

Explore the ways in which contemporary genetics both challenges and underpins notions of human freedom, value and identity

Introduction – the age of genetic change

Modern genetic technology and the ethical debate surrounding it was thrown into the spotlight in February 1997 when scientists at the Roslin Institute in the United Kingdom announced that they had successfully produced the first mammalian clone created using DNA obtained from an adult cell: Dolly the sheep¹. To the geneticists, given previous breakthroughs, this was an expected incremental step; the wider world treated the news with surprise, suspicion and outcry². Several days prior to the official publication in *Nature* the news was leaked by a UK newspaper, with the headline “Scientists clone adult sheep – Triumph for UK raises alarm over human use”. Concern over the potential for human cloning was immediately evident³. What ensued was a wave of opposition and apocalyptic predictions⁴. In the United States, President Bill Clinton voiced concern and instructed bioethical advisors to investigate and report back swiftly with what measures were necessary to prevent the misuse of this new technology.

These immediate fears have not been realised, but the ethical debate continues as to how cloning and other advances in genetic technologies may compromise beliefs about what it means to be human. This essay explores what is meant by notions of human freedom, value and identity and how these concepts may be supported or contradicted by the future of this scientific field.

The term ‘bioethics’ was first used by Fritz Jahr in 1927, and is today an interdisciplinary study of the ethics of advances in biology and medicine. Ethical controversy surrounding contemporary genetics has been a hot topic for bioethicists and the general public since Dolly’s arrival, but the question of how human worth and value is challenged by biology and medicine precedes this by centuries. Defining human worth and

¹ Wilmut I, Schnieke AE, Mchwir J, Kind AJ and Campbell KHS (1997). ‘Viable offspring derived from fetal and adult mammalian cell’. *Nature* 385, pp 810-813.

² Wadman M (2007). ‘Cloning special: Dolly: a decade on’, *Nature* 445, pp.800-801.

³ McKie R (1997). ‘Scientists clone adult sheep – Triumph for UK raises alarm over human use’. *The Observer* [online]. <http://www.guardian.co.uk/uk/1997/feb/23/robinmckie.theobserver> [Accessed 15 August 2012].

⁴ Wadman M (2007). ‘Cloning special: Dolly: a decade on’. *Nature* 445, pp.800-801.

value is an integral foundation of bioethics, but it is a definition that has changed over recent centuries as we have advanced in our scientific knowledge⁵.

Freedom – our right to self-determination

The right to freedom is one of the most important of all human rights. In Article 1 of the Universal Declaration of Human Rights (1948)⁶, it is stated that “All human beings are born free and equal in dignity and rights”, and the concept of being free and freedom is repeated multiple times throughout the preamble and Articles; as humans, we have freedom of thought, opinion, speech and expression. In addition to this, procreative freedom, such as the freedom to decide whether or not to have children, is a generally widely-accepted right. The issue of freedom is also addressed in the Universal Declaration on the Human Genome and Human Rights (1997)⁷, Article 12b: “Freedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole”. With these notions in mind, it is important to address how existing and new genetic technologies could affect human freedom.

The Human Genome Project was completed in April 2003 by a global consortium of geneticists headed by the National Human Genome Research Institute⁸, enabling us to read the complete genetic make-up of a human being for the first time, although the first gene sequencing began several decades earlier. Being able to read the genetic information of individuals was the earliest form of genetic technology that brought in to question ethical values, opening the doors to such applications as genetic testing for disease susceptibility and pre-implantation genetic diagnosis (PGD).

⁵ O’Mathúna DP (2006). ‘Human dignity in the Nazi era: implications for contemporary bioethics’. *BMC Medical Ethics* 7(2).

⁶ UN General Assembly (1948). ‘Universal Declaration of Human Rights’. [online] <http://www.unhcr.org/refworld/docid/3ae6b3712c.html> [Accessed 15 August 2012].

⁷ United Nations Educational, Scientific and Cultural Organization (1997). ‘Universal Declaration on the Human Genome and Human Rights’. [online] http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 17 August 2012].

⁸ National Human Genome Research Institute (2012). ‘All About The Human Genome Project’ [online] <http://www.genome.gov/10001772> [Accessed 15 August 2012].

When considering testing of the human genome, the issue of freedom occurs repeatedly. For example, there are established public health programmes for widespread screening of new-borns in the US via blood tests⁹. There are obvious advantages to such techniques; early diagnosis and treatment makes sense for the individual as well as long-term economic sense¹⁰. The World Medical Association, in their Declaration on the Human Genome Project (1992)¹¹, set forth the guidelines that it should be the decision of the individual whether or not to participate in screening and how the information will subsequently be used. Only if there is potential serious harm, and as a last resort, should relevant genetic information be disclosed to family members.

