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PROCREATING RESPONSIBLY: THE CASE OF PRENATAL DIAGNOSIS IN BULGARIA

This paper examines the practice of prenatal diagnosis in Bulgaria as an emerging mode of genetic governance, bringing new notions and norms of responsible procreation and "good" parenthood. Firstly, an overview is provided of some of the key controversies that have emerged during the routinization of prenatal testing and the selective termination of affected pregnancies, focusing on the potential of the new genetics to mould identities and communities in novel ways. Secondly, the local framing of prenatal diagnosis and selective abortion is presented, arguing that this framing actively participates in the construction and reinforcement of genetic norms of the "good" parenthood. The "good" parent is genetically responsible if she opts for the selective abortion of the affected pregnancy.

Keywords: prenatal diagnosis, genetic responsibility, biological citizenship, biopolitics.

Prenatal diagnosis is often praised by biomedical specialists, bioethicists and the general public as one of the most useful benefits to spring from reproductive genetics. It has been promoted as a safe way not only for individuals to ensure the health of their offspring, but also as a means by which states and populations can optimize expenditure on medical care. Prenatal diagnosis has become a routine part of antenatal care and is generally portrayed as an expert-sanctioned means of avoiding harm and unnecessary suffering. In spite of its broad acceptance, there is also substantial criticism of it, mainly from the disability communities, religious groups, scholars and rights activists.

This article examines how this practice is currently promoted and embraced in Bulgaria, with a special focus on the ways it operates as a biopolitical technology, producing new notions of responsible procreation and "good" parenthood. In what

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follows, I try to demonstrate how the expert discourse on prenatal diagnosis in Bulgaria functions, benefiting from the specific local constellation of factors, which effectively resonate with a majority of the audience. This is, in essence, the belief in and uncritical acceptance of technological innovation and its broad application (e.g. Simeonov, Krachunova 1993: 18; Boyadjeva et al. 1994) and the post-socialist neo-liberal affirmation of the necessity to run the state frugally and reject unreasonable expenditures. All this leads to an open defence of the economic value of this type of preventive intervention, which is left uncontested in the public space.

In the first part of the article a brief overview of some of the key controversies emerging from the process of routinization of prenatal testing and of selective termination of affected pregnancies is offered, revealing the potential of new genetics to mould identities and communities in novel ways. In the second section, an examination of local expert framing of prenatal diagnosis and selective abortion is provided, with the argument emerging that this framing plays an active part in the construction and reinforcement of genetic norms of "good" parenthood.

The main research methods used for this article are the analysis of documents alongside a qualitative analysis of interviews and media publications. The sources of data include several official documents of the Bulgarian National Genetic Laboratory (NGL) issued over the period 2009–2011 and available online. Also reviewed are the National Plan for Rare Diseases (2009–2013) and several documents issued from a variety of ministries and some public statements in online publications of some of the key figures in the field of genetics (working at NGL), publicized in the period 2013–2014. Finally, twelve semi-structured interviews were conducted in 2012 with specialists in medical genetics and genetic counsellors (including those working at NGL and several other leading public hospitals in the largest Bulgarian cities of Sofia, Plovdiv, Varna and Pleven).

Prenatal diagnosis anxieties and genetic citizenship

The conceptual framework of the analysis differs from some leading bioethical perspectives towards prenatal diagnostics, which will be mentioned briefly below, and interprets these selective practices as pertaining to the biopolitical regulation of populations, or, in other words, to the technologies of power, which view the biological processes of life and death as political issues (Dean 2004: 17). They are part of the modern art of governance, which aim to optimize the population through promoting its health, wellbeing, prosperity and increased effectiveness and also through protection from pathologies. "Pathological" elements are those that, in one way or another, threaten the overall productivity and viability of the population. This concern gives rise to projects that designate and manage life "unworthy" of resource investment, which has been referred to as state racism by Michel Foucault: "the elimination of unproductive ciphers of life through direct killing as well as abandonment. This death is a biopowerful death, which is to say it is productive, because it allows the overall life of a population to extend and prosper"

(Willse 2010: 177–8). In such a sense, the modern state simultaneously cares and protects life while it also seeks the elimination of those groups that have been deemed as drain on biological, social and economical resources. It would not be an exaggeration to say that the disabled and the chronically ill have always been identified in such a way and have been a target of diverse selective practices.

