
Genetics and the Legal Conception of Self

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Much feminist legal scholarship has attempted to critique the legal concept of selfhood for its reliance upon an artifice of physical boundedness and unity. Feminists who reject the law's embrace of a self produced in response to what Lacan called the "lure of spatial identification"¹ (Lacan 1977: 5; Meek 1998) do so because the political, social, and legal consequences that follow from this ascription of selfhood work against the bodies of women. Women's bodies, it is argued, are least able to conform to an optics of the skin, particularly in the context of pregnancy. Unbounded corporeality is not however, confined to women's bodies. Haraway, for instance, points out that in these days of biotechnological seeing, "even the most reliable Western individuated bodies . . . neither stop nor start at the skin, which is itself something of a teeming jungle threatening illicit fusions" (Haraway 1991: 215). The self is a construct that extends beyond the limits of the physical by simply being in the world. Its extension in time and space undermines the alleged autocracy of the individual. Susan Ballard argues, "every act of viewing becomes an event in which the boundaries of our bodies are imbricated in relations with other bodies" (Ballard 2001: 1). Similarly, Avital Ronell argues that once the telephone enabled the distant projection of the voice in space, the boundaries that demarcated our bodies were fundamentally questioned (Ronell 1989; see also Ronell 1994). In this chapter I want to show how genetic discourses, indifferent to the surface of the body as a marker of identity, demand a more complex understanding of the self in law. What happens, for instance, when genetic discourses reveal that we are all "leaky,"² boundaryless, and transgressive?

In her discussion of conjoined twins, Margrit Shildrick describes the leakiness of self as corporeal ambiguity. She says: “[a]bove all it is the corporeal ambiguity and fluidity, the troublesome lack of fixed definition, the refusal to be either one thing or the other, that marks the monstrous as a site of disruption” (Shildrick 1999: 78). I will argue in a related approach that biogenetic discourses, which emphasize shared identity and participation in the common genetic pool, reveal the monstrousness in all of us. This is challenging to law because such discourses expose the impossibility of the autonomous, self-sufficient individual of liberal legalism. The individual in the age of the gene is fundamentally connected and vulnerable. The individual in the age of the gene always contains a trace of the other; not-one but not-two (Karpin 1992).

I turn to the normative individual of liberal jurisprudence and show how even he (and I use the gendered pronoun deliberately) can no longer sustain the essential distance and difference between one and another (Callois 1987). Allen Meek writes of how Lacan extrapolated from Callois’s writing to explain that “the autonomous self is produced as an optical effect as a body attempts to conform to an encoded visual surface and to inhabit a landscape constituted as a field of the other’s gaze” (Meek 1998: 3) It is this differentiated self, certain of its limits, that we are taught to prize. The failure to articulate and determine fixed and impenetrable boundaries is a failure of selfhood. The discourse of genetics requires us to lose ourselves (or more correctly to find ourselves) in a genetic code that imbricates us with the other. In this case we recognize a selfhood that is based on interconnection and intermingled identity.

In this chapter I examine both legislative and quasi-legislative attempts to restore the visual surface of the body as the marker of individual identity. In the case of genetic discourses, the primary means by which this has occurred is through privacy legislation. Such legislation aims to secure one’s right to keep one’s genetic identity to oneself. The problem is how to identify the rights-bearing individual in the first place. Each person’s genetic code reveals not only who we are but also who else we might become. If we are always implicated in the genetic profiles of our relatives, can we hope to keep ourselves private and can it offer us any solace to do so? We share our genes with others by decreasing

degrees of exactitude reaching out from the familial and ending in the common genetic pool of the species. Individuality then is the recognition of ourselves in others. “He has my eyes.”

Genetic discourses reveal the individual in biomedical moments of self-recognition in the other. They do not do away with individuality but complicate it. They suggest that what makes us individual also joins us to others. In law, however, the liberal subject is still the preeminent mode of selfhood. This rights-bearing subject finds its greatest recognition in those moments when it fends off incursion by others. These are boundary-defining moments that carry with them the promise of invulnerability and autonomy—but the kind of autonomy that is characterized by self-interest. It is no surprise then that in this frame those most successful at asserting themselves are those who have garnered sufficient social, economic, cultural, and political resources to minimize the impact of their indistinction, dependencies, and interconnections. Bodily transgressions do reside within these individuals, but they are accommodated to a point where they appear value-neutral, enabling the façade of independence to be reified in their favor. Those who demand an autonomy of self that incorporates care, responsibility, connection, dependence, and even immersion with the other are seen as a definitional paradox—transgressive, messy, mixed-up failures. However, it is this conception of self around which law, social, and biomedical discourses must circulate in order to ensure equality and justice.