With this in mind, it would appear that mandatory genetic testing in the workplace, a phenomenon that is likely to become more common^{12,13}, is not a practice that can have a workable ethical structure. The idea behind this procedure is to detect which employees may be more susceptible to toxins in the workplace so that they may be made aware of the dangers and take steps, such as a change in role, to avoid enhanced risk. Employers have a duty to ensure the welfare of their staff, but, if genetic autonomy is to be maintained by the individual, such tests would have to be strictly voluntary and the employer could take no steps to enforce action as a result – to do so would be unjustly discriminatory as employees have no control over their genetic profile, just as they have no control over their sex, ethnicity or a disability¹⁴. Mandatory screening for the workplace would constitute a devaluation of our humanity and would be contrary to the International Declaration on Human Genetic Data (2003)¹⁵, Article 3, which states that a person's identity must not be reduced to genetic characteristics, going against human freedom.

⁹ Hodge JG (2004). 'Ethical issues concerning genetic testing and screening in public health'. *American Journal of Medical Genetics* 125, pp 66-70.

¹⁰ Khoury MJ, McCabe LL, and McCabe ERB (2003). 'Population Screening in the Age of Genomic Medicine'. *The New England Journal of Medicine* 348, pp 50-58.

¹¹ World Medical Association (1992). 'Declaration on the Human Genome Project'. [online] <http://www.wma.net/en/30publications/10policies/20archives/g6/> [Accessed 7 September 2012].

¹² Hodge JG (2004). 'Ethical issues concerning genetic testing and screening in public health'. *American Journal of Medical Genetics* 125, pp 66-70.

¹³ MacDonald C, and Williams-Jones B (2002). 'Ethics and Genetics: Susceptibility Testing in the Workplace'. *Journal of Business Ethics* 35(3), pp 235-241.

¹⁴ Ibid.

¹⁵ United Nations Educational, Scientific and Cultural Organization (2003). 'Universal Declaration on Human Genetic Data'. [online], http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 17 August 2012].

Using genetic testing and screening in order to improve public health carries different implications from a workplace programme. Widespread, mandatory population testing would provide valuable information to health services and research programmes interested in the prevention and treatment of disease, not least to target treatment in a more economically sound direction¹⁶. However, our dominant notion of freedom, and the current principles of bioethics, are centred on the individual, reiterated by the World Medical Association's guidelines that screening should always be voluntary. Herein lies a potential conflict of interest: respecting the individual's right to autonomy and improving the health of a population¹⁷.

Reproductive freedom, as previously mentioned, is widely accepted as an important value. Parents should have an inherent right to choose if, when and with whom they have children. However, some technologies used to achieve these freedoms, such as contraception, elective abortions, *in-vitro* fertilisation (IVF) and other assisted reproductive technologies, frequently raise concerns as to how much reproductive freedom we are entitled to. As a controversial example, genetic enhancement ('designer babies') could be viewed as an expression of the freedom parents have to influence the direction that their children's lives take¹⁸, similar to encouraging them into a particular school or sport.

Genetic enhancement carries myriad ethical objections, many relevant to the values of freedom and autonomy. Firstly, at this point in time, altering the heritable germline in humans is an unproven process with no guarantee of efficacy or safety; this inability to predict the outcome of genetic enhancement means that informed consent cannot exist – contrary to common ethical practice in medicine and research¹⁹. There is no guarantee that genetic enhancement will make any difference at all; there are scientists who believe it is not possible^{20,21}, never mind a guarantee that the desired 'improvements' will be expressed successfully.

¹⁶ Hodge JG (2004). 'Ethical issues concerning genetic testing and screening in public health'. *American Journal of Medical Genetics* 125, pp 66-70.

¹⁷ *Ibid.*

¹⁸ Agar N (2009). 'How to Defend Genetic Enhancement'. *The International Library of Ethics, Law and Technology* 2(1), pp 55-67.

¹⁹ Benatar D (1998). 'Informed consent and research'. *British Medical Journal* 31.

²⁰ Gordon JW (1999). 'Genetic Enhancement in Humans'. *Science* 283, pp 2023-2024.

²¹ Rosoff PM (2012). 'The myth of genetic enhancement'. *Theoretical Medicine and Bioethics* 33(3), pp 163-178.

There is also concern as to how genetic enhancement affects the autonomy of the child that is produced. The United Nations Declaration on Bioethics and Human Rights (2005)²² states that all humans are deemed equal in dignity and rights and should be treated justly and the same; it can therefore be seen that genetic enhancement of *some* children and not others is a contravention of this right. The 'designer baby' has no choice as to how its genes are altered and is potentially born to a more constrained future, due to expectations placed upon it²³. On the other side of the divide, there are those left disadvantaged from lack of enhancement, greater social inequality and potentially decreased tolerance for the diversity of human life²⁴. Increasing social divides and discrimination will surely reduce the sense of justice and freedom felt by those born into families unable to afford genetic technologies.

