

Genetic risk and the birth of the somatic individual

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Abstract

This paper considers the implications of the rise of the new molecular genetics for the ways in which we are governed and the ways in which we govern ourselves. Using examples of genetic screening and genetic discrimination in education, employment and insurance, and a case study of debates among those at risk of developing Huntington's Disease and their relatives, we suggest that some of the claims made by critics of these new developments are misplaced. While there are possibilities of genetic discrimination, the key event is the creation of the person 'genetically at risk'. But genetic risk does not imply resignation in the face of an implacable biological destiny: it induces new and active relations to oneself and one's future. In particular, it generates new forms of 'genetic responsibility', locating actually and potentially affected individuals within new communities of obligation and identification. Far from generating fatalism, the rewriting of personhood at a genetic level and its visualization through a 'molecular optic' transforms the relations between patient and expert in unexpected ways, and is linked to the development of novel 'life strategies', involving practices of choice, enterprise, self-actualization and prudence in relation to one's genetic make-up. Most generally, we suggest, the birth of the person 'genetically at risk' is part of a wider reshaping of personhood along somatic lines and a mutation in conceptions of life itself.

Keywords: genetics; risk; identity; Huntington's Disease; biopolitics; genetic counselling.

Introduction¹

Among the many consequences of recent advances in the life sciences – in human genetics, molecular biology, genetic medicine and biotechnology – has been a mutation in 'personhood'. This is not merely a modification of lay, professional and scientific ideas about human identity and subjectivity, but a shift in the

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presuppositions about human beings that are embedded in and underpin particular practices. In this paper we focus upon one of these: the human being who is 'genetically at risk'. This kind of person is born at the intersection of at least three trajectories. *First*, we see the growing belief that many undesirable conditions – physical illnesses or behavioural pathologies – have a genetic basis. This may be in the form of a 'genetic mutation' for a particular pathology such as Phenylketonuria or Huntington's Disease, or it may be in a certain genetic make-up, which may involve many genes and their interactions with one another, which increases the likelihood that certain individuals will develop a particular condition such as breast cancer. *Second*, researchers claim that they have the capacity to characterize the genetic sequences or markers associated with the occurrence of many conditions at the molecular level and that this capacity will increase. This arises, in particular, out of the use of large-scale databases that integrate DNA analysis of tissue samples with family histories and personal medical records.² *Third*, doctors claim that they are increasingly able to identify specific individuals with the genetic make-up linked to the development of particular conditions prior to their onset through diagnostic tests. This identification may be precise, where genetic screening is able to identify the genes or polymorphisms themselves. It may be probabilistic, where screening is based on the identification of genetic markers associated with increased probabilities of being affected, or where identification is through family histories or the identification of factors associated with the condition. These developments, and associated mutations in personhood, re-shape the ways in which we are governed, and the ways in which we govern ourselves.

Re-cataloguing illness and pathologies along a genetic axis does not generate fatalism. On the contrary, it creates an obligation to act in the present in relation to the potential futures that now come into view. The discourses and practices of genetics here link up with those of risk. While hereditary knowledges have long been associated with various forms of risk thinking, the availability of predictive and predisposition genetic testing introduces a qualitative new dimension into genetic risk, creating new categories of individuals and according genetic risk a new calculability. As a result of these new knowledges, individuals may be specifically identified as genetically at risk for a particular condition, and may then be treated, by themselves, and by others ranging from employers and insurance companies to future spouses and genetic counsellors, as if their nature and destiny was indelibly 'marked' by this genetic flaw. In some cases they may be treated as if they were virtually certain to develop a condition in its most severe form, despite the fact that the 'penetrance' of the genes may be unknown, that in most cases only a certain percentage of individuals in this class will suffer in this way, and that the timing of onset and severity of any disorder is unpredictable. Not only may such persons suffer various forms of social stigma and exclusion from certain opportunities, services or benefits, but they may also find themselves, voluntarily or involuntarily, under the aegis of the medical, psychiatric or legal professions, and the subject of various forms of surveillance or treatment in the name of prevention.³

But the new genetics also links up with contemporary practices of identity. It operates in a political and ethical field in which individuals are increasingly obligated to formulate life strategies, to seek to maximize their life chances, to take actions or refrain from actions in order to increase the quality of their lives, and to act prudently in relation to themselves and to others. As life has become a strategic enterprise, 'the categories of health and illness have become vehicles for the self-production and exercise of subjectivities endowed with the faculties of choice and will' (Greco 1993: 358). In this context, genetic forms of thought not only give life strategies a genetic coloration but also create new ethical responsibilities. When an illness or a pathology is thought of as genetic, it is no longer an individual matter. It has become familial, a matter both of family histories and potential family futures. In this way genetic thought induces 'genetic responsibility' – it reshapes prudence and obligation, in relation to getting married, having children, pursuing a career and organizing one's financial affairs. Hence, like Ian Hacking's interactive kinds (Hacking 1986, 1995), these descriptions do not merely inform the judgements, calculations and actions of agencies of control – they shape the self-descriptions and possible forms of action of the genetically risky individual.

The rise of the person genetically at risk is one aspect of a wider change in the vision of life itself – a new 'molecular optics'. Life is now imagined, investigated, explained, and intervened upon at a molecular level – in terms of the molecular structure of bodily components, the molecular processes of life functions, and the molecular properties of pharmaceutical products. Of course, geneticists still gather information on family histories. But increasingly this gross level of data is only a stepping-stone in the attempt to construct linkage maps which can then be the basis of DNA sequencing and gene-hunting which will identify the exact chromosomal location and sequence of the mutated gene in question.⁴ We can see this molecular optic at work when heredity is visualized in terms of the sequences of bases on the human genome and when illnesses or susceptibilities are identified in terms of mutations at particular locations on a specific chromosome. For example, one condition involving fronto-temporal Dementia and Parkinsonism is known as FTDP-17 because it is linked to a number of mutations in a specific region of chromosome 17. Increased susceptibility to breast cancer has been linked to the mutations known as BRCA1 and BRCA2 on chromosome 13. Researchers have tried to link variations in personality such as novelty seeking, or psychiatric disorders such as manic depression, with the synthesis or non-synthesis of particular proteins or the characteristics of particular neuronal transmitters or neural receptor sites – chromosome 11 being a particular favourite.⁵ As the body becomes the subject of a molecular gaze, life is recast as a series of processes that can be accounted for and potentially re-engineered at the molecular level.