My aim here then, is to use genetic discourses to generate anxiety about the stability of liberal identity so that its current beneficiaries find themselves at the margins with the rest of us. To do this, I posit a legal norm of transgressivity. Law, in this new frame, must take as its base unit a subject that is inevitably connected, vulnerable, and dependent. Because the transgressive is by definition that which goes beyond the limits, normative transgressivity is both an oxymoron and a standard state of being. (In being you I am me. In needing you I am self-sufficient. In having you I am free.)

Genetic discourses, then, are creating new tensions within the traditional conceptualization of the autonomous individual constructed around or out of a biogenetically connected family. Anthropologist Kara Finkler and legal theorist Janet Dolgin raise concerns about the relation

of the individual to a family that is constructed or mapped over a genetic pedigree.³ This form of individuality, which immediately connects one to genetically related others, disables the liberal individual premised on a distinct and separate selfhood. Instead, it enables or renders able-bodied a transgressive individual whose very selfhood is already connected and vulnerable to the embodiment of someone else. I argue that this is not the end of individuality or indeed autonomy, but that transgressive selfhood demands of us a new understanding of each of these two terms. Before I make this argument, however, it is useful to use both Finkler and Dolgin's concerns as a stepping-off point.

Finkler argues that the hegemony of the gene is undermining what she describes as the "mark of a modern individual" namely, "autonomy, independence and detachment from kinship ties" (Finkler 2001: 237). Her focus is on the way that the gene reestablishes kinship as a biogenetic connection rather than a relationship established on the basis of choice. She states:

Beyond issues associated with gender, family and kinship ties have been given a new dimension that stresses faulty genes rather than social status, position or even poverty. Cultural significance is given to genetic transmission for better or for worse. (Finkler 2001: 239)

Finkler bases her argument on research she conducted involving several adoptees who sought out the identity of their birth parents. Many of them were motivated by a need to ascertain their medical histories. Others found themselves seeking out genetic relatives because they suffered from a genetically inherited form of disease (Finkler 2001).⁴ In examining these cases Finkler argues that the geneticization of kinship⁵ has given rise to the possibility of a connection between individuals who may otherwise be nonintimate relations or strangers.

Although Finkler never expressly identifies what is wrong or right with these new directions, the language that she uses suggests that there are significant benefits in the biogenetic model of kinship. She says:

It recasts our dispersed and loose kinship ties as inexorable genetic ones and reestablishes our continuity with family and kin. Once uprooted we have been reunited by the medicalization of family and kinship. Willingly or not, we must recognize our connectedness, albeit by our dysfunction and disorders. DNA joins the compartmentalized, fragmented postmodern individual to his or her ancestors. (Finkler 2001: 249)

However, while Finkler reads the move back to connectedness as a cure for our postmodern fragmentation, there is more at stake than she appears to be aware of. The compartmentalized individual of contemporary America and other western nations is for law the liberal individual, a modernist construction determined to fend off intrusions and interconnections and enable a self-sufficiency that promises selfhood. The threat of incursion by others or unwilling connection to others is the threat of postmodern indistinction. This is what I have been describing as the transgressive, and it is what Janet Dolgin finds so troubling.

Dolgin laments the primacy of the biogenetic family over the new modern "family of choice," suggesting that it results in the demise of both individuality and autonomy. According to Dolgin, the family-by-choice is being surpassed and in its place a new family entity is created without recourse to the intimacies of social relationships. She terms this entity the "genetic family." Its coalitions are made across gene lines and shared genealogies, which offer the knowledge of an inheritance in the form of disease. As Dolgin describes it:

Genetic information alone becomes relevant. Genes suggest nothing about social relationships. They are simply data. As such, they neither represent nor demand particular moral links among the people they describe. The notion of the gene as the arbiter of personhood could replace culture, morality, religion, and history—indeed time itself—with mapped sequences of DNA. (Dolgin 2002: 544)

Dolgin goes on to describe the genetic family as giving rise to a new conception of personhood that has neither the traditional hierarchically arranged relationships nor the modern autonomy-based relations of "families-of-choice." In this context she argues there is a confusion between the individual and the group. It becomes almost impossible to tell them apart, to distinguish one from the other. Dolgin however, appears stuck in an old dyad between top-down oppressive power on the one hand (hierarchically based families) and individual power (autonomy-based families) on the other. There is no room in her imaginary for an empowered but vulnerable and connected self.