The work of German philosopher Immanuel Kant is frequently cited when discussing the ethics of human genetic technologies. Kant believed that due to: (1) people having their own desires and goals that give value to nonhuman things; and (2) people being rational agents who can make their own decisions, set their own goals and be responsible for their own actions; they therefore have intrinsic worth and value²⁵. The resulting ethos from Kant's philosophy is that humans must always be treated as an end, and never solely as a means to an end. This applies to genetic technology when the reasons behind the parents' wish for selection or cloning are in question. It is not a simple task to determine what is an acceptable or unacceptable reason for having a child; one might disregard reasons such as 'to save a relationship' or 'to look after parents in old age', whilst endorsing those such as 'to give an existing child a sibling' or 'to experience parenthood'²⁶. Whether these are considered 'good' or 'bad' reasons, they all share a common theme – the child is almost always at least partly a means to an end (no matter how socially

²² United Nations Educational, Scientific and Cultural Organization (1997). 'Universal Declaration on the Human Genome and Human Rights'. [online] http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 17 August 2012].

²³ Sandel MJ (2004). 'Embryo Ethics – The Moral Logic of Stem-Cell Research'. *New England Journal of Medicine* 352, pp 207-209.

²⁴ Wertz DC, Fletcher JC, and Berg K (2003). 'Review of Ethical Issues in Medical Genetics'. Geneva: World Health Organization.

²⁵ Rachels J (1986). 'The Elements of Moral Philosophy'. New York: Random House.

²⁶ Lotz M (2009). 'Procreative Reasons-Relevance: On the moral significance of why we have children'. *Bioethics* 23(5), pp 291-299.

accepted the end is) and, in any case, Kantian philosophy states that people should not be treated *solely* as a means to an end²⁷.

An important issue here is whether the reproductive freedom of the adult or the autonomy of the future child is deemed morally more important. Wrongful life cases – where a child has been brought into existence despite it being *known* they will experience severe hardship – are commonly rejected by the courts²⁸, so it would seem that, at present, the autonomy of the parents trumps the autonomy of future persons, whether or not this is contradictory to Kantian philosophy.

Along with safety worries and the fear of the unknown that accompany the prospect of genetic enhancement and human reproductive cloning, there is the frequently voiced concern that human freedom and autonomy will be overshadowed by scientific goals and the drive to improve our species – *again*. In 1933, the ‘Law for the Prevention of Progeny with Inherited Disease’ was issued by the Nazi government in Germany²⁹. This resulted in the involuntary sterilisation of at least 400,000 Germans and the ‘race hygiene’ programme, which culminated in a euthanasia programme that targeted adults and children with mental and physical disabilities, as well as millions of Jews. This is the most extreme example of coercive eugenics, a scenario that the human race does not wish to see in the future. However, concerns are repeatedly being raised that modern genetics is a new version of eugenics³⁰. Techniques such as PGD and antenatal testing for genetic diseases, and subsequent abortions, are becoming more commonplace; for example, a recent review of prenatal testing for Down’s syndrome found that between 89% and 97% of mothers receiving a positive diagnosis chose to terminate the pregnancy³¹. Testing and the choice on how to act following the diagnosis are strictly voluntary, but examinations of genetic counselling have found subtle pressures to abort children with disease or disability to be undermining this autonomy^{32,33}. One cannot imagine that we would return to the

²⁷ Savulescu J (2005). ‘The ethics of cloning’. *Medicine* 33(2), pp 18-22.

²⁸ Archard D and Benatar D (2010). ‘Procreation and Parenthood: The Ethics of Bearing and Rearing Children’. Oxford: Oxford University Press.

²⁹ Norrgard K (2008). ‘Human testing, the eugenics movement, and IRBs’. *Nature Education* 1(1).

³⁰ Shakespeare T (2010). ‘Choices and Rights: Eugenics, genetics and equality’. *Disability and Society* 13(5), pp 665-681.

³¹ Choi H, Van Riper M, and Thoyre S (2012). ‘Decision Making Following a Prenatal Diagnosis of Down Syndrome: An Integrative Review’. *Journal of Midwifery & Women’s Health* 57, pp 156–164.

³² Holtzman NA (1998). ‘Eugenics and Genetic Testing’. *Science in Context* 11, pp 397-417.

³³ Shakespeare T (2010). ‘Choices and Rights: Eugenics, genetics and equality’. *Disability and Society* 13(5), pp 665-681.

days of the Western eugenics movements of the 20th century, with enforced sterilisation of the physically or psychologically disadvantaged, but the lack of adequate genetic counselling, which includes unbiased information and the availability of alternatives, is a very real threat to reproductive free choice³⁴.

Value – our right to be treated equally

Defining human value is an integral foundation of bioethics, but it is a definition that has changed over recent centuries as we have advanced in our scientific knowledge³⁵. For thousands of years, most of the primary religions taught that humans and all life were created by a God. In Judaism and Christianity, human beings are significantly separated from the rest of life: “Then God said, Let us make man in our image, in our likeness, and let them rule... So God created man in his own image, in the image of God created them; male and female, he created them” (Genesis 1:26-27). It was against this philosophical background that Charles Darwin published *On the Origin of Species* in 1859, which included his theory of evolution by natural selection; biological variation could now be explained in totality by natural processes. Despite Darwin’s position as a prestigious scientist, the ideas of natural selection and evolution and their challenge to divine Creation were met with much hostility³⁶, even though in the *Origin*, he almost completely avoided the most contentious issue of all - the evolution of man.

