

Chapter 4

On Justice, Luck and Moral Responsibility Concerning Prenatal Genetic Diagnosis

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As the possibilities for significant and large-scale genetic interventions on human beings come closer to being actualized, we may be forced to expand radically our conception of the domain of justice by including natural as well as social assets among the goods whose distribution just institutions are supposed to regulate, to abandon the simple picture of justice being about distributing goods among individuals whose identities are given independently of the process of distribution, and to revise certain basic assumptions about the relationships between justice, human nature, and moral progress.

– Allen Buchanan, Dan Brock, Norman Daniels & Dan Wikler,
From Chance to Choice –

4.1 Introduction

Though many ethical reflections on genetics are of a speculative and futuristic kind, concentrating on techniques that “come *closer* to being actualized,” it is reasonable to say that in contemporary Western societies, at least one type of genetic intervention has *already* become widely actualised and well-established,

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viz. the framework of techniques of prenatal genetic diagnosis (PGD). Put shortly, these techniques make it possible to know in advance about the genetic condition and health status of the unborn child, thus making it possible either to prepare for the birth of a disabled child or to avoid this by aborting the foetus with congenital disorder.

By becoming common practice, these techniques indeed challenge the traditional conception of justice according to which *natural* inequalities among human beings are taken to be morally arbitrary, to be simply *given* facts that do not belong to the domain of justice (Rawls 1971, p. 102, 1999, p. 87). Put another way, they challenge the established idea that justice has to do with *agency*, with *directing* capacity, with things we can *control*, with a state of affairs that has either *resulted* from the actions of societies or individuals, or is at least capable of being *changed* by such actions. This conception of justice is convincingly expressed by David Miller's example of rain:

... though we generally regard rain as burdensome and sunshine as beneficial, a state of affairs in which half of [the country] is drenched by rain while the other half is bathed in sunshine cannot be discussed (except metaphorically) in terms of justice – unless we happen to believe that Divine intervention has caused this state of affairs, or that meteorologists could alter it. As long as a state of affairs is regarded simply as a product of natural causes, questions about its justice or injustice do not arise (Miller 1976, p. 18).

The challenge that techniques of PGD pose on this characterisation of justice resides in the fact that “the natural” no longer seems to be something that is simply “beyond our control.” They urge us to reconsider or at least refine the above definition of justice, since their existence makes it possible to say that “it is *unfair* to be born with lesser natural assets,” or “that it is an *injustice* to give birth to a handicapped child when you could have *prevented* it by genetic testing.” Arguments of this sort generally underlie claims of “wrongful birth” and “wrongful life.” In “wrongful birth,” the parents of a disabled child initiate a lawsuit, typically against a physician who is accused of not performing proper genetic screening or not adequately counselling prospective parents. The essence of wrongful birth is that the defendant's negligence resulted in the birth of a disabled child whom the parents would have aborted had they received adequate medical information. In “wrongful life,” the disabled child – or those acting on the child's behalf – sues for being alive. In the latter case, the parents may become defendants. In essence, the child claims that being born damaged him and that he should be compensated for his suffering and for extra financial costs, such as special education and medical care.

Claims of wrongful life and wrongful birth usually create general uneasiness in society, which results in much public debate, often of a heated and highly emotional kind. In this paper, I will sketch the philosophical background of this uneasiness in a threefold way. I will start with a short overview of some recent examples of wrongful birth and wrongful life (Sect. 4.2), followed by an analysis of the luck egalitarian approach to PGD (Sect. 4.3). Luck egalitarian theories of justice are very influential in contemporary political philosophy. They are essentially – though with internally differing interpretations – based on the distinction between choice and luck, in the sense that natural and social inequalities that are *involuntary* should be compensated for; inequalities that are the result of *choice*, however, should not. Using PGD as a

case, I will show that this distinction between choice and luck leads both to conceptual difficulties (in Sect. 4.4) and to moral problems (in Sect. 4.5). I argue that it is precisely these difficulties and problems that form the basis of the general indignation over claims of wrongful life and wrongful birth, when they come up in society. The case of PGD shows that the luck egalitarian approach fails to express equal respect for the individual choices of people, however diverse these choices may be.

4.2 About Nicola, Keeden, Chelsea and the Others...

Let me start with a quick look at some recent examples of wrongful birth and wrongful life cases. The most prominent cases are the French case of Nicolas Perruche, the Australian cases of Keeden Waller, Chelsea Edwards, and Alexia Harriton, the Dutch case of Kelly Molenaar, and the Belgian case of Rukiýé.

In November 2000, France's Supreme Court awarded damages to Nicolas Perruche, a 17-year old boy born with severe mental and physical disabilities, on the basis of wrongful life. His mother contracted rubella during the pregnancy and she argued that if doctors had correctly diagnosed the illness, she would have had an abortion. In 1992, the parents were already awarded damages on the basis of wrongful birth. The legal ruling of 2000, which established the "right not to be born" outraged the country and caused strong protests by disability communities, parents of people with disabilities, doctors, ethicists, theologians, and politicians. As a result, the French parliament has voted to overturn the legal ruling by stating that nobody can claim to have been harmed simply by being born. The law, which has come into effect on March 4, 2002, has thus brought an end to a year-long moral and legal controversy. Wrongful birth claims are still possible, but only on the grounds of a blatant error by doctors.

On June 13, 2002, a Supreme Court in Australia rejected the wrongful life cases of three disabled people. The first, IVF-baby Keeden Waller, 17 months at that time, inherited a blood-clotting disorder that screening could have detected. The second, Chelsea Edwards, 2, was born with a chromosome disorder after a failed vasectomy. The eldest, Alexia Harriton, 20 at that time, is blind, deaf, spastic and mentally retarded after her mother's rubella was not diagnosed during pregnancy. The central arguments of the judge were fourfold. (1) To recognise a duty to prevent the conception of these people, or to advise prospective parent's not to give birth to such children would be contrary to public policy. (2) Acceptance of such claims would pass over the precious nature of human life itself and the erosive effect that it would have upon the value to be accorded to human life. (3) Recognition of this class of claim would have a pervasive impact on the self-esteem of those born with disabilities and upon their perceived worthiness by other members of society. (4) In order to calculate the damages, it would be necessary to compare existence with non-existence, which is an impossible exercise.

Kelly Molenaar, 11 in 2005, was born with multiple mental and physical disabilities. She cannot walk, talk, or recognise her parents. She has deformed feet;

is believed to be in constant pain; and has had several heart operations. Like the cases of Nicolas Perruche and of the Australian girls, the parents of Kelly said that they would have had her aborted if they had known she would be disabled. On March 18, 2005, the Dutch Supreme Court awarded damages to Kelly Molenaar for having been born. Earlier, in 2000, the mother had been awarded damages on the basis of wrongful birth. Like in France, the legal ruling caused strong protests by disability communities, parents of people with disabilities, doctors, ethicists, theologians, and politicians, who are all urging the ministries of health and justice to take up the French example by voting a law to prohibit wrongful life claims. However, there is, as yet, no evidence of a parliamentary backlash such as arose in France.

In December 2010, the Court of Appeal ordered a Belgian hospital to pay €400,000 damages to the parents of Rukiyé. The girl had been born after a prenatal test, which was meant to show whether or not the foetus suffered from the hereditary metabolic disorder Sanfilippo. This disease leads to irreparable damage in tissue and organs and very limited life expectancy (Rukiyé became 10 years old). The parents of the girl had already had a child with Sanfilippo, which had died at the age of 12. As such, they knew they were carrier of the disease and had a significant chance for another child with Sanfilippo. They wanted PGD and an abortion in case of positive result, because they wanted to avoid a repetition of the experiences with their first child. The ultimate result of the test, however, was false-negative. The Hospital wants to lodge an appeal against the verdict by referring to technical flaws in the products that are being used in the tests (thereby referring to the responsibility of the firm that produces and delivers the tests). The verdict caused a public discussion, which was predominantly determined by the fear of over-legalisation of medicine, whereby a specific legal industry explicitly looks for medical flaws with a view to financial compensation. Another element in the discussion was the fact that PGD never provides 100% certainty. As such, the discussion was predominantly of a legal and scientific rather than ethical kind.

