

## **Designer Babies: Ethical Considerations** Nicholas Agar

## articlehighlights

Advances in genetics may make it possible to "select" our children's genes and characteristics. We need to consider • what are the moral and ethical limits of this choice?

- should we distinguish between selecting for therapy and enhancement?
- are human genetic modification technologies safe?
- what effect will human genetic modification have on society?

April 2006 Designer babies	In 2004 the term "designer baby" made the transition from sci-fi movies and weblogs into the Oxford English Dictionary, where it is defined as "a baby whose genetic makeup has been artificially selected by genetic engineering combined with in vitro fertilization to ensure the presence or absence of particular genes or characteristics." This coinage was prompted by recent advances in genetics that	
would be genetically modified.	may make such babies possible. We need to pause and ask what moral or ethical limits, if any, should apply to the selection of our children's genes or characteristics. Before we can answer this we must address other questions:	
What issues should we consider before modifying humans?	<ul> <li>How would designer babies be made?</li> </ul>	
	<ul> <li>Is there a moral or ethical difference between using genetic technologies</li> </ul>	
	to prevent disease and to enhance human capacities?	
	<ul> <li>Should we be striving to protect our humanity from genetic</li> </ul>	
	enhancement?	
	What effect will human genetic modification have on society?	Artist's depiction of fetus at 40 weeks after fertilizati about 20 inches (51 cm) head to toe. Source: Melch
	Designer babies: Not today, but perhaps tomorrow	Meijer, 3Dpregnancy.com.
	There are two types of moral or ethical questions one can ask about designer babies. The first addresses the specific technologies that might be used to modify or select a baby's genetic makeup. The second question looks away from technological details to focus on the very idea of a designer baby. <sup>2</sup>	
Is GM technology safe and ethical?	<ul> <li>Are the technologies of genetic modification and selection safe enough to be used on humans?</li> </ul>	
	Even if the technologies are safe, can they be morally defended?	
	The Oxford English Dictionary definition describes the way of making designer babies that at the same time is the most conceptually straightforward and raises the biggest concerns about safety. One way to make a designer baby begins with an embryo created by in vitro fertilization (IVF). Genetic engineers modify the embryo's DNA and then introduce it into a womb.	
Geneticists have enhanced learning in mice.	Farmers in many parts of the world now plant crops with genomes altered to make them resistant to pests or herbicides.3 Recent discoveries about the influence of genes on human traits such as susceptibility to disease, shyness, and athletic ability open the possibility of transferring these techniques to human beings. An experiment on mice performed at Princeton Universi suggests one way this might be done.	
	Geneticists introduced into mouse genomes an additional copy of a gene, NR2B, that codes for one type of glutamate receptor and is known to play a role in the development of the brain. <sup>4</sup> The resulting "doogie" mice, named for the teen genius central character of the early 1990s TV show "Doogie Howser, MD," seem to learn faster than other mice and retain information longe The NR2B gene exists in humans, prompting speculation about performing the same trick on one of us. Before this is done, we need to examine pressing safety concerns.	
There are several safety concerns about the technology.	• Current techniques of genetic modification introduce genes at random places in the genome. We should be concerned about the possibility that an inserted copy of NR2B may arrive in the target genome in a way that disrupts the functic of another gene crucial for survival.	
	• Many genes have more than one effect. The effect we intend may be accompanied by others of which we become awa only later. There is evidence for such effects on doogie mice, which seem not only to have improved powers of learning and memory, but also to have a greater sensitivity to pain, an enhancement of more dubious desirability. <sup>5</sup>	
	<ul> <li>Many of the traits that we may want to select are influenced by multiple ge combination with other genes. We are unlikely to find single genes whose r point boost in IQ, for example.6</li> </ul>	enes. A gene affects intelligence only in modification would reliably produce a 20-









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We should expand on the dictionary definition to consider other ways of selecting our children's characteristics. These ways of making designer babies will avoid some of the risks inherent in the genetic modification of human embryos while introducing others. One technology is preimplantation genetic diagnosis (PGD), currently used by some people at risk of passing serious genetic disorders on to their children.

Preimplantation genetic diagnosis is already used to screen for genetic defects.

One scientist argues

you can also screen for personality traits.

Preimplantation

not risk free.

Cloning is an

alternative method.

Cloning could lead to

parental preference

Animal cloning has

proven to be risky.

for an enhanced

child.

genetic diagnosis is

• People who use preimplantation genetic diagnosis to avoid passing on a disease to their child have a collection of embryos created for them by IVF.