Darwin was heavily influenced by the ideas of Thomas Malthus set forth in his 1798 *Essay on the Principle of Population*. In this essay, Malthus challenged the idea that human society would only get bigger and better; he presented humans as groups of individuals that are affected by the same forces of fertility and starvation as animals, and he condemned welfare laws that centred on hand-outs to the poor as only perpetuating the problem. Darwin used these principles in the *Origin* and in his work on the evolution of humans in *The Descent of Man*.

Some of Darwin’s ideas were adapted into the social policy eventually labelled as ‘social Darwinism’, which grew in popularity in the late 1800s. In 1864, Herbert Spencer,

³⁴ Wertz DC, Fletcher JC, and Berg K (2003). ‘Review of Ethical Issues in Medical Genetics’. Geneva: World Health Organization.

³⁵ O’Mathúna DP (2006). ‘Human dignity in the Nazi era: implications for contemporary bioethics’. BMC Medical Ethics 7(2).

³⁶ Van Wyhe J (2009). ‘Charles Darwin 1809-2009’. The International Journal of Biochemistry & Cell Biology 41, pp 251-253.

an enthusiastic evolutionist, coined the phrase ‘survival of the fittest’. This concept came to be linked with social Darwinism, as they share core components: (1) that biological laws govern all nature including humans; (2) that world resources are scarce and acquired by those who are fittest; and (3) that the fittest survive to reproduce³⁷. Darwin’s theory proposed that traits that have higher fitness are inherited more often, and through the process of natural selection for such traits we get evolution. *Social Darwinism* then applies all of these components to human culture, including religion, psychology and ethics³⁸.

These new trends in thinking served to alter the way that many prominent Western figures valued human life. Spencer advocated survival of the fittest as the rule for society, rejecting policies that provided care and support for the sick³⁹. Ernst Haeckel, scientist and author, was even more vehement in his beliefs – he believed that the value of a person was dependent on their fitness and the value of their potential contribution to society; he supported infanticide, abortion, assisted suicide and the involuntary euthanasia of psychologically and physically ill people⁴⁰. The assumptions underlying social Darwinism trend towards a devaluation of human life⁴¹, and have been used to justify such horrors as human experimentation in Nazi concentration camps.

This devaluation was not confined to extreme dictators. In 1904, Francis Galton published *Eugenics: Its Definition, Scope and Aims*, with the intention of introducing a new branch of science that would study genetic qualities and improve human races⁴². By the 1920s, there were eugenics movements across the world, supported by scientists and politicians from all sides⁴³. It was a movement founded on bad science, totally disregarding the complexity of genes and environmental factors, but before it could be scientifically discredited around 60,000 Americans were forcibly sterilised⁴⁴, under the

³⁷ Claeys G (2000). ‘The “Survival of the Fittest” and the Origins of Social Darwinism’. *Journal of the History of Ideas* 61(2), pp 223-240.

³⁸ O’Mathúna DP (2006). ‘Human dignity in the Nazi era: implications for contemporary bioethics’. *BMC Medical Ethics* 7(2).

³⁹ Claeys G (2000). ‘The “Survival of the Fittest” and the Origins of Social Darwinism’. *Journal of the History of Ideas* 61(2), pp 223-240.

⁴⁰ Ibid.

⁴¹ O’Mathúna DP (2006). ‘Human dignity in the Nazi era: implications for contemporary bioethics’. *BMC Medical Ethics* 7(2).

⁴² Galton F (1904). ‘Eugenics: Its Definition, Scope and Aims’. *American Journal of Sociobiology* 10(1), pp 1-25.

⁴³ Wikler D (1999). ‘Can We Learn from Eugenics?’. *Journal of Medical Ethics* 25(2), pp 183-194.

⁴⁴ Norrgard K (2008). ‘Human testing, the eugenics movement, and IRBs’. *Nature Education* 1(1).

practise of coercive negative eugenics, which sought to prevent people with undesirable genes from procreating⁴⁵.

Modern-day ethics concerning value centres on the inherent dignity of the individual. The etymological root of the word 'dignity' is the Latin *dignitas*, which means worth, so when discussing the inherent dignity of human beings, this can be taken to mean the intrinsic worth of people; that is, to award each of us an automatic, unquestionable value. The general consensus, as first declared by Thomas Jefferson in the US Declaration of Independence, is that "all men are created equal". The first sentence of the preamble to the Universal Declaration of Human Rights is "...recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world"⁴⁶; similarly, the UN Declaration on Bioethics and Human Rights, Article 10, states that "The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably"⁴⁷. It is using instruments such as these that governments form and refine social policies. If we uphold that all human life has equal value, there are some difficult questions to be answered in respect of some contemporary technologies.

The point at which human life begins in the development of an embryo is one such question. The current legal definition in the UK of a human embryo is a developing human from fertilisation up to eight weeks, at which point it becomes a foetus. Cloning and IVF technologies need another sort of definition: "a totipotent single-cell, group of contiguous cells, or a multicellular organism which has the inherent actual potential to continue species-specific ie. typical, human development, given a suitable environment"⁴⁸. Embryonic stem cells are primitive cells derived from blastocyst-stage embryos that develop in culture within five days of fertilisation⁴⁹, and are commonly used in therapeutic research.