4.3 A Luck Egalitarian Viewpoint on Prenatal Genetic Diagnosis

According to the luck egalitarian view, which is a family of positions associated principally with the works of Ronald Dworkin, Gerald Cohen, Richard Arneson, John Roemer and more recently Shlomi Segall, a person should not be worse off than anyone else in respect of some given metric of goods, as a result of *brute bad luck*, i.e. as a result of factors over which agents have *no control*. The fundamental impulse behind luck egalitarianism is the urge to correct, to compensate for, or to neutralise, *involuntary* inequalities between individuals. Accordingly, when inequalities are not involuntary – i.e., when they can be attributed to factors over which agents have control – they do not trigger egalitarian concerns (Dworkin 1981a, 2000a;

Cohen 1989; Arneson 1989, 2011; Roemer 1993, 1995, 1996, 1998; Segall 2007a, b, 2010a, b, forthcoming).

A fundamental issue in the luck egalitarian doctrine is Ronald Dworkin's famous distinction between brute luck and option luck (Dworkin 1981a, pp. 293–298, 2000a, pp. 73–77). *Option luck* is the sort of luck we might have in gambling, whereby we willingly take a risk in the full knowledge of its possible consequences. *Brute luck* is a matter of how things turn out without being a deliberate gamble. It refers to a result one could not anticipate or did not choose to run. It happens to someone without being the result of choice. Dworkin argues that while option luck is consistent with egalitarian theory – after all, it is reasonable to hold people responsible for the consequences of their willingly undertaken actions – he does not think that brute luck is consistent with equality, simply because it is not a matter of deliberate choice. Accordingly, egalitarian theory requires inequalities that result from brute luck to be redressed, but it does not require redress in the case of option luck, provided that the individuals had the opportunity to insure themselves against losses.

According to Dworkin's view, the welfare state functions as a large insurance company, which insures its citizens against all forms of brute bad luck (Dworkin 1981a, pp. 283–302, 2000a, pp. 65–82). Taxes for redistributive purposes are the equivalents of insurance premiums and welfare payments compensate people against losses traceable to brute bad luck, just like insurance policies do. The state provides social insurance when private insurance is not available to all on equal and affordable terms. Where private insurance is available, brute luck is automatically converted into option luck, for society can hold individuals responsible for purchasing insurance on their own behalf. In its pure form, luck egalitarian theory would insist that if individuals imprudently fail to do so, no demand of justice requires society to bail them out. However, Dworkin makes room for paternalist additions to justify a mandatory insurance scheme, in order to avoid imprudent insurance choices as much as possible.

An important part of the appeal of the luck egalitarian approach comes from its apparently humanitarian impulse that no one should suffer from *undeserved* disadvantages and that those undeservingly disadvantaged by nature – i.e. for their genetic endowments – or by social circumstances – i.e. for who their parents are or where they were born – should be compensated for this. To many people it seems unfair that some have fewer opportunities as a result of factors over which they have no control, and because of circumstances that did not result from their choices.

Furthermore, much of its appeal comes from the fact that the luck egalitarian approach has been most responsive to criticisms of equality, entailing the idea that just inequalities between people exist, namely those that are due to individual differences in effort and responsibility. The luck-egalitarian approach is able to respond to the ancient question why, in the name of equality, the ant who chose to work hard should subsidise the grasshopper who chose to sing and laze away the day (de La Fontaine 1693). Because the luck egalitarian distinction between choice and luck incorporates the idea of individual effort and responsibility into our egalitarian concerns, it finds much support not only among many contemporary egalitarians, but

also among people's spontaneous intuitions about distributive justice (World Values Survey 2005–2008).¹

A third aspect of its appeal comes from its being responsive to a fundamental characteristic of our contemporary knowledge-societies, in which many previous uncertainties have been transformed into risks, that can be taken or not (Beck 1986, 1992; Giddens 1990, 1999). Today, we know much more than we used to know. On closer look, however, this is a dubious appeal. On the one hand, our increased knowledge is generally considered as a welcome gift. For instance, it improves the quality and effectiveness of social policy, since we know much more about the causal relations between various phenomena. On the other hand, however, there is reason to believe that this may turn into a poisoned gift, especially when we consider the various ways in which the transition from brute luck to option luck appears in many domains in which welfare payments are at stake, such as for instance in issues of unemployment (Rosanvallon 1995), or in discussions of life style and responsibility for one's own health condition (Dworkin 1981b; Schwartz 1995; Denier 2005, 2007) and also in discussions of responsibility for the health condition of one's children, as it happens in claims of wrongful life and wrongful birth.

The luck egalitarian background of the latter discussion is the following. Whereas the genetic constitution of our children has long been a matter of brute luck, i.e. the result of the natural lottery over which we did not have any control, widespread techniques of prenatal genetic diagnosis have given the impression that this has become less and less the case. More specifically, they have given questions about the morality of reproduction – What sorts of children should we be attempting to create? What sort of children is it permissible to create? (Savulescu 2001) – an urgency that they may have previously lacked. It is an urgency of the following kind: when people choose to have a child, and can easily find out what birth defects are possible, and how often they occur, one may say that they choose to gamble. Accordingly, giving birth to a child that will have a certain type of condition has become less, it seems, a matter of *chance* than of *choice*. Put in Dworkin's terms, it has become less, it seems, a matter of *brute luck* than of *option luck*. Or put another way, though being born with a congenital handicap or disease, may remain a matter of brute luck for the child, it has become a matter of option luck for the parents: they knew, or should have known the gamble they were taking in choosing to have children. This gives rise to a complex series of questions regarding preventability, responsibility, attributability, source and kind of compensation, et cetera.

We may wonder whether this is a good evolution. Below, I will argue that even though the luck egalitarian distinction between choice (controlled) and luck (beyond

¹In the fifth wave of the World Values Survey (2005–2008), carried out in 57 countries all over the world, 76.9% of the respondents (n=71,421) found the following situation fair: "Imagine two secretaries, of the same age, doing practically the same job. One finds out that the other earns considerably more than she does. The better paid secretary, however, is quicker, more efficient and more reliable at her job. In your opinion, is it fair or not fair that one secretary is paid more than the other?" World Values Survey is accessible online: www.worldvaluessurvey.org. I am grateful to Erik Schokkaert for pointing my attention to this.

control) is most appealing, it cannot overlap respectively with the distinction between fairness and fortune. Although we might spontaneously think that both distinctions coincide, the case of PGD shows otherwise. Even more, it shows that too great an emphasis on the aspect of choice and control in matters of justice, leads to results that go *against* the essence of justice.

4.4 Conceptual Difficulties

First of all, there are several conceptual difficulties underlying the luck egalitarian approach. They become clear when we apply the approach to the case of PGD. Below, I will address three such difficulties. The first refers to the content of the concepts of “nature” and “the natural”, the second arises from the distinct varieties of luck that come into play, and the third difficulty comes with the question which concept of responsibility we have to use.

4.4.1 *Nature and the Natural*

The first difficulty resides in the fact that the content of the concepts of “nature” and “natural inequalities,” understood as “being beyond human control”, evolves alongside technological and medical evolution. At first sight, this is nothing new. It is merely a statement saying that technological and medical progress equals increasing control over nature. The boundary between what we can control and what we cannot is not static (Bayertz 2003). What is particularly interesting, however, is that this causes a peculiar shift in our understanding of the relationship between nature and justice; a shift that has been designated by Buchanan et al. as “The colonization of the natural by the just” (Buchanan et al. 2000, pp. 82–84).

On the one hand, “nature,” or “the natural” is often thought to be not only that which is *given* but also that, which must be accepted as something that is beyond human control, as something that is a matter of brute luck. It concerns our natural endowments, as Dworkin would say. To say that something is “natural” is to subsume it under the category of fortune and misfortune, rather than of justice and injustice. It is not surprising that traditional thinking about justice has associated natural disadvantages with misfortune, rather than injustice, since there was little or nothing that could be *done* to *prevent* them. What could be done, on the other hand, was to *compensate* for natural inequalities in the distribution of *social* goods, by providing additional welfare payments, special education, subsidies for extra medical or social support services, et cetera.

However, if it becomes within our powers to achieve greater natural equality by controlling the distribution of *natural* goods, by intervening in the natural lottery by which genetic endowments have previously been distributed, it follows that natural inequalities are no longer fully *given* facts that are morally arbitrary.

