# Introduction

The genetic self is the connected self. This claim underpins the key argument of this book, that our current ethical frameworks are flawed and actually offer little ethical protection. In fact, so limited is the dominant choice model of ethics that too often there are no effective safeguards in operation at all. If these arguments are correct, then current ethics and governance mechanisms and practices need to be transformed; and not only those of bioethics. Most obviously, systems of governance which present individual rights and goods in conflict with group goods and which promote individual rights at the expense of common and public goods need to be rethought. Mechanisms to prioritise and protect key public, common and social goods, which benefit all individuals, need to be devised and implemented with urgency if injustices are to be avoided and redressed.

The issues which *The Connected Self* addresses are important beyond genetic ethics and governance. They matter in debates about security and environmental ethics, and in all debates where there is controversy about how to balance individual and group goods.[1] It is based on the conviction that if individuals are to flourish it is necessary to recognise and respect communal and public goods as well as individual goods. The book argues that a first step in implementing appropriate ethics is to identify what harms and goods are at stake in any given situation. After this, appropriate practices can be put in place to protect relevant goods and prevent harms. This two-step process is the "ethical toolbox". This argument speaks to core concerns of contemporary public ethics and the ethical toolbox provides a means to identify and prioritise public and common goods.

How to balance such rights and goods is at the core of contemporary debates about the proper units of ethical concern (whether individuals or different types of groups), and ethical priorities. Group and public goods

---

[1] The security and environmental debates discuss how much individual choice can and should be curtailed. Parallels with the environmental debate will be used throughout to illustrate and clarify.

1

are at the heart of adequate genetic governance: for, if groups do not feature in the ethical framework then certain types of injustice are at worst invisible and at best parasitical (and secondary) to individual concerns. These conceptual concerns regarding groups and their goods speak directly to the practice and policy concerns of genetic governance: from the structure of ethical frameworks to political concerns regarding what counts as participation; to questions of ownership rights and decision-making powers in genetic governance; to traditional bioethical concerns regarding what counts as harm in research. This is because the framework which is adopted, and what *counts* as goods and harms, determines the practices which are put into place. This book proposes a framework which recognises the needs of both individuals and groups, and different types of groups, and explores the possibilities and potential problems involved in implementing such a framework. How debates about genetic governance are resolved impacts upon governance more generally and influences how individuals are envisaged and constructed in the private and public spheres.

While this book focuses on bioethics, and particularly on genetic governance, it resonates with the public ethics and governance debates more broadly and advocates frameworks of ethics and governance which respect and promote public goods and social capital and which enhance solidarity and trust. Such mechanisms fit with the claim that the genetic self is the connected self, since philosophical pictures of the self connect to the type of governance and policy which is constructed. Philosophical arguments about the nature of the self are far from "academic", especially when that word is used – oddly – to mean "irrelevant" or "unconnected to reality". In fact, philosophical views are fundamental in shaping ethical and policy claims, and in turn, policy and practice embed and ingrain dominant philosophical models. This book suggests that underlying the current dominant, and problematic, governance model is a particular philosophical picture, one of the individual as an isolated and separate, choosing self. By contrast it argues instead that a more accurate and representative model is one that presents the self in relationship, connected to significant others and wider communities and embedded in a particular context. This philosophical claim is supported by genetics – and philosophical theory provides a way to conceptualise the connected self which genetics requires.

The book begins with philosophical pictures of the connected self. It argues that these underlying pictures of the self are assumed in policy and practice and fundamentally affect the ethics and governance frameworks which are possible. However, one does not have to accept the philosophical claims to accept the ethical conclusions. But while policy makers might wish to focus on the ethical conclusions alone, only in the context

of the philosophical debate is the strength of current models properly explained. Only if one understands that the underlying pictures of the self have a huge influence on the systems which are actually put in place can one recognise and negotiate these and so make better policy likely. Thus this work is intended to be of use to both philosophers and non-philosophers. Moreover, it is hoped it will change policy and practice. Genetic governance is obviously a multi-disciplinary concern, of importance to philosophers, lawyers, scientists and policy makers. In this regard it sits well in the context of current applied ethics, particularly global ethics, where the interdependence of theory and practice is well recognised (Widdows 2012).