⁴⁵ Buchanan A (2007). 'Institutions, Beliefs and Ethics: Eugenics as a Case Study'. *The Journal of Political Philosophy* 15(1), pp 22-45.

⁴⁶ UN General Assembly (1948). 'Universal Declaration of Human Rights'. [online] <http://www.unhcr.org/refworld/docid/3ae6b3712c.html> [Accessed 15 August 2012].

⁴⁷ United Nations Educational, Scientific and Cultural Organization (1997). 'Universal Declaration on the Human Genome and Human Rights'. [online] http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 17 August 2012].

⁴⁸ Cameron C, and Williamson R (2005). 'In the world of Dolly, when does a human embryo acquire respect?'. *Journal of Medical Ethics* 31, pp 215-220.

⁴⁹ Wert GD, and Mummery C (2003). 'Human embryonic stem cells: research, ethics and policy'. *Human Reproduction* 18(4), pp 672-682.

Stem cell research raises two main objections: (1) that it is ethically wrong in itself to destroy human embryos; and (2) stem cell research is not wrong in itself but it will begin us on the slippery slope to the commodification – and devaluation – of human life⁵⁰. The key question is, does the destruction of human embryos equal killing human beings? There are those that maintain it does; for example, the Roman Catholic Church, which believes that life begins at conception, so the destruction of each embryo is treated with the same severity as abortion (the destruction of a foetus)⁵¹. Proponents of ‘embryo objection’ insist that as scientists can give no definitive moment for the beginning of life, we should treat embryos as we treat ourselves who came from embryos – as humans with inherent value and dignity⁵².

PGD is another genetic technology that uses embryos. The aim of PGD is to avoid the implantation of embryos at a high risk of genetic disease, thus avoiding the agonising choice between elective abortion or raising a disabled child. Generally, embryos are considered so primitive that they do not have human interests or rights⁵³, a view echoed in national policies. The UK Government’s Committee of Inquiry into Human Fertilisation and Embryology ruled that up to fourteen days after fertilisation an embryo is a pre-embryo and does not require protection under law; the American Society for Reproductive Medicine agreed. In these countries, stem cell research is permitted up until day fourteen of the embryo’s development, when the primitive streak appears, a stage associated with the beginning of neural development⁵⁴. There is public support for health-related PGD: a series of US studies found that 68% of Americans approved of PGD to select for children without genetic disease⁵⁵. Therefore, despite ethical objections, it would appear that the current consensus is that embryos are not afforded the same value

⁵⁰ Sandel MJ (2004). ‘Embryo Ethics – The Moral Logic of Stem-Cell Research’. *New England Journal of Medicine* 352, pp 207-209.

⁵¹ Cameron C, and Williamson R (2005). ‘In the world of Dolly, when does a human embryo acquire respect?’. *Journal of Medical Ethics* 31, pp 215-220.

⁵² Sandel MJ (2004). ‘Embryo Ethics – The Moral Logic of Stem-Cell Research’. *New England Journal of Medicine* 352, pp 207-209.

⁵³ Fasouliotis SJ, and Schenke JG (1998). ‘Preimplantation genetic diagnosis and ethics’. *Human Reproduction* 13(8), pp 2238-2245.

⁵⁴ Cameron C, and Williamson R (2005). ‘In the world of Dolly, when does a human embryo acquire respect?’. *Journal of Medical Ethics* 31, pp 215-220.

⁵⁵ Hudson KL (2004). ‘Preimplantation genetic diagnosis: public policy and public attitudes’. *Fertility and Sterility* 85(6), pp 1683-1645.

and rights as a human – although this does not automatically mean they should be treated carelessly or with moral indifference⁵⁶.

The question of how genetic technologies challenge the value of human life is also relevant to another group: existing disabled people. Many disability rights advocates oppose technologies such as PGD and gene therapy: “If prenatal diagnosis is used as a tool to eradicate as many disabilities as possible in society then it does discriminate against people with disabilities: those who are already living with disabilities and those potential babies who may have lived very successfully with disabilities”⁵⁷. The primary concern involves increased discrimination and devaluation resulting from the reduction in the number of people with disabilities – the fear is that a lower representation in society will lead to less funding and provisioning, as well as negative social attitudes towards couples who reject the option of PGD and have children with genetic diseases^{58,59}. Additionally, those who are already living with disability may feel demoralised, as they are reduced from a person to a single genetic trait. However, these negative outcomes are not a foregone conclusion. For a start, most disabilities arise from injury or non-genetic disease, so there is unlikely to be a significant decrease in the representation of disabled people in society. More significantly, any potential decrease in representation does not mean an automatic devaluation of those who are disabled, and does not mean we should discourage PGD on moral grounds; rights such as the parental right to exercise procreative freedom and the ethical advantages of improving the wellbeing of populations would probably outweigh a potential increase in discrimination^{60,61}.

