

# Seven ways of making people better

In this chapter, I introduce the practical themes examined in the book. After some preliminary remarks concerning the challenges that nature and scientific developments produce, I describe the topics of the subsequent chapters and identify, one by one, the main ethical questions to which they give rise.<sup>1</sup>

## 1.1 The genetic challenge

Humankind is challenged in its pursuit of happiness and wellbeing by three intertwined forces. The first is nonhuman nature. The natural environment sets limits and conditions to our actions, and we have for millennia created strategies to adapt to and to overcome these. On many occasions, our attempts to control nature have resulted in further problems, which have had to be dealt with separately. The second force is human nature in its psychological and social forms. We live, of necessity, in communities and wider societies, and to ensure their smooth operation we have devised a variety of political rules and arrangements. The systems produced have often generated unwanted friction and strife, which have had to be settled with new or additional procedures. The third force to be reckoned with is human nature in its biological sense. We are vulnerable to illness, injury, and death, and to counteract and postpone these we have established many kinds of healing and caring professions. Since their practices have sometimes been seen as futile or detrimental, ways have had to be found to regulate and reorganise them.

<sup>1</sup> Note: the page referencing system followed in the footnotes is designed to indicate whether I am referring to a whole chapter from a book or a journal article or to specific page(s) within a book or journal article. In references related to books, when I am referring to a whole chapter, the page range is preceded by a colon and when I am referring to specific page(s), the page range is preceded by 'pp.' (or 'p.'). In the case of journal articles, when I refer to specific page(s), the full page range is followed by the specific page numbers (e.g. 99–100, p. 97). All the websites referred to in this book were accessed on 15 May 2009.

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Matti Häyry

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The *genetic challenge*, as I understand the notion in this book, is a set of questions raised by the engineering, political, and medical solutions to the original threats posed by nonhuman and human nature. By ‘engineering’ solutions I mean our responses to natural obstacles; and by ‘political’ and ‘medical’ I refer to our attempts to control our own psychological, social, and physical shortcomings. The genetic challenge, like many other tests to humanity, arises when we cannot readily agree on what our reactions should be and on what grounds.

Our search for therapeutic and preventive measures against morbidity and mortality, combined with scientific knowledge and political aspirations, have led many to believe that a radical upgrade can and should be made to the human constitution to improve the lot of the race. Philosophers and scientists have throughout Western history argued that humanity could be made better by careful procreative planning and selection.<sup>2</sup> The birth of modern genetics in the 1950s and subsequent advances in molecular biology, reproductive medicine, and related subjects have taken this idea to new levels. Children’s inborn characteristics can be detected by prenatal and preimplantation tests; the molecular processes of the human body can be studied and modified; and changes can be introduced to our inherited and heritable features either individually or collectively. Some of these developments are not, strictly speaking, genetic. They have, however, been initiated and shaped by the scientific evolution which started with the discovery of the double helix structure of deoxyribonucleic acid (DNA).<sup>3</sup> As DNA is the basic element of genetics, it is fitting to group the questions under the common heading ‘genetic challenge’.

The subtitle of this book, *Making People Better?*, has many different meanings. We can make individuals healthier by preventing their illnesses and injuries, and by curing, treating, and caring for them when such maladies occur. These are tasks assumed by medicine, nursing, and health-care, including public health activities. We can try to improve the health of nations by population-level reproductive programmes. Eugenic movements, past and present, have attempted to do this by selecting either who

<sup>2</sup> I have traced the development of this idea from Plato and Aristotle through the philosophical movements of the eighteenth and nineteenth centuries to the eugenic programmes of the turn of the twentieth century in my article: Matti Häyry, 2008, ‘The historical idea of a better race’, *Studies in Ethics, Law, and Technology* 2, Article 11 – [www.bepress.com/selt/vol2/iss1/art11](http://www.bepress.com/selt/vol2/iss1/art11).

<sup>3</sup> See, e.g. *The Francis Crick Papers* – <http://profiles.nlm.nih.gov/SC/Views/Exhibit/narrative/doublehelix.html>. The original finding was reported in James Watson and Francis Crick, 1953, ‘Molecular structure of nucleic acids – a structure for deoxyribose nucleic acid’, *Nature* 171: 737–8.