However, the selective practices and the ethics of selection can also be examined with reference to another conceptual perspective. Enjoying a prominent place in bioethical discussions, this perspective puts emphasis on the parental right to make informed decisions and to avoid the birth of genetically impaired children. The aim of striving to select, shape and enhance our offspring and avoid harm cannot, however, be seen as unprecedented in the ordinary experience of raising children (see, for example Häyry 2010: 52). Although this perspective is undoubtedly the result of important and well-elaborated theoretical efforts, I believe that it misses a crucial point; namely that new technologies are creating opportunities for new ways of thinking about ourselves and our ethical practices (Mills 2011: 4). Attention and sensitivity towards this aspect of selective terminations is important to the disability studies perspective, which incorporates also the biopower problematics sketched above.

A notable critique of selective practices can be found in the so-called "expressivist argument". This claims that selective practices send discriminating message and express a disrespectful attitude towards those living with disabilities that are the target of selected terminations. As Rob Sparrow argues, "the real force of the expressivist objection lies in its capacity to draw our attention to political questions about the role of the state and about relationships between different social groups" (Sparrow 2008: 112). A key problem, identified by this type of critique, is that even if prenatal diagnosis is practiced in a non-directive manner, it

in and of itself establishes a directive context and serves to transfer moral responsibility to patients, since an offer of prenatal diagnosis implies a recommendation to accept that offer, which in turn entails a tacit recommendation to terminate a pregnancy if it is found to show any abnormality (Clarke 1991: 1000).

This aspect, however, is framed as a logical consequence of the improvement of antenatal care, enabled by the progress of genetics, and as a tool to enhance individual choice, on the other. In this way "the rhetoric of individual choice conceals a more complex reality, in which full information, non-directive counselling and informed consent are rarely available" (Shakespeare 2003: 203).

This is a serious issue for disability communities since it entails the re-biologization of disability, a situation in which new tools that work on our bodies instead on our environment, are produced and imposed. They contribute to the oblivion of the complex origin of individual suffering: "the easier it is to change our bodies to relieve our suffering, the less inclined we may be to try to change the complex social conditions that produce that suffering" (Parens 1998: 53).

These problems pertain to the more general conceptual framework of research, focusing on the potential of new genetics to construct new identities and social formations, to create new forms of group activism and to shape our notions of natural and normal, of therapy, prevention and treatment. Against this theoretical background as a conceptual framework of the analysis I employ the concept of genetic citizenship (Kerr 2003; Heath et al. 2004), which could be conceived as a subspecies of biological citizenship (Petryna 2002; Rose 2007; Rose, Novas 2005) through which we can illuminate the ways genetic health becomes an arena of governance, embodied self-discipline as well as a potential source of activism and engagement in resistance. As Carlos Novas and Nikolas Rose note "genetic forms of thought not only give life strategies a genetic coloration, but also create new ethical responsibilities... [G]enetic thought induces 'genetic responsibility' – it reshapes prudence and obligation" (Novas, Rose 2000: 487).

I would argue that one of the most tangible effects of this type of governance in Bulgaria is the introduction of new conceptions about what it means to be a "good" parent and what is "worthy" procreation, which could be referred to as the "genetic responsabilization of parenthood".

Genetic Governance in Bulgaria

Prenatal diagnosis and genetic counselling were eagerly embraced by the human genetics community in late socialist Bulgaria (1980s), who hoped it could assist in the building of a healthy, socialist social organism. This was a period that saw both the introduction and popularization of prenatal diagnosis among the population and the promoting of its effectiveness on an individual as well as a collective level. Today these services are offered by state and private clinics and are usually recommended in cases where an elevated risk (1/250) of genetic abnormalities has been detected through biochemical screening, which is offered as a part of routine antenatal care. Patients highlighted by the screening are referred for amniocentesis or, more rarely, for chorionic villus sampling. The controversy around these invasive procedures is connected to the risk of miscarriage, which is considered to equal the risk threshold of 1/250 or to be slightly lower.