Instead, they might become goods whose distribution just institutions are supposed to regulate. Or as Buchanan et al. put it, we bring “within the sphere of social control, and thereby within the domain of justice, what was previously regarded as the natural, and as merely a matter of good or ill fortune,” i.e. of good or bad luck (2000, p. 83). Paradoxically, we may say that nature brought within human control is no longer “nature.”

It is this shift that underlies claims of wrongful birth or wrongful life. For if it becomes within human power to *prevent* what we would regard as the misfortune of a congenital disorder or the tragedy of a genetically based degenerative disease, then we may no longer be able to regard it as a misfortune. Instead, we may come to view the person who suffers from these disabilities (in the case of wrongful life), or the parents who care for them (in the case of wrongful birth) as *victims of injustice*. As techniques of PGD make it possible to avoid a genetically based disadvantage by avoiding the birth of the individual who would have it, they may make it possible to say “that it is unfair to have been born with a congenital handicap” or “that it is an *injustice* to give birth to a handicapped child when you could have prevented it by genetic testing and selective abortion in the case of congenital disorder.” This line of reasoning underlies the concept of genetically responsible parenthood.

Two points can be made in response to this colonisation of the natural by the just. First, we encounter the problem of breakdown of the distinction between the subjects and objects of distributive justice, i.e. between persons and goods (Buchanan et al. 2000, p. 85). The basic problem of distributive justice, as it has always been conceived, is how goods ought to be distributed among persons when their *identities*, at least for purposes of justice, are *given*, independently of the distribution of goods. We think of justice as justice to given persons, whose natural endowments are beyond human control so that any resulting inequalities must be *compensated* for, rather than attacked directly by avoiding the birth of particular persons. But if it becomes possible to distribute the genetic bases of “natural” characteristics, including those that are constitutive of the identity of persons, then this fundamental assumption – of subjects receiving objects through an allocative mechanism – will no longer be applicable. Instead of asking what kinds of compensation we are indebted to people with lesser endowments, the main question becomes: what kinds of people are we allowed or even obliged to create? (Savulescu 2001) The special oddity of this problem of breakdown of the distinction between the subjects and objects of distributive justice becomes clear in the case of wrongful life claims and the related non-identity problem, to which I will come back below in Sect. 4.4.2.3.

The second point has to do with the relationship between justice and control. If a theory of justice is to be more than a mere utopian ideal, control, understood as directing capacity and capability to change the situation, is indeed a *necessary* condition for justice. Conversely, however, it is essential to bear in mind that not *everything* we can control is a matter of justice or injustice. As such, control is a *necessary* but not a *sufficient* condition for justice. We need further refinement of our conception of control as related to distributive justice and to the primary goal of

just institutions. Since there are many things we can control that do not belong to the domain of justice, the mere distinction between control and luck is not enough to determine the demands of justice. In this regard, it is necessary to determine *which* goods we can control are so important that they belong to the realm of justice. I will come back to this in Sect. 4.5.4. For now, it is sufficient to say that with this line of reasoning, we are moving away from taking the traditional distinction between fortune and justice, natural and social goods, luck and control, chance and choice, as a sufficient basis for determining society's distributive duties.

4.4.2 Varieties of Luck

The second conceptual difficulty follows from the first. The continuous alteration of the content of the concept of the *natural* implies that the related concept of *luck* also needs to be refined. After all, techniques of genetic testing and engineering, such as PGD, undermine the assumption that the results of the natural lottery depend on *mere* luck, and therefore escape our moral responsibility.

At first sight, this does not seem to pose much problems for the luck egalitarian approach since it has already introduced a fundamental refinement of the concept of luck in the discussion by its distinction between *brute luck* and *option luck*, i.e. between the kinds of luck that are involved in situations that are beyond our choice and control and the kinds of luck that are involved in gambling whereby we willingly take a risk in the full knowledge of its various possible consequences.

On closer look, however, it turns out that this distinction does not bring much clarity in the discussion about justice and the morality of reproduction. As Susan Hurley puts it, luck is a treacherous and curious concept, which ramifies into a *wide variety* of conceptions of luck, which very often may cut *across* moral responsibility (Hurley 2001, pp. 79–80, 2003, pp. 106–107). The case of PGD provides a very good example of this. This becomes most clear when we ask what *kinds* of luck are involved in cases of PGD, and *whose* luck we are talking about.

Let us take up the last question first: whose luck is involved in cases of PGD? This question derives its relevance from the fact that we normally only speak of something being a matter of luck, good or bad, if it is relevant to someone's interests in some way. As such, luck is identity-dependent (Hurley 2001, pp. 86–88, 2003, pp. 118–120). It is always luck *for someone*. Even more, there must be someone whose identity is *constant* between the various alternatives that would count as good or bad luck, in order for these alternatives to count as good or bad luck *for that someone*. Related to this, luck can be good or bad, involving benefit or harm. Consequently, we can speak of identity-dependent benefit or harm when it is benefit or harm *to someone*. Important, in a second instance, is that this constant identity, this *someone* in question, need not actually be a human person. It could also be an animal for instance, or a society, or a company, or a group of people. Nevertheless, it must be an entity treated as having a *constant identity* across the alternative ways in which luck may befall.

Applied to the case of PGD, it is relevant to distinguish three kinds of interests, which should be taken into account in questions about the morality of reproduction. Firstly, there are the direct personal interests, which are the interests of the child that will – or presumably, will not – be born. Secondly, there are the indirect personal interests, which are the interests of the child's parents and family affected by his existence – or non-existence. And thirdly, there are the general, impersonal interests of the society in which the child will – or will not – be born. By taking a closer look at the various ways in which these interests – i.e., *whose* luck we are talking about – can take form, the various *kinds* of luck come in the forefront more clearly.

4.4.2.1 Society

Let us start with the interests of society. Although we are initially inclined to think that a society's interests in questions about the morality of reproduction are very indirect and impersonal, maybe even non-existing, they are nevertheless highly influential because social institutions and the way in which they are organised shape the general framework and social climate in which people generally tend to think and feel about responsible parenthood. As such, they may influence people's reproductive decisions. For instance, if a society would give dominant priority to *economic and productive interests*, the profit motive may provide the basis for a climate in which avoiding the birth of severely disabled people is generally considered to be preferable because their existence could be seen as a drain on social resources. From such a one-sided economic viewpoint, the society may have an interest in interpreting the birth of a congenitally handicapped child no longer as a matter of *brute luck*, which requires social compensation, but rather as a matter of *option luck* for the parents. By stressing the point that once people try to get pregnant, they deliberately choose to gamble. If consequently, they refuse PGD and abortion in the case of handicap, their life with a handicapped is the result of their conscious and deliberate choice, for which they have to bear the consequences themselves. This kind of reasoning would relieve society of bearing the extra costs of congenitally handicapped life (like compensation in the form of welfare payments, subsidies for special care, special education, supporting material like wheelchairs, etc.).

This leads us into a dynamics in which PGD becomes an instrument intended for the sole end of either avoiding the extra costs that come with congenitally disabled life completely, or shifting the responsibility for the extra costs of care for the disabled child fully to the prospective parents. Within such a climate, the social pressure on the prospective parents to undergo PGD and avoid giving birth to a congenitally disabled child may be very high. On the other hand, however, the just society has important *moral interests* as well, including issues of humanity, of moral sensitivity, and of providing the social bases of equal respect. It is reasonable to say that the degree of moral refinement and justice of a particular society is reflected in the way in which it shows equal respect to everyone, i.e. *also* to the congenitally handicapped. The basic expression of this equal respect is to show, on a public level of society, that they are just as welcome in the world, and deserve to be treated with

the same respect as everyone else, by providing the care and support that is needed for them to live their lives with dignity.