Too often in genetic ethics and governance the influence of the underlying philosophical pictures is neglected. This omission makes critique of current models harder, as criticisms tend to address the symptoms rather than the cause. It is no good attempting to recognise the rights of third parties in practice if one can conceive of individuals only as separate and isolated selves. For conception of the individual self as discrete from all others readily gives rise to the view that respecting individual rights should be the primary – and often the only – goal of ethics and governance. This leads to a picture of the individual in conflict with other individuals and with the community as a whole. A connected view suggests that individuals are related to and caring for other individuals, and are connected to, and embedded in, the community. This does not mean that there is never tension between individuals, and between individuals and the community, but there is not constant conflict. This book begins with an examination of the philosophical understandings of the self. It shows how these have played out in the theory of bioethics and sets out the consequences in practice. It shows that philosophical claims do matter, and matter significantly, and that changing philosophical pictures is essential to changing policy and practice.

### The claims of the connected self

*The Connected Self* presents a new argument, and admittedly a controversial one. If the argument of this book is correct, and current ethical frameworks fail to respect the connected nature of the genetic self, then essentially current dominant ethical frameworks provide little and, in some cases, effectively no ethical protection. While this book builds on and utilises discussions and claims of previous work, the argument and claims of this book represent a comprehensive new argument which begins with critiquing pictures of the self and ends with suggesting a new ethical framework for genetic governance and one which is

potentially useful for governance more broadly.[2] The argument of *The Connected Self* is built up gradually step by step. It first argues that a philosophically realistic picture of the self is not the isolated choosing self so common to much post-enlightenment philosophy. It then shows how a false philosophical picture of the self underlies bioethics, and that this has resulted in a narrow choice model of ethics. Because this is built on a false model of the self the practices of bioethics are flawed, they are unable to protect connected others and common and group goods and therefore ultimately to protect individuals. It argues that this is particularly true in the genetic era, as genetic material and information is *shared* and *identifying*. Having set out the problem it then proceeds to seek better models. Ultimately it proposes the "ethical toolbox". The ethical toolbox is a two fold procedure. Its first stage – and possibly the most important – is an analysis stage, which identifies and prioritises the goods which should be protected and the harms which should be avoided in any given situation. The second stage is fitting appropriate ethical tools to these harms and goods, beginning with the most significant. The ethical toolbox is easily implemented, it is reflexive and it is responsive. It protects the connected self and, because it is built on better philosophical pictures of the self, results in a framework which contributes to social capital and engenders trust.

### The structure of the connected self

To make this argument the book begins, in Chapters 1 and 2, by assessing the picture of the self which underpins today's ethical frameworks, particularly bioethical frameworks. It argues that the picture of an isolated, individual, choosing self is a false one which is unrepresentative of the human person. It draws on philosophical critiques of the post-enlightenment, liberal individual, particularly those of feminism and virtue ethics. It goes on to show how this false picture of the self has been taken to extremes in bioethics, resulting in the adoption of the flawed individual choice model. The problems with this model are set out in general in Chapter 2, before moving in Chapter 3 to the core claim of the book, that the genetic self is the connected self. The claim that the genetic self is the connected self is built on two key features of genetic information – that genetic information is both *shared* and *identifying*. While these features of genetic information are widely recognised the consequences of these for ethics and governance frameworks have not yet been sufficiently recognised. In particular, the

---

[2] My previous work on this topic is detailed in the Foreword.

profound challenge that the *shared* and *identifying* nature of genetic informa-
tion presents for *the* primary bioethical ethical practice of informed consent
has not been addressed.