 These embryos are grown to the eight-cell stage, at which point one or two cells are removed and checked for genetivariants associated with the disease.

• Only embryos lacking these variants are introduced into the womb.

PGD is an expensive procedure currently offered only to couples at risk of having a child suffering from a serious genetic disease. But there is nothing inherent in the technology that limits it to such uses. For example, Dean Hamer presents evident that the gene for a vesicular monoamine transporter, VMAT2, influences a trait labelled self-transcendence, that is, the "capac to reach out beyond themselves, to see everything as part of one great totality." The proposes that different versions of VMAT lead to different degrees of self-transcendence and, therefore, to different propensities for religious or spiritual belief.

Hamer's proposal is controversial, but suppose he is right. You might use PGD to select your child's version of VMAT2. Presbyterians who select children with the high self-transcendence version of VMAT2 should, however, be warned that they may end up with a child who expresses this selected psychological characteristic by way of a devotion to astrology.

PGD does not involve the genetic modification of human embryos and hence avoids some of the risks described above. But it i not entirely risk-free. Some commentators fear that the removal of one or two cells from eight-cell embryos might have implications for the well-being of people created by PGD. Defenders of PGD respond that the cells of eight-cell embryos are totipotent, meaning that they are undifferentiated and equally capable of forming all the cells of the human body. As the technology has been in use for under a decade, it is too early to say with certainty who is right in this dispute.8

Another biotechnology-cloning-may enable the selection of children's characteristics.

- Cloning by somatic cell nuclear transfer uses a somatic, or body, cell from the person to be cloned.
- The nucleus of this cell is introduced into an egg cell whose own nucleus has been removed.
- The resulting reconstructed embryo is introduced into a womb.

Although some people may view cloning as a last-ditch response to infertility, others may see it as a way of selecting the characteristics of their child. This choice would be exercised through the choice of the person to be cloned. For example, you might pursue physical attractiveness on your child's behalf by using a somatic cell from Angelina Jolie or Brad Pitt, who may, i the future, have to be more circumspect about where they leave their saliva and hair follicles.

Those who hope to clone designer babies should be wary of genetic determinist misrepresentations of the technology.<sup>9</sup> Geneti determinism is the view that an organism's significant characteristics result mainly from the action of its genes, with environmental influences playing a negligible role. This view, now widely recognized as false, has been supplanted by the view that organisms emerge from a complex interaction of genes and environment. Roger Federer's clone would be subjected to a different collection of environmental influences from the original, meaning that the clone might easily lack any interest in or aptitude for tennis. Prospective parents who accept that cloning comes with no guarantee might reassure themselves that a clone of Federer would be more likely to be a tennis champion than a child they produced naturally.

This way of making a designer baby will not be attractive to prospective parents who place value on a genetic connection with their child. The woman who gave birth to a clone of Roger Federer would be no more genetically related to the clone than she to the original. She might establish a rather limited genetic connection by contributing the egg into which the nucleus of the Federer somatic cell is inserted. An enucleated egg retains the DNA of its mitochondria, cellular machinery residing outside of the nucleus. But the significance of this connection is vastly outweighed by that with the donor of the nucleus.

Even if we understand how somatic cell nuclear transfer might enable us to make designer babies, we are not yet ready to create children by cloning. There are major concerns about the health of clones. Animal clones suffer from a variety of probler that some scientists connect with incomplete reprogramming of somatic cell DNA or damage inflicted by the process of nuclea transfer. Human clones may also suffer from these problems.10

#### Preventing disease or enhancing attributes?

Suppose we move away from discussion of risks to focus on the reasons for having a designer baby. We can identify two different kinds of motivation:

- Replacing the version of the gene linked with heart disease, for example, aims to ensure that the resulting person's
  cardiac functioning does not fall below a level considered normal for humans. We call it "therapy" because we recogni
  that it aims to prevent a disease state.
  - Adding an extra copy of the NR2B gene to a human embryo, on the other hand, has the quite distinct aim of producir someone who, in some area, functions beyond a level considered normal for human beings and as such qualifies as a "enhancement."11

This prompts a question: Is there a moral distinction between treating or preventing disease and enhancing traits? Some think that we should pass different moral judgments on enhancement from those we pass on therapy. They say that while therapy i justifiable, enhancement is not.

divide between therapy and enhancement?

Is there an ethical

How do you distinguish between therapy and enhancement?