4.4.2.2 Parents

A second category of interests is that of the indirect personal interests of the parents. This category contains important *emotional interests*, which may come into conflict in the case of PGD. On the one hand, there is the prospective parents' wish to have children. On the other hand, there is the parents' fundamental concern for the quality of their child's life, which may be very low in certain cases of severe handicap. Additionally, there are interests concerning the *family's strength and capacity* (emotionally and mentally, as well as practically and financially) to care for the disabled child in a sufficient and respectful way. Furthermore, there are important *moral interests* involved. Within the context of PGD, the prospective parents may come to face a choice, i.e. whether or not to terminate the pregnancy of a handicapped child. By providing this choice, it is reasonable to say that techniques of prenatal genetic diagnosis have converted the former brute luck-situation of giving birth to a congenitally handicapped child into an option luck-situation involving choice.² However, the nature of choice varies according to the moral beliefs of the prospective parents. For some people, the decision to terminate the pregnancy may be a logical consequence of PGD and the right thing to do, whereas for others it creates a huge moral dilemma in which the right choice is not clear at all. For yet a third category of prospective parents it cannot even be rightfully said to be a matter of option luck, since for them there *is* no option: abortion is out of the question in any case. Nevertheless, with PGD, choice returns in yet another form. For choosing not to choose is also a choice, and thus an option. For instance, if the prospective parents consciously decide *not* to undergo PGD, and therefore willingly *choose* to take part in the natural lottery that determines the child's constitution, the result may still be said to be a matter of *option luck* for the parents.

Be that as it may, however, in order to clarify the important differences in the nature of choice one needs to bring in these differences in moral beliefs. The *mere* distinction between chance and choice, or more specified, between brute luck and option luck is not sufficient. Paradoxically enough, it seems that an important feature

² Here, I am expressly assuming that the situation of giving birth to a congenitally handicapped child *before* techniques of PDG became common practice indeed *was* a brute luck situation in the following sense. In previous times, before the sexual revolution of the 1960s, people gave birth to children on the rhythm of nature. As for the amount of children, or their health status, there was little to nothing that could be done to control it (except for fully abstaining from sexual activity). It was, much more than today, a matter of nature's course. Today, however, we can decide on much in these matters: whether or not to have children, when we want to have them, and whether or not we want the fetus to be tested for congenital disorder, and whether or not to continue the pregnancy in case of a congenital disorder. All this has become, much more than before, a matter of choice (see also van Tongeren 1995).

of people's lives is not covered by the luck egalitarian distinction, and that is the fact of reasonable pluralism³: people differ in their opinions about the good life, in their moral convictions and in their interpretations of luck. What counts as option luck for one person may not be thought of in the same way by another person. The same goes for the interpretation of good or bad luck. What counts as good or bad luck for one person, is not necessarily so for the other.

4.4.2.3 Child

Finally, we need to take a third category of interests into account, that is, the direct personal interests of the child. Although techniques of PGD may be said to convert a brute luck-situation into a situation of option luck *for the parents*, this does not change anything *for the child*. For him, his constitution remains a matter of *brute luck*, i.e. of *constitutive luck* understood as *lack of control of the causes* of who and what he is, of the causes of his native endowments and capacities (Nagel 1979, p. 28; Hurley 2001, p. 82, 2003, pp. 111–112). For the child, his constitution is the result of the way the natural lottery turns out *for him*, something that is beyond his control. Nevertheless, in taking the child's interests into account, the primary concern is that of the child's quality of life. In limiting cases, this concern comes down to the question whether it is possible to say that someone has been (or will be) born with a life that is so miserable that it is not worth living; that it is of no benefit to him. The combination of the possibility of PGD with such quality judgements forms the basis of claims of wrongful life (from the perspective of the child) and wrongful birth (from the perspective of the parents).

Two points can be made in response to this. Firstly, claims of wrongful life meet the non-identity problem (Parfit 1984, pp. 351–379). This problem originates from the identity-dependence of luck, and more specifically of lottery luck. Lottery luck requires that there is an agent whose luck is in question and whose identity is *constant* across the different possible results of the lottery (Hurley 2003, pp. 118–123). This condition is not fulfilled in the case of wrongful life, since here, the alternative is that that the person in question would not have existed at all. This creates a rather peculiar conception of “worth” or “benefit” *for that person*. From the statement that life is of no benefit to someone, it does not automatically follow that non-existence

³ With this, I refer to John Rawls's concept of *Reasonable Pluralism*, as an inherent feature of all modern democratic societies. It entails the recognition that citizens endorse different, often incompatible, comprehensive doctrines, that is, a pluralism of religious, philosophical, or moral world-views, which include “conceptions of what is of value in human life, and ideals of personal character, as well as ideals of friendship and of familial and associational relationships, and much else that is to inform our conduct, and in the limit to our life as a whole.” (Rawls 1996, p. 13). Many of these comprehensive and incompatible doctrines are endorsed by citizens who are “reasonable” in the sense that they recognize that there are limits to what can be justified to others and “will think it unreasonable to use political power, should they possess it, to repress comprehensive views that are not unreasonable, though different from their own.” (Rawls 1996, p. 60).

would have been better *for him*, since there would *be* no *him*, whose interests would be better served. Susan Hurley denotes this problem as the “bare self illusion” (Hurley 2001, pp. 88–90, 2003, pp. 120–123). Claims of wrongful life presuppose a pre-entity, a proto self, or bare self, who might have existed as me, or who might have existed as someone else, whose good or bad luck it is to have one or another identity, to have one or another constitution. But this does not apply here. It is not a question of a person being either such or such. On the contrary, it comes down to Hamlet’s question: “To be or not to be?”

Secondly, wrongful birth claims are based on the fact that parents would have terminated the pregnancy had they known in advance that their child would be disabled. Mostly, such a claim is directed against a physician who is being accused of not having given the parents the *option* to abort. Therefore, they claim that they should be compensated for the unwanted extra burdens (financial, material, emotional...) that come with having to take care for a disabled child, which is a child that would not have been born, had the parents have had the choice. This creates a situation in which a person is *explicitly* and *publicly* judged by the parents to have an inferior and burdensome constitution, something that is for the child itself a matter of constitutive luck, i.e. something he did not cause and cannot change. This is an astonishingly strange situation, presupposing a very peculiar expression of parental love. How can the interests of the child be served well if it is the parents’ message that the child would never have been born, had they had the choice? Among the worst problems that disabled people must confront are the condescending attitudes of many other people (Anderson 1999; Feder Kittay 1999; Glover 2001; Nussbaum 2004). A society that supports claims of wrongful life and wrongful birth, risks to reinforce those attitudes and to equality of respect for all human beings. As explained in Sect. 4.2, this has been the basic reasoning of the Australian Supreme Court in rejecting the wrongful life cases of Waller, Edwards and Harrington.

4.4.3 Responsibility?

The distinction between brute luck and option luck implies that people are responsible for the results of bad option luck. Applied to the case of PGD, this may lead to the conclusion that the prospective parents or, in some cases, the negligent physicians, are responsible for the extra costs that come with the life of a congenitally disabled child. From this, the third conceptual difficulty underlying the luck egalitarian approach can be deduced. Which conception of responsibility is adequate here? Let us concentrate on two conceptions that are relevant in this case.⁴

⁴ For this I am much indebted to Kurt Devooght. See his *Essays on Responsibility-Sensitive Egalitarianism and the Measurement of Income Inequality* (non-published Ph.D., KU Leuven, Faculty of Business and Economics), Leuven, 2003, esp. ch. 1, pp. 7–36 for an extensive and detailed analysis of various conceptions of responsibility.

4.4.3.1 Backward-Looking Responsibility: The Forfeiture View

The mainstream view on responsibility – with which the luck egalitarian approach agrees – holds that people are responsible for what they have chosen voluntarily. Responsibility as voluntariness assigns liability for the results of one’s own choices made knowingly, consciously, and freely (i.e. what I *want* to do, taking into account internal convictions). Closely related to this view is the conception of responsibility as control (which refers to what I am *able* to do – taking into account external limitations). According to this conception, inequalities due to factors within a person’s control are equitable. The basis of the mainstream view is the distinction between fortune or luck, on the one hand, and free will or control on the other hand. One can only be held responsible for what stems from free will or what one could control. As Thomas Scanlon puts it: “... a person to whom a certain outcome was available, but who knowingly passed it up, cannot complain about not having it” (Scanlon 1988, p. 193). If, on the other hand, fortune or luck determines the situation, people cannot be held responsible and should even be indemnified for the bad consequences; i.e. they are in a situation of brute bad luck.

Another important distinction that is relevant in this regard is the distinction between *actual* responsibility and *moral* responsibility, i.e. respectively between *being* responsible (in the causal chain of events) and *being held* responsible (which is possible even if a direct causal link is absent). If a theory assumes that these two variants of responsibility coincide with each other – as the luck egalitarian approach does – three problems crop up.

