is the distinctions that the author makes regarding ethnic boundaries and the uncertain claim about the prevalence of the disease in Roma communities.

In our work, we noted that a high percentage of our patients have a certain mutation which is very rare in the international literature. This could mean that this mutation is a highly frequent one in Hungary but it could equally mean that this is a mutation which is frequent in a Hungarian gypsy minority population – because we don't know the ethnic background of our patients (samples). However, we have data about ethnic Hungarian patients regarding cystic fibrosis. We know that these are from ethnic Hungarians because the clinicians sent the samples that way. By the way, cystic fibrosis is not really prevalent in gypsy populations. So we have two mutations, which are practically non-existent to the West of Hungary. I would say, where there are no Slavic populations. This is a beautiful evidence for the mixture of ethnicities. This mutation occurs in 5 percent of our patients, and this is zero in England, in Sweden, and Spain. And this is very important because it can help us to offer fast and cheap diagnoses for our Hungarian patients. Because we know that this exists in Hungarian patients, and in a diagnostic kit which is composed in England – and let's say we use that – that is not included because it is not typical in that population. (PI 20140210B).

The claim regarding the prevalence of two genetic forms of the cystic fibrosis disease in Hungarian populations suggests that medically relevant ethnic boundaries cross state boundaries. A medically valid argument was put forward by the interviewee to create disease

diagnostic kits that are relevant for the Hungarian and neighboring populations' genetic make-up since it would make diagnoses much more precise and faster. The author acknowledges the mixture of Hungarian and non-Hungarian populations from the perspective of the disease but on the other hand maintains that Roma populations differ from the non-Roma majority regarding the disease, when it seems that there is little evidence to claim that Roma groups are not at risk for cystic fibrosis at all. However, the argument still supports, in my view, the idea of mapping the variations of different mutations for the same genetic disease in local populations to be able to design diagnostic kits to treat patients effectively.

This argument stands for the members of Roma and Jewish groups as well, since their ethnic diversity is also important when discussing the medical relevance of sharing certain problems. The dominant approach in researching ethnic populations is connected to the works of Luigi Luca Cavalli-Sforza (2000), who suggested analyzing genetic data that is collected from ethnic communities defined by their shared geographical location, cultural behavior, and linguistic practices. Cavalli-Sforza argued that these factors determine the reproductive practices of community members and hence the gene-flow within the population. Regarding Roma diversity three main ethnic groups reside in Hungary; these are the Vlachian, Romungro, and Beasi communities scattered across the country. These communities came to Hungary on different migratory routes and they differ from each other culturally and linguistically, and in addition to this they are located in different geographical regions of the country. An example that helps to elaborate my point would be the Beasi community: they came to Hungary from two directions: (1) from the south, particularly from Croatian-Slovenian regions and (2) from the east, from Romanian territories. Their cultural customs were different, they spoke different languages, and they settled down in different parts of Hungary. The Beasi Roma who came from Croatian regions settled down mostly in Baranya and Somogy counties, while those who came from Romania firstly settled down in Szabolcs and Szatmár counties and then moved to

the Tiszafüred region (Kemény, 2005, pp. 50–51). István Kemény by accepting the differentiation of Katalin Kovalcsik, identifies three ethnic groups within the Beasi ethnicity. Members of Mucsán group live around the Hungarian-Croatian border and their linguistic dialect still has Croatian words in use, members of Argyelán group speak a Transylvanian dialect (called Bánátian) and they also live in Barany and Somogy counties, while the so called Ticsán communities came to Hungary through Szabolcs and Szatmár counties from Romania and they live around Tiszafüred nowadays. This anthropological differentiation suggests that medical genetic problems could be very different for the members of Beasi Roma communities living at a significant distance from each other and possibly mixing with non-Beasi Roma communities.

If we choose to analyze concrete medical situations when a quick and precise response is of crucial importance, the argument to use ethnic/racial markers in the sampling and diagnostic process seems to further strengthen the position. In the case of bone marrow transplantation for example, racial or ethnic ancestry is suggested to be of valuable information. The interviewee quoted below, is on the same theoretical footing as Neil Risch and his colleagues referred to above: in order to help patients have an equally positive outcome one has to take into account the diversity of the population. Hence, knowledge about ethnic belonging is a factor that is interpreted by clinicians that has enormous significance biologically.

Gypsies are different genetically from the surrounding white Hungarian population, and in order to help them, we must analyze precisely their genetic background. For example, it is necessary to map gypsy bone marrow donors, because gypsy and white Hungarians are so different immunologically from gypsies that they cannot get bone marrow transplantation from Hungarians because they would die. In order to be able to treat them properly because of their increased risks we must do these genetic assessments. There is no discrimination in this (PI 20131119).

Here the primary racial/ethnic differentiation happens along skin color and gypsy people are viewed as if they are living on islands surrounded by the majority white population without any

intermixture. It is explained from this position that because gene-flow does not occur significantly, the biological difference regarding bone-marrow structure between a Roma and a non-Roma patient is significant enough to cause the death of the recipient of the transplant. In this case, because there are fewer bone-marrow donors from Roma individuals than from non-Roma, in order to help Roma patients who are waiting for bone-marrow transplantation and shorten the waiting period, it is medically useful to create a bone-marrow donor bank in which the donated bone-marrow is from Roma people. This practice aims to counter unequal care. It is further argued by another interviewee, that transplantation donors must be identical in the relevant genetic markers, otherwise the transplant will probably be rejected by the recipient's body. Ethnicity helps medical professionals to find acceptable donors from a more reliable pool of sources. Because of the unique mutational events, or in other words, because of the founder effects, that took place in the bodies of people who belong to the same ethnic group because they lived and travelled together across the same geographical landscapes, ethnicity is argued to be a *fairly* reliable marker that can connect people together medically.

In the case of bone marrow transplantation donors mustn't be only approximately identical in order to be accepted by the recipient's body it must match a lot of genetic details. This means that there may be genetic characteristics in the Roma population for which it is better for a Roma person to receive the transplant from another Roma. It will be identical with a higher safety margin. With this approach we have higher probability rates because of the founder-effects. In other words, if we need a donor, we had better look for the donor in the same ethnic community because this way we have a better chance to find an identical in a shorter time period. It is not possible to exclude the chance of finding a donor from the Caucasian population but we would need to analyze many more samples (PI 20140307).

