Cystic Fibrosis Carrier Screening in Veneto (Italy) - An Ethical Analysis

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Text

Abstract: A recent study by Castellani et al. (2009) describes the population-level effects of the choices of individuals who underwent molecular carrier screening for cystic fibrosis (CF) in Veneto, in the northeastern part of Italy, between 1993 and 2007. We discuss some of the ethical issues raised by the policies and individual choices that are the subject of this study. In particular, (i) we discuss the ethical issues raised by the acquisition of genetic information through antenatal carrier testing; (ii) we consider whether by choosing to procreate naturally these couples can harm the resulting child and/or other members of society, and what the moral implications of such harm would be; (iii) we consider whether by choosing to *avoid* natural procreation carrier couples can harm current or future individuals affected by cystic fibrosis; (iv) we discuss whether programs that make carrier testing available can be considered eugenic programs.

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1. Introduction

The interaction between public health policies and individual choices is a complex issue. In some cases, public health programs make new options available to individuals and it may be

extremely difficult to predict how individuals will use the options and what kind of population-level effects will result. A recent study by Castellani et al. describes the population-level effects generated by the choices of individuals who decided to undergo molecular carrier screening for cystic fibrosis (CF) in Veneto, in the northeastern part of Italy, between 1993 and 2007 (Castellani et al, 2009). The study is interesting because it compares the population-level effects of two different policies adopted independently by two different medical centers in two different areas of the same region. The two centers made the carrier test available to two different segments of the population in two different ways.

In this article, we discuss some of the ethical issues raised by the policies and individual choices described in the Veneto study. An exhaustive analysis would need a much lengthier treatment. Our aim is simply to highlight some of the issues that we find most interesting. Our analysis takes into account the interests of various individuals – such as (would be) parents, individuals affected by CF, and other members of society – and the consequences that various courses of action would have on the protection and advancement of such interests. Such interests include the interest in reducing the burden of disease and disability, the interest in self-determination and the interest in living in a just and inclusive society. We proceed as follows. Section 2 reports some findings on the nature and incidence of cystic fibrosis. Section 3 summarizes the Veneto study. In section 4, we discuss the Veneto study by focusing on the ethical issues raised by the acquisition of genetic information through antenatal carrier testing. In section 5, we discuss the choices of carrier couples in relation to reproductive autonomy and the prevention of harm. In particular, we consider whether by choosing to procreate naturally (i.e. without recourse to IVF, PGD, pregnancy termination or other biomedical procedures) these couples can harm the resulting CF-affected child and/or society in general, and if so what the moral implications of such harm would be. In section 6, we consider whether by choosing to *avoid* natural procreation carrier couples can harm current or

future individuals affected by cystic fibrosis, and – again – we assess the moral implications. We conclude with section 7, where we discuss whether health programs that make carrier testing available can be considered eugenic programs and we assess the moral significance of such labeling.

2. Cystic Fibrosis

Cystic fibrosis (CF) is the most common lethal genetic disease in populations of European descent. In these populations, it occurs in about 1 in 3,000 births (O' Sullivan and Freeman, 2009). No cure is currently known. The median life expectancy for CF-affected newborns in 2009 was 35.9 years (Cystic Fibrosis Foundation 2009). The median survival age is approximately the same in the USA and the EU (Buzzetti et al, 2009). The disease is due to mutations in a gene on chromosome 7 that encodes a 1480 amino acid protein known as CFTR (cystic fibrosis transmembrane conductance regulator) (Moskowitz et al, 2008). CFTR is expressed in epithelial cells carrying out exocrine functions, such as the production of mucus, sweat and pancreatic juices. Its main function is to act as a chloride channel, even though other functions have also been identified (Vankeerberghen et al, 2002).

Epithelial cells lacking correctly functioning CFTR accumulate water in the cytoplasm, leading to dehydration and, consequently, thickening of secretions. Since CFTR is expressed in many epithelial cell types, CF affects several organs and tissues, notably the pancreas, airways and the male reproductive system. Treatment of the respiratory symptoms is expensive and time consuming. Lung disease is by far the most common cause of death among CF patients. Only some mutations of the CFTR gene cause CF, but those that do are among the most frequent. A single mutation, the deletion of the phenylalanine residue at

position 508 (F508del), accounts for more than 66% of worldwide CF cases, although this percentage varies in different ethnic groups.