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should or who should not have children, or both.<sup>4</sup> We can help parents in their attempts to have healthier babies by allowing genetic tests, embryo selection, and abortions by choice. This alternative has been made possible by advances in the life sciences. And we can make people's lives better by increasing their material wellbeing or promoting compassion and justice in our dealings with each other. Communities and societies can take on this mission by education and political endeavours.

This book deals with seven ways of making people better. These do not include education, population-wide eugenics, or political undertakings; rather, they are all related to genetics and medicine at a more individual level. The headings under which the topics will be treated, first briefly in Sections 1.2, 1.3, 1.4, 1.5, 1.6, 1.7, and 1.8 below and then more fully in Chapters 3, 4, 5, 6, 7, 8, and 9, are:

- the best babies;
- deaf embryos;
- saviour siblings;
- reproductive cloning;
- embryonic stem cell research;
- gene therapies; and
- considerable life extension.

I will explain, in this chapter, the practices I see falling under these seven headings; how I think that they are linked to making people better; and what philosophical questions I can see arising from them for my closer analysis in Chapters 3, 4, 5, 6, 7, 8, and 9.

## 1.2 The best babies

Under the first heading, the question of making people better is approached from the angle of 'making better *people*', or more accurately, of letting only individuals who are considered good come into existence. The science behind this is that genetic testing allows us to find out many things about potential individuals before they are conceived, born, or implanted. Tests on prospective parents can indicate certain or probable health conditions; prenatal tests during pregnancy are used to reveal undesired mutations; and in the context of in vitro fertilisation (IVF), preimplantation embryos

<sup>4</sup> Good descriptions of these can be found in Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler, 2000, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press).

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can be tested for many inherited and congenital qualities. Public health services offer some of these tests routinely, whereas many more are gradually becoming available through commercial channels. Parents can determine or preclude certain qualities and conditions, and increase or decrease the probability of others, by selecting their offspring on the basis of the test results. But should they, and if they should, in which cases and to what extent? And should we, as a society, permit, and even encourage, them to do so?<sup>5</sup>

The arguments *for* the option of reproductive testing are easy to state. Scientists should, in the name of free thought and speech, be allowed to develop the techniques and to publicise them. Laboratories and clinics should, in the name of free enterprise, be permitted to market the tests. Parental autonomy demands that potential mothers and fathers can purchase or otherwise acquire information about the essential physical qualities of their children, if this is pragmatically possible. Parental responsibility may even require that they ought to have this information to ensure their children the best possible lives. The condoned existence of reproductive tests will satisfy our scientific curiosity, uphold market freedom, support procreative self-determination, and, in due course, serve the children's best interests and provide societies with healthy, efficient citizens.

The duties of parents towards their children have been intensely debated in recent bioethical and related discussions. One view is that when people contemplate having offspring, they should try their best to have the healthiest, strongest, and most intelligent progeny they can. If this can be achieved by picking the right reproductive partner or by making lifestyle adjustments, these options should presumably be pursued. More to the point here, however, is the obligation to genetically test one's potential children at their embryonic or fetal stages and to select for subsequent existence only those who can be expected to have the best lives. According to this notion, reproducers fail to honour their parental responsibilities if they do not make full use of the knowledge provided by genetic testing.<sup>6</sup> Another view is that people should aim at a reasonable

<sup>5</sup> An additional question here is *who* forms the society making these judgements? I have presented some preliminary remarks on this in Matti Häyry, 2009c, 'Is transferred parental responsibility legitimately enforceable?', in Frida Simonstein (ed.), *Reprogen-Ethics and the Future of Gender* (Dordrecht: Springer): 135–49.

<sup>6</sup> Julian Savulescu, 2001, 'Procreative beneficence: why we should select the best children', *Bioethics* 15: 413–16; cf. Matti Häyry, 2004a, 'If you must make babies, then at least make the best babies you can?', *Human Fertility* 7: 105–12.