While I do not agree with Finkler that the biogenetic family represents a recuperative antipostmodern turn, Dolgin's alternative analysis, with its failure to offer an account of our humanity outside either the hierarchy or the autonomy model, raises an even greater concern. Her

discomfort with the way in which the individual cannot sustain its distinction from the group in the face of genetic immersion fails to recognize that group membership or identification is not self-evidently negative. It only becomes so when one is aligned with a disadvantaged group in society. Just as the gene can replace culture, morality, religion, and history as the arbiter of personhood, so can skin color, disability, sexuality, gender, and so on. It is for this reason that the gene is so interesting—it may draw into the web of potential social disadvantage those who have so far managed to keep themselves out of it. In response to Finkler, Dolgin remarks:

[T]his construction of family . . . replaces the notion of autonomous individuality with a notion of a larger group, defined through the metaphor of the individual but within which each person is indistinguishable from each other and from the genetic group. (cited in Finkler 2001: 250)

Dolgin here reiterates a point she has made elsewhere that the move from individual to group implicates “individuals assumed on other grounds to belong to that group” (Dolgin 2002: 544).

For Dolgin this kind of indistinction results in the subordination of the individual’s interests to the larger group. This is an affront to the primacy of the liberal individual that has been the project of liberal legalism.

Both Dolgin and Finkler, along with many scholars examining familial claims to genetic information, fall prey, however, to the same inexcusable assumption that it is my aim here to challenge. Namely, that by giving effect to our connectedness we must subordinate our individuality to the claims of the community. This assumption has led many scholars to describe the debate as an argument between individualist and communitarian accounts of identity. For instance, this has been the limited response to innovative scholars such as Loane Skene, who have sought to challenge the rigidity of individualist accounts of the self by, at a minimum, creating a communal familial genetic identity.

In her article “Patient rights or family responsibilities?: Two approaches to genetic testing” Loane Skene (1998) describes two possible models for dealing with genetic information. The first closely reflects the rationale behind both the Australian genetic privacy and nondiscrimination bill and its U.S. counterpart—a legal, rights, privacy model—and is based on

autonomy and self-determination (discussed later). The second model was developed by the Cancer Genetic Ethics Committee of the Anti Cancer Council of Victoria and is a medical and family-centered model (Skene 1998: 1–41). In this second model, it is envisaged that genetic information (and the tissue that is tested) would be shared among blood relatives. Furthermore, individuals would not have the ultimate right to “control . . . their information and the use of the tissue taken for genetic testing” (Skene 1998: 24). Instead, ownership would reside in the doctor or hospital that prepared the tissue or genetic information. This is an approach that accords with the treatment of medical records in Australia (Skene 1998: 27).

Bennett and Bell, among others, have called this family-centered model communitarian and have responded by arguing that it is unnecessary because the current common and statute law allows encroachment on the rights of the autonomous individual in the extreme circumstances in which it is warranted. Instead, they prefer to rely on a notion of autonomy that encompasses one’s relationship to others. Bennett and Bell suggest that the assumptions behind moves to communalize genetic information “rest on highly individualised and atomised notions of autonomy, which fail to take account of the relational aspects of the exercise of autonomy” (Bennett and Bell 2001: 158). They rely on Nedelsky’s view that “autonomy is a capacity that exists only in the context of social relations that support it and only in conjunction with the internal sense of being autonomous” (Nedelsky 1989: 7). This conceptualization of relational autonomy offers a useful strategy for empowering the interconnected individual of transgressive normativity. However, Bennett and Bell do not consider such a radical revision of autonomy as requiring amendment to existing legal structures. Instead we are asked to accept the existence of this form of autonomy and to find its accommodation within the legal structures currently in place. I argue, however, that this kind of accommodation is simply not possible because it challenges the very framework that the legal structure seeks to enforce.

In contrast to Bennett and Bell, Ann Sommerville and Veronica English take communitarian theory as a way to modify liberal individualism in order to take into account the interconnectedness that genetics exposes. According to them:

Interconnectedness and responsibility to others are brought to the fore in the genetic sphere in a manner which seems to run counter to current ethical and legal orthodoxy. Extreme notions of individual rights and autonomy are insufficient to deal with these complex and interwoven interests. A more useful framework is gained by combining notions of autonomy with a modified version of communitarianism which recognises decisions made by one person inevitably affect others and that an individual cannot have rights without also accepting that he or she has certain duties. (Sommerville and English 1999: 150)

While Bennett and Bell's relational autonomy and Somerville and English's modified communitarianism are significant attempts to grapple with the problem of the transgressiveness of selfhood, neither is, in my view, adequate. In both versions the subversive potential of transgressivity is not realized. In Bennett and Bell's account, the moments when an autonomous individual must accede to his or her relation with others are anomalous moments for which law can always make an exception. In the normal course, however, laws must be written to protect individual rights to control information about the "individuated" self. In Somerville and English's choice of communitarianism, a certain kind of coherence is sought in the formation of tight bonds of responsibility and connection. Just as with Finkler, the move toward interconnection, when read through a communitarian lens, is a desire to create "ties that bind."