⁵⁶ Sandel MJ (2004). ‘Embryo Ethics – The Moral Logic of Stem-Cell Research’. *New England Journal of Medicine* 352, pp 207-209.

⁵⁷ McKie R (1997). ‘Scientists clone adult sheep – Triumph for UK raises alarm over human use’. *The Observer* [online]. <http://www.guardian.co.uk/uk/1997/feb/23/robinmckie.theobserver> [Accessed 15 August 2012].

⁵⁸ Croyle RT (1998). ‘The new genetics: Psychological responses to genetic testing’. *British Medical Journal* [online] <http://www.bmj.com/content/316/7132/693.full> [Accessed 7 September 2012].

⁵⁹ Gillam L (1999). ‘Prenatal diagnosis and discrimination against the disabled’. *Journal of Medical Ethics* 25, pp 163-171.

⁶⁰ Ibid.

⁶¹ Petersen TS (2005). ‘Just diagnosis? Preimplantation genetic diagnosis and injustices to disabled people’. *Journal of Medical Ethics* 31, pp 231-234.

Identity – the right to know who and what we are

The greatest opposition raised against any potential genetic technology is afforded to human cloning, with doubts raised from all corners of society⁶². Opposition is greatest from religious groups, with the majority supporting a law against human cloning⁶³. Currently, human cloning is endorsed for therapeutic research into diseases or injury that have no other potential treatments. Following the creation of Dolly the sheep, there have been fears that human cloning could lead to ‘photocopying’ and mass production, *Brave New World*-style, and an imminent loss of human identity⁶⁴ – but are fears about genetic technologies altering our human identity genuine, or are they skewed by the media, books and films seeking to make sales by dramatising the possible outcomes?

Assuming that there is no bodily harm caused to a cloned child, there are still the unknown potentials for psychological or psychosocial harm, which as yet cannot be predicted⁶⁵. Instinctively, many automatically reject human cloning as a repugnant idea that constitutes a denial of individuality. Ian Wilmut, leader of the team that created Dolly, declared that a unique genome is essential to individuality; if one has the same DNA as another they will be forever viewed as a copy and have a severely reduced sense of identity. However, this argument is immediately countered by anyone who has experience of monozygotic – identical – twins. Identical twins have identical genotypes and strikingly similar appearances, but each twin is treated as an individual, with their independent rights and freedom. To have the same genotype as another, then, is not to say you are not an individual. This thinking can readily be applied to cloning; cloning may produce copies of the same genotype but can never produce copies of the same individual person, because it is not only a genotype that makes a person who they are. Genetic identity, thus, is not an essential component of personal identity or individuality⁶⁶.

Social science defines personal identity as the collection of attributes that make someone a unique person, especially as understood by themselves; it is a concept of

⁶² Roberts MA (1996). ‘Human cloning: A case of no harm done?’. *Journal of Medicine and Philosophy* 21(5), pp 537-554.

⁶³ Bainbridge W (2003). ‘Religious opposition to cloning’. *Journal of Evolution and Technology* 13.

⁶⁴ Petersen A (2002). ‘Replicating Our Bodies, Losing Our Selves: News Media Portrayals of Human Cloning in the Wake of Dolly’. *Body and Society* 8(71).

⁶⁵ Roberts MA (1996). ‘Human cloning: A case of no harm done?’. *Journal of Medicine and Philosophy* 21(5), pp 537-554.

⁶⁶ Harris J (1997). ‘“Goodbye Dolly?” The ethics of human cloning’. *Journal of Medical Ethics* 23, pp 353-360.

identity as “uniqueness in relation to others”⁶⁷. The International Declaration on Human Genetic Data, Article 3, on Personal Identity, states: “Each individual has a characteristic genetic make-up. Nevertheless, a person’s identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom”⁶⁸. These definitions support the view that no person is purely the product of their genetic identity – personal identity is founded in life experiences such as education or becoming a parent, as much as inherited traits such as freckles or eye colour, and many traits are influenced by both, such as height and general health. On the basis of these definitions of personal identity, it is impossible to reject human cloning as an affront to individuality through identical genotypes.

A more ethically worrying question is whether or not the identity of a saviour child is undermined by the *reason* why they are brought into existence. A study of public opinion regarding saviour siblings in Germany found that German citizens believe family relationships and dynamics to be complex, and that individuals should therefore have the autonomy to decide for themselves, not have their identity as a saviour sibling decided before birth; saviour siblings are prohibited in Germany. At the same time, the same study found that Israeli culture deems saviour siblings to be a gift whose identity will be enhanced as they are a blessing for all members of the unified body of the family; PGD for saviour siblings is supported in Israel⁶⁹. The main question is: will a child born via PGD to be a saviour sibling have their own identity contradicted by this instrumentalisation? Various studies have found no reason to believe that parents who apply for permission to save their sick child via this method would not be equally loving and committed to the new child^{70,71}.