In what follows the strategies of promoting prenatal diagnosis are reviewed, in particular those adopted by the NGL in Bulgaria and the attitudes of the interviewed geneticists. The conclusion is offered that the local context differs considerably from those areas where more influential and audible disabled communities and/or religious sentiments exist. Prenatal diagnosis and selective abortion are affirmed in environments lacking alternative voices: in Bulgaria there are no official statements of activist organizations for people with rare diseases or disabled people and no serious discussion in the public space of the moral, ethical, legal issues, stemming from these practices. Patient organizations, e.g., the parents of children with Down syndrome, have yet to make efforts to influence the practice and process of genetic counselling in cases where Down syndrome has

been diagnosed. Studies show that the rate of terminations falls when expectant parents are introduced to other parents of children with Down syndrome and hear stories about the rewarding experience of raising such children (Parens, Asch 2000: 8).

In this sense, the medical community in Bulgaria is able to impose its definition and model of a life (un) worthy of living on the public and generally is not disturbed by any interference on the part of groups such as pregnant women¹, disabled people and their families, interest groups, associations of people with rare diseases, organizations for the disabled, social scientists, the media or religious communities. All this allows the key expert actor, the NGL, to promote a professional discourse that explicitly advocates "genetic prophylactics", which has the aim of eliminating genetic diseases through the selective abortion of those born with these conditions. Although in principle genetic counselors should be morally neutral in providing information and assisting clients, the general framing NGL adopts for this issue is a sort of a directive politics, having strong impact on the popular conceptions of responsible and "good" parenthood and citizenship: the "good" parent and citizen generally opt for prenatal diagnosis and choose to selectively terminate affected pregnancies.

Since biological citizenship is fundamentally related to information and knowledge, there is much negotiation as to how complicated facts about genetics and genetic screening should be delivered to laypersons and how they can be made to understand and use these facts "correctly" (Poutanen 2005: 60–1). That is why it is important in first place to explore how the expert actors in the field structure this information landscape.

The NGL has been taking serious efforts to popularize its activities for a number of years. This is particularly stressed in its annual reports, especially for 2008 and 2009. It organizes annual meetings dedicated to the issue of genetic disorders with leading national and regional media, provides a special information phone service and two Internet forums, where genetic testing is discussed. These forums alone have over several thousand visitors monthly. The NGL continuously publishes new materials on its official webpage and in the media. This large-scale activity is in fact directed at strengthening the institutionalization of the fear of genetic disorders and congenital impairments, which could be termed as "geneticization" (Lippman 1992). The latter is a problem as attention is directed to the prevention of genetic risks, while ignoring a number of other factors: "most childhood disabilities are not, of course, either chromosomal or genetic, but are caused by low birth weight, which accompanies poverty and insufficient prenatal nutrition or care, or by accidents and infant illnesses" (Rapp 2000: 71–2).

In a 2010 report, the drive to promote prenatal diagnosis was developed further through the inclusion of the issue of rare diseases: "new rare diseases are discovered. At the moment over 7000 are known and we can expect this number

¹ On the subject of iatrogenic effects of prenatal diagnostics on pregnant women, see for example (Rapp 2000; Katz–Rothman 1986).

to exceed 23 000 (this is the number of genes in the human genome)" (National Genetic Laboratory 2011a: 2). The result is a steady increase in the demand for genetic testing services –we could speak of the "exponential growth" of the "number of candidates for genetic testing" (National Genetic Laboratory 2011a: 2). Within this process, according to Thomas Lemke, when subjected to genetic testing virtually any pregnancy becomes a "risk pregnancy", with the pregnant woman being called upon to optimize the foetus's health and to behave in such a way as to minimize risk (Lemke 2005: 92).