But speaking about ethnic/racial boundaries, it is important to note that this standpoint does not exclude the possibility of finding a bone-marrow donor with identical markers from a different racial/ethnic community, it is only assumed that it would take more time to run into an exact match. This position does not create biologically grounded and divided races or ethnicities;

according to this direction it is possible to imagine that people who have been living in the same geographical area, who have similar dietary habits, but perhaps who have rarely chosen their reproductive partners from another ethnic community would still match for bone-marrow transplantation for the ethnic other.

The medically relevant information that comes with racial/ethnic identification is inextricably connected to migration, geographical history, and ancestry. Race or ethnicity in itself is not a sufficiently precise marker to draw any medical consequences. The following quote from one of my interviewee suggests a limited usefulness: genetic studies on ethnic/racial ancestry would suggest the use of these markers in medicine but with a restriction that would mandate the inclusion of geographical ancestry. This position counters the view that skin color is not a superficial marker; it rather states that because skin color variation is the result of multiple genomic combinations, it is of no use for precise diagnosis in medicine.

[A]s I said skin color, and other superficial characteristics are defined by multiple genes and this disease is also defined by multiple genes. From a medical perspective, it is important to know the ancestry of a human community. I think it is important to do population genetic studies that can result in the ascertainment of disease susceptibility that is higher in a given geographically defined population than in another one (PI 20130328).

In this sense, skin color is understood to be superficial, which means that population genetic studies are perhaps designed in a manner that race and ethnicity is considered, but without any information on geographical ancestry disease susceptibility cannot be defined adequately. And this approach entails that perhaps skin color on the molar level acts as a dividing factor thus we need molecular level information in order to provide medically precise diagnosis for ethnically different patients having the same genetic disease.

Addressing the development of racial/ethnic identification in medical genetics is a charged topic in every social context including Hungary. The possibility of discrimination or

racial bias is frequently addressed in the literature. My interviewees regularly reflected on this issue and throughout my research, they were claiming that they think racial/ethnic categorization helps both parties: medical professionals and patients. It was concluded by one of the researchers that s/he believes that screenings can be designed to bring only benefits to those who live with this medical service. In other words, medical genetic screenings could be designed in a manner that would eliminate the possibility of racial/ethnic discrimination at all stages. To prove this point s/he used the Greek minority as a paradigmatic example which is a politically neutral ethnicity in the Hungarian discourse.

Let's take a fairly neutral ethnic community. We know that thalassemia is more frequent in populations with Greek ancestry. Therefore we suggest - because we already have drugs for thalassemia - for those who know that they belong to this community to get themselves screened where they won't be identified ethnically. There they will be examined whether they are at risk for this disease, or whether they have the trait. This way they can get the medicine they need a lot faster. I think these screenings can be designed to avoid ethnic identification at all stages (PI 20140123).

In this excerpt the author says that the knowledge that population geneticists accumulated about the prevalence of thalassemia in the Greek population can be used to suggest screenings for those individuals who know about themselves that they have Greek ancestry, or they know someone who had the disease in their family, or they are from the geographical region of Greece. Of course Greece is geographically diverse, and it is known that thalassemia is more prevalent in the Mediterranean regions (crossing national borders) where malaria was a threat to the human populations, hence the development of the thalassemia mutation. But, the argument goes, if there is no need for ethnic or racial identification in a screening facility, both parties the medical professionals and the patients can focus on the question of diagnosing the thalassemia mutation without ethnically or racially classifying the person. I think this perspective avoids identifying the patients in terms of their Greek ethnic identity, so it does not necessarily stabilize race/ethnicity on the molecular level, therefore this is compatible with the

performative understandings of identity categories. A patient can identify as Greek and therefore understand his/her situation to be at risk for thalassemia but in a clinical setting it would not be required to state his/her ethnic identity to get a diagnosis. And it works from the other way around as well, medical geneticists know that any knowledge about a genetic mutation would not provide information about ethnic/racial identity. It would be a serious professional flaw to screen someone for Greek, Roma, or Jewish genes.

8.3. Arguments to Problematize Ethnic/Racial Classification

In the early 2000s as the Human Genome Project approached its final years, during a conference on June 26, 2000 President Bill Clinton evaluated the results, and placed emphasis on the finding that humans share 99.9 percent of their genome which renders racial differentiation genetically meaningless. This politically significant position was supported by the human geneticist Craig Venter, who said that they “have shown that the concept of race has no biological basis,” and only one year later Francis S. Collins further emphasized that “those who wish to draw precise racial boundaries around certain groups will not be able to use science as a legitimate justification” (Bliss, 2012, p. 1). Catherine Bliss, who is a sociologist of science claims that it is observable globally that geneticists try hard to give new meaning to the concept of race on the genomic level. Presently scientific interest in race is so wide that Bliss and others compare it to early twentieth century eugenics. This racial turn in genomic thinking about the concept took place in the second half of the first decade of the new millennium. Scientists are busy looking for medically applicable data regarding someone’s racial identity; this results social critics argue, in the racialization of certain illnesses, and the racialization of various drugs as possible responses to the medical problems of racially identified target communities.

One of the key differences between the American and Hungarian medico-political contexts is the emphasis on race and ethnicity. While in the United States there is a significant emphasis that human rights activists, legal professionals, medical professionals, and politicians have placed on racial identity since the human rights movements of the 1960s there is no comparable historical development since the 1950s in Hungary. It is a recent change in the Hungarian medical discourse that human geneticists became interested in populational differences and the application of this knowledge for medical treatment. And as a result of this interest they started to focus on ethnic identity as a possibly useful marker for medical treatment and genetic testing.

Genetic tests are useful on different levels and for different purposes. It is useful for example for individuals in order to gain knowledge about their health prospects, it is useful for couples who want to know genetic data about their reproductive capacities, it is also useful for them to get medically relevant information about their newborn child, and genetic tests are useful on an epidemiological level to manage the healthcare of population. The primary direction in which researchers began to work was toward epidemiological screening. It was in the United States that population screenings were first introduced during the 1960s. These first screenings were phenylketonuria (PKU) screenings which were introduced in the following ten to twenty years in countries that had systematically organized healthcare system (Kosztolányi, 2013, pp. 70–77). This was the case with Hungary as well, where it was introduced in the 1980s and since then because of the rapid biotechnological developments compulsory screenings were supplemented by 25 other genetic problems and are tested since 2007 following the decree of the Healthcare Ministry 44/2007 (IX.29.).