Most generally we will suggest that the birth of the individual 'genetically at risk' has to be understood as one dimension of a wider mutation in personhood that we term 'somatic individuality' – in which new and direct relations are established between body and self. New biomedical languages of description and

judgement – high blood pressure, abnormal heart rhythm, raised blood cholesterol and the like – have moved from the esoteric discourse of science to the lay expertise of citizens. Genetic ideas of personhood are already beginning to infuse these languages of somatic individualization, inscribing an indelible genetic truth into the heart of corporeal existence (cf. Kenen 1994). Like earlier languages – that of intelligence, or that of ‘hormones’ – these genetic languages render visible to others and to oneself aspects of human individuality that go beyond ‘experience’, not only making sense of it in new ways, but actually reorganizing it in a new way and according to new values about who we are, what we must do, and what we can hope for.

New genetic languages and techniques thus come into an association with all the other shifts that are assembling somatic individuality, with the norms of enterprising, self-actualizing, responsible personhood that characterize ‘advanced liberal’ societies, and with the ethics of health and illness that play such a key role in their production and organization. We begin this paper by saying a little more about the way in which we propose to think about personhood and its contemporary genetic mutation. Next, since the identification of persons in terms of their hereditary make-up and defects or propensities is not itself new, we will provide a brief history of the ideas and practices of genetic risk. We then consider two sets of practices. Through an examination of recent controversies about genetic discrimination in education, employment and insurance, we shall argue that this marks the birth of a distinctive, although not completely novel, mode of personhood which operates alongside, and intersects with, other modes of personhood operative in diverse practices and locales. However, we shall try to show that this mode of personhood cannot be understood simply in terms of the birth or rebirth of genetic essentialism, and, in particular, that it does not efface, but indeed links up with, prevailing forms of enterprising responsible personhood. Second, through an analysis of the ways in which those at risk of a particular disorder, Huntington’s Disease, debate the dilemmas that face them, we shall explore some of the ways the forms of subjectivity generated by genetic risk are bound up with new ethical problematizations and new ethical relations. We shall argue that, far from generating resignation to fate or passivity in the face of biological destiny or bio-medical expertise, these new forms of subjectification are linked to the emergence of complex ethical technologies for the management of biological and social existence, located within a temporal field of ‘life strategies’, in which individuals seek to plan their present in the light of their beliefs about the future that their genetic endowment might hold. These new modes of subjectivity produce the obligation to calculate choices in a complex interpersonal field, not only in terms of individuals’ relations to themselves, but also in terms of their relations to others, including not only actual and potential kin, past and present, but also genetic professionals and biomedical researchers.

Somatic individuality

A number of authors have suggested that we are witnessing a whole-scale geneticization of identity with the consequent reduction of the human subject to a mere expression of their genetic complement (Dreyfuss and Nelkin 1992; Lippman 1991, 1992). While these authors accept that genes play a role in all sorts of illnesses, in interaction with one another and with social, biographical psychological and environmental factors, they claim that 'geneticization' is a determinism which asserts that genes 'cause' disorders. They argue that these genetic narratives of health and disease orient the ways in which problems are defined, viewed and managed within society. They suggest that this legitimates funding and support for the projects of the gene mappers, and hence defines more and more problems of health and disease as 'genetic disorders'. Geneticization is seen as an individualizing tactic that redirects scarce resources away from social solutions to social problems, and represents a threat to doctrines such as equal opportunities, as well as to ideas of free will, intentionality and responsibility. 'The individual affixed with a genetic label can be isolated from the context in which s/he became sick. . . . The individual, not society, is seen to require change; social problems improperly become individual pathologies' (Lippman 1992: 1472–3). Hence the application of genetic knowledge in diagnosis, assessment and treatment is associated – wittingly or unwittingly – with strategies for the subjection and control of individuals and groups.

These arguments make some significant points, but taken as a whole we find them misleading.

The geneticization argument implies that to ascribe genetic identity to individuals or groups is to objectify them, hence denying something essential to human subjectivity. But to make human individuality the object of positive knowledge is not 'subjection' in the sense of domination and the suppression of freedom – it is the *creation* of subjects that is at stake here. Today, as at the birth of clinical medicine, the sick person bears their illness within their corporeality and vitality – it is the body itself that has become ill. But this somaticization of illness did not, in fact, mandate the eternal passivity of the patient. In fact, clinical medicine, increasingly over the last half of the twentieth century, constituted the patient as an 'active' subject – one who must play their part in the game of cure (Armstrong 1984; Arney and Bergen 1984). While not denying that illness was inscribed in the body, medical practice required the patient to offer up their voice in the diagnostic process in order to permit the disease itself to be identified, to commit themselves to the practice of the cure as part of a therapeutic alliance, and to conduct themselves prudently prior to illness, in the light of information about risks to health. The same is true of the role of contemporary medical genetics in the fabrication of the person genetically at risk. The patient is to become skilled, prudent and active, an ally of the doctor, a proto-professional – and to take their own share of the responsibility for getting themselves better. Patients at genetic risk and their families are not passive elements in the practice of cure. The studies carried out by Paul Rabinow (1999) as well

as Vololona Rabeharisoa and Michel Callon (1998) have shown that such persons – the ill patients themselves, those ‘asymptotically ill’ and their families – are increasingly demanding control over the practices linked to their own health, seeking multiple forms of expert and non-expert advice in devising their life strategies, and asking of medics that they act as the servants and not the masters of this process.⁶ These persons defined by genetic disease have an investment in scientists fulfilling their promises and discovering the basis of, and the cure or treatment for, genetic conditions. Medicine, including medical genetics, notwithstanding its resolutely somatic understanding of the mechanisms of disease, has been one of the key sites for the fabrication of the contemporary self – free yet responsible, enterprising, prudent, encouraging the conduct of life in a calculative manner by acts of choice with an eye to the future and to increasing self well-being and that of the family.

