Introduction

The genetic lottery of life

I was born in 1970. And the generation of children born in that year entered the world in the same way all previous generations of humans ever had. Namely, we inherited our genetic endowments from our parents, our parents had inherited their genetic endowments from their parents, etc. The life prospects of the babies born in 1970 were profoundly influenced by this 'genetic lottery' of life. Children born with infantile or early-onset Tay-Sachs disease typically died by five years of age. People born with a mutation of the *FMR1* gene developed fragile X syndrome, the symptoms of which can vary from slight learning disabilities to mental impairment. No one deserves the genes they are born with. The results of the genetic lottery are arbitrary and they are often tragic, both for the victims themselves and their loved ones and families. In 1970 there was no real prospect that humans could directly intervene in this natural lottery to alter our health prospects.

When my eldest son was born in the year 2000, just thirty years after I was born, the story of the genetic lottery of life had changed in significant ways. The first child to receive somatic cell gene therapy, Ashanti DeSilva, had already done so a decade earlier. The first gene therapy intervention began on 14 September 1990. Ashanti 'was the first of two children to receive a dose of her own cells in which a functioning counterpart of her malfunctioning gene had been previously inserted' (Walters and Palmer 1997: 17). The subjects of the earliest gene therapy experiments were children who suffered from a rare genetic disease called adenosine deaminase (ADA) deficiency.

Over 1,800 gene therapy clinical trials have been completed, are ongoing, or have been approved worldwide (Ginn 2013). These include trials for treatments for a host of diseases and disorders, including Parkinson's disease, HIV, congenital blindness, and cancer. Rapid advances are also being made with respect to a possible 'anti-ageing' intervention for humans. Caloric restriction (CR) has been studied for

decades in a variety of species (like mice) and is shown to extend lifespan. CR induces stress response pathways in organisms, which results in longer life by slowing the rate of molecular and cellular decline. What is truly exciting about CR is not that organisms simply live longer. Longer life is not necessarily desirable, especially if it is achieved by simply keeping an organism alive in a frail and incapacitated state. But CR does the opposite of this. It extends life by keeping an organism *healthy* for a longer period of time. Reducing normal calorie intake by about 30 per cent can increase maximal lifespan by approximately 30–40 per cent. CR delays and even eliminates many of the problems of senescence. This has led some scientists, including Robert Butler, the first director of the National Institute on Aging, to propose age retardation as a new model of health promotion (Butler *et al.* 2008).

Caloric restriction is too burdensome to be pursued as an 'anti-ageing' intervention for human populations, but the prospect of developing a drug that mimics CR might be a viable way to safely and effectively retard ageing. Two potential drug interventions that are now being extensively studied are those which activate the sirtuin genes (sirtuins are proteins that are activated by CR) and drugs which target a protein called TOR (*t*arget *o*f *r*apamycin). Rapamycin (also known as sirolimus) is a drug that was developed from a bacterium found in soil on Easter Island. It is currently used to help prevent the rejection of transplanted organs in patients undergoing organ transplant. But recent experiments have found that consuming rapamycin can extend lifespan, including in mammals. The most significant study (Harrison *et al.* 2009) was published in the journal *Nature* in 2009. In that study mice that were already 600 days old (which is roughly equivalent to a sixty-year-old human) were fed rapamycin. This intervention increased the median and maximal lifespan of both male and female mice.

Another avenue of biogerontological research is the study of the 'longevity genes' in centenarians (age ≥100) and supercentenarians (age ≥110). Individuals that live such exceptionally long lives also experience a compression of morbidity in late life (Andersen *et al.* 2012, and Perls 1997). The development of a drug that activates the longevity genes these rare individuals enjoy could add decades of healthy life and improve the average person's health prospects.

The idea that we could directly alter the biology of a person via genetic intervention, or develop an 'anti-ageing drug', or utilize genetic tests for screening genetic diseases (or for non-medical purposes such as sex selection for embryos) would have been considered pure science fiction just a few decades ago. And yet all these prospects either have become, or might soon be, a reality. And as science progresses we may be able to

promote the health prospects of the current generation (and all future generations) by improving our biological capacity to fend off infectious and chronic diseases.