There are arguments put forward by researchers for designing screening protocols that target ethnic communities. Perhaps it is sufficient for this argument to name two racial/ethnic target communities with their respective genetic problems (here I draw on Kosztolányi 2013,

pp. 72–74). It was observed in the United States that sickle-cell anemia is more prevalent in the members of African American communities than in non-African-Americans so it was integrated into the screening programs of several states. In a similar manner, it is argued that cystic fibrosis is a disease that occurs more frequently in Caucasian populations than in others. Particularly the $\Delta F508$ mutation is responsible roughly for the two-thirds of the occurrences. In these cases, it is argued, that it is both rational and economically beneficial to design racially/ethnically sensitive screenings that would help these communities to tackle these genetic issues. It is important to underline in this regard that ethnicity has played no role in the development of genetic screenings in Hungary. Screenings are understood so as to be centralized on biological averages as is evident in the quote below:

In Hungary every newborn is screened for these deficiencies. It doesn't matter if the newborn is German, Dutch, Russian, or Ukrainian this is a compulsory screening for every newborn. Blood samples are collected on a filter paper and half of the country's samples are sent to Szeged, and the other half to Budapest. Only those will be notified whose results diverge from the norm. This is not a diagnosis, this is a precaution. They are called back to the clinic and undergo a focused examination. To set up a diagnosis is only possible after the examination. There is absolutely no distinction on ethnic grounds. (PI 20121018)

The whole population was studied to establish mean values for various problems such as PKU to be able to give meaningful medical answers for those who are affected by the disease. It is important to note however, that today there are arguments provided by researchers for example about CF that there are various forms of cystic fibrosis mutations around but different populations are affected by only a given set of these. And certainly, this can be true for various ethnic groups within a larger population, so the perspective to screen a given community with the same parameters may well be imprecise. But the question remains whether ethnic or racial identity serve best the medical needs of the community members or does it play into a discourse that freezes the otherwise fluid social categories. In other words, how far does this medical

discourse affect the possibility of free self-identification of individuals if screening panels are designed to cover different diseases for different ethnicities?

Here another relevant question comes in regarding the medically guided distinction of the Hungarian population on genetic grounds. Mainly Roma people are referred to in the literature as Asian regarding their ancestry. Recent studies argue that the ancestors of Roma people presently living in Europe can be traced back to their ancestral geographical origins in Northwestern India (Martínez-Cruz et al., 2016; Pamjav, Zalán, Béres, Nagy, & Chang, 2011). In opposition to this position other geneticists – see below – argue that this type of differentiation is not tenable and practically not useful.

Geneticists do not take Roma people to be an Asian group, with this mindset we Hungarians could be Asians too. I don't know about any genetic abnormality which has a higher frequency in Roma communities than in non-Roma communities. According to our present knowledge from the perspective of diagnostics there is no difference between a Roma and a non-Roma: we must take them to be a Caucasian ethnicity. It would be an exaggeration to consider them to be Indians. In everyday screening practice, there is no difference between the white population and the Roma population. (PI 20121210)

The counter argument centers on tacit linguistic, anthropological, historical knowledge that Hungarians migrated to their present geographical area from Asia. Despite this accepted view Hungarians are classified as Caucasians or Europeans while Roma people as non-white but genetically taken to be Caucasians as well. Importantly, there is no significant genetic difference regarding disease prevalence in the Hungarian Roma population that the above geneticist knows. But this also entails that there is no official disease panel suggested by the Hungarian Human Genetics Society that would recommend ethnically focused screenings. In other words, the above position can be viewed as one that voices the official standpoint on screening protocols regarding race or ethnic identity. What I wanted to show with this initial example is the untidiness of boundaries that the genetic discourse creates for white Hungarians and non-white Roma as possible identification schemes, because these are still based on classic

racial markers such as skin color or hair texture when it is widely acknowledged that there are no biological grounds for racial differentiation (Raskó, 2015, pp. 147–148). However, as Raskó argues there are mutations, which accumulate in various groups who intermarry for long time, and this prompts researchers to suggest further sensitivity in screening. This perspective is explained below with a joint problem called Bechterew-syndrome that is perceived to be more common in the members of Roma communities.

There can be biological differences regarding ethnic belonging. Let's take an example: in gypsies the occurrence of Bechterew-syndrome is much higher than in the non-gypsy population. So when a gypsy young man comes and tells us, that his waist hurts him, this is the first thing we have to think about because almost every second gypsy man will have this problem. And this is not racism. This is an empirical fact. And it is right to think about why this has developed this way, it is right to think about it, however this is how it is (PI 20130311).

Ankylosing spondylitis or as it is otherwise more widely known Bechterew's syndrome is a "chronic multisystem inflammatory disorder that affects primarily the sacroiliac joints and the axial skeleton" (Brent, 2018). But it can occur in the joints of hips, knees, and ribs as well. The initial symptoms are lower back pain or back pain that usually occurs during the night with changing intensity but it can worsen in the morning or with inactivity (Brent, 2018; Sáfrány, 2010). Its occurrence in populations is 0.1-1.4 percent (Braun, 2007, cited in Sáfrány, 2010) and it is more prevalent in males than in females.

It is unknown what is the precise cause of the syndrome but it has been shown that familial transmission of the gene is frequent. In addition to this observation it is pointed out that the presence of the HLA B27 allele can be detected in most pathological cases. However, this HLA B27 allele most probably could only be held responsible for 20 to 30 percent of risk factors that cause the disease (Sáfrány, 2010, p. 13). Enikő Sáfrány, a medical geneticist, studied nine single-nucleotide-polymorphisms of the IL27R gene. The IL-23R is a transmembrane protein that can be detected on the short arm of the first chromosome (1p31.3) (Parham, 2002, cited in

Sáfrány, 2010, p. 6). Sáfrány has found that certain SNPs are higher in frequency in the population that has the disease in comparison to the control group. The rs11805303 T allele, rs1004819 A allele, the rs10889677, and the rs2201841 SNPs are detected to be more frequent in populations that exhibit the disease. She claims that in the case of the IL27 R haplotype in connection to the development of the syndrome the ATCACAG and ATCACAA haplotypes consisting of the rs1004819, rs7517847, rs7530511, rs10489629, rs2201841, rs10889677, rs11209032 variants were understood to be susceptibility factors; while in the case of those patients who carried the B27 allele only two haplotypes have shown connection with the disease. The GGCATCG haplotype was proven to be a defense factor while the ATCACAA haplotype was understood to be a risk factor in the examined Hungarian population (Sáfrány 2010, pp. 30–31). In the papers that were published by Sáfrány and her colleagues (2009) and later by Sáfrány herself (2010) regarding this problem, neither racial nor ethnic categories were mentioned by researchers to classify their subject material. However, it is possible to make distinctions on racial/ethnic grounds regarding the frequency of the disease in various communities.