The first is the metaphysical problem of free will and control. If choice and control are the criteria for assessing responsibility and if the question of *moral* responsibility implies having to answer the question of *actual* responsibility, we have to be sure that people’s choices are *truly* voluntary, that they are freely and consciously made, and that they truly are within their control, i.e. that they could have done otherwise, but that they freely and consciously decided not to. This assumption shows great confidence in the free, voluntary and independent character of individual choice making. However, in view of the physical, psychological, social and economic determinants of preference formation – as shown by Jon Elster’s arguments of the contented slave and of the sour grapes (Elster 1982, 1989) – and therefore in view of the related metaphysical question of how free the free will *really* is and how much is *truly* within our control, the problem of distributive justice and responsibility no longer seems to be solved by the mere distinction between chance and choice, between luck and control.

Related to this is the problem of infinite regression. Responsibility as voluntariness and as control are both *regressive* conceptions of responsibility. In this regard, Susan Hurley has pointed at the problem that comes with Thomas Nagel’s regressive control conception of responsibility, which implies that in order to be responsible for something, one must also be responsible for its causes. According to this conception, responsibility requires control all the way back the chain of causes. Indeed, this makes *actual* responsibility impossible because human actions, thoughts and decisions are always, in one way or another, related to a

variety of events and factors beyond one's control (Nagel 1979, p. 35; Hurley 2001, pp. 80–84, 2003, pp. 109–114). Applied to the case of PGD, a regressive conception of responsibility may give rise to the following question: Who is responsible for the child's genetic constitution? Initially, one might say that it is caused by the genetic constitution of the parents. But it seems hardly right to speak of responsibility here, since there is an essential element of constitutive luck or brute luck in having genes for certain talents or for certain diseases, both for the parents themselves regarding their own genetic constitution, and for the child regarding his constitution. Nevertheless, claims of wrongful birth and wrongful life show that when a congenitally disabled child is born, the possibility of PGD may generate a chain of regress of the following buck passing kind: the child sues the parents (because they did not make use of the necessary genetic screening) or the physician (because he did not offer it to the parents, or wrongly interpreted the results) for being born; or the parents sue the physician, or the hospital, for negligence in prenatal care; the physician or hospital, in turn, might sue the producer of the genetic tests or the distributor of the medical equipment in case it was due to faultiness on their behalf, et cetera.

The idea of genetically responsible parenthood conceives of responsibility in this same regressive, backward-looking spirit. Furthermore, it is a conception of responsibility with a negative bias to it. In this regard, we may reasonably refer to Aristotle's conception of corrective justice (*Nicomachean Ethics*, V in Aristotle (2000)). Something went wrong and has to be corrected for. The situation has to be rectified by punishing the guilty party and by compensating the party that is the victim. The punished party has to pay a *forfeit* of a certain kind. However, the problem of the negative bias is less of a conceptual than of a moral kind and I will come back to this in Sect. 4.5 below. For now, suffice to say that by using the forfeiture view on responsibility in issues of distributive justice, we risk mistaking distributive justice for corrective justice. It is, however, important to bear in mind that these are quite distinct types of justice.

4.4.3.2 Forward-Looking Responsibility: Attributability

An alternative way of interpreting responsibility is, what I would like to call, the progressive, or forward-looking way. This perspective sheds a different light on the distinction between *actual* responsibility and *moral* responsibility. For next to the question of responsibility for the birth of a handicapped child, the question of responsible parenthood also refers to issues as meeting the child's needs in surroundings characterised by love, care, respect, et cetera. From this perspective, PGD receives a different significance. Instead of being merely an instrument for avoiding the birth of a handicapped child, it may also become an important instrument, which helps people to prepare (psychologically, emotionally, but also practically) for the birth of a child with a certain disorder and for the very specific forms of care that their child will need in order to lead a good life, however confined that life may seem to be.

A different conception of responsibility enters the stage here. It is a conception of a non-metaphysical and non-regressive kind, and is defended, among others, by Thomas Scanlon. Scanlon rejects, what he calls, the *forfeiture* view because it puts too much weight into the hands of choice:

[The Forfeiture View] exaggerates the importance of the fact of choice relative to that of the [social] conditions under which the choice was made. The Forfeiture View suggests that these conditions are important only insofar as they bear on the voluntariness of the choice. This is a mistake. The fact that a choice was voluntary does not always establish that we ‘did enough’ for an agent by placing him or her in the position from which the choice was made. Nor does the fact that an agent did not voluntarily choose an outcome, or choose to take a certain risk, establish that what resulted was not his fault (Scanlon 1988, p. 196).

Scanlon’s view is known as ‘responsibility by delegation’ or as ‘responsibility as attributability.’ According to this view neither control, nor voluntariness are the criteria for the assessment of responsibility. On the contrary, we are responsible because we are given the opportunity to choose by the society who has made sufficient efforts to provide the necessary conditions for us to make decisions, the outcomes of which we are ourselves responsible for. Whether we have made our choices voluntarily is unimportant. Whether we have control over our decisions is equally unimportant. The real issue is whether *society* provides the *necessary social conditions* for people to make responsible decisions. This means that responsibility is not to be traced back to metaphysical assumptions on how free the free will really is, but is simply assigned, or attributed, by society.

Why is this viewpoint forward-looking? Because instead of focusing on the regressive question of responsibility, searching for the guilty party (as happens in claims of wrongful birth or life), one now looks at society’s role in providing the *framework* in which people – in our case, the prospective parents, possibly in deliberation with the physician – can make responsible choices with regard to their own future according to their own conception of the good life. Scanlon’s conception of responsibility shows the importance of reflecting on the role of *society* in fulfilling the conditions for people to make free and responsible choices according to their own conception of the good. Applied to the case of PGD, this implies that *society* has a moral responsibility in providing for appropriate social support (such as providing for caring institutions, special education, financial and material support) of people with special needs (which are not only the cared-for, but also their family members and other care-takers). Only then, one can say that prospective parents can truly make a free and responsible choice in the context of PGD. Only then, the choice to whether or not give birth to a disabled child is not reduced to the question: “Can I afford this?”

In the following and final section, I will focus on the relation between social and personal responsibility in matters of PGD by examining the social conditions for technological progress to be moral progress as well. Or put another way, by examining the conditions that have to be fulfilled for issues of PGD to meet the requirements of social justice.

4.5 Technological Progress – Moral Progress?

Let us now focus on the moral problems, which found the public debate that comes with claims of wrongful life and wrongful birth. These moral problems are all aspects of one and the same movement, *viz.* of the transition from the natural jungle to the social jungle.

As I have mentioned before, the boundary between the natural and the social, and between the realm of fortune and of justice, is not static. Moreover, what we have long taken to be *moral progress* has often consisted in pushing back the frontiers of the natural; in bringing within the sphere of social control, and thereby within the domain of justice, what was previously regarded as ‘the natural.’ As such, compensation for arbitrary natural inequalities is a matter of human and moral progress. It is a way of countering the capriciousness and harshness of the natural jungle. And this is also, as we have seen, one of the main appeals of the luck egalitarian approach, which advocates that the fundamental aim of egalitarian theory is to compensate people for undeserved bad luck, such as being born with poor native endowments within a poor social environment, and suffering from brute accidents and illnesses.

The flipside of this idea is that people should bear the costs of chosen or preventable inequalities themselves. However, by making personal choice central, we run the risk of replacing the natural jungle by a *social jungle*, in which people could be stigmatised and even marginalised by society as a result of individual choice. The problem is that this social jungle might be just as harsh and merciless as the natural jungle. In her influential article ‘What’s the Point of Equality?’, Elisabeth Anderson analyses the various ways in which the luck egalitarian approach runs this risk (Anderson 1999). By focusing on correcting a supposed cosmic injustice, Anderson argues, luck egalitarian theory has lost sight of the distinctively political aims of egalitarianism. The essence of the argument is that the luck egalitarian approach or equality of fortune, as she also calls it, fails “the most fundamental test every egalitarian theory must meet: that its principles express equal respect and concern for all citizens” (Anderson 1999, p. 289). Below, I will address four main arguments illustrating the above-mentioned stigmatisation and marginalisation by using the case of PGD.