CF is an autosomal recessive disease, i.e. two mutated alleles of the CFTR gene are necessary to elicit the condition. Homozygous carriers, as well as compound heterozygous carriers – carriers with two *different* CF-causing mutations – are affected by the disease, while single-mutation carriers are asymptomatic. If two unaffected carriers procreate, there is a 25% chance of a CF-affected newborn. In European populations the frequency of unaffected carriers is about 1 in 30.

3. The Veneto Study

Castellani and colleagues (2009) report data on the incidence of CF in newborns in Veneto (Italy). Newborns were screened for CF in this region between 1993 and 2007 using a non-genetic test (immunoreactive trypsinogen, IRT) followed by genetic screening of those positive to IRT. The screening involved around 780,000 children, i.e. 99% of the newborn population. In the 14-year period, 195 CF-affected newborns were detected, an overall incidence of 1 in 3998, or about 2.5 cases/10,000 newborns. The incidence decreased by 0.16 cases/10,000 newborns per year. The reduction was concentrated in the eastern part of Veneto (0.24 cases/10,000 newborns per year), whereas the incidence in the western part of Veneto remained almost constant (a decrease of 0.04 cases/10,000 newborns per year).

What could account for this difference? After excluding population mixing (the influx of populations of non-European origin with a lower CF incidence) and partial detection by the neonatal screening system, the authors focused on another factor: the different policies for carrier testing. The Verona Cystic Fibrosis Center, in the western part of Veneto, made testing available only to individuals with a positive family history of CF and to their partners, as well

as to couples with fertility problems undergoing IVF. In contrast, the University of Padua, in the eastern part of Veneto, offered CF-carrier screening at a nominal cost to anybody who wanted it. From 1993 to 2007, 91 carrier couples – couples with two carriers – were identified, 9 of these in the western area and 82 in the eastern area. The authors found a statistically significant negative correlation between the number of carrier tests and CF cases in the eastern area and a statistically significant link between the increase in the number of screened carriers over time and the decrease of incidence in the whole region.

Regarding the 82 carrier couples identified in eastern Veneto, Castellani et al. hypothesize that, had they been uninformed of their carrier condition, they would on average have generated 1.39 children each (Italian average), a total of 82×1.39=113 children, 25% of whom would have been affected by CF. That is, had these 82 couples been uninformed, 28 additional CF-affected children would have been born. Given that in eastern Veneto 114 cases were detected by neonatal screening, without the antenatal screening program there would have been a total of 142 CF-affected newborns, and thereby virtually no difference in incidence between eastern and western Veneto. These data indicate that the imbalance in incidence was due to the different carrier screening practices.

Why did the two centers adopt two different policies? The decisions were taken independently in the mid-1990s. We interviewed two of the authors of the 2009 article, Castellani, at the Verona Center, and Picci, at the Padua Center. We also interviewed Dr Franco Zacchello, former Director of the Department of Pediatrics at the University of Padua. According to Castellani, the Verona Center opted for restricting the availability of the test because its sensitivity was under 95%. (C. Castellani, personal communication, 18 December 2010). According to Picci and Zacchello, the Padua Center deemed sensitivity to be sufficiently high for a non-restrictive policy (L. Picci, personal communication, 3 September 2010; F.

Zacchello, personal communication, 21 December 2010). The motivation for offering the service was the desire to offer prospective parents the possibility to find out about their chances of giving birth to an individual with a severe genetic condition with a relatively high incidence in the Italian population. Information about the service was given in a non-directive way.

The test can yield three possible results: double negative (neither of the members of the couple is a carrier), positive-negative (only one is a carrier), double positive (both are carriers). Problems arise only for double positive (henceforth, carrier) couples. Such couples can choose among the following options:

1. forgo having a child;
2. adoption;
3. pre-implantation genetic diagnosis (PGD) followed by embryo selection, or heterologous fertilization;[1]
4. natural conception followed by prenatal diagnosis (chorionic villus sampling or amniocentesis) and pregnancy termination in the case of a CF-affected fetus;[2]
5. natural conception, no PGD or termination, with the associated 25% risk of giving birth to a CF-affected child.