Investigations to understand the links between various immunological diseases and the above-mentioned SNP variants of the IL23R gene were initiated by Richard Duerr and his colleagues (Duerr et al., 2006); in their study, they have compared the IL23R gene variants in samples taken from Jewish and non-Jewish patients. They have stated that there is significant correlation between the function of the gene variants in the development of Crohn's disease. Studies were conducted in a similar direction across the world. Researchers were looking at various SNPs regarding the IL23R gene mutations that can be relevant to Crohn's disease in Brazilian populations, in New Zealanders, in Koreans, in Chinese, and in Germans (listed in (Magyari et al., 2014, pp. 150–151). This is the direction in which Hungarian researchers started to investigate the prevalence of the IL23R SNPs in ethnically identified samples. Lili Magyari

and her colleagues compared the IL23 receptor gene variations in Roma and Hungarian populations samples. They have “examined five susceptible, one protective and two neutral variants of the IL23R gene, and found significant increased genotype and allele frequencies in rs10889677, rs1004819, rs2201841, rs11805303, rs11209032 in Roma samples compared with the Hungarian population, and the rs7517847 showed significantly decreased genotype and allele frequencies in the Roma samples compared to the Hungarians” (Magyari et al., 2014, p. 151). Because various studies pointed towards the correlation between the susceptible variants of the gene and the disease their finding implies, they argue, that hypothetically Roma people are more prone to develop the Bechterew’s syndrome than non-Roma Hungarians.

In the above discussed case medical genetic findings are paramount for a better public health for both Roma and non-Roma Hungarian citizens. The question is how one understands it and how citizens are capable of using the information. I would argue against the starting position of my interviewee, who states that when a Roma male individual with lower back pain enters his office they (the medical professionals) must consider the possibility of Bechterew’s syndrome. I think it would be misleading for both parties to think about Bechterew’s syndrome only in the case when racial/ethnic identification match the description of the patient and the perception of the doctor. I think those people are left out from this perspective who are non-Roma but similarly carry the gene variants which make them more susceptible to develop the disease. According to Sáfrány (2010, p. 29) 47 percent of the healthy control group had the same genetic variant, namely the presence of the rs11805303 T allele in one instance, and also the rs1004819 A allele variant was more frequent in groups who had the disease than those in the healthy control groups. With these results geneticists argue (Sáfrány et al., 2009; Sáfrány, 2010; Magyari et al., 2014) because of the difference in frequency of the variant between Roma and non-Roma carriers, most probably Roma people are more susceptible to Bechterew’s syndrome. And I think this information can work to the advantage of both Roma communities

and health professionals, but I would argue only on the condition that they are careful to screen non-Roma patients with similar symptoms for the same genetic variants. And with this move the work that geneticists do can be seen as a contributing force to re-think the divide between Roma and non-Roma Hungarian communities and consider them as genetic hybrids who share certain genetic features. Members of both vaguely defined communities (Roma and non-Roma Hungarians) carry these variants the only medically significant difference is the fact that one in one of these groups' carriers, is *more* frequent. In my understanding, this research points toward personalized medicine which is about the construction of genetically defined disease groups that cross-cut race/ethnicity, class, gender, or religion. Let me use a quote from one of the interviews that explicitly discusses this possible avenue.

One of the consequences of personalized medicine is to target groups with the same genetic background. As a result, groups with the same ethnic background can become a target population. What is known for example is that the Hungarian gypsy population belongs to an entirely different tissue type from the Hungarian-Hungarian population hence it is necessary to find different donors within the same group. Thus, there can be, and there are ethnic differences but it is not usual to call them ethnic, but it is called genetic groups of identical backgrounds. As a result of this stratification personalized or targeted therapies can be applied (PI 20140123).

In this direction regarding the use of race/ethnicity two problems are related. The first problem is about the difficulty of identifying someone's ethnicity, and the second problem is the precise application of the acquired knowledge. It is important to address this issue, because it can happen that an individual cannot define precisely his/her racial or ethnic ancestry. This can be for various reasons, but let's take one: incomplete ancestral information was passed down across generations. In those cases what is the best solution? And how can this approach accommodate the individuals' freedom to choose ethnic or racial identity according to his/her social circumstances? Let's say a white immigrant from Europe who lives in an African country permanently, perhaps even without planning to return to his/her 'home' country, chooses to

identify as White African. A related question immediately enters the frame: if geneticists more and more use stratification why do they rely on folk race/ethnic categories? In what ways can we secure precise information flow regarding these performatively constructed social categories in medical settings when we must ensure precise diagnosis? And for my questions I received the following answer which posits that in any case it is a must to secure the necessary identification of two biological samples before any medical use.

But even knowing the self-identificatory ethnic category is not helpful because the Hungarian Roma population belongs to many ethnic backgrounds thus they belong to different genetic groups. Consequently, it is necessary to find their group membership. His or her identification does not matter. In this case modern genetics can help to provide personalized or group targeted therapy (PI 20140123).

The discussion from which I lifted the above response is related to a previously analyzed medical problem namely bone marrow transplantation. Although this medical problem is different in comparison to the steps that it is necessary to take in order to offer help to patients suffering from Bechterew's syndrome, I think the logic is the same; therefore, the response in order to be inclusive must start out from the biological ground that there are different genetic mutations which must be identified since these are crucial for a successful medical response. Ethnic/racial markers understood by either patients or health professionals in a superficial manner can lead the diagnosis astray. Let me use an example with which I can refer to a problem that I mentioned previously, namely cystic fibrosis; it is understood primarily to be a Caucasian problem, in other words one that largely affects white people, and as such this understanding directs the medical gaze of health professionals along racial fault lines⁶⁷.