4.5.1 Abandonment Objection

The first problem is that of exclusion of the imprudent, which comes down to the fact that hard-core luck egalitarianism may treat the victims of bad option luck most harshly for once people risk and lose due to bad option luck they have no claims on others to help them (Anderson 1999; Segall 2007a, b, 2010a). They become excluded from the realm of social compensation and support. Anderson calls this the problem of lack of a safety net, which is only there either for the victims of brute bad luck or for those who prudently decided to prevent such fates by purchasing private insurance,

but not for the so-called “imprudent”. The essence of the problem is that an egalitarian approach that

guarantees equality only *ex ante*, before adults start making choices for themselves, and makes no provision for people *after* that, will in fact generate substantial inequalities in people’s fates as they lead their lives to the point where the worst off might be extremely badly off (Anderson 1999, p. 300).

Applied to the case of PGD, and the possibility it creates of understanding parenthood of a congenitally disabled child as a question of bad option luck, the position of the parent as a willingly and consciously chosen dependent caretaker becomes very vulnerable. As John Roemer says, explaining Arneson’s and Cohen’s position:

Society should not compensate for their choice of [a more altruistic, self-sacrificing] path because it owes people no compensation on account of their moral views (Roemer 1996, p. 270).

This assimilates the performance of moral obligations to care for the disabled child to the class of *voluntary expensive tastes* for which people are supposed to take full individual responsibility.

The same idea seems to be included in Dworkin’s view of the welfare state as a large insurance company (Dworkin 1981a, pp. 283–302, 2000a, pp. 65–82). Dworkin argues that basic insurance (for welfare, health care, and unemployment schemes) should be provided for everyone, and it must be financed out of income taxation or some other compulsory insurance at a fixed premium. The insurance coverage and the level of the premium can be computed, Dworkin argues, by modelling a *hypothetical* insurance market in which insurance is offered to everyone on the basis of community rating, that is, based on the question how much coverage the average member of the community would purchase. As such, the hypothetical insurance mechanism would function as a theoretical guide with which we can determine the real-time issues for which we are collectively, if not, then personally responsible. The point of the hypothetical insurance principle is that if *most* prudent people would buy a certain level of coverage in a free market if they had average means then the fairness or unfairness of our real time society can be measured according to the amount of people that do not have such coverage now. On the other hand, if very *few* people would want to buy insurance covering a much higher level of coverage it would be unjust to force everyone to have such insurance through a mandatory scheme. There are of course exceptions to the insurance principle: some people have special preferences and would make decisions different from those of most others. It seems fair however, Dworkin argues, to construct a mandatory coverage scheme on the basis of assumptions about what *all* but a small number of people would consider appropriate, allowing those few who would be willing to spend more on special insurance to do so, if they can afford it, through supplementary private insurance (Dworkin 2000a, p. 315, endnote 10, p. 492).

This is a very reasonable argumentation. However, against the background of our problem in hand, we must be cautious and raise the following question: what happens if the majority of the average community members would terminate the pregnancy in case of certain handicapping conditions of the foetus? This is a reasonable question, since surveys show that, in the case of children with Down’s syndrome,

about 80% would want the pregnancy terminated when asked hypothetically, and over 90% in such cases chooses to terminate in reality (Glover 2001, pp. 429–444; Christiaens and Kloosterman 1997, pp. 52–61; Vamos et al. 1997, pp. 7–13). Given these facts, what does it imply with regard to the *hypothetical* insurance mechanism as it is meant to be a guide to determine the issues for which we are collectively, if not, then personally responsible? Two possibilities remain.

The first is that we interpret giving birth to a congenitally disabled child as a matter of option luck. Together with the fact that most people would terminate the pregnancy, it would be unjust then to force everyone through a mandatory scheme to share in the extra costs that come with caring for the congenitally disabled child. Accordingly, the parents of the child lose every form of *social* protection and support, and are left to purchase additional *private* insurance. It is doubtful, however, whether it would be possible to purchase private insurance in such cases. One may reasonably doubt whether such cases are insurable at all on the private market.⁵

If we want to avoid such forms of exclusion, we could move over to the other possibility, which contains that we “on average” consider purchasing insurance for protection and support in the case of giving birth to a congenitally disabled child as a prudent thing to do, thus making it part of our *collective* responsibility. In this case, however, the scope of solidarity is not determined by the mere distinction between choice and luck or between brute luck and option luck, but by other arguments to which I will come back in Sect. 4.5.4. The essence of these other arguments is that some things are basic entitlements for every human being, i.e., they are just *too important* for human functioning to allow exclusion. This point is also being stressed by Shlomi Segall (2007a, 2010a) who develops a luck egalitarian approach that wants to escape the abandonment objection and justify universal and unconditional health care.

4.5.2 Problem of Paternalism

The second problem follows on the first. I have mentioned before that the luck egalitarian approach makes room for the imprudent to be entitled to special paternalistic

⁵ Insurance is a form of risk management, primarily used to hedge against the risk of a contingent loss. Insurance is defined as the equitable transfer of the risk of a loss, from one entity to another, in exchange for a premium, and can be thought of as a guaranteed small loss to prevent a large, possibly devastating loss. A crucial element in insurance is *uncertainty* about the *probability* of the loss. If the likelihood of the insured event is high, and the cost of the event is known to be large, the premium to be paid will be high as well. Furthermore, the event that constitutes the trigger of a claim should be *fortuitous*, or at least outside the control of the beneficiary of the insurance. The loss should be ‘pure’ in the sense that it results from factors we don’t control. Otherwise, the events are generally not considered insurable. Congenital handicaps are problematic in these respects since techniques of PGD make it possible to *know* in advance about the genetic condition and health status of the unborn child and to *avoid* the birth of a handicapped child by aborting the handicapped foetus. Furthermore, the costs that come with the birth of a handicapped child – life-long support of special needs – may be so high that the premium to be paid becomes unaffordable or even useless, or insurance companies may simply deny coverage on grounds of the fact that the insurance does not involve an unpredictable risk, but a given fact.

protection by society against their poor choices (Arneson 1989, p. 239; Dworkin 1981a, pp. 293–295, 2000a, pp. 74–77). As Anderson puts it: paternalism is the only way to escape the problem of lack of safety net (Anderson 1999, p. 289). But whereas she gives the impression that paternalism is a problem *tout court*, I believe it is necessary to make a distinction between legitimate and illegitimate forms of paternalism. In this regard it is illuminating to recapitulate Nussbaum's threefold answer against an oversimplified critique of paternalism (Nussbaum 2000, pp. 51–60).

Firstly, Nussbaum argues that not *all* forms of paternalism are illegitimate. For if paternalism means telling people that they cannot behave in some way that they want to behave, then any system of law and any bill of rights is paternalistic with respect to certain inhuman practices that treat people with insufficient or unequal respect. It is clear that this is hardly a good argument against the rule of law, or, more generally, against opposing the attempts of some people to tyrannise over others. We dislike paternalism because we like each person's liberty of choice in fundamental matters. Therefore, it is fully consistent to reject some forms of paternalism while supporting those forms that are liberty-supporting.

Next, we should note that liberty has *material preconditions*. Liberty is not just a matter of having rights on paper, it requires being in a position to *exercise* those rights. And this requires material and institutional resources, including legal and social acceptance of claims. A state that is going to *guarantee* people rights *effectively*, is going to have to take a stand about more than the importance of these basic rights themselves. It will have to take a stand on the distribution of resources to guarantee citizens what John Rawls has called the "fair value" of the various liberties – for example by raising revenue through taxation in sufficient quantity to make education and health care available to all. Such redistributive measures are paternalistic, meaning interference with activities that some people choose. The question is, is this acceptable or not? It is when it is meant to create forms of *empowerment* that are crucial to making liberties *truly* available to people.

And finally, Nussbaum argues, there is the *principle of each person as end*. If we agree that citizens are worthy of equal respect, and grant that they live their own lives, we ought to conclude that politics should treat each of them as ends, as sources of agency and worth in their own right, with their own plans to make and their own lives to live, therefore as deserving of all necessary *support* for their equal opportunity to be such agents. To do this implies that we have to take a stand on some fundamental values that will be made central for political purposes, and *against* some ways of treating persons disrespectfully. However, taking a stand in this way should not raise the charge of illegitimate paternalism, since we do so in order to treat *each* person as an end and permit *all* citizens to search for the good in their own ways.