The data of Castellani et al. suggest that in a significant number of cases carrier couples avoided natural procreation (option 5). At the population level this resulted in a reduction in the incidence of CF.

4. Information and autonomy

The Padua Center made the test available to a larger segment of the population than the Verona Center. This had an impact on the incidence of CF. In many cases, accurate information affects decision making in a positive way. In general, when they have accurate information about how to satisfy their preferences, individuals are better able to act in ways that are more likely to get them what they want. Also, accurate information can make individuals more likely to make sensible decisions about what to want. But information is not always beneficial to the individual who receives it. Obviously, inaccurate and/or false information can be harmful, since it can mislead and induce a person to act in ways that are bad for her and for others. Was the information given to couples at the Padua Center sufficiently accurate? As said, the reliability of the genetic test used was not perfect. Despite that, if the couples were given not just the result but also an explanation of it, the information given was accurate.

Obviously, irrelevant information – even when accurate – does not benefit the individual. But even when accurate and relevant, information may not be beneficial. For example, it is possible to produce a negative effect on someone's decision-making abilities by providing too much information. Given standard decision-making abilities, informing individuals of their CF-carrier status cannot generate information overload. However, information overload is not the only way in which accurate and relevant information can have negative effects. When it concerns things that are extremely important to the individual, the acquisition of information can result in strong emotions, and such emotions can interfere with good decision making. Also, by acquiring information that is relevant to the pursuit of one's cherished projects, a person can discover that her cherished projects cannot in fact be pursued, that some of the

things she most values in life are not attainable. This may result in depression, which can have a paralyzing impact on decision making (Kitcher, 2001, ch. 12).

Genetic information about one's own and one's partner's carrier status can impinge on one's cherished project of having a healthy biologically related child. The couples that cherish this project can be divided in two groups: those who find abortion, IVF, PGD, etc. ethically objectionable and those who do not feel moral uneasiness with such procedures. Knowing about the 25% risk of begetting a CF-affected baby constitutes a problem for the pursuit of this project. When given this information, couples that find IVF, PGD and abortion morally unacceptable need to decide whether to accept the 25% risk or whether to abandon the project of having biologically related children. In contrast, couples that do not find the procedures mentioned above unacceptable can decide whether to accept the risk or whether to try to use biomedical procedures to bring a child into existence. There are also couples that find the use of IVF, PGD and abortion morally problematic though not necessarily morally unacceptable; these couples will have to decide whether the use of such procedures is justified in the presence of the risk of having a CF-affected child. In any case, knowledge of the existence of the risk may cause negative emotions. But there seem to be no reason for assuming that, in general, such emotions will impair decision making or will result in depression. People are often confronted with difficult decisions in medical and nonmedical contexts. The decision about whether to accept the 25% risk does not seem to be any more difficult than many other such decisions.

In the case at issue, we do not just have individuals who acquire information but also individuals and institutions that *give* information. One important issue is whether the Padua Center violated the prospective parents' autonomy by supplying them with information that is likely to have a significant impact on the prospective parents' choices. Giving information can

in some cases encroach on individual autonomy. A situation where carrier screening is mandatory for couples and couples cannot choose not to know the result would constitute an unacceptable infringement of autonomy. But obviously, this is not what happened at the Padua Center. The Padua Center made the test available at a nominal cost to all those who wanted it. No pressure was exercised on couples in order to induce them to take the test. All the information and the counseling provided were non-directive in nature.

A public health campaign influences decision-making according to the way it is organized. A mandatory screening program is more invasive than an opt-out program where individuals are automatically enrolled and can decline to participate by declaring that they do not wish to. In turn, ceteris paribus, an opt-out program is more intrusive than an opt-in program. The Padua program was an opt-in program. Moreover, couples interested in getting tested had to pay a nominal cost. This cost, however small, constitutes – just like the opt-in procedure – a small obstacle that couples have to overcome in order to get the test. Such small disincentives can be used to increase the probability that only those individuals that have thought about the implications of getting the test participate in the program.