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prospect of a good life for future individuals. This means that embryos and fetuses must not be chosen if their test results predict excruciating diseases or severely incapacitating disabilities. Parents should not, however, be prevented from or pressurised against having children with adverse but more manageable conditions. They may have society's permission to avoid this, too, but they do not have an obligation to do so.<sup>7</sup> Yet another view states that people should not pay any attention to genetic tests. Once aspiring parents have made clear their commitment to having offspring, they should simply take what nature gives them and love their children unconditionally, whatever their physical qualities or health conditions.<sup>8</sup>

Arguments *against* reproductive testing are based on moral principles and psychological concerns. The existence of the technology and the availability of the services confront parents with the initial question, which is whether to test or not to test. Positive results, that is, results showing that the condition or mutation scanned for is present, pose the further challenge of a decision between forsaking a life and accepting a different and possibly difficult parenthood. Critics of genetic tests argue that neither choice is free or uncoerced. If attitudes towards acquiring the information are favourable, social pressures make it almost impossible to take the path of ignorance. An example is provided by the test for Down's syndrome, which is routinely available in many countries, socially accepted, and seldom rejected in the cases in which it is medically indicated. Likewise, if popular opinion favours a particular image of health and normality, positive test results for deviations from this during pregnancy tend to lead to abortions.

Selective abortions and the selective destruction of embryos can be seen as morally problematic from the complementary viewpoints of dignity, solidarity, and precaution.<sup>9</sup> *Dignity*, or life's sanctity, is violated when human lives are ended for whatever reason. Justified punishment, warfare, and self-defence are possible exceptions, but they have nothing

<sup>7</sup> Laura Purdy, 1995, 'Loving future people', Joan Callahan (ed.), *Reproduction, Ethics and the Law* (Bloomington, IN: Indiana University Press): 300–27; Michael Freeman, 1997, *The Moral Status of Children: Essays on the Rights of Children* (The Hague: Kluwer Law International); Peter Herissone-Kelly, 2006a, 'Procreative beneficence and the prospective parent', *Journal of Medical Ethics* 32: 166–9.

<sup>8</sup> Simo Vehmas, 2002, 'Is it wrong to deliberately conceive or give birth to a child with mental retardation?', *Journal of Medicine and Philosophy* 27: 47–63; Michael J. Sandel, 2007, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Cambridge, MA: The Belknap Press of Harvard University Press), pp. 45, 86.

<sup>9</sup> Matti Häyry, 2003a, 'European values in bioethics: why, what, and how to be used?', *Theoretical Medicine and Bioethics* 24: 199–214.

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to do with prenatal decisions. *Solidarity* is questioned when some people are treated differently from others, based on their physical characteristics. Selection means that individuals with undesired conditions and qualities are not allowed to be born. While this may not have an effect on them, since they do not and will not exist, it will influence others who currently live with the same conditions and qualities. They will feel unwanted to the extent determined by their own self-image and by other people's attitudes and actions. *Precaution*, in its turn, requires us to be alert to future risks that are caused by our present actions and policies. Even if selection could be, in theory, condoned in some mutually recognised cases, it is not wise to open, in practice, the door for similar-looking but more sinister activities. Testing for intolerable diseases can lead, indirectly and inconspicuously, to testing for eye colour or something equally frivolous.<sup>10</sup> According to these lines of argument, the best babies are the babies people have and care for, as they should as responsible parents.

In Chapter 3, I will study these and related views in more detail, trying to identify their shared and conflicting premises and the implications of this mix to moral judgements and legislative decisions.

### 1.3 Deaf embryos

In discussions on reproductive genetic testing, the default value has been that its purpose is to prevent the birth of individuals who would be physically or mentally ill or disabled. Many philosophers and ethicists have argued that any children who are brought into existence should have at least a decent chance of living a fulfilling and relatively independent life, without major bodily or intellectual impediments that could jeopardise the achievement of this goal. The argument is reasonable in the light of current ethical theories and also in line with most established population policies and healthcare practices. Recently, however, the tests have been put to another use which seems to contradict the original aim. Parents who themselves have a particular condition, most notably individuals who are congenitally deaf, have used genetic selection or preimplantation tests in attempts to produce

<sup>10</sup> The objection based on precaution takes here the form of a 'slippery slope' argument, where initially good things are suspected to lead to atrocities in other fields or in the future. This is frequent in the genetic context, because the primary intention of interventions is in most cases to do good, although the ensuing practices can raise new questions.

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children who would be similar to them.<sup>11</sup> Is this a case of making people better or worse? Should these attempts be somehow regulated or discouraged?