Critics also tend to suggest that the new medical genetics leads to a focus upon the individual as an isolate. We disagree. Within such practices, individuals are subjectified through their location in a matrix of networks. Consider, for example, the practice of genetic counselling, which we shall discuss in detail later. In a study of genetic counselling consultations, Armstrong and his colleagues show how the genetic identity of the counselled individual is established by locating him or her within a network of relations – mapping a set of remembered relations of lineage onto a remembered web of illnesses – at the same time as those social and familiar relations were reworked in genetic terms (Armstrong *et al.* 1998). The illness or condition becomes a ‘family’ matter. The ‘cause’ of the patient’s problem might be a family member in a previous generation; the diagnosis in one person has all kinds of implications not only for themselves but also for their relatives. New connections are traced in terms of the genetic threads that connected one person with another. Genetic identity is revealed and established only within a web of genetic connectedness, which is overlaid upon a web of family bonds and family memories, with their burden of mutual obligations and caring commitments, and with all the ethical dilemmas they entail. In becoming part of a genetic network, the subject genetically at risk may re-think their relation to their current family – lovers, potential and actual spouses, children, grandchildren and so forth – in terms of these issues of risk and inheritance. They may reshape their form of life – lifestyle, diet, leisure activities, alcohol, smoking – in these terms, which also reshapes their relations with those with whom they interact. They are brought into relation with novel networks of interaction – those not of ‘society’, but of ‘community’ – groups, associations, communities of those similarly at risk; groups of patients at particular hospitals or clinics; participants in trials of new therapies; subjects of documentaries and dramas on radio, television and the movies.

Further, the mutations in personhood associated with the new life sciences and bio-medical technologies of life are multiple and not simply genetic. For example, new reproductive technologies have split apart categories that were previously coterminous – birth mother, psychological mother, familial father, sperm donor, egg donor and so forth – thus transforming the relations of kinship

that used to play such a fundamental role in the rhetorics and practices of identity formation (Franklin 1997; Strathern 1992, 1999). Developments in psychopharmacology have transformed the ways in which individuals are understood, as the very features that seemed to constitute their individuality – such as personality or mood – now appear to be amenable to transformation by the use of specially engineered drugs such as Prozac (Fraser 2000; Slater 1999). New visions of personhood are coming to the fore associated with the growing interest and sophistication in brain-imaging techniques, which localize the features of the personality, affects, cognition and the like in particular regions of the brain (Beaulieu 2000; Dumit forthcoming). Practices of subjectification that operate in genetic terms – in terms of genetic forms of reasoning, explanation, prediction and treatment of human individuals, families or groups – find their place within this wider array of ways of thinking about and acting upon human individuality in ‘bodily’ terms. Or, to put it more positively, recent developments in the life sciences, biomedicine and biotechnology are associated with a general ‘somaticization’ of personhood in an array of practices and styles of thought, from techniques of bodily modification to the rise of corporealism in social and feminist theory and philosophy. This is what we mean when we speak of ‘somatic individuality’.

In any event, we suggest, the geneticization of identity has to be located in a more complex field of identity practices. Advanced liberal democracies are traversed by multiple practices of identification and identity claims – in terms of nationality, culture, sexuality, religion, dietary choice, lifestyle preference and much more. Only some of these ascriptions of, and claims about, identity are biological or biomedical. Indeed, biomedical identity practices and identity claims, including those that operate in terms of genetics, find their place among a bewildering array of other identity claims and identificatory practices, sometimes taken up, by subjects or by others, in a rewriting of identity in biological terms, sometimes vehemently contested. If anything, identities are plural and multiple: one is identified as a gay man within some practices, as a Muslim within others, as a carrier for sickle cell disease within others. Even when regulatory practices utilize biological conceptions of personhood, genetic identity is rarely hegemonic. In insurance, as we shall see, genetic information is considered alongside other non-genetic aspects of personhood – medical history, habits such as smoking, risks associated with lifestyle choices and so forth. In the courtroom, a range of biological evidence is now entering, including that from brain scans, in the determination of aspects of personhood such as capacity to stand trial or responsibility – but courts have proved remarkably resistant to arguments that responsibility or intentionality at law should be re-conceptualized in terms of evidence from genetics (Rose 2000a). Ideas about biological, biomedical and genetic identity will certainly infuse, interact, combine and contest with other identity claims; we doubt that they will supplant them.

A brief history of genetic risk

While hereditary thought has a long history, the twentieth century saw the emergence of a range of practices that defined individuals in relation to their genetic constitution. We wish to focus on one of these practices: genetic counselling. This developed as a venue within which individuals were made to reflect upon their inherited constitution, with the explicit aim of affecting their conduct. The history of this practice shows the ways in which the subject constructed in the genetic consultation has varied across this history, as have the modes of acting upon conduct that are produced. This variability is linked to the normative frameworks in which genetic knowledge is located, the techniques available for the detection of 'defective' genes, and the methods employed to shape conduct. It is against this background that we can identify the distinctiveness of the person genetically at risk who has come into being since the early 1970s.

Genetic counselling occupies a critical space between the objectifying knowledge of genetics, which operates at the level of the soma, and the human sciences, which work upon the conduct of human conduct. We employ the concept of *technologies of genetic selfhood* to understand the ways in which the practices of genetic counselling incite an individual, couple or family to reflect upon their genetic constitution with the aim of affecting their conduct in light of this knowledge. Technologies of genetic selfhood are heterogeneous assemblages. They involve a combination of forms of knowing, expertise and diagnostic techniques. Knowledge forms an integral component of such technologies and practices of self-government. At different times, this knowledge can range from Mendelian genetics to Rogerian psychotherapy, all of which can legitimately be employed in the genetic consultation, usually tailored to the perceived needs of the consultand. The practice of providing genetic counselling is not restricted to a particular professional group. It can be performed by such experts as physicians, paediatricians, geneticists, neurologists, psychiatrists or psychotherapists. However, at particular historical moments, contests arise over the appropriate form of professional expertise and the training required to perform genetic counselling. Our concept of technologies of genetic selfhood further attempts to capture how the provision of genetic advice is a technical process that makes use of family pedigrees, clinical observation, risk and probability analysis, serological analysis, tremometers, electroencephalographs, prenatal diagnosis, and predictive genetic testing (either through linkage or mutation), in order to help visualize, diagnose or communicate to a consultand their genetic status. And technologies of genetic selfhood can be differentiated according to the extent to which the very freedom of individuals is taken into consideration.