Against this threefold argument of liberty-supporting paternalism, the material preconditions of liberty, and respect for persons as ends in themselves, it is reasonable to ask whether the luck egalitarian protection of the imprudent against poor choices is a legitimate form of paternalism. In order to answer this question we must ask, in a luck egalitarian spirit: what is a prudent decision in the case of PGD? Or put inversely: who are the imprudent? What exactly is a poor choice? Within the

spirit of the distinction between brute luck and option luck, it is reasonable to believe that it is the choice *not* to undergo PGD. Or as Dworkin puts it:

Suppose it were possible to correct serious genetic defects of different kinds in embryos, for example, either through genetic engineering or through more conventional forms of therapy. Then the principle of special responsibility [i.e., every person is individually responsible for the success of his own life] would no longer justify allowing a pregnant woman to *refuse* tests to discover such a defect in an embryo she carries, and the first principle of ethical humanism – an objective concern that any life, once begun, be a successful one – would counsel *mandatory testing*. It is true that modern democracies share a visceral distaste for requiring anyone to submit to a medical procedure to which she objects, particularly when the objection is founded, as an objection to genetic testing and the treatment that follows might well be founded, on religious conviction. The flat principle of bodily integrity may, however, be one of those artefacts of conventional morality that seemed well justified *before* the possibilities suggested by modern genetic medicine were plausibly imagined, but *not after*. If we are to accept a more fundamental principle of concern for the lives of everyone, that principle of bodily integrity may one day have to be qualified (Dworkin 2000b, p. 450, *my addition, my italics*).

This quotation perfectly illustrates the way in which the possibility of achieving control over our children's genetic structure undermines our most basic assumptions about the boundary between what we are responsible for choosing and what lies beyond our control because it is fixed by nature. Our genetic identity – who we and our children are – has long been a paradigm of nature's responsibility and not ours, and a substantial shift of that determination to the sphere of our own responsibility destabilizes much of our conventional morality. What can we reasonably say about this?

I agree with Dworkin that we must take up the challenge of improving our understanding of what happens here rather than to turn back from it. However, I strongly believe that the only legitimate way to do this would be to take up this challenge but *without* putting social pressure on the prospective parents to undergo PGD, that is, to make testing mandatory. This is the risk we take if we subsume procreative decisions under the category of option luck. The same goes for the idea of genetically responsible parenthood and for cases of wrongful life. These can hardly be called cases of legitimate paternalism, since the latter is meant to *create* space for choice and liberty, to provide the material preconditions for making free choices, and all this with respect for *each* person as an end, permitting *all* citizens to search for the good *in their own ways*.⁶

⁶ In this context, it is necessary to reflect on the distinction between two ways in which the previously mentioned idea of constitutive luck appears, that is in the *natural* and in the *social* way, and their respective implications in matters of social justice. Both natural endowments (having genes for certain talents) and the social conditions (the social environment) in which individuals were born are given facts, things that are bestowed on them. They did not cause them, nor can they change them, and both are integral or essential to people's constitution or self-identity. Why then, are corrections of social conditions (like eradicating poverty, compensating for racial or gender discrimination in the past) necessary measures to be taken by every just society, whereas correcting natural conditions (like avoiding congenital handicaps on a large-scale social level) is problematic? What's the difference? Two things can be said by way of reply. Firstly, it is important to point at the fact that measures like eradicating poverty or compensating for discrimination intend to *support* people by eradicating social obstructions to their possibilities to lead a good life. These obstructions are generally seen as bad social circumstances. This is not necessarily the case for

Again, we must bear in mind that the content of what is imprudent and what it is that makes a particular choice a poor choice is a matter in which everything depends on the *individual* case, and on the individual beliefs of who decides. There is a relevant pluralism of conceptions of the good that strangely enough, does not seem to be backed up by the luck egalitarian approach. Or as Anderson puts it:

Equality of fortune, in attempting to ensure that people take responsibility for their choices, makes demeaning and intrusive judgements of people's capacities to exercise responsibility and effectively *dictates* to them the *appropriate* uses of their freedom (Anderson 1999, p. 289, my italics).

4.5.3 *A Social Signal of Hierarchy*

The third problem is related to the already mentioned problem of the condescending attitude towards handicapped life that is reflected in claims of wrongful life and wrongful birth (cf. supra, Sect. 4.4.2.3). These claims express the idea that their life is actually not worth living. Put sharply, such claims send the message that people are products that can be rejected if quality control failed. In such cases, and especially against the background of a regressive conception of responsibility, someone is to blame.

Consequently, another group of people also becomes stigmatised, that is, the prospective parents who choose imprudently. Either, they have to be protected by society against their poor choices, or they lose all form of social compensation and support. On the one hand, however, we have seen that, in the case of PGD, it is far from clear to judge objectively what a poor or prudent choice is without meeting the problem of illegitimate paternalism. On the other hand, they meet the problem of exclusion for the lack of an adequate safety net for victims of bad option luck deprives them of the claim for social support.

As such, we come to a society of two groups of people. On the one hand, we have the good and prudent, who act responsibly. They are 'the insiders,' so to say. On the other hand, there are the imprudent, who either have to be protected against their

measures like eradicating congenital handicaps. It is much less clear that mandatory testing can be said to support people in leading a good life, since many people do not see congenitally handicaps, such as Down syndrome, for instance, as bad circumstances, necessarily to be avoided by collective measures. Secondly, the flip side of this first argument is the following: a given natural or social fact can become a blessing or a burden by the way in which societies and social institutions deal with them. The basis of corrections of social conditions (like avoiding discrimination on the basis of social class, race, gender or sexual preference) has been the idea of equality of respect. The idea of correcting natural conditions (by preventing the birth of congenitally handicapped people) does not start from equality of respect. On the contrary, it implies discrimination on the basis of handicap. Instead of collectively preventing handicapped people to be born by making testing mandatory, a just and respectable social policy should compensate for it by providing the necessary social support for these people to lead a good life.

poor choices, or else are left outside the realm of social compensation and support, becoming marginalized, an inferior group.

Contrary to this, I believe that if the primary subject of social justice has to do with providing basic institutional arrangements that generate people's opportunities over time; and with providing the social conditions of freedom and *equal* respect; with assuring that *all* citizens have the means to develop and exercise their capacities as citizens; while guaranteeing them the freedom to pursue their own conception of the good life, provided that they comply with the principles of justice, Thomas Scanlon is right in saying that the luck egalitarian forfeiture view: "exaggerates the importance of the fact of *choice* relative to that of the [*social*] *conditions* under which the choice was made" (Scanlon 1988, p. 196, my italics). The just society should not make a social signal of hierarchy about its citizens. This has been illustrated by the many and heated social reactions against the legal ruling in France (cf. Sect. 4.2).

4.5.4 *The Scope of Solidarity*

If we decide to make choice central in determining the demands of justice, we risk creating a society in which solidarity only means solidarity with the good and prudent. As such, claims of justice generate endless questions of regressive responsibility, voluntary choice and blameworthiness in order to decide who are the good and prudent and who are not. With this, we have done nothing more but to replace the natural jungle by the social jungle.⁷ Within such a climate, certain groups of people, like for instance dependent caregivers, become very vulnerable. For one could say

⁷One might consider whether replacing the natural jungle with the social jungle does not constitute progress, albeit incomplete progress toward a goal of increased justice. Two points are important to bear in mind in this regard. The first is based on the idea of moral arbitrariness and refers to what we consider as being relevant or irrelevant in matters of justice. In *A Theory of Justice* John Rawls writes: "The natural distribution is neither just nor unjust [...]. These are simply natural facts. What is just and unjust is the way that institutions deal with these facts" (Rawls 1971, p. 102, 1999, p. 87). Here, Rawls refers to the fact that natural differences (such as race, gender, sexual preference, ...) can be reinforced or mitigated by social policy. Bear in mind the fact that in previous times, being black or being a woman implied that one was less worthy, and that homosexuality was a disease, necessarily to be cured. This brings me to the second point. The answer to the question whether replacing the natural jungle with the social jungle does not constitute progress, is that it all depends on what is being reinforced or mitigated, to what extent, and in which respects. We condemn gender or race discrimination because the principle of equal respect demands that social barriers to equal treatment are being removed (*negative action*) rather than being reinforced. On the other hand, though, it is sometimes necessary that certain *positive actions* are being taken in order for people to be able to participate in social life on an equal basis (such as the provision of ramps in buildings or wheelchair access in busses, etc.). The essence of the argument is the following: in dealing with natural differences, social institutions have to promote and preserve equality of respect. Only then, one can speak of progress toward the goal of justice. When speaking of the natural jungle, I refer to the opposite, *viz.* to the fact of socially reinforcing inequality of respect.

that it has been their own choice to do this. By taking this path, we risk creating an atomistic society. Or as Anderson puts it:

People who want to avoid the vulnerabilities that attend dependent caretaking must therefore decide to care only for themselves. This is egalitarianism for *egoists* alone. One wonders how children and the infirm are to be cared for, with a system that offers so little protection to their caretakers against poverty and domination (Anderson 1999, p. 300).