The book proceeds to look at the areas in which there have been
attempts in bioethics to produce frameworks which address the failures
of the individual choice model, and it maps the 'communal turn' in
bioethics. Following this two of the most prominent alternative models
of genetic governance, those of benefit sharing and trust, are considered.
In the final chapters a new approach is suggested. This approach begins,
in Chapter 8, by proposing a mechanism by which the significant goods
and harms of any circumstance can be recognised; part 1 of the ethical
toolbox. Unlike the individual choice model the ethical toolbox recognises
the whole range of goods and harms: a necessary first step in any adequate
effective ethics and governance framework. Once such harms and goods
have been identified then appropriate ethical practices can be applied in
the situation to protect the important goods and prevent the potential
harms. This is the second stage of the ethical toolbox: the application of
current, new and alternative practices. The advantage of the ethical tool-
box, in addition to the fact that it recognises the connected nature of the
genetic self, is that it provides a means to address the worst failures of
the dominant individual choice model, while not asserting an equally
restrictive "one-size-fits-all" model of ethics. Furthermore, and impor-
tantly for ethics and governance more generally, it has additional benefits
in that it is likely to contribute to social capital and to trust and so will
enhance public goods.

# 1   The individual self and its critics

### Introduction

This book is grounded in philosophy, and from its philosophical starting point it proceeds to make policy and practical recommendations. The claim that the self is a connected self is a philosophical and moral claim – as well as an empirical and policy claim. It is an argument that individuals are not best conceived of as isolated and separate selves and that individual rights are not best regarded as always in conflict with group and communal interests. The pictures of the self which underlie systems of governance, legal and policy systems, as well as social structures, are fundamental to understandings of what human beings are. If these are wrong, then the systems of governance built on them will be limited and will result in alienation and mistrust rather than in flourishing and enhanced wellbeing. Pictures of the self are vitally important. If the picture of the self is wrong so too are the legal, ethical and social structures which are built upon it. What matters to human beings is that key goods are protected and that possibilities of flourishing and wellbeing are ensured. What is possible is intrinsically tied to how human beings are envisaged. There is no neutral conception of such pictures – those which are claimed to be neutral tend simply to be those which are closest to the current dominant picture. Interrogating the pictures of the self upon which governance mechanisms are built is not a dry or hypothetical philosophical discussion. Rather it profoundly affects real world policy and practice. It affects whether or not people are harmed, exploited and mistreated. It is crucial to building governance mechanisms capable of actually respecting people and the goods which matter to them. Ethical and governance pictures are all built upon pictures of the self, albeit often upon assumed and unquestioned pictures. Thus philosophical preoccupations about the self are intimately connected with the structures which are created using and presuming them; moreover, the structures also feed back into the pictures and make other pictures of the self less possible.

6

## The individual, separate self

The over-individualistic picture of the self which is the foundation of currently dominant ethical frameworks is not a correct one. This is shown dramatically in the genetic era as the genetic self overturns current over-individualistic conceptions. Adding the genetic challenge to already existing philosophical debates is important. It bolsters philosophical critiques by providing incontrovertible empirical support for those who argue for connected models of the self. This debate has relevance to related philosophical debates about the self as well as to ethical debates.[1] In practical terms, the consequences of failing to revise current ethical and governance frameworks are extreme. They include the likely exploitation and harm of current and future individuals and the neglect, to the point of destruction, of social and communal goods (goods which enhance human flourishing and in some instances are necessary to survival).[2] Finally, and perhaps most seriously, if the dominant picture of the self is not challenged soon, revision will become increasingly difficult. The more established the model becomes, the more social capital and common goods, upon which all individuals depend, will be eroded.