It is clearly very important to avoid situations in which prospective parents ask for carrier screening as a result of prejudice, misconception, or undue pressure from health professionals or from others. Similarly, it is important that the decisions couples take on the basis of the test result are not due to prejudice, misconception, or undue pressure. This is why it is crucial that the counseling the couples receive both when they ask for the test and when they are communicated the result is genuinely non-directive. Genuine non-directiveness may not come automatically, and health programs should take appropriate measures in order to achieve it. But, as we shall argue below, there are good moral reasons for wanting to take the test and for

acting on the knowledge of the result. Not allowing couples to take the test means not allowing couples to act on these moral reasons.

5. Reproductive choices

Individuals have an interest in reproductive autonomy. They have an interest in being free to make important decisions concerning their reproductive activities, such as whether to reproduce or not, how many children to have, with whom to reproduce, when and where to reproduce, etc. Given the impact that reproductive matters have on a person's life and the importance that many attribute to such matters, the interest in reproductive freedom is an important and fundamental one, and thereby it needs special protection.

The extent to which reproductive freedom should be protected is controversial though. On an extreme view, reproductive autonomy should be unrestricted. Other views allow for the possibility that limitations on reproductive freedom may in some cases be justified. Some may want to argue that the use of technologies that allow prospective parents to decide *what kind of children* they are going to have should be forbidden. In the case at hand, one possible view is that technologies that allow couples to decide whether their children will be affected or unaffected by CF are morally unacceptable. An opposite view is that, when carrier screening is available, carrier couples would do something morally unacceptable in risking bringing to life a child with CF. But when are limitations on reproductive freedom warranted? An obvious thought is that, in order to determine whether an individual should be granted the right to make certain choices, it is important to know whether those choices can harm other individuals, and if so whether the nature and magnitude of the harm are such as to justify restrictions on freedom of choice.

Consider those carrier couples that give birth to a child affected by CF as a result of choosing natural procreation. Do these couples harm their child? It can be argued that they do not. The reason is the following: had the parents decided not to procreate naturally, that particular child would not have been born. This is an instance of what in the literature is known as the *non-identity problem*, and it occurs when the reproductive choice of the (prospective) parents determines the identity of the (future) child (Parfit, 1986/2003). The resulting child cannot legitimately complain that that reproductive choice of her parents made her worse off than she would otherwise have been, since it is not the case that had her parents chosen differently she would have been born CF-free. Had the parents chosen differently, she would not have existed at all. The parents might have had a CF-free child, but it would have been a *different* child. In a standard – i.e. comparative – sense of 'harm', the CF-affected child is not harmed by her parents' reproductive choice.

Had it been the case that a life with CF was a life not worth living, things would have been different. In that case, the CF-affected child could have legitimately complained that her parents' reproductive choice – which resulted in her coming to existence – harmed her, since for her non-existence would have been better (Buchanan et al, 2000: 241-242). The notion of a life not worth living is controversial. Not everyone agrees that the notion makes sense, and those who do often disagree on how the notion should be applied. But while it may be possible to apply this notion to genetic conditions like Tay-Sachs disease, there seem to be no good reasons for using it with reference to CF. Despite CF being a debilitating condition, CF-affected individuals nowadays have a relatively long life expectancy and their quality of life is not as low as to be plausibly deemed worse than non-existence.

Apart from the resulting child, does the choice of carrier couples to procreate naturally harm other individuals? One consequentialist consideration is that insofar as the costs of healthcare

are paid collectively – e.g. by the state – bringing to life an individual who will need costly healthcare increases the costs for all members of society and makes everyone worse off. Similarly, insofar as public resources for healthcare are scarce, bringing to life an individual who will need to make considerable use of such resources makes others worse off. Healthcare, and public healthcare in particular, is obviously extremely important. It plays a crucial role in the effort to alleviate human suffering and to ensure that individuals have a decent quality of life and that their opportunities are not impaired.[3]

These facts, while important, are not by themselves sufficient to argue that carrier couples who accept the risk to bring to life a CF-affected child are doing something morally wrong. We all do things that result in the imposition of risks and costs on others. Whenever an individual travels by car or plays sports, there is a risk that she may injure herself. That risk is not just a risk for the individual. It is a risk she imposes on others as well, especially to the extent that the costs of healthcare are shared and to the extent that healthcare resources are scarce. If she injures herself, other individuals will be worse off as a result. Despite this, it is normally thought that imposing risks and costs of this kind on others is in general morally permissible. But there are also cases where imposing risks and costs on others is not considered acceptable. So, for example, some may argue that if a person gets lost or injured while mountain hiking, and she did not bother getting the training and the equipment needed for pursuing this activity safely, the cost of the rescue service should be paid by her and not by society.