The key line of argument, typical for many of the documents and public announcements of the NGL, is to focus on the potential economic benefits, confirmed through a perfunctory cost-benefit calculation. It is claimed to be obvious that "the most economically efficient practice is to diagnose the pathology prenatally" (National Genetic Laboratory 2010: 10), since it opens up the possibility of "prevention of cases":

preventing the birth of even one case of mucopolysaccharidose type II or Gaucher's disease saves from 250000 to 500000 euros per year, which is 30 percent of the financial resources used to fund the whole programme. A similar situation can be found with those "rare" diseases that have the highest incidence – beta-thalassemia and cystic fibrosis. Annually, without prophylactics, we have 15–20 newborns suffering from this, each needing 15000 euros per year for an average life span of 35 years (National Genetic Laboratory 2010: 10).

The same striving towards the "prevention of births" can be found in the section of the Report called "Medical and Social Perspectives", where it is proper to mention, at least briefly, the ethical, legal and social implications of reproductive genetics. Instead, it is added that, as well as providing economic efficiency, diagnostics and the prevention of genetic diseases are also proven to be "medically and socially efficient" (National Genetic Laboratory 2010: 23).

In 2011 the same claim was even more authoritatively stated: "Prophylactics of genetic disorders are acknowledged to be one of the most economically efficient practices" (National Genetic Laboratory 2011a: 19). The evidence follows: "The treatment expenses impose an excessive burden on health finances not only for the Bulgarian health care system. The only realistic approach towards solving the problem is prophylactics by *prenatal diagnosis* (which costs less than 500 euros)" (National Genetic Laboratory 2010: 23; National Genetic Laboratory 2011a: 19). The warning that the failure to diagnose even one case could lead to serious expenditures, which in turn could threaten the funding of the whole national program (National Genetic Laboratory 2011: 12), reappears. Report 2011 again promotes "preventing the birth of severely ill, who require long, very expensive and, in some cases, ineffective treatment" (National Genetic Laboratory 2011b: 7).

The same economic argument is present in a variety of public forums, such as the online portal BG Mamma; the leading Bulgarian online venue for discussions, sharing information and experience, and providing emotional support among future and present parents (predominantly women). It is also on the official page of Bul-

garian Ministry of Health, in a section designed to provide information for patients. Here the claim is repeated that "the prevention of genetic disorders has no alternative". Much of this is justified by reference to the rhetoric of cost-effectiveness, which has become popular in post-socialist Bulgaria. The open defence and promotion of the economic benefit of selective terminations can clearly be challenged on moral grounds with the argument that it amounts to revival of the old eugenic practices of measuring the economic burden that the "unfit" supposedly impose on the productive part of society. This could be criticized as an insensitive and uninformed way to describe the lives of people with disabilities in purely monetary terms. But perhaps the most important point here is that the proposed cost-benefit calculations are not based on a real economic analysis of prenatal screening and do not take into account its complexities. According to one commentator:

... economic analyses of the kind in question are not really capable of demonstrating any economic *result*, like a profit or a loss. Rather, what they may show is that the estimated costs for practising prenatal diagnosis (and selective abortion) are balanced by an expected reduction of certain costs in the future. That is compatible with the claim that the practice runs at a loss, all things considered (Munthe 1996: 60).

It is also necessary to note that the most controversial and difficult aspect of cost-benefit analyses in this case is the determination of what is cost and what is benefit, as this depends on different conceptualizations of the aims of prenatal diagnosis. Simply defining the averted costs of caring for a disabled person as benefit is generally rejected (Clarke 1993; Phin 1990) and:

more sophisticated cost-benefit analyses of genetic-screening programmes have been produced... In [which] the main benefit is taken to be the making of informed choices by couples at risk... The birth of an affected child to a couple who have declined prenatal diagnosis or termination of pregnancy is described as a benefit, not a cost of the programme (Clarke 1993: 48).

Another way to convince and, in fact, coerce patients, is laid out in another document of the Laboratory on the subject of screening for Down syndrome. It is an area of special interest for the NGL; it is discussed in three very active Internet forums and four telephone information lines have been set up. It is the target of a separate action plan, described in the document "The Bulgarian model of Down syndrome screening". It reveals precisely why this genetic disorder receives special attention as a target for prenatal "prophylactics": "the high incidence, the severe consequences and the relatively high average life expectancy qualify the Down disease as a main target of prenatal screening and are among the factors, defining it as an exceptionally significant economic, social and medical problem" (National Genetic Laboratory 2011: 1). In this document we can find an explicit appeal for state pressure and coercion; prenatal diagnosis for Down syndrome could be made mandatory by withdrawing all public financial support to those families either opting out of genetic screening or rejecting termination.