A number of philosophical debates could provide a philosophical grounding for the connected self of genetics. Feminism and virtue ethics offer pictures of a connected self: pictures which are arguably more accurate, representative and fulfilling pictures of human being. Communitarians, among others, also provide additional critiques of the individual self and argue that the person can *never* realistically be considered in isolation from the community and influences from which they come (Miller 2000; Taylor 1989).[3] But the feminist and virtue positions are themselves sufficient to show that ethical models which are based on the connected self will be able to recognise and protect the full range of goods which matter to individuals,

---

[1] See for example Graham 2002; MacIntyre 1999; Mackenzie and Stoljar 2000; Marx and Engels 1999; Sandel 1984; Taylor 1989.

[2] See discussions of communal goods throughout.

[3] Communitarians deny that there is some "authentic self" where the self's true wants, desires, identity, rights and interests can be separated from that of the wider community (Bradley 1927). Quite simply they ask who is the '"person" that exists independently of, and able to freely choose, the ends that give her life meaning and value?' (Mulhall and Swift 1996, p.10). To portray the individual as a separable moral agent 'misunderstands the relation between the individual and her society or community, and more specifically, ignores the extent to which it is the societies in which people live that shape who they are and the values that they have' (Mulhall and Swift 1996, p.13). Samuel Scheffler argues about the influence and constraints of personal history, communities and relationships, and states that '[w]hether we like it or not, such relations help to define the contours of our lives, and influence the ways that we are seen both by ourselves and by others' (Scheffler 1997, p.204).

including public and common goods. These claims will be expanded in detail and illustrated using examples from bioethics throughout the subsequent chapters of this book. First, however, the philosophical critiques which mirror and parallel the practical genetic critiques will be examined. These philosophical arguments for the connected self, while different from each other, show that the dominant view of the isolated individual is a philosophically unconvincing view. Criticisms of the self as an isolated, separable individual are familiar in post-enlightenment moral and political theory. The claim is that to present the individual as separable from the community and a nexus of relationships is a misrepresentation of what human beings are actually like. This position is now beginning to have influence in applied ethics, which has tended simply to assume the individual, liberal model. For instance, in environmental ethics, it has become essential that common goods and future generations are seen as central and not peripheral to ethical deliberation. A model which places the separate choosing individual as the primary focus of ethics simply cannot address such contemporary dilemmas. The importance of common goods and the difficulty individual models have in recognising such goods will be returned to throughout the book.

### Feminism

Feminist theorists reject the notion of a separated and isolated individual and argue for a socially integrated and interconnected conception of the self.[4] They argue for an alternative picture of the moral agent; of persons not as isolated autonomous individuals, but as relational, social and connected beings making choices in the context of their relationships. "Feminist ethics", like other generic terms, denotes a vast range of perspectives. However, almost all versions of feminism suggest that, at the very least, the liberal model of the individual needs supplementing, reforming and updating as 'the basic presuppositions of liberal political theory are often seen as conflicting with much feminist theorizing' (Held 2006, p.76). Even feminists who fall within the broadly liberal tradition are critical of the over-individualism of this position: for instance, Carole Gould asserts that 'it is by now commonplace to criticize traditional liberal democracy for its abstract individualism' (Gould 2004, p.7).[5]

[4] Feminist critiques have been influential in the bioethics field and feminist bioethicists have emphasised the importance of difference and championed the values of social justice over those of individual choice (Donchin and Purdy 1999; Tong 2001; Wolf 1996).
[5] Gould is primarily focusing on rights – and criticisms that human rights are over-individualistic – in order to present a revised, relational conception of rights.

Gould, following many critics of liberal over-individualism, asserts the relationality and connectedness of human beings. She asserts that human beings must be understood as social beings and that the need to recognise this is 'a truism in social philosophy' (Gould 2004, p.63). Gould's liberal feminism endorses a conception of individuals not understood as separate individuals, but as 'individuals-in-relations or social individuals, in place of the externally related individuals characteristic of traditional liberal theory' (Gould 2004, p.63). Accordingly while Gould's selves are "individuals" they are not isolated and separate. Indeed, 'the characteristic mode of being of these individuals, that is, their activity, essentially involves their relations with others' (Gould 2004, p.33).[6] In Gould's schema choices are made and characters develop through the 'concrete interactions of particular caring and choosing individuals, who are often concerned for each other and make choices together with others with whom they are engaged in common projects and interdependent networks (economic, technological, social, cultural or personal)' (Gould 2004, p.63). Her conception of the self is one in which individuals are not separate, but exist in relation to one another.