Is it morally acceptable for carrier couples to procreate naturally and, thereby, to impose risks and costs on society? This is a difficult question. How high are these costs? Are they high enough to justify the claim that these couples are doing something morally wrong in imposing them on others? According to one view, no matter how high are the risks and costs, the

reproductive domain – being some important to human beings – is one where individuals have absolute discretion. We find this view implausible. People's reproductive decisions – by definition – help shape the nature and composition of the society others will live in. Given this, the absolute-discretion view seems problematic. More plausibly, one can say that there should be a presumption in favor of the individual's discretion in this context and that such presumption can be withdrawn in cases where we realize that the choices of individuals can inflict significant harm on others.

Obviously, the magnitude of the risk and costs imposed on others is an important factor, but other factors are relevant too. If an individual imposes high risks and costs on others because of a whim, she is doing something morally wrong. But if the same high risks and costs are due to deeply held values, then – at least in some cases, depending on how those values have been reached – it may be possible to argue that imposing those risks and costs on others is not morally wrong, or at least not as morally wrong as it would have been had the risks and costs been due to a whim.

We believe that in the case of carrier couples the risks and costs imposed on society, especially in countries with a public health system, are high. This provides strong *prima facie* support for the claim that the decision to procreate naturally for these couples is morally wrong. We realize though that for some of these couples the decision not to procreate naturally may be a difficult one to take, and we concede that this is something that needs to be taken into account in the moral assessment of these couples' decision. Some options available to carrier couples – such as IVF and adoption – involve financial expenses that many of these couples may not be able to afford. Such options are not available to these couples and the couples cannot be morally wrong for not choosing them. Deciding not to have a child is financially unproblematic – at least in countries (like Italy) where contraception is relatively

cheap – but it may be psychologically problematic. Some people may have extremely strong desires to have children, desires that cannot be easily eliminated. Some people may even have strong *reasons* for wanting to have children, and this needs to be taken into account.

In countries (like Italy) where pregnancy termination is legal and can be obtained through the public health system, pregnancy termination is also financially not burdensome. But many people endorse moral beliefs that condemn pregnancy termination and would never be able to bring themselves to choose it. Similarly, many people morally disapprove of embryo selection and heterologous fertilization – including some of those who would be able to afford them – and would never be able to bring themselves to use these reproductive technologies. While we do not believe in the existence of strong moral arguments against pregnancy termination, embryo selection, and heterologous fertilization, we realize that many people believe these procedures are morally objectionable. People's strong feelings about these issues need, in some way, to be factored in.

These complexities are important, but the initial claim still stands: the risks and costs imposed on others by carrier couples that decide to procreate naturally are high enough to support – at least *prima facie* – the claim that what these couples are doing generates significant harm and is morally wrong. Notice, importantly, that saying that natural procreation is morally wrong for carrier couples is not in any way equivalent to saying that legal restrictions on the reproductive freedom of these couples are called for. There are cases where people should be left free to do what is morally wrong. These are often cases where restrictions on freedom, if implemented, would be more morally problematic than the morally wrong actions the restrictions are designed to avoid. Coercing carrier couples not to reproduce naturally – forcing them not to conceive, or to adopt, or to undergo IVF, or to terminate pregnancies –

would be so intrusive and so disrespectful of their autonomy as to be morally much worse than the option such coercion is aimed at eliminating.