I began working on this book in the year 2000. That was the same year two rival teams were racing to sequence the human genome. The 'race' to sequence the genome ended in February 2001 when the two teams published their draft versions of the human genome. The publicly funded Human Genome Project published its results in the scientific journal *Nature*,[1] while the private US firm Celera Genomics published its results in *Science*.[2] As I began to follow the field of human genetics, and to think about the importance of science more generally, I realized that there was very little written by political theorists on these topics. Over the years the neglect of science, especially the biomedical sciences, began to trouble me more and more. It troubled me both as a teacher and as a scholar.

As a teacher I found it disturbing that my students learned about topics such as justice, freedom, and equality but did not really learn about the important role science and innovation play in helping humanity create more fair and humane societies. Current debates about distributive justice often give students the impression that justice only involves the distribution of wealth and income, or giving priority to basic liberties like free speech. But government decisions to stifle or promote basic and applied scientific research can also have profound impacts on our life prospects. What constitutes 'well-ordered' science?[3] Would we know *unjust* science policies when we see them? Neglecting these issues comes with great peril, as many of the most pressing challenges humanity faces this century will require new knowledge and innovation.

The divide between theoretical discussions of justice and the topics of science and science policy also troubled me as a scholar. My plans to write a book on genetics and justice were stifled and continually delayed by the fact that these issues do not fit neatly into the theoretical positions and discussions that have dominated debates in political theory for the past four decades. Most theorists presuppose that justice requires us to distribute things *external* to us (e.g. wealth, education, legal rights, etc.). So how could we make sense of the idea of extending the domain of justice to include the distribution of things *internal* to our own biology, like our genes?

[1] See International Human Genome Sequencing Consortium (2001).
[2] See Venter *et al.* (2001).
[3] 'The pursuit of science is well-ordered when the research effort is efficiently directed toward the questions that are most significant to answer' (Flory and Kitcher 2004: 59).

At first I tried to simply extend existing theories of justice to help bridge this divide by adding our genetic constitutions as one more *resource* to be added to the list of resources justice requires us to fairly distribute. But I soon realized that this approach was deeply problematic, for at least two reasons. Firstly, as the science was very new, and the potential applications uncertain, there was a danger of *over-hyping* one's conclusions if one just assumed that successful genetic interventions would be realized within the next few years. Of course, one could just add 'simplifying assumptions' to one's analyses, like the assumption that such interventions could be easily, safely, and cheaply developed, but that seemed to me to run counter to what a theory of justice aspires to do. Namely, provide some practical guidance to help us address the challenges we face in the 'here and now'. I wanted to develop an 'interim' theory of justice, one that addressed the dilemmas that arise for societies that find themselves in the situation between complete ignorance about the role genes play in different phenotypes and a futuristic scenario where biological knowledge will be successfully utilized to develop a host of safe and effective biotechnologies for humans.

The second difficulty I encountered as I developed this project was my realization that normative theories which functioned at a very abstract level of *idealization*[4] (O'Neill 1996: 41) actually impaired, rather than enhanced, our deliberations about justice. For example, if one assumes, as John Rawls did in his original book *A Theory of Justice*, that the principles of justice should be derived via assumptions, such as everyone is healthy, then the topic of genetics and justice is already moot. Indeed, I believe this is part of the reason why many normative theorists do not take human biology (or science) very seriously. Our theories and debates have, from the outset, been framed in ways that neglect important empirical realities, like the existence of infectious and chronic disease or population ageing.

Rather than simply extending existing theories of justice to encompass the new developments of the genetic revolution, I came to the conclusion that the genetic revolution that was unfolding around us required political theorists to *re-think* the basic premises of what the demands of justice are, as well as what we wanted or expected from our theories of justice. Rather than opting for an 'add genetics and stir' approach, I decided to start afresh, and to use the genetic revolution as a way of bringing to the fore some methodological concerns which I believe theorists ought to give more consideration to. Hence I ended up opting for a *contextual*

[4] Idealization involves making claims that are actually false, in order to simplify an argument.

approach. This approach takes human biology seriously (e.g. our susceptibility to different kinds of disease), and draws the theorist's attention (rather than blinding her) to a number of relevant considerations (e.g. limited public funding available for basic research).