Arguments to use racial/ethnic markers put forward by geneticists include time efficiency in a clinical setting where the patient's interest is to find medical solutions to their

⁶⁷ I use fault lines, because this term entails a rigid understanding of racial/ethnic identities and their relationships to various diseases.

problems as soon as possible, hence medical professionals need reliable markers that efficiently guide the therapeutic process. In addition to this criterion, it is often argued that it is simply not economically efficient for a patient to screen for everything since it is a costly procedure, and it is not efficient for the state either for the same reason. Therefore, it is suggested that racially or ethnically different populations be screened for health problems which are more prevalent in those communities. Dorothy Roberts, a legal scholar, approaches contemporary medical discourse that focuses on race and genetics from the perspective of critical race theory. She discusses an exemplary case where the racial bias of healthcare professionals caused harm instead of fast and efficient treatment (2011, p. 99). In this case description, Roberts tells a story about “Lela, who was described by doctors as a ‘2-year-old black female with fever and cough’ and later as a ‘4-year-old with another pneumonia,’ as she continued to suffer from an unshakable respiratory ailment” (Roberts, 2011, p. 99). After six years of continuous imprecise diagnosis at the age of eight her chest X-ray was read by a radiologist who identified her condition to be cystic fibrosis. The radiologist did not have any previous knowledge about her, Lela was not classified as black patient by this radiologist; it was only the X-ray image that allowed the doctor to give a racially unbiased diagnosis about her respiratory problem. In Lela’s case, it is highly probable that if she had been white she would have been diagnosed early on with CF and treated correctly. Roberts emphasizes that because of the racial lenses that the crude statistical data provides about various racially or ethnically significant diseases medical professionals mistreated Lela because they interpreted racial difference in a way that was translated into clinical practice that CF is a predominantly white disease which means that black patients are very rarely suffer from it. Thus, it was not considered by her doctors to check her for CF despite the symptoms that she has shown during her physician office visits.

The above described logic that takes race/ethnicity to be a central medical category can be detected in drug related research as well. In addition to the previously described directions,

in contemporary research that works toward the personalization of medical care, pharmacogenetic and pharmacogenomic studies aim to contribute to healthcare equality by placing emphasis on racial/ethnic variations. Personalized medicine is understood as the application of the knowledge that both patients and doctors gain with genetic tests (with the patient's genotype) to tailor medical care. "Pharmacogenetics is the study of differences in drug response due to allelic variation in genes affecting drug metabolism, efficacy, and toxicity" (Nussbaum et al., 2007, p. 497). Its significance is supported by statistics; for example only in the United States more than two million adverse drug reactions occur resulting in 100 000 excess deaths that could be avoided if genetic profiles were easily accessible for physicians who could choose therapies accordingly. The aim is to move beyond the paradigm that gives medication for everyone in a general way.

Pharmacogenomics develops towards the personalization of medical treatments. Let's take an example: today if one has a headache and takes medication to relieve his or her pain there are three possible outcomes: (1) it helps and the headache passes away; (2) it does not help; (3) if the person is very unlucky the medication will cause side-effects. (PI 20130409)

The aim of personalization of medical treatment is to avoid the latter two outcomes and make sure that the right medication in the right amount is given to the patient. The goal of pharmacogenomic studies is to map social groups that have the same genetic background for a certain problem and make medical professionals capable of offering precise therapies for their patients' medical situation. This stratification allows for a re-thinking of the population along the lines of genetic similarities without the integration of social categories – such as race, ethnicity, gender, or religion - into the framework. However, it is widely acknowledged in the medical discourse (Nussbaum et al., 2007, p. 504) that racial groups respond to drug therapies differently. The explanation is not simple at all; there are various places within the genetic structure of an individual that interact with each other during a metabolic response and they either help, or obstruct the effectiveness of a drug, or even increase its harmful effect. But in

addition to this, environmental factors also play significant role; diet, lifestyle choices, or social factors, for example stress caused by racial discrimination complicates the picture. In other words, it is widely acknowledged that there are underlying mechanisms which are shared by various social groups that must be considered if one wants to offer personalized medical care. The controversial issue is around group construction; whether there is legitimate evidence that would support the use of racial or ethnic categories in the process of designing drug therapies. Hungarian geneticists debate this question as well, as it is visible from the following example. But in addition to this genomic problem explained below various other issues were laid out by social scientists to question this trend.

I don't think that it is right to develop drugs such as the BiDil in the United States, which is designated only for Blacks. Because as I said skin color, and other superficial characteristics are defined by multiple genes and this disease [heart failure] is also defined by multiple genes. (PI 20130328)

When integration happens for example, as it happened in the case of BiDil, the first drug that was accepted by the Food and Drug Administration (FDA) in the United States in 2005 as a racially specific drug, it has quickly caused controversy. BiDil is a drug that was developed for heart failure and suggested by the FDA to be used for patients who self-identify as black. However, this racializing approach falsely divides the population into groups that are understood through racial categories and explicitly supports the idea that racial groups react to medication differently because they are genetically different from other races. With this move their genetic difference is racialized and their racial difference is medicalized and exploited by pharmacological companies. Perhaps one of the most important critiques regarding this racialization is the social and scientific context in which the drug itself has emerged.

Although after the Second World War interest in racial specific therapeutics had its low-point in the twentieth century, but it never disappeared from medical research. It was observed during the 1940s and 1950s that African Americans affected with hemolytic anemia responded

to medication differently from White Americans. Drawing on these observations it was argued that if there are racial differences regarding disease processes then therapeutics should differ from race to race. BiDil was developed by Jay Cohn, a cardiologist in the field of cardiac therapy that had a long history of documented racial differences between white and black Americans. The drug itself was created in 1989 as a combination of two already existing generic drugs called hydralazine and isosorbide dinitrate, which were already approved by the FDA for the treatment of hypertension and angina. It was around the 2000s that clinical trials began and their results by 2004 seemed to convince both patients and clinicians about the race-specific effectiveness of the drug. As it was well known that cardio-vascular morbidity rates were extremely unequal among Black and White Americans, BiDil seemed to have the potential to reduce health disparities and contribute to social justice in healthcare (Dorr & Jones, 2008, pp. 443–445). Besides this optimistic vision critical studies were written by social science researchers to sensitize the population about the re-racialization of therapeutics that began its new phase with the drug.

In their analysis, George T. H. Ellison and his colleagues (2008), provide a detailed critique on the methodological flaws of the trials and the approval of BiDil by the FDA, moreover they point out the ethical issues that they consider important regarding the use of race and ethnicity in genetic research. They think that the most important methodological problem comes from the comparative study that Jay Cohn and his colleagues did during the trials. It was a post hoc subgroup analysis meaning that they divided their groups into races and after the results they started their analysis. One of the most important problems with such studies, as critics say, is that when researchers start to look for patterns they usually find one. They find arbitrary group differences by chance. But apart from this important methodological issue, what they did was a study already pre-structured by an institutionalized racial lens without any critical reflection on how racial differentiation came about. This flaw is crucial because they

were not looking for patterns across the whole material but only for racially specific patterns that excluded any solution for heart failure for both blacks and whites – and the members of other racial groups – if they happened to share the same traits and responded similarly to the drug. Because of this flaw, they were missing genuine similarities and differences among the participants.