If the choice of carrier couples to procreate naturally generates harm, it may be sensible to try to find morally acceptable ways of preventing or reducing the harm. As said, coercion would not be morally acceptable. But other means might be acceptable. It might be possible to identify legitimate, respectful, and non-intrusive ways of encouraging or incentivizing such couples to avoid natural procreation, i.e. to avoid doing what is morally wrong. What such ways might be is a complex issue that deserves careful analysis.[4]

6. Harm to the disabled

So far, we have only considered whether carrier couples' choice to procreate naturally causes harm. We also need to consider whether the choice to *avoid* natural procreation can cause harm, and if so what the nature and magnitude of the harm is. According to one view, carrier couples that intentionally avoid natural procreation in order to avoid the risk of having a CF-affected child wrongly harm existing and future CF-affected persons. On this view, such choice not to procreate naturally is morally wrong, and so are those health programs that allow and make it easier for – or, even worse, encourage – couples to make such a choice.

One way in which CF-affected persons could be harmed by carrier couples' decision to avoid natural procreation is the following. As shown by the Veneto study, these couples contribute to there being fewer CF-affected individuals. In a situation where there are fewer CF-affected individuals, public interest in this disorder may diminish. CF may become an *orphan disease*. As a result, the level of support for CF-affected individuals will decrease, and so will the funding for research aimed at improving the life quality of these individuals and at curing the disorder. CF-affected individuals will be worse off, and thereby harmed.

Even if what described in this scenario were to happen, it can be argued that the harm suffered by the CF-affected would not be such as to make couples' decision morally unacceptable, especially given the personal and societal reasons couples may have for avoiding having a CF-affected child. Having said that, we agree it is extremely important to make sure that support for the CF-affected does not diminish as a result of health programs like the one launched by the Padua Center. This obviously can be done, and in fact it may become easier to support CF-affected individuals and to fund CF-related research in a situation where the number of such individuals is smaller and the resources can divided among a smaller number of people.

Another way in which, allegedly, CF-affected individuals could be harmed by carrier couples' choice to avoid natural procreation in order to avoid having CF-affected children is the following. This choice is thought by some to express a negative value judgment on CF-affected people and, as such, to contribute to their stigmatization. Because of this, it is argued, the choice of these couples is morally unacceptable. Public health programs that allow and make it easier for couples to make such choice express the same judgment and, thereby, are to be condemned too. This is the so-called *expressivist objection* to genetic screening programs and to the kinds of choices that such programs make possible.

One reply is that, to the extent that the choice and the program express a negative value judgment, the judgment is on CF itself and not on CF-affected *individuals*, whether extant or future. Nonetheless, it may be difficult to disentangle CF and CF-affected individuals in the case at issue.[5] Insofar as carrier couples' choice to avoid natural procreation constitutes a form of CF prevention, it is a form of prevention that involves preventing the coming into existence of individuals of a specific kind, the CF-affected ones[6]. So, one could argue that in this case the negative value judgment is inevitably directed at the individuals themselves and not just at

the disorder. The choice to avoid having a CF-affected child as well as the health programs that facilitate such choice, on this view, express the judgment that CF-affected individuals – and not just CF – should not exist.

We agree that the choice to avoid having a CF-affected child expresses an evaluative judgment, but it is not one that devalues the CF-affected and ignores their moral status as human persons. The judgment expressed by such choice is this: a world with fewer new CF-affected individuals is a better world for everyone, including the CF-affected. It is a better world because, instead of new CF-affected persons, healthy individuals are born, so that more resources and more opportunities will be available, including resources and opportunities for the CF-affected. We realize that some CF-affected individuals may feel devalued and offended by the choice of prospective parents to avoid having a CF-affected child. Albeit ungrounded, these feelings are real and produce actual psychological uneasiness that should not be ignored. But, in the context of a variety of important interests that need to be balanced, this psychological uneasiness is not a good reason to stop trying to bring about a world with fewer cases of cystic fibrosis.

Respecting the moral status of CF-affected individuals is obviously a *sine qua non* of any acceptable health program. Also, stigma is often the greatest source of harm for people with disabilities, and so fighting stigmatization is mandatory. At a minimum, one needs to make sure that carrier couples' choice to avoid natural procreation is not due to prejudice, and – in case such prejudice exists – that health programs do not make such prejudice stronger. But respecting the moral status of CF-affected individuals and fighting stigmatization are not incompatible with carrier couples' choice to avoid natural procreation and thereby, a fortiori, with the health programs that make this choice possible.