An editorial in the journal *Nature* notes that 'the relationship between the social sciences and the natural sciences has historically been fraught'. However, the pace of scientific advancements, coupled with pressing societal concerns like climate change, is beginning to chip away at the barriers that traditionally separate these academic disciplines.

> There remains something of a dialogue of the deaf between these two wings of the academy, separated as they are by language, custom and methodology. But barriers are coming down. Senior scientists and administrators, especially those in socially contentious areas such as climate change and reproductive technologies, realize that they need to collaborate with scholars of society-at-large. Sociologists and philosophers of science, in turn, are acquiring a more intimate understanding of the scientists that they study.
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> (Editorial 2009: 825–826)

The intellectual gulf that exists between the humanities/social sciences and the natural sciences should be particularly troubling to political theorists. Historically, the seminal works in political theory took seriously empirical insights from diverse disciplines. What would Aristotle's contribution to political theory be, for example, if he cared little about the relevance of insights from biology? Or imagine what the state of political theory would be if Thomas Hobbes or John Locke expressed indifference to, rather than excitement about and engagement with, the scientific revolution of their day.

Political theory has a long and celebrated tradition of integrating normative reasoning with interdisciplinary empirical insights. Thus, political theorists should, like C. P. Snow, be troubled by the gulf that often exists and persists between scholars working in diverse intellectual traditions. This book attempts to help (at least partially) bridge that intellectual divide. It is written by a scholar trained in the humanities (philosophy), who now teaches in the social sciences (political science), and who teaches undergraduate and graduate-level courses that address ethical and social issues related to advances within the biomedical sciences (especially genetics and biogerontology).

For more than a decade now I have been teaching an advanced seminar on 'Science and Justice', which focuses on biotechnology and the genetic revolution, to graduate-level students in (mostly) political science and philosophy (at Manchester University, Waterloo University, and Queen's University) as well as in public policy (at UCLA in the fall of 2013). Each year I begin the course by getting students to participate

in a mini deliberative democratic experiment. Before the class discusses any specific topics in the course, I ask the students to write down their initial ('knee-jerk') reaction to a number of different questions which engage their moral sensibilities on the topics we will address in greater detail during the course.

At the end of the year I return to the students their initial answer sheet, and I ask them to consider the same questions again, only this time to answer the questions in much greater detail. In their more detailed answers at the end of the course, students can explain how their views changed after they read specific writings on these topics, or discussed and debated the topics with other students on the course. Some students change their answers from their original answers, but even those that hold the same position often explain they better understand their own position as well as the most compelling reasons why anyone would hold an opposing opinion.

Below I reproduce five of the questions I typically ask at the start of the course each year, which the reader might find useful as a primer for some of the topics to be addressed in Parts I and II of this book.

(1) It is often claimed that a fair society should be judged by how well it treats its *least advantaged members*. How would you describe who the least advantaged members of your society are?
(2) Which statement best captures your attitude towards disease.
    (a) Justice requires us to search for treatments or a cure for disease. This duty of justice is so stringent that we should utilize public funding (raised through taxation) to fund the basic science that might lead to these discoveries.
    (b) It is unfortunate that people develop disease. But society is not obligated to help (as a matter of justice) these people. If people want to voluntarily donate money to fund cancer research, that is their prerogative, but the government should not compel people (via taxation) to fund this research.
    (c) I do not agree with either (a) or (b).
(3) Many different things contribute to a person's overall well-being or welfare. For example, one's wealth, education, job, friends and loved ones, health, etc.
    How important do you think the genes you were born with are to your life prospects?
(4) Do you think parents undergoing in vitro fertilization (IVF) should be legally permitted to utilize preimplantation genetic diagnosis to test embryos for their sex (for non-medical purposes)? In other words, should parents with a strong desire to have a boy or a girl have

the freedom to screen the viable embryos and decide to implant only those embryos of the sex they most desire?