Some technical options destroy the embryo to avoid genetic defects.

The Nazis tried to design babies by practicing eugenics.

Is the way parents rear a child also a way of designing a child?

Some think we will lose our humanity if we modify human genes.

Are geniuses accidental posthumans because they're above the norm?

Transhumanists see designer babies as a goal rather than an issue.

Will genetic enhancement lead to a discriminatory society?

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The problem is that it is difficult to make the therapy-enhancement distinction principled. It is hard to find definitions of diseas suitable to serve as a moral guideline for genetic technologies. Social constructivists consider diseases to be states to which society takes a negative attitude. Cancer seems to satisfy the requirements of this definition, but so might homosexuality and practicing a religion different from the norm in your society. Objectivist accounts avoid these difficulties by making the definition of disease independent of our attitudes. According to the most widely advocated version of this view, I suffer from disease wh some part of me fails to perform its biological function. For example, cholesterol deposits on the arteries constitute or conduce to disease because they impede the heart in the performance of its function, which is to pump blood. The problem with this wo of defining disease is that it may sometimes set goals irrelevant to human flourishing. Suppose we were to discover that homosexuality was a consequence of malfunction in the part of the brain responsible for sexual attraction. Should this rather obscure fact about biological functioning count more than the fact that many homosexual people seem to be living excellent lives?12

A further moral complication emerges from the different approaches to treating disease and those who suffer from them. Genetically modifying an embryo so as to remove a gene linked with a higher than average risk of asthma may prevent asthm but it need not prevent the existence of the person who might have suffered from it. Compare this with the use of PGD to avo having a child at a high risk of asthma. This seems to prevent the disease only by preventing the patient's existence.<sup>13</sup>

#### Should parents be permitted to enhance their children?

Finding a difference between treatment and enhancement does not in itself show that enhancement is impermissible. Some think we should reject genetic enhancement because of its connection with the eugenics programs promoted by the Nazis. The scientific minions of Adolph Hitler sought to shape the German population by murdering those judged inferior and encouraging those they saw as their betters to reproduce. Advocates of what has come to be called "liberal eugenics" would take responsibility for human enhancement from the state and pass it to individuals who would be guided by their own distinctive values in their selection of genetic advantages.<sup>14</sup>

Parents in liberal democracies already make choices about which schools to send their children to, how to feed them, who counts as a suitable after-school companion, whether children are to be given religious instruction, and if so of what type. In effect, they manipulate their children's environments to improve or enhance them.14-16 The moral parallel between upbringir and genetic enhancement draws support from modern understanding of the contributions that genes and environment make t human development. As we saw above, the genetic determinist view of development has been displaced by the view that organisms emerge from a complex interaction of genes and environment. The comparison of genetic enhancement with upbringing suggests that we were all designer children. Prospective parents who avail themselves of genetic engineering, PGD or cloning are simply making use of another means of design.

#### Are designer babies "posthumans"?

Opponents of the liberal argument for enhancement argue that there are morally significant differences between upbringing a genetic enhancement. Francis Fukuyama thinks that genetic enhancements may change our descendents to such an extent th they lose their humanity.17 According to Fukuyama, environmental influences operate only within limits set by genes, meanin that even ambitious education programs leave their subjects' humanity intact. A genetically enhanced child is more fittingly described as a "posthuman." The price for her super intelligence will be the experiences that give human lives meaning.

We might ask whether there are already posthumans among us. Albert Einstein and Ray Charles achieved well beyond the nor in their areas of endeavour. Some of the explanations for this achievement may be traced to their genomes. Would a parent w modified her child's genome so that it contained some of the genetic advantages of Einstein or Charles be taking the first step toward posthumanity? If we answer this question in the affirmative, should Einstein and Charles be considered accidental posthumans?

The most forthright response to the concern that genetic enhancement might deprive our descendents of their humanity come from a group of thinkers who call themselves "transhumanists."<sup>18</sup>

- Transhumanists propose posthumanity as a goal rather than something to avoid.
- They allow that we may have difficulty relating to the inhabitants of the biotechnological future but claim that if they are free of disease, super-intelligent, and routinely compose symphonies whose brilliance surpasses that of Beethove Ninth, this failure of identification is our problem, not the posthumans'.