There are ethical issues regarding the approval process itself, because the FDA overlooked, dismissed, or ignored the serious methodological problems that accompanied the trial process (Ellison, Jay, Head, Martin, & Jonathan, 2008, p. 454). What Ellison and his colleagues claim regarding this matter, is that the approval and the trial process itself was commercially rather than scientifically motivated. Ethical concerns are also related to the scientific validity of racial identities; researchers misused them as if they were natural genetic categories and they neglected the possible negative outcomes of such practices. Among the consequences of genetic reification of racial identities are racial stigmatization, and discrimination – and there are other healthcare disadvantages as well. Researchers by accepting race as biologically real divert attention from social determinants that contribute to racial difference in the health standards of various races; and with this practice, geneticists suggest that race or racial differences are inherent, innate differences that are not changeable (Ellison et al., 2008, p. 454). In other words, they treat the observed differences as intrinsic racial characteristics instead of viewing them as extrinsic consequences of their genetic, behavioral, and socioeconomic background which together cause health disparities among various groups depending on the ways they are privileged or marginalized in a social context.

8.4. Conclusion

This chapter started out from the argument that racial categorization in a society where minorities are systematically marginalized and discriminated against by various state institutions could further oppress the members of these communities. I find it important to take into account the findings of the previous chapter as well, as I think there is no tension between doing epidemiological studies to map the most important diseases of a state and finding ways to use the knowledge gained in a manner that the members of various social groups will find it beneficial. To start with an example from reproductive medicine: it is useful to gather and distribute knowledge about various inheritable disorders, because we know that certain diseases are more frequent in certain populations. Let us say above a certain age of the parents more genetic abnormalities occur in the fetus, thus this information can be useful for both men and women who meet the criteria and they are about to make reproductive decisions and want to prevent the birth of a child who is affected. I think this approach works with race/ethnicity as well if individual cases are examined by clinical geneticists. If parents know that they are raised in a relatively closed community and they chose their partners from within, or they know about the same disorder in their families, genetic screening can help them to have a healthy child. Thus, medical information about racial groups can help reproductive decision-making.

I believe this perspective is compatible with the presented criticism. If patients, clients are involved in the decision-making process and they can interpret the medical information in relation to their biological background, then they will be capable of cooperating with clinicians in order to find the best solution for their case. Thus, I argue, if patients are educated and made capable of articulating their medically relevant identities during an interview with their clinician, they can take part actively in the process of shaping medical practice. Racial

stratification is a social reality in the Hungarian context as well and this unfortunately implies binary thinking about Roma and non-Roma Hungarians in an exclusionary fashion. This dominant understanding of distinct racial/ethnic identities is represented in the medical discourse also. However, if there is room in medical thinking for both biologically and socially multiple racial/ethnic identities on a personal-level, diagnostic processes could be enhanced by the constructivist understanding of race.

I believe this line of argumentation is compatible with the criticism articulated in favor of being cautious with the applicability of genetic knowledge for racialized/ethnicized groups in different societies. As it is evident that eugenics is present in contemporary liberal medical techniques, it is important to scrutinize how racial/ethnic classification could influence medical services. These social categories, as it is the case with gender, class, age, or religion, might provide useful directions for both clinicians and clients on how to change their lifestyle in order to attend their health, which is in itself undoubtedly useful. But it is important to be vigilant about the social processes that make certain diseases racial/ethnic, gendered, or class based problems in different cultural contexts and in different historical periods. Both discursive practices, that is, practices of everyday interactions, including scientific conduct as well play a role in the construction of the semantic layers of diseases, and these scientific interactions are informed by historically contingent cultural assumptions and scientific knowledge. Critical analyses must point out that genetic traits are attached to the classified populations through such activities and thus medical treatments are offered from the naturalized lens of the social category that define the target of medical intervention.

9. Conclusion

Although a significant number of academics, politicians, and clinicians viewed eugenics skeptically when it entered the public discourse, they had managed to reach a common ground by fusing eugenics with public health interests thus grounding eugenic ideas in the history of Hungarian medicine within the first two decades of the twentieth century. Individual health problems became socially significant thanks to the establishment of connections between contagious diseases and the financial resources used to cover those expenses. This relationship was further deepened by pointing out transgenerational issues regarding the heritability of tuberculosis. The problem of tuberculosis and its possible heritability was viewed from the perspective of middle class professionals who wanted to control the health of the working class – if needed by making medical decisions on their behalf – by arguing that this type of medical control was in the best interest of the Hungarian race.

The discourses about eugenics and public health in the first and second decades of the twentieth century paved the way for the wider institutionalization of eugenics in the interwar period. Although my work hasn't addressed the processes that took place in this period regarding the wider applications of eugenics in various fields of medicine, it is evident that the medical discourse of the 1950s relied heavily on the preventive logic that was developed in the first half of the twentieth century. The integration of eugenics into institutional conduct was an established goal of the 1910s and parallel to this direction a crucial goal was to educate citizens about eugenic values and to enable them to make eugenically informed decisions. In this eugenically motivated public health framework individual health interest was understood from the perspective of racial interest, that is, it was subordinated to the interest of the state. One of

the key areas where this was evident was marriage counseling where the aim was to give medical advice to citizens that would help their healthy reproduction.

During the 1950s the most important public health problems that influenced health statistics were contagious diseases. But by the end of the decade this had changed because vaccinations became available as tools of population control. When vaccinations became accessible to large masses of people medical concerns shifted away from this issue. It is notable that during this period it was primarily class relations that shaped the focus of medicine. The financial and educational aspects of large segments of the population would have made it impossible to pay for medical services, hence the socialist state organized free access to vaccinations, and thus managed to reduce the public health significance of contagious diseases. When contagious diseases started to receive less attention a paradigm change occurred in appreciating the public health significance of congenital abnormalities. In this new focus the attention of clinicians shifted towards the closer surveillance of women and the process of pregnancy. In this frame, the reasoning that supported prevention remained largely in line with the values of the previous explicitly eugenic discourse. In the socialist period economic arguments, such as valuing the birth of healthy productive children who would not represent a burden for the state remained central in fostering research in this direction, thus the trope of economic burden overlaps between the two politically distinct discourses. The trope of economic burden fosters bonds between citizens to rationalize eugenic decision making by pointing towards shared interests.