Traditional moral doctrines can be easily geared towards banning or discouraging practices like the selection of gamete donors or embryos to create a deaf baby. Virtue theories evoke an imagery of human flourishing which, if given an individual-oriented slant, advocates health, independence, and ability to function in society without special aids or arrangements. Deontological theories emphasise unhampered reason as the basis of morality, and seem to be fundamentally opposed to choices that could deprive a future individual of a good instrument of intellectual communication and growth. Consequentialist views stress happiness and wellbeing, as well as the absence of suffering and woe, so if deafness is the source of any unpleasantness, there seems to be a case against it. Alternative interpretations can be given to the three theories, and the assessments can then be different, but these are the surface readings that are reflected in, or reflect, contemporary policies on selecting against impending deafness.

A natural defence for selecting donors and embryos to have deaf babies is offered by the ideas of free choice and parental autonomy, already used in the justification of more widely approved types of genetic testing. Scientists should be allowed to develop the tests, laboratories ought to be permitted to make them commercially available, and people planning to reproduce cannot be denied the benefits of the technology just because their intentions are not shared by all others. After all, the aims of the currently condoned tests are not universally approved either, but the inviolability of family life is seen as a sufficient justification for them. Advocates of tests against disease and disability may want to claim that their goals are better and more ethical, but this can be, and has been, contested.

Disability scholars and parents of children with impairments often contend that physical conditions which can be regarded as adverse do not necessarily hinder individual flourishing.<sup>12</sup> It is true, they say, that painful ailments hurt; that mental retardation curbs cognitive

<sup>11</sup> Liza Mundy, 2002, 'A world of their own', *Washington Post*, 31 March, p. W22; Merle Spriggs, 2002, 'Lesbian couple create a child who is deaf like them', *Journal of Medical Ethics* 28: 283; S. Baruch, D. Kaufman, and K. L. Hudson, 2008, 'Genetic testing of embryos: practices and perspectives of US in vitro fertilization clinics', *Fertility and Sterility* 89: 1053–8.

<sup>12</sup> A divergent view is stated by Jonathan Glover, 2006, in his *Choosing Children: Genes, Disability, and Design* (Oxford: Clarendon Press), pp. 6 ff., 25.

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functions; that restricted mobility slows down movement; that the blind cannot see; and that the deaf cannot hear. None of these prevents, however, individuals from enjoying their lives and making a contribution, especially with proper medical services and social support. This is a particularly understandable and credible line of argument in the case of deafness. In an environment where many people are deaf and sign language is a universal method of communication, deafness can be seen as a culture instead of a disability. Like all minority cultures, it can have difficulties in its dealings with the majority's rules and attitudes, but sensitivity, nondiscrimination, and mutual respect make the personal and interpersonal flourishing of its members every bit as probable as anybody else's.

As for deontological and consequentialist objections, they seem to be mostly inapplicable here. Deafness as such cannot be associated with reduced intelligence,<sup>13</sup> so there are no grounds for believing that the condition would make people less capable of formulating moral judgements in the light of their reason. And although a 'deaf child will not hear the car coming',<sup>14</sup> congenital deafness is not an inherent source of harm and suffering, nor does it lead to less subjectively experienced happiness in life unless its effects are amplified by discriminatory attitudes or behaviour.

An interesting question, and one that I will examine in Chapter 4, is the relationship between morality and the law in the regulation of genetic testing for deafness. Some theorists hold that attempts to create deaf babies are immoral, whereas others maintain that they are understandable and acceptable. Despite the moral disagreement, most of them agree, however, that parents should legislatively be left free to make up their own minds.<sup>15</sup> As I will show, this is an uneasy compromise, because the ethical convictions underlying the opposite views, as can be expected, also draw their advocates into different directions when legal solutions are considered.

<sup>13</sup> McCay Vernon, 2005, 'Fifty years of research on the intelligence of deaf and hard-of-hearing children: A review of literature and discussion of implications', *Journal of Deaf Studies and Deaf Education* 10: 225–31.

<sup>14</sup> Glover, 2006, p. 23.

<sup>15</sup> E.g. John Harris, 2000, 'Is there a coherent social conception of disability?', *Journal of Medical Ethics* 26: 95–100; John Harris, 2001, 'One principle and three fallacies of disability studies', *Journal of Medical Ethics* 27: 383–7; Tom Koch, 2001, 'Disability and difference: balancing social and physical constructions', *Journal of Medical Ethics* 27: 370–6; Tom Koch, 2005, 'The ideology of normalcy – the ethics of difference', *Journal of Disability Policy Studies* 16: 123–9; Peter Singer, 2005, 'Ethics and disability: A response to Koch', *Journal of Disability Policy Studies* 16: 130–3.