#### The end of liberal democracy?

Some of the most challenging moral and ethical questions about a licence to design babies concern the societies it might lead The movie Gattaca depicts a future in which genetically enhanced people take the lead, viewing unenhanced people as fit only clean up after them. Liberal democracy is a cooperative venture in which all are seen as having something to offer.<sup>17</sup> Will genetic enhancement bring this social arrangement to an end, creating societies in which unenhanced people are viewed by their genetic superiors in much the same way that we currently view chimpanzees, suitable for drug testing and zoo exhibits t little else?

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- Learn how we can use a kind of repetitive element in the human genome to determine genetic diseases.
- What does genetics mean to us as humans?
- Read a proposal for enhancing undergraduate education in bioethics.
- A prominent biologist offers a broad view of the promise of evolutionary biology.

#### learnmore links

#### What is a designer baby?

- » Bionet features articles on the topic, including how it's done, legal and ethical implications, and suggests further reading.
- http://www.bionetonline.org/English/Content/db\_cont1.htm
- » A Washington Monthly article provides some history and perspectives.
- http://www.washingtonmonthly.com/features/2001/0203.brownlee.html

#### **Human Cloning and Genetic Modification**

Easy-to-read explanation, with numerous graphic illustrations, about the difference between reproductive and therapeutic cloning, as well as info on human genetic engineering and techniques. http://www.arhp.org/uploadDocs/cloning.pdf#search=%22human%20cloning%22

#### Inheritable Genetic Modification

This overview is provided by the Center for Genetics and Society. Be sure to the check out the links to related articles and off-site links. http://www.genetics-and-society.org/technologies/igm/

## Preimplantation Genetic Diagnosis (PGD)

The Infertility Center of Saint Louis provides a summary of PGD. http://www.infertile.com/infertility-treatments/pgd.htm

#### U.S. survey on reproductive technology

A detailed U.S. survey, conducted by the Genetics and Public Policy Center of Johns Hopkins University, reveals fears and hopes about reproductive genetic technology (Dec. 2002).

http://www.dnapolicy.org/research/reproductiveGenetics.jhtml.html

#### Scientific Origins of Eugenics

The eugenics movement arose in the 20th century as two wings of a common philosophy of human worth. Francis Galton, who coined the term eugenics in 1883, perceived it as a moral philosophy to improve humanity by encouraging the ablest and healthiest people to have more children. Learn more:

http://www.eugenicsarchive.org/html/eugenics/essay2text.html

#### Posthumans

A scientific paper looks at the pros and cons of the debate, by an author who takes a stand on the issue. http://www.nickbostrom.com/ethics/dignity.html

#### getinvolved links

#### Genetic Alliance

This group offers news, support groups, information on genetic conditions, as well as ethical, legal, and social issues. Also, they suggest a variety of ways to get involved, such as "action teams," "advocacy groups," and "e-mail discussion lists," on their membership page. http://www.geneticalliance.org

#### **World Transhumanist Association**

An international nonprofit membership organization that advocates the ethical use of technology to expand human capacities. http://www.transhumanism.org/index.php/WTA/index

#### The Hastings Center

This independent, nonpartisan, and nonprofit bioethics research institute was founded in 1969 to explore fundamental and emerging questions in health care, biotechnology, and the environment. http://www.thehastingscenter.org/default.asp

#### educatorresources

#### Teaching Resources from the Northwest Association for Biomedical Research (NWABR)

# NWABR.ORG

### ActionBioscience - promoting bioscience literacy

The Northwest Association for Biomedical Research (NWABR) strengthens public trust in research through education and dialogue. Its diverse membership spans academic, industry, non-profit research institutes, health care, and voluntary health organizations. Through membership and extensive education programs, it fosters a shared commitment to the ethical conduct of research and ensures the vitality of the life sciences community.

#### **Ethics Primer**

The Ethics Primer provides engaging, interactive, and classroom-friendly lesson ideas for integrating ethical issues into a science classroom. It also provides basic background on ethics as a discipline, with straightforward descriptions of major ethical theories. Several decision-making frameworks are included to help students apply reasoned analysis to ethical issues. http://www.nwabr.org/curriculum/ethics-primer

#### **Bioethics 101**

Bioethics 101 provides a systematic, five-lesson introductory course to support educators in incorporating bioethics into the classroom through the use of sequential, day-to-day lesson plans. This curriculum is designed to help science teachers in guiding their students to analyze issues using scientific facts, ethical principles, and reasoned judgment.