Contrary to this, it is reasonable to say that the scope of solidarity cannot be determined by choice, option, regressive responsibility and blameworthiness. Rather, it should be determined by our common humanity and the things that are necessary for every human being in order to lead a good life. This means that we have to concentrate on those things that are so *important* for every human being's opportunities in life that they become *entitlements* of citizens based upon justice (such as the right to life, education, health care, the right to vote, being part of the political community, etc.).⁸ With this, we enter a domain that is just too important to allow exclusion. As Martha Nussbaum argues, when any one of these entitlements is abridged this is an especially grave failure of the socio-political system. The abridgement is then not just a huge cost to be borne, but also a cost of a special kind, involving a violation of basic justice (Nussbaum 2001, 2003). In the same line of reasoning, Thomas Scanlon loosens the connection between equality and responsibility by arguing that it depends on the *objective value* of the equalisandum whether inequalities are just or unjust. Preferences and tastes are excluded from the distribution problem, not because people can be held responsible for them, but because they are less *urgent*. That people can be held responsible for their preferences should only mean that they can do *without* them. They are not necessities and thus lose their urgency. Responsibility for preferences is in itself not a reason for rejecting claims; it is at most a sign of their not being very urgent. The degree of urgency depends on the *objective value* of the claim, not on the subjective stress one can lay on it (Scanlon 1975, 1986, 1988).

⁸ With this, we touch upon the rights and freedoms, as laid down in the Universal Declaration of Human Rights, especially article 1, "All human beings are born free and equal in dignity and rights", article 3 "Everyone has the right to life, liberty and security of person", article 22 "Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality", article 25 "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control", article 26 "Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms." We also touch upon the list of Central Human Capabilities, which are the central elements of truly human functioning, as formulated by Martha Nussbaum (2003). For an extensive discussion of the capabilities, and their function within just health care, see also Denier (2007).

Interestingly, Shlomi Segall has stressed in his luck egalitarian approach, that luck egalitarianism can only escape the abandonment objection if it is *complemented* with *other* moral considerations like those of meeting basic needs. This means that the solution cannot be found from *within* luck egalitarianism, but has to be found in a basic needs theory that provides a universal and unconditional, non-exclusive layer of sufficientarian concern for meeting everybody's basic needs regardless of their antecedent health-related conduct or choices (Segall 2007a, 2010a).

So, if we want to avoid a situation in which legal rulings such as wrongful life and wrongful birth are the *only* possibility for people to receive the funds that are necessary to cover the extra costs that come with caring for disabled life, the scope of solidarity cannot be determined by the mere distinction between choice and luck. On the contrary, justice and solidarity have to do with a *forward-looking* policy of inclusion. A policy of inclusion is based on the idea that justice does not permit the abandonment of *anyone*, not even the imprudent, in matters of *objective, intrinsic importance*. In this line of reasoning, Elisabeth Anderson rightly argues that consistent egalitarian theory should *identify* certain types of goods to which *all* citizens must have effective access over the course of their whole lives, because they are more important from an egalitarian point of view than others (Anderson 1999, pp. 316, 327). A policy is forward-looking when it has to do with providing a 'fallback framework' that contributes to *all* persons' receiving a fair chance in life, that is, a safety net below which *no one* would be allowed to fall. Because of this, it would be unfair to cut off fair equality of opportunity in the *future* because of *past* choices. Although it sounds paradoxical, holding people responsible for their ends means that in assuming the presence of fair and just arrangements and institutions, we are acting as if they can exercise their underlying moral power to *form, pursue*, and possibly to *revise* their own conceptions of the good and valuable. Or as Norman Daniels has put it: "I think Cohen misses the mark. It is not actual choice that matters but *the underlying capacity for forming and revising one's ends* that is at issue" (1996, p. 222).

Taking it all together, the argumentation with regard to the scope of solidarity is threefold.

4.5.4.1 Freedom of Choice Presupposes a Real Range of Options

People are indeed responsible for the consequences of their freely made choices. However, in order for a choice to be free, the range of actual alternatives has to be sufficiently broad. This means that certain choices have to be supported by society. Otherwise, these choices will be *de facto* impossible. Nowadays, for instance, people can choose to have children, they can choose to undergo PGD, and they can choose to terminate the pregnancy in the case of congenital disorder. Within a just society, it should also be possible to choose otherwise, i.e., not to undergo PGD, and to keep and raise a handicapped child. Equal respect for both alternative choices, presupposes that society provides sufficient support also for people who choose to keep the handicapped baby. Otherwise, this alternative is not a real option.

4.5.4.2 Not All Options Have to Be Supported by Society

The second point of the argument refers to the question why society has to support the life and care for people with a congenital handicap? Because the choices that people have to make in the case of PGD do not involve superficial things like having to choose between chocolate or vanilla ice cream. Neither does it involve an expensive champagne taste. On the contrary, the choice to have children, even when they have a handicap, is of a *fundamental* and *existential* nature. It determines the lives of the prospective parents in a fundamental and significant way. This requires respect and support by society. The necessity of support by society also goes for having healthy children, as the saying ‘It takes a village to raise a child...’ aptly expresses.

4.5.4.3 Not Infinitely

The third point of the argument refers to the question whether these options have to be funded *infinitely* by the public for a society to be just? Does it involve limitless support in all possible ways? No it does not. It involves the support that is necessary for people to have a fair chance in life. The just society guarantees fair equality of opportunity in life for all. This implies that some people – like the handicapped – need more support than others in order to actually have a fair chance in life (like special education, supportive material like a wheelchair for instance, or a special telephone for the deaf, etc.) and that society has to make a special effort to create a culture of respect for people with a handicap (by providing adapted entrances to public buildings, by stimulating job creation for people with a handicap, etc.), thus supporting their participation in public and social life. In essence, these forms of social support (in education, in supportive care, in job creation) are the same for everyone, for they refer to things that people need in order to have a fair chance in life. For people with a handicap, it involves just more of an effort to realize this. But all in all, it refers to the basic things (education, care, a job) that constitute a person’s well-being and that people need in order to have a fair chance in life.

Within this general framework, I argue that the only legitimate value that can be attached to PGD is that it serves as an instrument that prospective parents may or may not use, in all freedom, in accordance with their own capacities and their own conceptions of the good life. No one, in this regard, should be forced to undergo prenatal genetic testing, or otherwise, be excluded from the realm of social support. Or put differently, if our solidarity becomes reduced to solidarity with the “prudent” only, then it seems that legal claims of wrongful birth and wrongful life are the only possibility left to get the necessary funds to cover the extra costs that come with caring for congenitally disabled life. Or one should be rich enough to cover the costs privately.

4.6 Conclusion

In this paper I have explicitly chosen not to concentrate on the prevailing and typical problems that are usually tackled in ethical reflections on issues of wrongful birth and wrongful life – such as harm, identity, degree of disability, playing God-arguments, eugenics, etc. On the other hand, it has been my aim to concentrate on the *principles of justice* that should guide our social dealings with issues of PGD, wrongful birth and wrongful life; and more specifically, to analyze the influential *luck egalitarian* view on such issues.

It is true that the crucial boundary between chance and choice is the spine of our ethics and morality, and that any serious shift is thoroughly dislocating. As was already suggested by the opening quotation, it asks us to rethink certain basic assumptions about the relationships between justice, human nature, and moral progress. Perhaps the most important conclusion of my analysis is that if we want technological progress in genetic medicine to be moral progress, then it is the responsibility of the just society to make sure that it is guided by principles of justice, which above all, serve the *equal freedom* of all its citizens. The case of PGD shows that the luck egalitarian approach cannot vouch for this.

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