This is a crucial point as it could be interpreted as revealing a tacit attitude in the expert community in favour of more harsh measures in the prenatal care. When geneticists were directly asked to express their attitudes towards this kind of state coercion, they were generally inclined to make evasive statements and avoid any radical comments. However, one of them offered open support of "mass genetic prophylactics" and another claimed: "In some other countries you need a mandatory vaccination before being allowed to visit day care centres, schools" (age group 45–60, male, Sofia (NGL)).

Statements in the media also show an inclination to bind the practice of genetic prophylactics to the right of receiving state support or benefits when a child with a genetic condition is knowingly brought to term and alternatively, withdrawing all support if genetic prophylactics have been refused during pregnancy:

Over the 30 years during which over 1000 families have been diagnosed prenatally, only two have rejected termination. It is not clear whether they understood much at all about the disease (Down syndrome). The situation is quite different in the Nordic countries, where many families choose to keep their children with Down syndrome. But we are not Scandinavians. Besides that, their health insurance contracts stipulate that the state shall cover all expenses, as long as the pregnant woman has undergone all the prophylactic measures offered to her. If she has omitted one and her decision to give birth to the child has not been an informed one, the family must cover all expenses related to the treatment. Prenatal diagnosis is the most efficient ... human activity. 500 euros for prenatal diagnosis saves millions... Obviously, the problem ... concerns not only these families but society as a whole... ("To give..." 2013).

In this statement it is obvious, firstly, that as benefit of prenatal diagnosis is considered one particular choice of the future parents, namely, to terminate the pregnancy. This raises serious doubts as to whether non-directive counselling is possible. And, secondly, the inclination to coerce parents through economic measures and through imposing the feeling of guilt before society.

The same pursuit of genetic prophylactics is reflected also in the Bulgarian National Plan for Rare Diseases (2009–2013). It has the same priorities as are expressed above: improved prevention of rare diseases with genetic origin through the use of screening programmes, new genetic tests, decentralization of laboratory activities and better access to genetic counselling. The fifth section of the Plan is entitled "The improvement of prevention and the diagnosis of rare genetic diseases, predispositions, and congenital anomalies" and reveals the objectives: "To decrease the number of newborns with severe hereditary and congenital genetic diseases..." (Ministry of Health 2009: 19). It is expected that the implementation of the national action plan shall ultimately result in a reduction in the number of children born with such conditions (Ministry of Health 2009: 20). It is worth noting that the national programmes, plans and strategies for patients with rare diseases are formulated quite differently in other European countries; in some of them the fact that about 80 percent of these conditions are with genetic origin is not in

the focus (as it is in the Bulgarian version) and respectively, prenatal screening and diagnosis are not even mentioned (Recommendations 2010; Enquête 2011); in others, these procedures are mentioned with regard to early diagnosis and the serious ethical dilemmas are strongly emphasized (Maßnahmen 2009:95). The point here is that these programmes and action plans are primarily conceived as a means to improve the quality of life for people with rare diseases through early and adequate diagnosis, treatment, rehabilitation, social inclusion and integration, rather than as a means to prevent their birth.

Genetic prophylactics is also a priority action in the Plan for 2011 for implementation of the national strategy for demographic development of Bulgaria (2006–2020) in the context of the section "Increase in average life expectancy": "Expanding the practice of prenatal diagnosis of pregnant women with the objective of avoiding births of children with severe disabilities" (Ministry of Labour and Social Policy 2010:3). The same priority is described as an already achieved result in the Report for implementation of the objectives of Ministry of Health for 2010 (Ministry of health 2011:12). This adds another dimension to genetic state biopolitics; not only is economic efficacy important but statistics are also; as a crucial part of the official image of the state¹.