However, Michael Walzer describes the transgressive as antithetical to communitarianism because no community can be a stable entity where there is always the possibility of rupture and interposition. In other words, the kind of transgressions, if we even call them that, that will be sustainable in the context of communitarianism are those that enable interconnection among self-sustaining individuals rather than interpenetration among individuals. It is because of this that Walzer argues that a communitarian critique must be continuously applied as a corrective to the excesses of liberal individualism. He says:

If the ties that bind us together do not bind us, there can be no such thing as a community. If it is anything at all communitarianism is antithetical to transgression. The transgressive self is antithetical even to the liberal community which is its creator and sponsor. (Walzer 1990: 14-15)

Here we see the limits of even the kind of communitarianism about which Somerville and English write. Those who are most marginalized in the community are generally those who find themselves least accommodated

by the social, political, and economic structures in place. They are seen as transgressive because they cannot meet the standards of selfhood in place. It is unlikely, therefore, that bonds of responsibility and duty can operate fairly to bind individuals who are struggling for a legitimate position within the community in the first place (discussed in the next section). Indeed, their insistence on membership in that community will itself be seen as disruptive.

Unruly transgressive bodies threaten the stability of the community because those bodies do not abide by its limits. Nevertheless, finding ourselves necessarily connected with, dependent upon, and vulnerable to others is in fact the state in which we all exist. The only question is where power resides in these interconnected selves. It is the operation of power moving within these inevitable interconnections that needs to be regulated.

In the next section I expose the transgressive body of the apparently autonomous individual through the use of legal discourses surrounding genetics. In particular, through some examples of failed attempts to regulate the use and disclosure of genetic information it becomes clear that an individuated and separate subject around which a cohort of legal rights and responsibilities are built is unsustainable. Rather than suppress that transgressivity, I argue we should embrace it as a starting point for dealing justly with people. We should give significant value to those identities that are not self-contained and independent but instead rely on a transgressive interconnectedness to sustain selfhood.

The Genetic Privacy and Non-discrimination Bill of 1998 (Cth) was the first major attempt in Australia to pass national legislation specifically dealing with issues arising out of the genetic biotechnologies. Its primary aim was to protect the individual's privacy rights over their genetic information and to prevent discrimination that might arise when information about genetic status is revealed. The bill failed to get the necessary support in Parliament, and the Australian Law Reform Commission, in conjunction with the Australian Human Ethics Committee, has now been charged with the role of reporting on the issues raised by the bill.⁶

This bill attempted to create a regulatory regime that dealt with not only the collection, storage, and analysis of human DNA samples and the genetic information characterized from them, but also discrimination

that might arise generally and in employment and insurance as a consequence of disclosure of that information. The bill was based heavily on its U.S. counterpart and, as such, the emphasis was primarily on genetic privacy. However, it quickly became evident that it is very difficult to reconcile the individualist premise of privacy legislation with the nonindividual nature of genes. The nature of personal genetic information is that it is never just personal. Knowing an individual's genetic makeup means that you also know something about his or her genetic relatives. Who or what an individual is cannot be taken for granted, and in fact there is recognition of this in the bill itself, where an individual was defined as:

the source of a human tissue sample from which DNA is extracted or genetic information is characterised. The term includes a subject of genetic research and, where appropriate, includes the parent, guardian or legal representative of the individual. (*Genetic Privacy and Non-discrimination Bill 1998*: Clause 4)

The individual who is protected by the legislation is the individual who physically gave up the tissue for analysis. Yet as we have just seen, an individual's consent to disclosure of DNA information about him or herself may also reveal information about that person's genetic relatives. If an individual were defined in the bill in terms that recognized this interconnected status, a very different kind of legislative regime would result. A genetic relative might be able to deny access to the DNA information of an individual who had freely given his or her consent to its release. The bill would have to protect both its source and those who can be characterized as connected to that source. Indeed, the second part of the existing definition, which includes the parent or guardian (of the source) within the terms of the individual, accepts that legally and socially the individual may not correspond to a spatially identified physically bounded subject. In this way the normative status of the transgressively embodied (inevitably connected, vulnerable, and dependent) subject takes a central position. This is a reasonably simple accommodation where the example involves intimate relatives, although many would see it as a clear violation of the rights of the autonomous individual to do with their bodily bits and pieces as they see fit. However, when the connections are more tenuous or less human, transgressivity as a norm is significantly more radical.