⁶⁷ Brey P (2008). ‘Human Enhancement and Personal Identity’. In ‘New Waves in Philosophy of Technology’, eds. Berg Olsen J, Selinger E, Riis S. New Waves in Philosophy Series, New York: Palgrave Macmillan.

⁶⁸ United Nations Educational, Scientific and Cultural Organization (1997). ‘Universal Declaration on the Human Genome and Human Rights’. [online] http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html [Accessed 17 August 2012].

⁶⁹ Hashiloni-Dolev Y, and Shkedi S (2007). ‘On new reproductive technologies and family ethics: Pre-implantation genetic diagnosis for sibling donor in Israel and Germany’. *Social Science and Medicine* 65(10), pp 2081-2092.

⁷⁰ Pennings G (2004). ‘Saviour siblings: using preimplantation genetic diagnosis for tissue typing’. *International Congress Series* 1266, pp 311-317.

⁷¹ Sheldon S, and Wilkinson S (2004). ‘Should Selecting Saviour Siblings Be Banned?’. *Journal of Medical Ethics* 30(6), pp 533-537.

Another issue to consider is how genetic enhancement may impact on personal identity. It is likely that genetic enhancement will have an effect on identity if it changes the abilities or characteristics of the person – that person will obviously define themselves differently from people without those abilities or characteristics, as with normal genetic variation⁷². Self-identity and self-esteem are morally and socially important as they determine how a person feels about themselves⁷³ – if we can enhance traits, such as intelligence, which increase our self-esteem and well-being, a person may in turn have an enhanced sense of personal identity. The desire to improve, whether it be to support our children to have greater intelligence or to exercise our way to the ideal body, and the drive to further our knowledge and unravel the mystery of our existence, are part of human nature⁷⁴. For these reasons, some believe that human enhancement via genetics is an inevitable path^{75,76}. However, the consensus of the general public does not support, and has strong concerns over, the idea of genetic enhancement for non-health reasons^{77,78}.

There are those who uphold that improving humans is not only an inevitable and positive advance but is a moral obligation^{79,80,81}. Julian Savulescu is a University of Oxford bioethicist who is particularly vocal concerning this issue; he advocates that parents are obligated to choose the best child they can have – “procreative beneficence” – and if genetic enhancement for traits such as intelligence and confidence is available then parents should choose these, rather than leave it to chance. This rationale, however, may be contradicted by the market forces which would allow genetic enhancement to become a possibility; if we turn genetic characteristics such as height and intelligence into a

⁷² Brey P (2008). ‘Human Enhancement and Personal Identity’. In ‘New Waves in Philosophy of Technology’, eds. Berg Olsen J, Selinger E, Riis S. New Waves in Philosophy Series, New York: Palgrave Macmillan.

⁷³ Ibid.

⁷⁴ Baylis F, and Robert JS (2004). ‘The inevitability of genetic enhancement technologies’. *Bioethics* 18(1), pp 1-26.

⁷⁵ Ibid.

⁷⁶ Stock G (2002). ‘Redesigning humans: our inevitable genetic future’. New York: Houghton Mifflin Company.

⁷⁷ Hudson KL (2004). ‘Preimplantation genetic diagnosis: public policy and public attitudes’. *Fertility and Sterility* 85(6), pp 1683-1645.

⁷⁸ Condit CM (2010). ‘Public Attitudes and Beliefs About Genetics’. *Annual Review of Genomics and Human Genetics* 11, pp 339-359.

⁷⁹ Savulescu J (2005). ‘The ethics of cloning’. *Medicine* 33(2), pp 18-22.

⁸⁰ Savulescu J (2001). ‘Procreative Beneficence: Why We Should Select the Best Children’. *Bioethics* 15(5-6), pp 413-426.

⁸¹ Harris J (2007). ‘Enhancing Evolution: The Ethical Case for Making Better People’. New Jersey: Princeton University Press.

commodity, these traits become a social, rather than a natural, good and will no longer be used as markers of one's identity – instead, they will become markers of wealth for those who can afford to buy them. This returns us to the concern over genetic enhancement causing increased social inequality, which would undoubtedly be bad for the personal identity of those unable to afford enhancements.

Case in point – mitochondrial replacement technology

The most recent genetic announcement to hit UK headlines is that scientists now believe it is possible – and safe – to prevent mitochondrial disease by using donor mitochondrial DNA (mtDNA) to replace that of the mother⁸². Mitochondrial disease can have debilitating and often fatal symptoms including visual impairment, kidney failure and premature death caused by heart and lung disease⁸³. The proposed solution to this comes in the form of two techniques: pro-nuclear transfer (PNT) and maternal spindle transfer (MST). PNT involves transferring the pro-nuclei from the fertilised embryo that has faulty mtDNA into an embryo donated with healthy mtDNA. MST involves transferring the maternal spindle from the mother's egg into the healthy donor egg, which can then be fertilised with the father's sperm. The primary difference in the procedures is that in MST eggs are destroyed, whereas in PNT embryos are destroyed⁸⁴. Controversially, in both cases the resulting children will have DNA from three people: their mother, their father and the mtDNA donor⁸⁵.