Technologies of genetic selfhood need to be located within particular biopolitical rationalities. While many view the role of genetics within contemporary biopolitics through the prism of eugenic segregation, sterilization and extermination, we think that such dystopian visions fail to grasp either the specific rationalities or the particular technologies of the contemporary politics of life (Rose 2000b). For present purposes, we can make a broad heuristic division into three

periods that differ in the objectives, problematizations, normative orientation and practices of genetic advice giving. The first 'eugenic' period runs through the 1930s and 1940s. While eugenic forms of thought were born in the 1880s, they spread across Europe, North America and elsewhere in the first half of the twentieth century and were accompanied by the development of a whole range of control strategies involving segregation, sterilization and, in Germany at least, elimination, of those of defective stock. But they also gave rise to attempts to reshape 'voluntary' individual reproductive decisions in the light of eugenic considerations, and in the 1930s genetic counselling took its place alongside strategies of public education and the use of film and propaganda. As is well known, the concern of eugenics was to improve the quality of the national population at the genetic level, through eugenically informed curbs on immigration and through limiting the reproduction of those of inferior stock through their sterilization or incarceration. In the genetic counselling of the early 1930s to the late 1940s, the dominant biopolitical and normative orientation in which the field of genetics was situated was eugenic, and concerned with improving the quality of human stock. Genetic advice in the eugenic age required an assessment of good and bad genetic qualities, and of the seriousness of the heredity defect. Couples who were intelligent and of good physique should be encouraged to bear greater numbers of children, while those that were not should be encouraged to restrict their childbearing or family size (Gates 1934: 35). While some subjects were thought to possess the moral capacity to control their reproduction, most were represented as passive individuals who often unwittingly bore more children than they should due to their failure to acknowledge they faced any genetic risks or due to the effects of the disease itself – especially in the case of Huntington's Disease (Davenport and Muncey 1916; Hughes 1924).

The period from the 1950s to the early 1970s witnessed the ascendance of a preventive genetic health model and the evolution of non-directive genetic counselling in an attempt to dissociate the field from the negative eugenics associated with the Nazi regime. The non-directive approach to genetic counselling in the early 1950s entailed the argument that the prevention of genetic disease in democratic societies could take place only through voluntary measures (Dice 1952: 2). The prevention of genetic disease was focused on the optimization of the health of the population and was mostly concerned with the prevention of birth defects (Fine 1993). The dominant normative orientation was the belief that parents wanted healthy children: hence it was thought that they would make use of knowledge of heredity risk to act responsibly, to choose not to have children, to limit their family size, or to adopt (Dice 1952: 2; Herndon 1955: 89). This marks the birth of the ideal of the responsible genetic subject, one who takes into consideration hereditary knowledge and uses it to make decisions concerning reproduction.

During this period, the role of genetic counselling was redefined as a form of guidance to help relieve the anxieties, fears and inner tensions of being provided with genetic risk information (Kallmann 1956, 1961, 1962; Roberts 1961). The use of psychology within the genetic consultation at this time was to optimize

the assimilation of genetic risk information. Individuals confronted by genetic risks were thought likely to resort to immature patterns of behaviour, resulting in the neutralization of genetic realities through pathological defence mechanisms such as repression, displacement, rationalization and projection (Kallmann 1956: 97; Tips *et al.* 1962). Genetic counselling was conceived as a form of short-term psychotherapy with the aim of instilling a sense of responsibility within consultands, and a recognition of the value of a well-planned family (Kallmann 1962: 253).

It is against this background that we can identify the distinctiveness of the psychosocial counselling that became dominant from mid-1970s to the present. This has taken place in the context of the reconstitution of much disease along a genetic axis. The identification of genetic risks has become bound up with a concern to maximize life chances and improve quality of life understood, in part, in somatic terms. The objectives of genetic counselling were redefined: it should no longer be exclusively concerned with the *prevention of genetic disease*, but must be involved in the *communication of genetic risk* (Kenen 1984). At the same time, new technologies for prenatal diagnosis of genetic risk were developed: first linkage testing and more recently presymptomatic and predisposition testing. In the case of linkage and presymptomatic testing for late onset disorders, there was considerable debate in the field of medical ethics about the ways in which research and practice in these areas might maintain the principles of autonomy and choice. Psychology was seen as the key tool to improve the effectiveness of genetic counselling in relation to these criteria as well as helping individuals cope and adjust to living at risk. In this process, the subject of the genetic consultation was increasingly addressed as an autonomous individual making informed and responsible choices in a process of self-actualization. This was the individual who was confronted with the range of new choices that developments in biomedicine had placed before them. Such individuals had to make complex decisions concerning their own life and the lives of their actual or potential offspring in the light of new genetic knowledges, and in the light of a range of new techniques such as prenatal testing, pre-implantation diagnosis and the abortion of foetuses thought to carry, or potentially to carry, genetic pathologies.

As presymptomatic and predisposition genetic testing became more widely available, psychometric testing was incorporated into testing protocols, initially for late onset disorders such as Huntington's Disease, in order to identify those who were also at risk for adverse outcomes such as depression or suicide as a result of the testing process. Those undergoing genetic testing were also evaluated in terms of their coping resources, sources of support from spouses, friends, family, or participation in support groups (Bloch *et al.* 1993: 370; Decruyenaere *et al.* 1996, 1999). The at-risk individual thus becomes either willingly or unwillingly implicated in a web of professional and lay support networks as part of being identified at genetic risk.

Most recently, psychosocial genetic counselling has come to focus upon the modification of lifestyle (Marteau 1999: 426) and, in particular, upon promoting the autonomy and self-directedness of the client (Elwyn *et al.* 2000, quoting

Kessler 1980). Through techniques such as shared decision making, the client is themselves to be a party to the relevant information, and take a portion of the responsibility for any decision, including, for example a decision to disclose genetic information to kin who may also be genetically at risk. And such disclosure is itself seen as vital, in the light of the need to 'give them the opportunity to plan their lives, to make informed decisions about reproduction, and to seek surveillance for early signs of a complication for which medical intervention can be effective'. The 'genetic counselling session must not be construed as the passive transference of information from expert to layman, but as a dynamic, or ongoing, process in which the counsellor and counsellee both have a role to play in determining what occurs and what is understood' (Hallowell and Richards 1997: 40). The good subject of the genetic consultation thus becomes the individual who will modify their lifestyle responsibly in relation to their genetic risk.

Thus we can see that the subject that is fabricated in the contemporary genetic consultation is not merely a subject at genetic risk, but also a responsible subject who exercises choice wisely (cf. Ogden 1995). Through the availability of presymptomatic, predisposition and prenatal genetic testing combined with an array of psychological techniques, the genetic consultation now performs a genetic re-mapping of a person's life in a biological and temporal space which contains the potential to reconfigure identity in terms of a genetic past, a genetic present and a genetic future. Genetic counselling here joins up with a different trajectory concerning the regulation of women's bodies in relation to reproduction and the obligation of women to make choices about their own reproduction in the light of expert knowledges and techniques. On the one hand, this opens the possibility for new strategies of control, in which psychology plays a key role in attempts to modify the behaviour of those deemed genetically at risk. But, at the same time, the reconfiguration of identity within the temporality of genetics establishes a new ethical field for the formulation of life strategies.