Race and racial discrimination did not disappear from the public health discourse after 1945. Actually, certain discriminatory practices, against Roma could be traced back to the interwar era. A clear example of such an issue is forced bathings that lasted until the 1980s. These 'public health' measures were supported by the fear that Roma people could spread contagious diseases in the population and working class people were especially at risk for such

health problems as they were living in close proximity to Roma people. But this was relevant primarily until contagious diseases were not manageable on a large scale. However, when statistics of newborns were closely monitored for congenital abnormalities researchers realized that Roma birth results offset the overall results for the country. During the process of monitoring healthcare workers used the standard measurements of the majority non-Roma population such as the mean length and weight of the newborns. These numbers were not adequate for the description of Roma newborns and produced imprecise results. Researchers discovered that the financial situation of Roma families influenced the birth results and concluded that in order to influence their reproductive results they must find ways to distribute information to them. Although this strand in the discussion was primarily about enabling healthy reproduction for both Roma and non-Roma citizens the underlying aim, or the hidden values were rooted in eugenic grounds since the primary aim was the prevention of newborns with congenital abnormalities backed by economic reasoning.

The 1960s brought about a technological paradigm change in medicine since diseases were beginning to be placed on molecular grounds after the discovery of the structure of DNA in 1953. The institutional system of genetic screening and genetic counseling was developed from the end of the 1960s because these were the medical tools that contributed to ensuring the health of the population most effectively by using the recently gained molecular knowledge. This was also the discourse where eugenic concerns were most clearly articulated. In the discussions on rules of genetic counseling medical, economic, and eugenic concerns were openly represented. This was particularly evident from the guidelines that clinicians agreed to. Medical geneticists advised their patients in the direction of pre-structured eugenically informed choices. Although it was accepted by the profession that patients must choose the type of medical support they needed from the help offered on their own, however, it was also agreed that the success of genetic counseling as an institution – established to control the population –

could only be measured by the number of children whose births were prevented because they managed to diagnose any serious genetic disorder. But on the other hand it must be noted that genetic diagnosis was also used to provide medical therapies to those newborns who suffered from some type of ailment that it was possible to cure, and thus help the integration of these children into the society. In addition to these findings from the discourse on Down syndrome, I managed to point towards the changes that took place regarding eugenic values. By the mid-1990s clinicians, medical geneticists, and bioethicists developed a common standpoint that the previously, largely paternal doctor-patient relationship must be transformed into an equal relationship between the medical professional and his or her client. This latter standpoint was influenced by the medical discourses of liberal democracies that Hungary was exposed to after 1989. In this new framework the emphasis was laid on the autonomous decision making of the client. I have argued that although the responsibility is shifted towards the parents, it means practically that eugenically informed choices are made autonomously by parents, without any direct influence from their doctors. Undoubtedly, the positive development of this medical discourse is that it can accommodate diverse views on what valuable life means for the clients so counseled.

In the literature on the medical significance of genetics one of the key turning points is considered to be the Human Genome Project that started in 1990 and it was completed in April 2003. Decoding the human DNA resulted in a significant increase of knowledge regarding the applications of genetic information in medicine. An especially important area is epidemiology where population based genetic knowledge could be put to use to tackle health inequality among groups of people socially defined along identities such as race/ethnicity, gender, class, religion, geographic origin, or age, and so on, depending on the medical problem and the determining factors of the social context. In the case of Hungary, epidemiologically significant inequalities among Roma and non-Roma citizens became a high-priority when the country wanted to join

the European Union in 2004. This approach acknowledges that economic marginalization, racial/ethnic discrimination, and gender inequality are defining factors that must be addressed in order to facilitate equality in healthcare services. In addition to these factors, medical geneticists worked towards mapping the most important inheritable genetic disorders that members of Roma communities have to face and also to provide scientific explanation as to why Roma are at risk for various disorders. On the one hand this approach manages to point out that ethnic and racial identities are significant for medical services in so far as they point towards the complications that they cause. Ethnic/racial identities are seen as factors that either negatively or positively influence well-being, thus medical professionals must take into account the social order that structures race relations; otherwise they may provide an inadequate service to their clients. But a stricter view on how ethnic/racial identities work in medical settings sheds light on possible biases that racial thinking may cause for professional conduct. Through the analysis of the interview materials I have argued that racial/ethnic bias could be at work in clinical contexts, and thus it must be ensured that the medical genetic knowledge acquired is used voluntarily by patients; and, furthermore, that clinicians are sensitized to the complexities of racial/ethnic, gender, and class inequalities so that their clients can maximize the benefits of medical consultations and clinical care.

Mapping of disease frequencies and the prevalence of genetic traits through epidemiological studies provide a theoretical background to design preventive programs and facilitate better healthcare by accumulating medical information for both healthcare professionals and patients. By analyzing the case of genetic research on Hungarian Roma I explored how racialization of medical conditions takes place. I have argued that the medical discourse not only represents Roma and non-Roma identities in a separate fashion but it reinforces these social constructs through its practices. Although it is undoubtedly useful to produce epidemiological knowledge about populations this knowledge works best if the

information itself is distributed to the self-identified members of these communities; they should be educated about its values and possible medical applications. Thus if medical knowledge is regarded as context dependent and subject to change the concept of race (as gender does) can serve the interest of individuals if they are sensitized to its limitations. By applying the methods of constructivist grounded theory I demonstrated that eugenics is present in the Hungarian medical techniques hence in order to ensure equality in healthcare and avoid discrimination those factors that play a role in viewing health problems as gendered, racial, or class based must be brought to the forefront through critical analysis. I have argued throughout my empirical work that medical knowledge is produced interactively with the social and technological elements of the discourse. Thus naturalized social categories, such as race, ethnicity, or gender, must be deconstructed by critical analysis in order to facilitate equitable medical treatment.

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11. Appendix

11.1. Expert Interviews

1. Arányi, Tamás. Hungarian Academy of Sciences, Institute of Enzymology. Transcriptional regulations, analysis of epigenetic factors.
2. Ádány, Róza. University of Debrecen, Department of Preventive Medicine. Epidemiology, genetic polymorphisms.
3. Bálint, Bálint László. University of Debrecen, Center for Clinical Genomics and Personalized Medicine. Epigenetics, functional genomics.
4. Balogh, István. University of Debrecen, Institute of Laboratory Medicine. Gene diagnostics, multifactorial diseases.
5. Beke, Artúr. Semmelweis University, Doctoral School of Clinical Sciences. Genetics, prenatal diagnostics.
6. Béres, Judit. National Institute for Health Development. Medical genetics, population genetics.
7. Bujdosó, Györgyi. Hungarian Academy of Sciences, Institute of Forensic Medicine. Forensic medical expert.
8. Czeizel, Endre. National Institute of Child Health. Family Planning and Childcare Department. Medical genetics, genetic counseling.
9. Dienes, József. Borsod-Abaúj-Zemplén County Hospital and University Training Hospital. Obstetrician, gynecologist, genetic counselor.
10. Falus, András. Hungarian Academy of Sciences. Semmelweis University, Department of Genetics, Cell and Immunobiology. Medical genetics, epigenetics.
11. Fekete, György. Semmelweis University, II. Children's Hospital. Medical genetics, DNA diagnostics, genetic counseling.