7. Eugenics

Are health programs that – like the one of the Padua Center – make it possible for couples in general to know their carrier status for a particular genetic disease and to choose how to reproduce on the basis of this knowledge *eugenic programs*? If so, is this a reason to think that such programs are morally problematic? The answers to these questions depend on how one defines *eugenics* (Neri, 1998). If eugenics is simply the attempt to use genetic knowledge to reduce the incidence of certain traits, then eugenic efforts are not necessarily morally problematic. Traits like genetic disorders often impair opportunities, have in general a negative impact on the quality of life of those who have them, and can inflict harm on others and on society at large. Using genetics to reduce the incidence of such traits is a good thing.

Now suppose that in addition to the attempt to use genetic knowledge for reducing the incidence of undesirable traits, for a program to count as eugenic we require that this attempt involve preventing the existence of certain individuals. We saw in the previous section that preventing the spread of a condition by preventing the coming into existence of individuals with that condition is not necessarily wrong. Even on this way of understanding what eugenics is, eugenic efforts are not necessarily morally problematic.

Finally, suppose that in order to classify a program as eugenic we require (i) that it is an attempt to use genetic knowledge to reduce the incidence of undesired traits, (ii) that the reduction in incidence is supposed to be achieved through avoiding the coming into existence of certain individuals, and (iii) that such avoidance is achieved through murdering or illegitimately limiting the reproductive options of existing individuals, those that by reproducing would generate children with the undesired traits. On this understanding of eugenics, eugenic efforts are clearly morally unacceptable. Many eugenic programs in the

second half of the nineteenth century and the first half of the twentieth century were of this kind. And that is why the term ‘eugenics’ has such negative connotations nowadays.

We certainly need to make sure that the mistakes of the past are not repeated. Programs like the one launched by the Padua Center, obviously, do not satisfy part (iii) of this definition. Those who want to classify such programs as eugenic programs should decide: either they are using the term in a way that does not automatically imply moral wrongness, or their use of the term to refer to these programs is mistaken.

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[1] Both PGD and heterologous fertilization became illegal in Italy in 2004 (Law n. 40 of 19 February). Part of the law has recently been declared unconstitutional (Italian Constitutional Court, sentence no. 151/2009). With regards to the Veneto study, the couples that got a double positive result after 2004 could not decide to undergo PGD or heterologous fertilization in Italy, but the option of traveling abroad to access these services remained available.

[2] This is legal in Italy (Law n. 194 of 22 May 1978, article 6).

[3] It is also possible to argue that bringing to life individuals affected by a severe disability is bringing to life individuals whose opportunities will be impaired and who thereby will have fewer chances – on average – to enter into mutually beneficial relationships with other humans and to contribute positively to society. Benefits and contributions should *not* be thought only or primarily in financial terms. But the point still stands when one takes on a broader, and more relevant, understanding of benefits and contributions.

[4] Independently of the harm caused to other individuals, it is possible to argue that carrier couples have moral reasons to avoid natural procreation by using Parfit's *Q principle*: "If in either of two possible outcomes the same number of people would ever live, it would be worse if those who live are worse off, or have a lower quality of life, than those who would have lived" (Parfit 1986/2003:360) or some other non-person-affecting principle (Buchanan et al 2000: 249). Such principles do not require that any actual individual be made worse off – harmed, in the comparative sense. They only require that the quality of life of the CF-affected child resulting from the couple's choice to procreate naturally be lower than the quality of life of the CF-free child resulting from the couple's choice to avoid natural procreation. Whether such principles can be properly justified is a controversial matter.

[5] A measles vaccination campaign is designed to decrease the likelihood that the population will in the future contain measles-affected individuals. But it does not express a negative value judgment on individuals who are currently or will in the future be affected by measles. In the case of measles, though, the prevention of the disease does not involve an attempt to avoid the coming into existence of certain individuals. It only involves an attempt to prevent extant or future individuals from acquiring the condition. The case we are discussing is different.

[6] See what was said in section 5 about the identity-determining power of reproductive choices.