Other feminists, such as care ethicists, have gone further and focused not on the individual-in-relation, but on relationships and the nexus of relationships themselves (Gilligan 1982; Noddings 1984). The ethics of care constructs persons as interdependent, 'enmeshed in relations with others' (Held 2006, p.156). In the ethics of care framework the 'moral life is populated by caring relations in which the interests of self and others are mingled and trust is crucial' (Held 2006, p.157). Feminists who have focused on relationships and contexts have often promoted the concept of 'relational autonomy' (Mackenzie and Stoljar 2000) which regards social relations as constituent parts of an individual's autonomy. Individuals are not only connected, but inseparable, in the sense that the self is defined within and through relationships.

The ethics of care in its strongest form overtly critiques the liberal models since, 'from the perspective of care, the person seen as a holder of individual rights in the tradition of liberal political theory is an artificial and misleading abstraction' (Held 2006, p.145). Moreover it accuses individual models of distorting 'reality by leaving out vast areas of human experience that it claims to apply to but in reality cannot cover' (Held 2006, p.80). In particular, 'it fails to address, for instance, the appropriateness, implications and effects of treating just any social

---

[6] For Gould this is true of all aspects of individual decision making and thus she considers 'individuals-in-relation as the basis for the extension of democratic decision making to all context of common activity, whether political, economic or social' (Gould 2004, p.4).

relations as if they were between independent, autonomous, self-interested individuals' (Held 2006, p.80). Held herself regards the model of isolated individuals as false. Furthermore she considers such liberal positions to be damaging and pernicious, claiming the ethical frameworks built upon it are morally undesirable:

[It] promotes only calculated self-interest and moral indifference in the place of caring and concern that citizens often have for fellow citizens (albeit less intense than for family and friends), that members of smaller communities still more often have for each other, and that most persons could have for other persons, even in foreign places and distant lands ... Adopting the assumptions of liberalism contributes to making actual indifference to others more pervasive (Held 2006, p.83).

These criticisms are pertinent to the claims of this book: that the model of the self profoundly affects the ethical frameworks that are possible.[7] Also relevant, and again central to the argument of this book, is Held's claim that 'the liberal ideology has been increasingly leaving no room for anything else ... there must be room for much more than liberal individualism for either persons or societies to flourish' (Held 2006, p.77). Held's position will be echoed in the claims for the genetic self and the failings of bioethics, particularly the claim that liberal models ignore key common and social goods and results in disconnection, alienation, and the reduction of trust and social capital. In her words, this model 'is not a morally good model for relations between persons ... To encourage morally better social relations we should limit rather than expand the use of the liberal, contractual model, both in our institutions and practices and in the ways we think about social issues' (Held 2006, p.81).

These arguments prefigure much of what follows. They will be applied in the context of bioethics to show the failings of the individual model and its undesirable consequences, and are supported and bolstered in the claims made regarding the connectedness of the genetic self. Importantly, the feminist critique recognises the context and circumstances that surround choice: it 'requires us to pay attention to, rather than ignore, the material, psychological, and social prerequisites for autonomy ... Autonomy is exercised within social relations, not by abstractly, independent, free and equal individuals' (Held 2006, p.84). Furthermore, and again significantly, a model such as Held's has the advantages of having 'resources to understand group and cultural ties and relations between groups sharing histories or colonial domination or interests in nonmarket

---

[7] This argument will be echoed in Chapter 2 when the "silencing" feature of the individual choice model is discussed and critiqued.