12. Gál, Anikó. Semmelweis University, Clinical Institute of Neurology, Molecular Neurological Center. Molecular genetics.
13. Garami, Miklós. Semmelweis University, Second Children's Hospital. Molecular genetics, genomic research of the prognostic factors of solid tumors.
14. Karcagi, Veronika. National Institute of Environmental Health. Department of Molecular Genetics and Diagnostics. Genetic diagnostics, family planning; main focus: diagnostics of neuromuscular diseases.
15. Kónya, Márton. Istenhegyi GeneDiagnostic Center. Molecular genetics, gene diagnostics.
16. Kosztolányi, György. University of Pécs, Medical School, Institute of Medical Genetics. Medical genetics.
17. Lakatos, Péter. Semmelweis University, First Department of Medicine, Clinical Research and Isotope Diagnostics Laboratory. Medical genetics, molecular genetics.
18. Melegh, Béla. University of Pécs, Medical School, Institute of Medical Genetics, Human Genetics and Pharmacogenomics Research Group. Medical genetics, theoretical medical sciences.
19. Molnár, Mária Judit. Semmelweis University, Clinical Institute of Neurology, Molecular Neurological Center. Medical genetics, genetic counseling.
20. Nagy, Bálint. Semmelweis University, Doctoral School of Clinical Sciences. Molecular biology, prenatal diagnostics, screening of genetic diseases.
21. Nagy, Károly. Semmelweis University, Institute of Medical Microbiology. Medical microbiology, virology and immunology of human retroviruses.
22. Nagy, László. University of Debrecen, Institute of Biochemistry and Molecular Biology. Molecular genetics.

23. Nagy, Sándor. Petz Aladár County Teaching Hospital of Győr, Department of Obstetrics and Gynecology. Obstetrician, gynecologist, genetic counselor.
24. Oláh, Éva. University of Debrecen, Institute of Paediatrics, Clinical Genetic Center. Clinical genetics, molecular genetic diagnostics.
25. Pamjav, Horolma. Eötvös Lóránd University, Doctoral School of Biology. Mapping the genetic structures of populations with the aid of Y-STR and SNP markers.
26. Papp, Zoltán. Semmelweis University, Doctoral School of Clinical Sciences. Maternity Private Department of Obstetrics and Gynecology. Foetal medical sciences, medical genetics, genetic diagnostics.
27. Raskó, István. University of Szeged, Doctoral School of Clinical Sciences. Human molecular genetics, population genetics.
28. Sarkadi, Balázs. Semmelweis University, Doctoral School of Molecular Medical Sciences. Biological membrane structures, proteins of stem cell membranes.
29. Schuler, Dezső. Semmelweis University, Second Children's Hospital. Cytogenetics, leukemia, brain tumors.
30. Szabó, János. University of Szeged, Institute of Medical Genetics. Prenatal diagnostics, genetic counseling, molecular genetics of multifactorial diseases, nutrigenomics, epigenetics.
31. Szalai, Csaba. Semmelweis University, Doctoral School of Molecular Medicine. Genomic backgrounds of multifactorial diseases, and pharmacogenomics.
32. Török, Olga. University of Debrecen, Department of Obstetrics and Gynecology. Clinical genetics, human genetics, genetic counseling.
33. Váradi, András. Hungarian Academy of Sciences, Research Center of Natural Sciences, Institute of Enzymology. ABC transporters, ATPase mechanisms, diagnostics of hereditary diseases.

34. Vászárhelyi, Barna. Semmelweis University, Doctoral School of Clinical Sciences.
Health complications of newborns, clinical medical sciences, health sciences.

11.2. Interview Questions

Introduction

1. What is your field of research? And how is your field connected to human genetics?

Related to Reproductive Health Politics

2. Is there any continuity between the contemporary health policy of reproduction and what were accepted in the socialist regime?
3. Do you see any connection between the contemporary human genetics and the reproduction health policy of the socialist period?
4. Could you talk about the history of genetic screening and diagnostics in Hungary?
5. Can you explain what are the goals of genetics screenings and genetic diagnostics focusing on reproductive practices?
6. Can you talk about the institutionalization of medical genetics in Hungary? When and how genetic counselling practices got institutionalized?
7. Could describe what were the main theoretical and methodological trends in reproductive genetics from the 70s until today?
8. How did the goal of genetic screening practices changed since the 70s?

9. Would you describe the genetic screening process for family planning? Can you recall moments when there was any significance of knowing the patients' ethnicity in your work?
 - a. For men and women before conception?
 - b. In the case of a pregnant woman?
 - c. What are the technological/financial limits of a genetic screening today?
10. Can you tell X and Y linked diseases that are screened presently and the practice itself poses ethical dilemmas?

Population genetics

11. Could you describe how did the genetic screening of ethnic minorities begin in Hungary?
 - a. Can you give examples where the screening of ethnic minorities happened similarly?
12. Why do think that ethnic based genetic screenings are important?
13. Could you please define what do you mean by the terms population, ethnicity and race?
 - a. What kinds of race concepts are applied in biological research? How do you apply these concepts in your genetic research?
 - b. To what extent do you think that these concepts are stable according to your empirical research?
14. If you joined the research of Roma people of Hungary would you describe the biological characteristics that help the construction of (ethnically) different groups?
 - a. What are your expectations of researching Roma people?
 - b. Are there any advantages that you can think of that the research will benefit the Roma communities?

15. How human genetic research contribute to forming social values?
16. How health preservation, aiding healthy lifestyle, and furthering health figure in designing genetic research?

Personalized Medicine

Could you map briefly what are the main trends in today's personalized medicine?

17. What are the biological markers that are applied in defining susceptibility to a genetic disease?
18. Is there any significance that is attributed to sex (biological structure) by geneticists?
Could you tell an example?
19. What is the role of familial genetic anamnesis in personalized medicine?
20. What is the significance of race/ethnicity in personalized medicine?
21. What is the role of exploring the interactions between the social and natural environment in their shaping of the bodily processes?
22. How this discourse changes the doctor-patient relationship? And does it change the relation of the subjects to their own body?
23. How do you see the possibilities of wider social access to these personalized medical tests and treatment?

Epigenetics

24. Epigenetic research brought paradigm change in human genetics. In your opinion what are the possible directions in the future for genetic screenings taking into consideration the results of epigenetic research?