#### http://www.nwabr.org/curriculum/bioethics-101 **Introductory Bioinformatics: Genetic Testing**

The curriculum unit explores how bioinformatics is applied to genetic testing. Students are also introduced to principles-based bioethics in order to support their thoughtful consideration of the many social and ethical implications of genetic testing. Throughout the unit, students are presented with a number of career options in which the tools of bioinformatics are used.

http://www.nwabr.org/curriculum/introductory-bioinformatics-genetic-testing

#### **Advanced Bioinformatics: Genetic Research**

This curriculum unit explores how bioinformatics is used to perform genetic research. Students examine DNA sequences from different animal species, investigate the relationship between protein structure and function, and explore evolutionary relationships among eukaryotic organisms. Throughout the unit, students are presented with a number of career options in which the tools of bioinformatics are developed or used.

http://www.nwabr.org/curriculum/advanced-bioinformatics-genetic-research

#### Genetic Lesson Plan Ideas

A directory of lesson plans on genetics and genomics. http://www.kumc.edu/gec/lessons.html

#### **Genetics Educator Center**

Resources on the human genome project, curricula, and lesson plans. http://www.kumc.edu/gec/

#### **Reinventing the Human**

This page provides a selection of projects that may be done before class, during class, or after class on the topic of 'designer children'. These activities may be assigned to individuals or groups of students.

http://www.choicesandchallenges.sts.vt.edu/modules/children\_activities.htm

## articlereferences

- 1. Soanes, C., and A. Stevenson (eds). 2005. Oxford Dictionary of English. Oxford, UK: Oxford University Press. http://www.oed.com (accessed Mar. 30, 2006)
- 2. Agar, N. 2004. A pragmatic optimism about enhancement technologies. In Liberal Eugenics: In Defence of Human Enhancement. Oxford, UK: Blackwell.
- 3. Winston, M. 2002 Travels in the Genetically Modified Zone, Harvard, MA: Harvard University Press.
- 4. BBC News. September 1, 1999. Genetic engineering boosts intelligence. http://news.bbc.co.uk/1/hi/sci/tech/435816.stm (accessed Mar. 30, 2006)
- 5. Stull, D. 2001. Better mouse memory comes at a price. The Scientist 15: 21. http://www.the-scientist.com/yr2001/apr/research1\_010402.html (accessed Mar. 30, 2006) Editor's note 4/16/12: link no longer available
- 6. Pinker, S. 2003. Session 3: Human nature and its future. President's Council on Bioethics meeting. March 6-7, 2003. Arlington, VA. http://www.bioethics.gov/transcripts/march03/session3.html (accessed Mar. 30, 2006) April 7, 2010, link no longer available. 1. Hamer, D. H. 2004. The God Gene: How Faith Is Hardwired into Our Genes. New York: Doubleday.
- 7. BBC News. April 25, 2005. Baby gene test safety "unchecked." http://news.bbc.co.uk/1/hi/health/4481839.stm (accessed Mar. 30, 2006)
- 8. Brock, D. 1998. Cloning human beings: An assessment of the ethical issues pro and con. In M. Nussbaum and C. Sunstein (eds). Clones and Clones: Facts and Fantasies about Human Cloning. New York: W. W. Norton; and P. Kitcher. 2000. Human cloning. In G. McGee (ed). The Human Cloning Debate. Berkeley, CA: Berkeley Hills Books.
- 9. McGee, G. 2001. Primer on ethics and human cloning. http://www.actionbioscience.org/biotech/mcgee.html (accessed Mar. 30, 2006)
- 10. Buchanan, A., D. Brock, N. Daniels, and D. Wikler. 2000. From Chance to Choice: Genetics and Justice. Cambridge, UK: Cambridge University Press.
- 11. Kitcher, P. 1996. The Lives to Come: The Genetic Revolution and Human Possibilities. New York: Simon and Schuster.
- 12. Kass, L. 2002. Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics. San Francisco: Encounter Books.
- 13. Agar, N. 2004. Liberal Eugenics. Malden, MA: Blackwell.
- 14. Harris, J. 1998. Clones, Genes, and Immortality: Ethics and the Genetic Revolution. Oxford, UK: Oxford University Press.
- 15. Jürgen Habermas, The Future of Human Nature (Polity Press, 2003) for a response. 1. Fukuyama, F. 2002. Our Posthuman Future: Consequences of the Biotechnology Revolution. New York: Farrar, Straus and Giroux,
- 16. World Transhumanist Association: http://www.transhumanism.org/index.php/WTA/index/ (accessed Mar. 30, 2006)