The Nuffield Council on Bioethics has already performed an ethical review of this new technology, as a change in the law would be required for the procedure to go ahead in the UK. The review addressed issues such as identity and autonomy, and the overriding consensus is clear, as summed up by Dr Geoff Watts, the Chairman of the Nuffield Council Enquiry: "If further research shows these techniques to be sufficiently safe and effective, we think it would be ethical for families to use them if they wished to, provided they

⁸² Walsh F (2012). 'Ethics of using three peoples' DNA to create one baby'. BBC [online] <http://www.bbc.co.uk/news/health-19604004> [Accessed 19 September 2012].

⁸³ Human Fertilisation and Embryology Authority (2012). 'Medical Frontiers: debating mitochondria replacement'. HFEA [online] <http://mitochondria.hfea.gov.uk/mitochondria/> [Accessed 19 September 2012].

⁸⁴ Ibid.

⁸⁵ Walsh F (2012). 'Ethics of using three peoples' DNA to create one baby'. BBC [online] <http://www.bbc.co.uk/news/health-19604004> [Accessed 19 September 2012].

receive an appropriate level of support”. This review was published early in 2012, and now the evidence exists that there should not be any safety concerns⁸⁶.

The debate over ethical concerns has moved to the UK Human Fertilisation and Embryology Authority, which has opened a public consultation on the matter⁸⁷. The consultation addresses many of the same questions as the Nuffield review. The issue of freedom once again is crucial. Is it right to remove the prospective child’s autonomy by making a decision on its behalf? Does a child that does not already exist have such a right? In this case, it would appear that the reproductive autonomy of the parents should outweigh the child’s, because the ultimate goal is to protect their future child from potential harm. Likewise, it is difficult to see how this technology would challenge the value of the child – this is implied by the fact that the parents wish to embark on such a process.

The main cause for concern is the identity of a child born with DNA from three different people: their mother, their father, and an unknown donor. As we concluded earlier that genetic identity is not the same as personal identity, it would be contradictory to conclude that having mtDNA from a donor would have a negative effect on how the child will view itself in the future. The Nuffield review echoes this – “the brand of battery does not affect the functioning of the camera”⁸⁸. Additionally, research carried out on children who have been conceived from a donor egg or sperm suggests that there are no detrimental effects on their sense of identity, as long as they are made aware relatively early in life⁸⁹. The effects of mitochondrial DNA are limited to the mitochondria, only noticeably affecting the phenotype if it has a faulty mutation. With this in mind, it is easy to compare to tissues such as blood or bone marrow, which are frequently donated. The difference is that the mtDNA will be passed onto future generations through the maternal line, but if there is no effect on the health or characteristics of the progeny, does this matter?

⁸⁶ Ibid

⁸⁷ Human Fertilisation and Embryology Authority (2012). ‘Medical Frontiers: debating mitochondria replacement’. HFEA [online] <http://mitochondria.hfea.gov.uk/mitochondria/> [Accessed 19 September 2012].

⁸⁸ Nuffield Council on Bioethics (2012). ‘Novel techniques for the prevention of mitochondrial disorders: an ethical review’. London: Nuffield Council on Bioethics.

⁸⁹ Human Fertilisation and Embryology Authority (2012). ‘Medical Frontiers: debating mitochondria replacement’. HFEA [online] <http://mitochondria.hfea.gov.uk/mitochondria/> [Accessed 19 September 2012].

This case study is important to the ethics of genetic technologies. If the public and politicians support mitochondrial transfer and the law is amended, the children born using this technique will be the first from genetically modified embryos. A significant line will be crossed, and the slippery slope argument will be once again in play, as concerns that it is a first step on the road to genetic enhancement will be voiced⁹⁰.

Conclusion – human freedom, value and identity are inherent regardless of genetics

This essay has explored how developments in genetic technology may impact our notions of human freedom, value and identity. We have found that there is undoubtedly potential for genetic technologies to be abused and cause harm to the autonomy and value of persons, if we do not address issues such as biased genetic counselling before they occur. However, we have also found that genetic technologies do not challenge our personal identity as much as many initially feared. No person should be reduced to their genetic make-up – our identity is much more than the content of our genome.

All human life should be valued as equal, no matter how we may enhance it, and it is part of our freedom and reproductive autonomy to choose whether or not to do so. Clear information, education and alternatives should always be available so that parents can make the choice best for them and their children. In light of concerns regarding disability discrimination and social inequality, there should be continued support to reiterate the value, equality and inherent dignity of *all* human life.

“It is the prospect of genetic engineering that helps us to appreciate what it means to be human: it means to be mortal, to be imperfect, to be flawed. It also means to wish to be better.”⁹¹

⁹⁰ Nuffield Council on Bioethics (2012). ‘Novel techniques for the prevention of mitochondrial disorders: an ethical review’. London: Nuffield Council on Bioethics.

⁹¹ Dyer AR (1997). ‘The Ethics of Human Intervention: A Postmodern Perspective’. *Experimental Neurology* 144, pp 168-172.