(5) Ageing has a profound impact on a person's health prospects. As adults age, their risk of cancer, diabetes, stroke, Alzheimer's disease, bone fracture, infection, etc. increases. Which of the following statements best captures your attitudes towards ageing?
   (a) Ageing is perfectly natural and we should not intervene in our biology to change this natural process.
   (b) Because many diseases are age-related diseases, we have a duty of justice to retard the rate at which we age and thus postpone age-related disadvantage.
   (c) Ageing itself is a disease. And just like cancer or diabetes, we should search for a cure to ageing so that no person will be incapacitated or die from ageing.
   (d) None of the above sounds sensible to me/OR I am not sure what I believe.

For many students in the humanities and social sciences, the five questions I ask them to contemplate, with the exception of the first question, are ones they have not previously encountered, let alone seriously considered. As such, the initial answers they provide are often based on whatever intuitions they think it is appropriate to invoke in the case at hand.

Students of political theory will have encountered the first question, concerning who are the least advantaged, before. Most of them typically identify 'the poor' (in either absolute or relative terms) as the least advantaged. Others might supplement this with further categories like 'marginalized groups' (such as national minorities or visible minorities). In my experience, very few students specifically mention persons born with disadvantageous genetic endowments. That is, deleterious genetic mutations that lead to, or significantly increase the probability of developing, disease. I believe this reflects the fact that most contemporary theoretical debates about distributive justice focus primarily on the distribution of material goods, such as wealth and income.

A basic type of 'categorical thinking' commonly employed in political theory is to divide members of society into those that are privileged (e.g. the rich, members of the majority culture, men, etc.) and those that are disadvantaged (e.g. the poor, minority groups, women, etc.) by some metric of distributive justice. Biologically modified justice requires us to transcend (though not completely abandon) some of these categorical divisions when we turn our attention to the *natural* as well as social determinates of health.

When it comes to those born with single-gene disorders (such as cystic fibrosis or Huntington's disease) or the 'longevity genes' associated with exceptional longevity (e.g. centenarians and supercentenarians), we shall see that genetics does play a very significant role in determining a person's health prospects. How should this fact influence our determination of what the duty to aid those vulnerable to suffering and disease requires?

When answering the second question, concerning the relationship between scientific research/medical interventions and justice, I have found that many students tend to once again invoke the moral sensibilities they have concerning the distribution of wealth and income. Students that believe the state can legitimately impose taxation on the citizenry to provide affordable housing, education, and job re-training for the unemployed see answer (a) as a logical extension of their moral sensibilities. Whereas students partial to a libertarian 'minimal' state conception of justice will answer (b).

In my experience, most students in the humanities and social sciences simply do not know what to make of question 3. They know what genes are but are unsure of how important they are for particular phenotypes (e.g. health, happiness, intelligence, etc.). They know that environment is very important. For example, being born into a rich or poor family or country has a profound impact on one's life prospects. Most assume that environment is much more significant than the genetic endowments they inherit from their parents.

Reproductive freedom is a topic many students are passionate about. Abortion, for example, is a very topical issue and most students (at least at the universities that I have taught at) consider reproductive freedom, especially a woman's right to make decisions affecting her body, a fundamental liberty. But when asked about the scope and limitations of reproductive freedom when considering new technologies such as sex selection, students have vastly different opinions. Some worry that sex selection will create a sex imbalance between males and females. Others worry that such a practice will further entrench patriarchal practices, and still others believe such technologies should be banned because it is simply 'creepy' for parents to try to determine the sex of their offspring.

By far the question that stumps my students the most concerns ageing. Most assume that any talk of intervening in ageing is just pure science fiction, and only a few have an accurate understanding of the magnitude of the impact ageing has on a person's health prospects. Again, students will point out that being born into a rich family (or country) versus a poor family (or country) can significantly impact

your health prospects. But they have little understanding of the different morbidity and mortality risks that a person over age sixty-five faces, compared to, for example, a person who is aged twenty-five, or even a child that is aged five.