Genetic discrimination

On 8 February 2000, at a meeting of the American Association for the Advancement of Science, the then President of the United States, Bill Clinton, signed an executive order that prohibited every federal department and agency from using genetic information in any action involving hiring or promotion (for details of these steps, see White House 2000). On the same day, Clinton endorsed the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, which extends such protections to the private sector, and to individuals purchasing health insurance. This was in the context of a 1996 study that had shown that 25 per cent of the respondents or affected family members believed they were refused life insurance, 22 per cent believed they were refused health insurance, and 13 per cent said that they or a family member had been denied a job, or fired from a job, because of a genetic condition in the family; many of those

questioned had refused genetic tests because of fear of genetic discrimination or had not revealed genetic information to insurers or to employers (Lapham *et al.* 1996). Other studies had found a widespread fear that employers would, in the future, demand that potential employees took genetic tests, and that many would be deterred from taking such tests in the present if employers could access the results. Clinton re-asserted the view he had expressed since 1997: the effort to find genetic cures for diseases should not undermine protections for patients.

The potential for genetic knowledge to be used in discriminatory ways has been warned against for many years. In 1992, Paul Billings and his colleagues defined genetic discrimination as 'discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the "normal" genotype' (Billings *et al.* 1992: 476) and found some evidence of such discrimination in the health and life insurance industries and elsewhere. They warned of the possible growth of stigmatization and denial of services and entitlements to individuals who have a genetic diagnosis but are asymptomatic, and pointed to the dangers of creating 'a new social underclass based on genetic discrimination ("the asymptotically ill")' (1992: 476). Since that time, further studies have argued that there is evidence of genetic discrimination – that is to say, discrimination against currently healthy individuals on the basis of genotype alone, sometimes based upon misunderstandings, such as when an individual is a carrier for a mutation for a particular disorder, but will not develop the disease. Some have suggested that the rise of genetic testing blurs the boundaries which were previously used to define 'pre-existing conditions': an individual carrying a detectable mutation or mutations that predispose them to develop a particular disorder in particular circumstances might be considered to have a 'pre-existing condition' – even if they are unaware of it. Studies have also suggested that the fear of genetic discrimination is widespread among those who have family histories of particular disorders, and that this is leading to reluctance to take genetic tests, concern about disclosure of information on such tests by medical practitioners, and in some cases to the falsification or non-disclosure of relevant aspects of medical histories to insurers, employers or others. And many have argued that existing anti-discrimination provisions are insufficient to deal with these issues.

Since 1991, over half the states in the USA have enacted laws that prohibit the use of genetic information by insurance companies in the pricing, issuing or structuring of health insurance (Hall 2000). However, a recent study by Hall concludes that such laws do not seem to have had much impact, for, in fact, there are almost no well-documented cases of health insurers asking for or using presymptomatic genetic test results either before or after the passage of such laws, or whether or not such laws exist in the state in question. Perhaps, as Hall says, industry norms are more significant than laws in organizing practices of this type. And, one might add, perhaps the fear of such discrimination is more real a force than actual discrimination. In any event, our aim here is not to analyse the current and future extent of, or potential for, genetic discrimination itself. The injection of debates over genetics into practices of educational assessment,

employee recruitment and actuarial calculation is significant in its own right – for such debates are acting as vectors for the spread of genetic conceptions of personhood, for the generation of ‘genetic responsibility’, and for the partial reshaping of ethical dilemmas in molecular terms.

Education is a key surface of emergence for these new ways of thinking. Medical diagnoses of educational difficulties and explanations of failure in biological terms have a long history. Diagnoses of minimal brain dysfunction, hyperactivity, attention deficit disorder and attention deficit hyperactivity disorder have been the site of medical and psychiatric expansion for some decades, with the widespread use of Ritalin as a ‘treatment’. More recently, there is evidence from the United States of the widespread diagnosis of depression in children, coupled with the prescribing of anti-depressive medication, notably serotonin selective reuptake inhibitors such as Prozac, to children. According to a report in the *Washington Times* (7 September 1998) from 1996 to 1997 the number of children aged 5 and under taking the most commonly prescribed anti-depressants climbed from 8,000 to 40,000; during the same 12-month period, the total number of under-17s who were prescribed the three most common SSRIs (Prozac, Zoloft and Paxil) rose from 669,000 to 792,000.

The molecular optic of the new genetics adds the possibility of predictive tests to such practices, and hence of genetic screening and presymptomatic intervention. Of course, strategies of screening and preventive intervention have long been advocated in relation to juvenile delinquency and criminality. Direct genetic screening for pathologies of conduct together with preventive intervention was first advocated in the late 1960s, when the claim was made, later disproved, that the XYY condition – the possession of an extra Y chromosome – was linked to immaturity, inadequate control of aggressive instincts and hence to an increased probability of violent crime.⁷ In the recent examples, screening of schoolchildren would not merely be for genes linked to future psychiatric disorders, but for genes that are claimed to link directly to problems arising within the schoolroom. As early as 1987, reports in popular science journals claimed to locate a particular gene on chromosome 15 possessed by members of a family in which there was a history of reading disability, holding out the hope of predictive tests and presymptomatic treatment to avoid the problems of dyslexia (Velutino 1987, cited in Hubbard and Ward 1999). In 1995, articles appeared in *Developmental Brain Dysfunction* reporting pilot projects to screen schoolchildren for major chromosomal abnormalities (duplicate X or Y chromosomes, fragile X syndrome) with the aim of providing genetic counselling and other forms of medical intervention (Roy *et al.* 1995; Staley *et al.* 1995). Recent research claims that childhood ‘hyperactivity’ is highly heritable, and that specific genes encoding aspects of the dopamine transport and reception system (DAT1 and DRD-4) may be implicated, though admitting that the findings need further replication and validation (Thapar *et al.* 1999). Dorothy Nelkin and Laurence Tancredi (1989) suggest that, over time, such claims will lead to the use of genetic and biologically based tests as part of the standard testing regime in schools, and that educational authorities and parents will come to see them as

objective assessments that have predictive value. This illustrates the two faces of genetic individualization. On the one hand, such tests would be justified and adopted because of the necessity of providing such children with special attention and tailored regimes of learning. On the other, they may also lead to discrimination in the acceptance of children by certain schools, they are likely to be transmitted along with other information to post-school institutions such as colleges or potential employers, and may thus generate a long-lasting spoliation of identity at the molecular level, and a life sentence to existence under the gaze of the helping and therapeutic professions. Whatever their direct consequences, however, the unique visibility that the practices of schooling confer upon children, which is both universalizing and individualizing, will play a key role in the dissemination of these new molecular visions of conduct and its determinants.