## 1.4 Saviour siblings

In attempts to produce the ‘best babies’ and in decisions to select ‘deaf embryos’ preimplantation genetic tests are used to make better *people*, at least in the eyes of their parents. Similar tests can also be utilised to make people *better* in the medical sense. Some children have conditions that can be treated effectively only by tissue or stem cell transplants. Matching donors cannot always be found among the living and when this is the case, parents can try to produce another child who could fulfil the role. A number of embryos are produced by IVF, they are tested for their suitability, and good ones are implanted to initiate a pregnancy. If all goes well, a child with the planned qualities is born and its umbilical cord blood or tissue can be collected to help the ailing sibling. A new human being, a ‘saviour sibling’, is designed and created to restore the health of an existing individual.

The obvious rationale of the practice is medical. Someone whose life could not be saved or whose illness could not be cured otherwise will have a chance to live a longer and better life. The parents will probably be happier and society can benefit from the contribution of the citizen rescued from the brink of death or permanent injury. Apart from this, further reasons are provided by the principle of procreative autonomy. If people are allowed to set limits and conditions to the kinds of offspring that they want to have in other respects, then why draw the line here? The survival and health of an older sibling is surely as important a concern as the physical condition of the future child.

Objections to creating saviour siblings range from appeals to the sanctity of life through the consideration of probable and possible harm to the condemnation of designing lives and using people as a means.<sup>16</sup> As in all preimplantation genetic testing, some embryos are discarded in the selection of the donor candidates, and this can be seen as a violation of the sanctity-of-life principle. I will discuss this criticism in the context of stem cell research (Section 1.6 below and Chapter 7). And as in all reproductive testing, parents and geneticists are in these cases planning the qualities of children and by doing this, it can be argued, assuming a role that is not rightfully theirs. I will return to this view, and

<sup>16</sup> The major arguments for and against the practice can be found, e.g. in Sally Sheldon and Stephen Wilkinson, 2004, ‘Should selecting saviour siblings be banned?’, *Journal of Medical Ethics* 30: 533–7; Caroline Berry and Jacky Engel, 2005, ‘Saviour siblings’, *Christian Medical Fellowship Files* 28 – [www.cmf.org.uk/literature/content.asp?context=article&id=1317](http://www.cmf.org.uk/literature/content.asp?context=article&id=1317).

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other variants of the 'design' objection, in the discussion on reproductive cloning (Section 1.5 and Chapter 6). In the meantime, what about the other arguments against saviour siblings?

The children created to provide a donor for their siblings can be physically harmed in the process. This is not necessary or inevitable, but it is a possibility. If the tissue needed can be taken from the umbilical cord, no bodily harm is inflicted. But if the initial treatment fails and a bone marrow transplant is required, a relatively painful and possibly dangerous procedure will be imposed on a child without its consent. It is commonplace in the literature to assert that this is not harmful, since no permanent damage usually occurs. This view conflates two separate things. The pain and the risk can be deemed trivial in comparison with the agony of the older sibling.<sup>17</sup> They are, nonetheless, real, and this can be counted as harm, whatever the reasonable attitude towards the practice in its entirety.

Saviour siblings can also be psychologically harmed by their parents' expectations, especially but not only if the older child cannot be helped by their tissue. Again, this is not necessary or inevitable, but it is a genuine possibility. Since the number of cases so far is very small and since it is probably unsafe to draw analogies from other types of situation, we have no real knowledge about the severity of the issue. The parents who have gone through the experience have asserted that they would have had another child anyway and that they would have loved the planned baby regardless of its medical performance. But disappointment can show in many ways, and the mere awareness that one has been produced for an external purpose may influence the self-esteem of the individual earlier or later in life.

Another objection based on the impacts of the practice is that the creation of saviour siblings, while acceptable in and by itself, would be a step on a genetic slippery slope. We could, so the argument goes, condone in principle attempts to produce a donor for a sick child. By doing this we would, however, also authorise parental choices in less significant cases, or at least send a message saying that it could be done. As a result, the number of genetic tests for less significant reasons would increase, until everybody would be choosing their children by eye colour, gender, height, intelligence, and jocularity. Critics of this popular idea have countered it with two observations. The link between kinds of

<sup>17</sup> I would like to see everyone who claims this immediately register as bone marrow donors, though, to put their flesh where their mouths are.