The influence of John Dewey

My experiences of teaching a course on ethical and social issues related to the genetic revolution have played a formative role in the writing of this book. The curiosity and interest my students have taken in these topics, as well as their initial reaction to the questions posed above, helped convince me that political theorists should engage with these topics more than we typically do. While not a book about his philosophy, this book is very much inspired by the work of the American pragmatist John Dewey. For Dewey, education was 'the continuous reconstruction of experience' (Dewey 1916: 93). Dewey believed that the curriculum students were taught should be relevant to their lives. The first task of the philosopher is thus to address issues that arise in our times (Kitcher 2011). This book attempts to do so by integrating an analysis of normative issues with insights from the biological sciences (especially concerning the prospect of developing novel biotechnologies).

Dewey's thought was profoundly influenced by Charles Darwin's theory of evolution by natural selection. And yet a century after Dewey published *Democracy and Education* (1916), very few political theorists have followed Dewey's lead in integrating insights from evolutionary biology into their normative theorizing. Much more attention has been given to hypothetical thought experiments, like John Rawls's construction of the 'original position', or Peter Singer's analogy between helping a drowning child in a shallow pond and tackling global poverty.

While this project will address some of these theoretical devices in the chapters to come (including John Rawls and Peter Singer), I do so primarily to illustrate the *limitations* of such intellectual exercises. Rather than helping the theorist create the emancipatory knowledge needed to meet the pressing challenges of today, these thought experiments often obstruct important empirical insights that ought to weigh heavily on the normative theorist's mind. Determining what constitutes justice in today's ageing world cannot be derived from an idealized thought experiment that assumes (as Rawls did in his initial (1971) account of justice as fairness) everyone is healthy and productive. Instead, the theorist should understand why we age, how it impacts our health prospects, and the feasibility and desirability of interventions that could modulate the rate of molecular and cellular decline.

Another admirable feature of John Dewey's work is that his normative theorizing is informed by, and integrated with, teaching. Rather than writing work only for specialists in one narrow area or field, Dewey encouraged a much more ambitious and transformative approach to political theory. The Deweyian approach to education encourages 'socializing natural impulses in ways that reconstruct them as constructive and expansive rather than *reductive*, and far-ranging and comprehensive rather than exclusive' (Hickman 2006: 76). In this book I hope to socialize some of the natural impulses people might have to the prospect of directly altering our biology via genetic intervention or age retardation. To accomplish this, one must bring to the fore the relevant empirical considerations, such as the difference between extending lifespan and increasing the time people live beyond the 'biological warranty period'. A contextual inquiry of biology's relevance to political theory can help bring to the fore the diverse array of considerations that must be considered before arriving at an 'all-things-considered' judgement about the demands of morality and justice in the world today.

Biologically modified justice

A 'biologically modified' account of justice, at least the version defended in this book, is a theory of distributive justice that possesses three distinct characteristics. Firstly, it brings insights from biology to the foreground of a normative analysis of the demands of justice. The fundamental orienting assumption of biologically modified justice is Dobzhansky's claim that 'nothing in biology makes sense except in the light of evolution'. Admittedly, a theory of justice does not have to invoke the lens of evolution to know that humans must eat daily in order to survive, or that access to sanitation and essential vaccines help prevent disease and death. A theory of justice can defend rights to a minimal basic income and medicine and health care without being 'biologically modified'. All of those topics are extremely important ones, and biologically modified justice does not seek to replace or reject those basic demands of justice. Rather, biologically modified justice is meant to *supplement* and, in some cases, provoke *critical reflection* upon the more general demands of justice and the empirical assumptions upon which they are premised.

Biologically modified justice highlights those demands of morality and justice that are ignored when normative theorists fail to take biology seriously. A biologically modified account of justice extends the scope of justice beyond the confines of traditional theories of justice, because it concerns itself with the evolutionary, as well as proximate, causation of disease, health, and behaviour. This can add new moral insights into