Another surface of emergence for these new forms of thinking is the workplace. This is a particular issue in the USA where, in the absence of any universal schemes of health insurance, many workers receive health insurance through schemes established between employers and private insurers. As employers invest more in the recruitment, training and retention of workers, and are faced with growing insurance premiums and other costs associated with accidents, injury and ill health among their workforce, they are increasingly seeking to adopt hiring practices that screen out those employees most at risk of future ill health and disability. The debate focuses upon whether it is legitimate for genetic screening to join older techniques – such as the requirement for information on personal medical history, the use of psychological tests and examinations, and the taking of family histories – in the attempt to identify individuals who may be ‘accident prone’ or are particularly liable to develop physical illness or psychological conditions rendering them unable to work effectively, or who may be particularly vulnerable to certain features of particular working conditions.

In the United States, most health insurance is obtained either through private schemes or through workplace-based group schemes (for a good early review, see Gostin 1991; for a comparative study focusing on Canada, see Lemmens and Poupak 1998). Individual insurance is individually underwritten, on the basis of risk factors such as age, medical history, occupation, health-related habits such as smoking and the like – hence the relevance of individual information on genetic risk. Group insurance is underwritten on the basis of the risk characteristics of the group, such as type of industry, age and gender characteristics, experience of prior claims and the like – hence the relevance of biomedical information in employers’ recruitment practices. In Britain the situation is different, because health insurance is obtained through a national scheme, the National Health Service, funded through universal compulsory taxation set at levels unconnected with medical history or risk category. Unlike the private and group systems in the USA, a universal system inescapably must cope with the aggregate levels of genetically related diseases in the population – levels that are unlikely to be directly affected by genetic testing (O’Neill 1998; Wilkie 1998). This distinction is, however, only partial. This is not only because increasing

numbers of people in the UK are opting for private health insurance, or being given entry into such schemes through their employment, and hence having to undergo medical screening prior to the issuing of the employment contract. Nor is it because some other, perhaps more optional, insurance products, such as travel insurance, are also individually underwritten and require disclosure of relevant medical information. It is also because life insurance, in the UK as well as the USA, is individually underwritten, and life insurance in the UK is virtually obligatory for those wishing to obtain a mortgage or loan for house purchase.

Where insurance is individually underwritten, insurers are concerned about accurate and full disclosure of information, first, to allocate the applicant correctly to a risk pool, but, second, because of the fear of anti-selection or adverse selection: where an applicant deliberately withholds information that indicates they are at increased risk – for example, cigarette smoking – in order to take advantage of premiums set for those with a lower level of risk. Thus, for example they worry about the possibility that an individual who has genetic knowledge unknown to his or her insurers will conceal the test result and buy life insurance at the standard rate, knowing that their life expectancy is short, hence greatly enhancing their inheritance in the short term and driving up premiums for other policy-holders in the long term – or driving others to companies that could offer lower rates because they had more effective methods of screening out those at high risk. They are concerned that the impact of such shifts might be exacerbated by those who have tested negative for various genetic conditions deciding that they do not need insurance coverage; these were the people whose premiums would have provided the resources – the unwitting subsidization – for the demands made by those who did need to claim. While historically insurers and applicants have largely operated on the basis of mutual genetic ignorance, insurers in the United States by and large argue that there is no significant distinction between genetic information and other health-related information concerning risks, and that the distinction between genetic information and other information on medical risk is unsustainable (Pokorski 1997). Pokorski, an executive of a leading US reinsurance company, points to a host of evidence in support of his view. Textbooks routinely suggest that almost all medical conditions have a genetic basis, the National Center for Human Genome Research has observed that ‘For policy purposes, it will become increasingly difficult to distinguish genetic from non-genetic diseases, and genetic information from non-genetic information’ (National Center for Human Genome Research 1993), and an editorial in *The Lancet* argued that ‘it will soon be impossible to talk of medical and genetic tests as separate creatures’ (*Lancet* 1996). Indeed, as technology companies develop inexpensive biochips to screen for hundreds of genetic defects, drop-in shops and centres are envisaged where individuals can obtain information on genetic testing and common genetic disorders and which even offer ‘walk-in testing’, mail-order kits and home test kits, it seems likely that genetic information may come to be as widely known to individuals as information on other insurantly relevant risk factors such as raised blood pressure, high cholesterol levels, abnormal heart rate and high body-mass indices.

In the light of these developments, it is easy to understand the view of the Association of British Insurers in the code of practice it issued in December 1997 – that it is not only conceptually unwarranted, but also practically impossible to distinguish genetic information from other medical information of relevance to insurers (Association of British Insurers 1997). Yet, on the same day, the Human Genetic Advisory Commission set up by the British Government published a report recommending precisely the opposite: a moratorium for at least two years on any requirement for an applicant for life insurance having to disclose the results of any genetic test to a prospective insurer, until sound actuarial evidence supporting the use of specific tests in relation to specific insurance products has been scientifically validated and is publicly available (Human Genetics Advisory Committee 1997; see Wilkie 1998 for a discussion of these two reports). Critics of the insurers' demands for disclosure of purportedly predictive genetic information argue that those making use of such information are often ignorant of the exact implications; that genetic predictions have rarely been validated and therefore do not allow accurate assignment of an individual to a risk pool; that there is a high level of uncertainty as to the age of onset and severity of most genetically related conditions; and that there is lack of knowledge as to the interaction between genes and between genes and environment and between genes and lifestyle (e.g. O'Neill 1998). Newspapers are beginning to warn of the dangers of the creation of a 'genetic underclass' (*Daily Telegraph* 2000: 1). In the United States, as we have seen, many individual states have passed laws prohibiting insurers' use of genetic information; some authors have argued that health-care providers are under an obligation *not* to disclose genetic information to insurance companies or employers who might use it to discriminate against them; genetic counsellors are being advised to counsel their clients on how to minimize potential insurance problems; some are urging that genetic testing is carried out on an anonymous basis wherever possible to limit the potential for identification of the testees; others are advising individuals to buy all the life and health insurance they require before they undergo genetic testing; individuals are being advised to apply for a large number of small life insurance policies that are less carefully scrutinized rather than applying for a single substantial policy; and physicians are being urged to keep two sets of records, one complete set to be used for health care and one, without adverse test results, which can be accessed by insurers (all examples cited from Pokorski 1997).