The submission by the University of Sydney's Faculty of Medicine to the Senate Constitutional and Legal Issues Committee inquiry into the bill, pointed out, for instance, that an ambiguity arises when an individual's DNA is incorporated with a viral DNA. The point made in the submission is that the viral DNA actually becomes part of the individual's DNA, and the question that necessarily follows is whether the viral DNA is part of the individual (Leeder 1998) This is obviously of concern to research scientists who may want to conduct research and analysis of viral DNA intermingled with human DNA and to exploit that research for commercial gain. From a legal perspective, a determination of where the human begins and ends appears to be impossible. In this sense rather than, as Dolgin would have it, undermining individual autonomy, a radically transgressive understanding of human identity is necessary to ensure the autonomy of the connected individual involved. Obviously a person whose DNA is intermingled with viral DNA is still a person. If we take the geneticization of identity to its extreme, we will find ourselves inexorably defined out of existence unless a level of transgressivity is embraced. However, the law is not in the habit of accommodating infiltration by the other.

How then does this most unreliable of individuated bodies, to refer back to Haraway's question, seek legal protection for its privacy and against discrimination? The law requires its subject to be stable, autonomous, self-sufficient, and independent, but the body as the law knows it is in fact a fabrication that mimics material fixity. Accordingly, legal responses to bodily transgressions are generally boundary policing, and a singular individual is artificially carved out through juridical force. This sometimes occurs literally on living bodies, as in the case of conjoined twins, or through the sterilization of intellectually disabled girls (Shildrick 1999, Karpin, 1992, 1999).

Here we are exploring how it occurs at the microlevel of genes. We see how the law and scientists struggle to find the viable individual. Yet another example of this struggle to identify exactly who or what is the rights-bearing individual occurs, not surprisingly, in the section of the now defunct bill dealing with rights over the DNA of a fetus. Clause 24 reads:

(1) Where genetic information is available from genetic analysis before the birth of a person about that person's genome, the genetic information is the genetic

information of the person's biological mother but becomes the genetic information of that person when he or she is born alive. (Genetic Privacy and Non-discrimination Bill 1998)

This was perhaps the most disputed clause in the bill because its critics claimed it failed to understand the basic difference that genes make. If, for instance, the biological mother is what is sometimes called a gestational surrogate, that is, she is carrying the fetus in her womb for the genetically related mother, then, some would argue, it is inappropriate for the bill to give ownership of genetic information about the fetus to her. Alternatively, the biological mother could be the recipient of a donor ovum, so that even though she is not genetically related to the fetus, it is the intent of all parties that she, as the guardian of the fetus and subsequent child, ought to have all rights over the genetic information pertaining thereto.

The Australian Medical Association, in their submission, further complicate fetal DNA ownership when they question the bill's choice of the biological mother as the appropriate recipient of these rights. They suggest "it is possible to identify which component of DNA, gene or chromosome is paternal and which is maternal; therefore why should the genetic information belong solely to the 'biological mother'?" (Australian Medical Association 1998: 345).

This medical response is interesting in light of the legal conception of the fetus. Kristin Savell examines the English case of *Attorney-General's Reference (No. 3 of 1994)* ([1997] 3 WLR 421) where a pregnant woman was stabbed, causing the birth of a premature child who died shortly after (Savell 2002). At each instance the court came up with a different conceptualization of the fetus. At the first instance it had no existence in law; on appeal to the court of appeal, it was held to be part of the mother; and in the House of Lords it was held to be an *organism sui generis*. The basis of the House of Lords decision is most interesting. Both Lord Mustill and Lord Hope rejected the argument that the fetus was a part of its mother on three grounds. The first ground was the fact that the genotype of a fetus consists of shared genetic material from its mother and its father. The second was the fact that an embryo could be created outside the womb, and the third was the characterization of the relationship between a woman and her developing fetus as symbiotic.

What is interesting is how the court used the genetic connection with both the father and the mother as a signifier of individuality and therefore separation, rather than considering these joint contributions as giving rise to an interconnection between the genetic progenitors and the fetus.

It is clear from both the scientific and legal discourses discussed here that geneticization of identity is a kind of underpinning ideology, which means that those issues that would otherwise be determined by normal social arrangements are instead complicated and in some instances overridden by a genetic claim. The interesting twist is that in this intense classificatory activity the autonomous individual is not so much fragmented but revealed as already grafted onto others. In other words, the process of geneticization reveals the very transgressivity of our selves at the same time as genetics is touted as offering the capacity to identify us in our very uniqueness.