In the interviews conducted for this article, geneticists demonstrated the unanimous belief that should counselling not only be non-directive in principle, but that this idea actually guides their practice. Despite this confidence in the regulative principles of genetic counselling, the majority of geneticists recommended termination of the affected pregnancy when presented with genetic conditions such as Down syndrome, achondroplasia, cystic fibrosis, Huntington's disease and Turner syndrome. Only one genetic counsellor claimed that she would not advise aborting a fetus diagnosed with achondroplasia or with Down syndrome (age group 30–45 years, female, Varna). This shows that the majority of the respondents generally do not have even a vague set of criteria for what could make life "unworthy of living": for example, mental retardation as in the case of Down syndrome, short life expectancy and daily care as in the case of cystic fibrosis, cognitive and physical decline but with late onset as in the case of Huntington's disease or loss of reproductive function and risk of other medical problems as in the case of Turner syndrome.

Respondents generally viewed the practice of prenatal diagnosis followed by termination positively. One of the most prominent geneticists and genetic counsellors in Bulgaria has said that prenatal diagnosis is:

¹ It is important to note that this effect of prenatal diagnosis and selective abortions, namely to make the rates of child mortality look better, has been seen as positive ever since the late socialism. For example, in 1984 one of the key actors on the scene of medical genetics in Bulgaria in 1980s, Maria Tsoneva, noted: "Through the introduction of prenatal diagnosis ... we guarantee the real reduction of child mortality – an indicator that has great social importance for each society" (Tsoneva 1984:319). And in 1993 another renowned geneticists wrote "through prenatal diagnostics ... perinatal mortality has been reduced with 1,78% for a three-year period" (Todorov 1993:33).

the right decision of Bulgarian women and the most effective current medical procedure in terms of its medical, social and financial aspects... It solves financial problems, which are too hard for the state, society and family (age group over 60, male, Sofia (NGL)).

The respondents also vigorously rejected the allegation that such a view expresses disrespectful attitude towards those living with such genetic conditions. It is interesting to note also that although they firmly believe in the non-directiveness of their practice and the autonomy of parents, implicit attitudes and beliefs about what is a "good" life and "good" parenthood can be detected. One respondent described life with a Down syndrome child in the following way:

Yes, they are extremely sweet and amicable – just like a small child, yes. And this means that they should not be isolated, they are human beings... but imagine the same picture – a girl and a boy – friends, playing together with a Down syndrome child, also a friend of theirs – after fifteen years: what will they have achieved, in what university will they study... The information [regarding Down syndrome – I.D.] is important not in the moment [during infancy – I.D.], parents must think in perspective... (age group 45–60, male, Sofia (NGL))

And adds:

This is because, believe me, people want to have children, but they want healthy children. If the mother does not care about this, she will say: "I gave birth, I have a child, I do not care what it is. But this is not the case – they care". Another respondent in a media interview reflects on the change in the attitudes of prospective mothers in the following way: "The Bulgarian woman appears to be more in-formed than the majority of the physicians. She has started to care for her health, for the offspring, for the future" (age group over 60, male, Sofia (NGL)) ("The best..." 2012).

A tacit notion of parenthood is visible here, which measures the "value" of the prospective children, according to their achievements and their ability to lead independent lives. The subjectivity of the "good" parent inevitably comprises "care for the future" through keeping oneself properly informed.

In such a sense, it could be summarized that in Bulgaria prenatal diagnostics operates as a biopolitical technology, promoted by the state, whose interest in prenatal testing "is not about women making *any* informed choice but about making a *particular* choice, namely to have an abortion" (Ettorre 2005: 117–8). It functions smoothly since there is no public discussion on its ethical, legal and social implications and the notion and culture of genetically (ir) responsible parenthood is thus reinforced.

The process of promotion and routinizaion of prenatal diagnosis and selective terminations introduces and affirms the notion of genetic risk as a crucial aspect of our "will to health" (Rose 2001), which in this case involves an active relation to our offspring, creating new types of surveillance and management of procreation and parenthood. This paper presented the local expert discourse on prenatal diagnostics and stressed one of its key effects – the construction and reinforcement of genetically

responsible procreation and parenthood, which favours termination of pregnancies, when genetic abnormality is detected. The “good” parent generally opts for selective abortion, otherwise she is to be deemed to be irresponsible, to harm her future children and to impose an excessive burden on the rest of society.

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