No doubt this dispute will be resolved differently in different jurisdictions, at least in the short term. Genetic information has significance, in part, because of a more general shift that is occurring in insurance towards risk segmentation (for what follows, see Ericson *et al.* 2000, in this issue). While insurance can act so as to socialize risk, the current tendency has been to utilize knowledge about populations and information about individuals to 'unpool' risks and to allocate individuals to tightly defined risk categories. Such tightly defined risk pools will then not only determine the cost of insurance and its benefits and exclusions for those included, but may also lead to the exclusion of those whose risks make them unfit for inclusion in a commercially viable risk pool. This strategy is

justified in terms of twin obligations: not to burden prudent consumers with the cost of risks incurred by the imprudent; to safeguard and maximize profitability for shareholders by incorporating all known relevant information into risk calculations. But the result is not only to encourage moral hazard (lying about one's history in order to obtain insurance at preferable rates, or even at all), but also to drive those whose risks are deemed too high (those with poor driving records or in areas with high rates of burglary) to specific niche market insurance companies, usually not only charging high rates but also offering limited cover. Within this logic, it is clear that genetic risk is a key factor for such segmentation and unpooling practices. These practices can undoubtedly be seen as congruent with the emphasis on personal responsibility and prudence in advanced liberal practices of government. But, where high risk is a matter of inheritance, it seems that the old adage still applies: if you want to be successful, choose your parents carefully. In a regime of fragmented communities of risk, private insurance no longer redistributes accident to mitigate the arbitrariness of fate and the hazards that, but for the grace of God, may face us all. Where backdated genetic prudence is an impossibility, the individual and his or her family has few options when required to take personal responsibility for the governance of their genetic risks. For the wealthy or articulate in this situation, this may enhance the development of risk communities who take their own measures to ensure their security. However, especially in the USA, where upwards of 40 million people have no health insurance whatsoever, those who are excluded from this option are likely to find themselves abandoned to whatever residual provision the 'facilitating' state may offer.⁸

The actual penetration of genetic reason into insurantal practices will clearly depend upon these contestations. The truth of certain genetic claims will be disputed. Reductive genetic arguments are likely to be rejected by all parties. Legal measures may restrict the occasions where an individual may face compulsory genetic testing at the demand of some authority. Factors such as cost may limit the general use of predictive screening. Irrespective of these actual outcomes, however, disputes over insurance are acting as a key vector for the spread and proliferation of genetic reasoning and its penetration into conceptions of personhood. In these struggles over the way in which the body should enter insurantal practices of calculation, the somatic individual has become inescapably genetic. Individual fate, and hence individuality itself, has acquired a genetic dimension. And perhaps the key sites of innovation here are to be found neither in the calculative practices of the insurers nor in the vociferous defenders of privacy and rights, but in the forms of life of the actors themselves, the subjects both of genetic risk and of insurantal practice. Somatic individuals do not relate to themselves as simply the expression of an underlying genetic identity. Even when genetically at risk, such individuals consider themselves to be creatures of rights, legal subjects whose somatic personhood grants them entitlements as well as obligations. As we shall see presently, among the rights that may be claimed is the right to know one's genetic status, one's level and pattern of genetic risk. And, further, the somatic individual, incorporating their genetic status, is also a

subject of self-actualization, responsibility, choice and prudence – ethics that can only be operative in the light of a knowledge of one's bodily truth. Individuals themselves are faced with questions as to whether to take genetic tests in order to predict their own future and act prudently within it, in relation, say, to their obligation to their family, the need to make provisions by way of insurance in the event of their death or incapacity, their wish to conduct their affairs in the world in the light of a knowledge of their genetic status. Genetic identity, that is to say, induces 'genetic responsibility'.

Genetic responsibility

The advances in the life sciences associated with molecular genetics and the mapping of the human genome create new possibilities for thinking about and acting upon the conduct of human beings as somatic individuals. The merger of the language of genetics and risk provides a rich vocabulary by which to render intelligible in new ways our identities, our conceptions of health and our relations with others. This opens up novel and distinctive fields for ethical self-problematization.⁹ The language of genetic risk increasingly provides a grid of perception which informs decisions on how to conduct one's life, have children, get married or pursue a career. With the emergence of the genetically at risk person, genes themselves have been constituted as what Foucault (1982) might term an 'ethical substance' that one works upon in relation to the self (genetic identity, reproduction, health) and in relation to others (siblings, kin, marriage, children). Rather than seeing these practices of genetic subjectification in isolation, we suggest that they intersect with, and become allied to, contemporary norms of selfhood that stress autonomy, self-actualization, prudence, responsibility and choice.

We can investigate some aspects of these new forms of personhood through a study of webforums and chat rooms. These are sites on the Internet where subjects at risk and others can discuss their own ways of understanding and responding to issues related to risky genes and genetic disease.¹⁰ Of course, these are not 'representative' – only a tiny minority of those genetically at risk are involved in such activities, probably disproportionately drawn from those who are young, relatively wealthy and better educated. Yet, we suggest, they exemplify the formation of a new ethics of biomedical subjectivity that Paul Rabinow suggests is emerging out of the plethora of new movements organized around the new sciences of medicine and life. In which actual and potential patients – in other words, all of us – have come to be 'passionately curious about their health, happiness and freedom' (Rabinow 1994: 63). We focus on one particular webforum concerned with Huntington's Disease (HD).¹¹ Like earlier practices of confession and diary writing, the practices of posting, reading and replying to messages in these webforums and chat rooms are techniques of the self, entailing the disclosure of one's experiences and thoughts according to particular rules, norms, values and forms of authority. Through these practices of

disclosure, individuals develop a language to narrate and reflect upon their genetic identity, seek advice on how to conduct their lives appropriately, and assume responsibilities for the management of genetic illness. In HD, key issues concern the decision as to whether to have children, the decision to get married, and disclosure to other family members that they face the prospect of developing a debilitating neurological disorder. These informal practices of mutual disclosure around such issues among those who identify themselves with a virtual community are significant because they constitute a novel form of authority – an authority based on not on training, status or possession of esoteric skills, but on experience. And, like those older forms of authority, experiential authority, the experiential authority of others, can be folded into the self (Dean 1996; Rose 1996, 1998). As we shall see, relations with older forms of authority, such as medical and genetic expertise, mutate. These small, yet important mutations are starting to shape the ways in which novel life strategies are formulated and developed. Within such life strategies, the governance of risky genes is intimately tied to identity projects, the crafting of healthy bodies, and the management of our relations with others, in relation to a wide range of authorities that are folded into the self.