Having identified the ways in which genetics forces the recognition of a state of interconnection and interpenetration, I now go on to show how that interconnectivity cannot be neutralized through a legal or social regime that prioritizes a shared heritage, since this significantly underdescribes the complex interplay of power, expertise, and resource distribution in the context of genetic heritage. I show how there is a danger in looking to discourses of genetics as a way of describing interconnection because at the same moment that connection is foregrounded, it is also territorialized and racialized. Without an understanding of the transgressive in the context of the communal there will be no means by which to realign the existing inequities and power claims. In the final part of this chapter I examine the proposal by various indigenous and environmental groups for a "genetic commons" to see if this radical reconceptualization of the rights over and access to genetic information offers a partial solution.

Many have argued that the Human Genome Project (HGP), which had as its goal the mapping and sequencing of "the" entire human genome, relates to everybody while in fact relating to nobody at all. As the HGP confined its sampling to largely white, northern populations and yet premised its usefulness on the creation of a generic genome, the Human Genome Diversity Project (HGDP) was conceived as a necessary corrective

aimed at mapping ethnic diversity. The HGDP originally sought to collect samples from a broader range of ethnic populations. However, the project quickly became focused, not on obtaining samples from all the world's populations, but on targeting particular populations that were on the verge of disappearing, and on preserving, not the populations, but the cell lines. In other words, where the HGP created an apparently generic human genome (but where generic means primarily white and northern European), the HGDP identified marginal genetic identity (the exotic other). In these two projects we see a tension between non-territorial "human genome" and a racially specific "community genome." The former can only claim its normative generic status by presenting the specified identities in the HGDP as marginal, small, threatened outposts of the other that cannot endanger the normativity of the generic genome.

This is why the decision by indigenous groups to object to the HGDP is so poignant. Indigenous groups represent the point of view of those whose bodily interconnection has been used as a means to subordinate them. In the context of the HGDP they are offered the opportunity to further negotiate the transgression of their bodies, while there is no recognition of the ways in which the most reliable western individuated bodies are never open to negotiation. The language of altruism, used in the context of discussions about the human genome as the common heritage of humanity, fails to take account of the myriad ways in which marginal bodies are already operating as common property. For instance, when the World Medical Association resolved that "the information [from the HGP] should be general property and should not be used for business purposes" (World Medical Association 1992), or when the guidelines to the HGDP describe its primary aim as "[u]ltimately, to create a resource for the benefit of all humanity and for the scientific community worldwide" (International Planning Workshop 1993: 4), there is a fundamental failure to understand the unequal distribution of common resources worldwide and the way that inequality is mapped along race and gender lines. The harvesting of genes from indigenous people is to be compared, for instance, with the harvesting of the genetic information of the people of Iceland, which has become both a multimillion dollar joint venture between the government and two multinational corporations

(deCode Genetics and Roche Pharmaceuticals) and a debate about nationalism and the ideology of racial purity (see later discussion).

Yet scientists involved in the HGDP are, it seems, genuinely perplexed when having offered a rigorous commitment to informed consent (the liberal individual model) in conjunction with a generous sensitivity to group cultural attributes, they are rebuffed by indigenous groups of would-be participants. Victoria Tauli-Corpuz, an indigenous activist, describes the difference in understanding:

I was on a panel with Andre Langanay a former committee member for the Human Genome Diversity Project (HGDP) at the "Patents, Genes and Butterflies" conference in Berne, Switzerland. He was asked to talk about the HGDP and I presented my critique of this project. During the open forum he said he couldn't understand what indigenous peoples have against the extraction of their blood in order to help others get well, he would have no second thoughts about it, he argued. (Tauli-Corpuz 2001: 252)

Andre Langanay's statement shows the importance of a commitment to a situated account of identity. While Laganany sees the project as benign, Tauli-Corpuz views the project from the perspective of someone who knows all too well the power of colonizing forces to appropriate and control bodies, territories, resources, cultures, and knowledges. In the same way, the submission by the Aboriginal and Torres Strait Islander Social Justice Commissioner, Dr. Bill Jonas, to the Australian Law Reform Commission's inquiry into the protection of genetic information highlights the context in which indigenous Australians think about the extraction of genetic information from their citizenry:

As the most disadvantaged members of Australian society, Aboriginal and Torres Strait Islander peoples are especially vulnerable to exploitation. Their past encounters with colonisers have been characterised by the stealing of land, knowledge, culture and the arts. Genetic mutations found in discrete populations are providing yet another rich field for exploitation, this time by trans-national pharmaceutical companies acting with the explicit or implicit support of national or state governments. (Jonas 2002: 3).

It is clear then, that one can no more advocate an altruistic model premised on the sharing of what is already shared genetic material, than a model in which individual rights over that shared material are enshrined.

The HGDP Model Ethical Protocol for Collecting DNA Samples, for instance, attempts to overcome these inequities by requiring those

collecting samples to obtain appropriate consents from the communities being sampled and to work in partnership with them (Human Genome Diversity Committee 1993: 18). At the same time, long-term storage of the information is contemplated that would enable general access to the scientific community, and the expertise to make use of that information resides squarely in the hands of that scientific community (Human Genome Diversity Committee 1993: 20, 29). The set of ethical issues enumerated in the Model Ethical Protocol indicates how researchers might return some of the benefit to the sampled population. Ethical issue no. 3, for example, states:

Researchers should actively seek ways in which participation in the HGD Project can bring benefits to the sampled individuals and their communities. Examples of such benefits include health screening, medical treatment or educational resources (Human Genome Diversity Committee 1993: 32).

However, these gestures insist upon using a liberal individualist model of consent and profit. It is taken for granted that the means to achieve justice is through this model.

An alternative model posited by Hilary Cunningham exposes the way in which the liberal individualist model fails. She describes her model as relational and rejects a model in which the scientist and the indigenous group operate as two separate negotiating identities. Instead she posits the following:

I do not mean a traditional collaboration in which a project is designed and then implemented with the consultation of a research constituency. The collaboration which I mention here makes the scope, design, goals, methods of implementation and access to research results all negotiable items. Empirical researchers in particular, whose objectives and methods are said to be governed by acontextual laws and procedures will find this collaboration particularly difficult since it challenges the very epistemological basis of scientific knowledge. Such collaboration suggests that just as valuable to any project's scientific objectives is the formation of a viable relationship with research subjects. This social hermeneutic indicates that the object of research is not simply "information" (a knowledge commodity that can be acquired and controlled by one party) but "insight," a relational kind of knowledge that can be developed only through negotiation of two engaged parties. (Cunningham 1998: 227-228)

It is clear that what is being suggested here is more along the lines of my transgressive normativity model. The research subject is no longer kept at arms length but instead becomes both researcher and researched.

The boundaries between the two, no longer strictly held, challenge the way in which western research is standardized or apparently made objective. Cunningham recognizes the radicalness of this position when she says:

Yet how many granting agencies—especially in the sciences—would be willing to fund projects whose goals and methods were so fundamentally contingent upon the negotiation of research methodologies and results? (Cunningham 1998: 227-228)

It is the power plays of interconnection that are operational when, for example, the target of research is not a disenfranchised indigenous group but a group who, in racialized terms, identify themselves with the norm and in so doing posit the purity of their genetic pool as an indicator of superiority. I am referring to the genetic database of the Icelandic population constructed by deCode in collaboration with Roche Pharmaceuticals. In this case, the subjects of the research—the Icelandic population through their government representatives—negotiated the terms under which the research would take place. Arguably the Icelandic statutes, the Health Database Act of 1998 and the Biobanks Act of 2000, represent a substantial governmental intrusion into research methodologies. The opt-out form of consent, although not everyone's idea of a fair and appropriate method of obtaining research subjects, was something that was explicitly legislated in both acts.⁷ While controversy continues over whether the results and profits from the research should be in the hands of a private corporation, the fact remains that the license provided to deCode under the legislation is for twelve years only. Icelanders then, are not unconnected research subjects, but have had a say in the manner in which the research will proceed and have set in place provisions to ensure that some of the financial achievements are funneled back into Iceland.

It is worth considering then why Iceland has been able to do this and yet indigenous groups targeted by the HGDP have not. Skuli Sigurdsson has characterized the debate around the advantage of Iceland as a research population for genetics as surrounded by the "invocation of myths, clichés, fantastical tales about Iceland, past and present, pieties and regurgitated half-truths." He identifies the eugenic past of Iceland as having "hardly left a dent in public memory" (Sigurdsson 2001: 108).

That past, however, is quite significant. Finnbogason, one of the most influential Icelandic intellectuals of the first half of the twentieth century, invoked the “science of eugenics” to argue for the “purification of the Icelandic race to preserve its spiritual and physical assets” (Pálsson and Harðardóttir 2002: 282). Einar Arnason, professor of evolutionary biology and population genetics at the University of Iceland, has made similar statements about the way that the deCode project has “evoked the myth of the homogen[e]ous Aryan Icelanders” (Arnason, 1999) and has challenged those claims with research suggesting that Iceland is one of the most genetically heterogeneous nations in Europe (Arnason et al. 2000: F3).

What we are left with then is two different kinds of interconnected communities. The Icelandic community has to some degree (although within the bounds of an all too inadequate democratic governance) ensured that the power plays over their interconnectivity do not result in their exploitation. Here their connectivity does not undermine their power but instead gives effect to it. However, in the case of indigenous communities, their connectivity is negated by the requirement for individual consent imposed by researchers coming from western legal traditions that favor the autonomous individual. These groups then find themselves with seemingly no legal recourse for protection of their genetic information as a group.

Conclusion

My aim in this chapter has been to utilize genetic discourses to challenge the stability of the autonomous and individuated liberal self. I have done this in order to open a space for subjects who are connected, vulnerable, and dependent and who cannot shed their dependencies in order to become the liberal subject. These are the people whose very selfhood is then seen as unruly and threatening. Once we have taken as a base unit the interconnected self, regulatory effort will need to be directed to determining where power resides in these interconnected selves. This is in contrast to the call for a “genetic commons” which, while offering the genome and genetic discourses as a resource held in common to be used equally by all people, will not be successful unless some further account

is taken of the unequal society onto which such a commons must be mapped. The treaty initiative to share the “genetic commons” that was formally launched in February 2002 at the World Social Forum in Porto Alegre, Brazil, reveals this tension in its text, which states:

Therefore, the nations of the world declare the Earth’s gene pool, in all of its biological forms and manifestations, to be a global commons, to be protected and nurtured by all peoples and further declare that genes and the products they code for, in their natural, purified or synthesized form as well as chromosomes, cells, tissue, organs and organisms, included cloned, transgenic and chimeric organisms, will not be allowed to be claimed as commercially negotiable generic information or intellectual property by governments, commercial enterprises, other institutions or individuals. (*Treaty to Share the Genetic Commons* 2002: 6)

However, in the explanatory material that accompanies the text, the authors say that the “Treaty must support the sovereignty of nations and of communities to exchange or withhold genetic materials they hold in trust. . . . We wish to affirm national sovereignty and community rights as well as the right of individuals whose genetic makeup is subject to discrimination . . . to have their own genetic integrity and rights ensured” (*Treaty to Share the Genetic Commons* 2002).

It is this tension that I have been discussing throughout this chapter. How do we assert our autonomy over our genetic integrity yet recognize our inevitable interconnection with others? I argue that if we have an account of the self that is transgressive, that understands that we are both one and an other at once, we offer a self that is vulnerable to the interests and incursions of others as well as being sensitive to them. The law must accommodate this newly dependent interconnected self. It is this that the authors of the treaty are trying to accomplish when they say:

The Treaty to Share the Genetic Commons is designed to make every government and Indigenous Peoples a “caretaker” of their geographic part of the global genetic commons and to establish the appropriate statutory mechanisms to ensure both national sovereignty and open access to the flow of genetic information. (*Treaty to Share the Genetic Commons* 2002: 2)

In this statement we have an attempt to bring together the traditionally opposed positions of self-sufficiency and dependence. What I have been arguing is that the concept of the idealized individual of western liberal legalism is challenged by genetic discourses. However, rather than regard this as an assault, we should embrace the transgressivity of all selves.

In so doing, those traditionally disempowered by a vulnerable and uncontained selfhood would find some recourse in the law.

Notes

1. Lacan cites Roger Callois's essay "Mimicry and Legendary Pyschaesthesia" to explain how the formation of the ego has its origins in a process of depersonalization by assimilation to space (Lacan, 1977). See also Meek's discussion of this point (Meek 1998).
2. This term is borrowed from Shildrick (1997).
3. Geneticists distinguish between a pedigree, which is a representation of biological relatedness, and a family, which is the named, identified collection of individuals defined in terms of their kinship relations with one another.
4. In one case, for example, "Eve noted she felt closer to her sister and husband and her father but had also become closer to her cousins" because they shared a genetic susceptibility to cancer.
5. In Finkler's response to her critics she notes, "I prefer to use the concept of hegemony of the gene instead of geneticization because the Gramscian construct of hegemony encompasses the concept of the power of dominant institutions to impose an ideology by their very authority which permeates the social and cultural fabric of daily life, without the use of force" (Finkler 2001: 257).
6. The Australian Law Reform Commission and the Australian Health Ethics Committee released a final report, discussion paper 66, 'Protection of Human Genetic Information,' in August 2002.
7. Icelanders were given the right to opt out of the database, but until they do so, they are presumed to have opted in. This was further entrenched in the BioBanks Act, which was passed in May 2000 without any public discussion (Sigurdsson, 2001). By the middle of March 2001, 19,697 citizens had opted out of the HSD and as Sigurdsson describes it, "in the process become entities in a second-order HSD, registering those socially deviant whereas the first-order HSD is still empty" (2001: 113).

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