Molecular-genetic identities

The practices of the self through which individuals constitute themselves as at risk from their genes are complex and multiple. One such technique is biographical narration in genetic terms. On the HD webforum, this is sometimes accomplished through mapping a family tree. These charts are not simple traces of familial lineage, but a form of medico-genetic biographical narration, which can encompass several generations, such as grandparents, and include kin such as aunts, uncles and cousins. The construction and interpretation of a family pedigree draws upon some elementary knowledge of genetics and its mode of transmission for a particular genetic illness. In the HD webforum, the elaboration of a medico-genetic family pedigree forms one means through which subjects are constructed by others and the self as being at genetic risk for Huntington's Disease. In narrating such biographies, HD comes to affect family members whether they carry the mutation or not.

Within the HD webforum, the decision to undergo a predictive genetic test is presented as a monumental and potentially life-altering decision that one makes for oneself, in relation to one's genetic legacy, and for significant others. The availability of predictive genetic testing in HD is shaped by the ethic of the autonomous medical subject; hence it occupies a unique space situated at the crossroads between expert technologies of genetic selfhood and those operations one performs on the self. Hence predictive genetic testing for HD serves to create productive alliances between genetic forms of subjectification with enterprising, responsible, prudent, and self-actualizing forms of selfhood. Predictive genetic tests thus introduce qualitatively new possibilities into the experience of

being constituted as a subject at risk from one's genes. This technology multiplies the descriptions humans can apply to themselves and act in accordance with. Predictive genetic tests serve to create new categories of persons. They accomplish this in two ways. First, genetic tests have the potential to modify risk status from one of uncertainty to certainty. With this technology, it becomes to possible to come to know the 'real' truth about oneself at any time through the use of a medico-genetic diagnostic technique and thus significantly modify or resolve this risk situation. Second, predictive testing creates categories of individuals who can be described as at risk, but not tested: HD positive, HD negative or HD intermediate. In the case of HD positive or negative, the undertaking of a predictive genetic test serves as a confirmation of one's 'true' genetic identity and may act as a catalyst to the formation of a new genetic identity that sheds the at risk label. In the case of testing negative for the HD gene, the person's risk is modified to zero and it can thus lead to a significant transformation of identity. The predictive test can also be indeterminate in that it does not positively confirm or negate one's true genetic identity. This occurs when the number of CAG repeats used to evaluate the presence of the HD abnormality falls in a borderline range of the normal and the pathological. In these instances, the identity of the molecular genetic self is put into question.

As we can see, predictive genetic testing is one technique through which individuals come think of themselves as molecular-genetic beings. In the case of HD, key aspects of self-identity come to be defined in terms of the sequence of bases at a particular location on the short arm of chromosome 4. In HD genetic testing, this process of molecular somaticization takes place through the analysis of the number of CAG repeats on the affected chromosome. These are significant as they not only indicate the presence of HD, but are also considered indicative of age of onset and the severity of symptoms experienced. This genetic knowledge becomes important in shaping ethical decisions concerning reproduction, introducing new norms of reproductive health shaped in terms of a concern for others.

The risky genetic self as a domain of ethical problematization

Genetic forms of reason shape reproductive decision making in particular ways. Perhaps one of the most frequently posed ethical questions in the HD webforum concerns the decision to have children in light of knowledge of being genetically at risk or presymptomatic. This arises in the context of concerns about passing the HD gene to subsequent generations. One example of the ways in which quite complex molecular genetic knowledge has begun to permeate the field of reproductive decision making concerns paternal transmission of HD. In the case of HD, fathers at risk for HD have the potential to transmit more severe and earlier onset forms of HD to their offspring. This clearly serves to complicate the decision to have children for such men, and also for their actual or potential partners, who must take into account the small risk of transmitting earlier

and more severe forms of HD. Once the field of reproductive decisions becomes structured by knowledge of molecular risk, each individual becomes obliged to inform themselves of the potential genetic risks that may be transmitted in the course of reproducing their genetic selves. The genetic future – the quality of life that potential offspring will have in terms of genetic illness – now becomes an ethical concern for each risky individual in the genetic present.

The genetically at risk individual must engage with a communicative problem space. When should they tell siblings or children that are also at risk that they have decided to undergo predictive genetic testing? When should they tell children or other family members they face the prospect of inheriting a severe neurological disorder? As genetic information is familial, it has the potential to affect our relations with others. Hence the governance of one's own risky genes intersects with the governance of one's communicative relations with others. In our age of authenticity, the norm of truthful speech increasingly infuses familial relations. How, then, should we shape our communicative conduct with regard to potentially life-altering information? For those genetically at risk, genetic knowledge is now constructed as valuable in making life-planning decisions concerning education, careers, relationships and children. And once choice is seen as paramount, knowledge is required to make informed decisions. In this context, where genetic information is thought of as containing the potential to transform one's life, the disclosure of genetic risk information gets framed in terms of the language of rights – the right to know – a right of one's kin, a right of one's children – the withholding of this knowledge is seen as an incursion upon the right to choose. Yet, as our earlier discussion of genetics and insurance makes clear, the right to know comes into tension with another right, the right not to know, the right not to be known, the fear of the consequences that that knowledge may bring for one's conduct of one's own life and for one's treatment by others – friends, employers, teachers or insurers.

Relation to expertise

Nonetheless, for some at least, the combination of genetic and enterprising forms of selfhood creates new relations with expertise, reconfiguring power relations in significant ways. The responsible-genetic subject is one who reads and posts messages in the HD webforum and who takes an active role in the management of HD genes, rather than being the passive subject of medico-genetic discourses. The responsible-genetic subject becomes a lay expert in the governance of HD. This takes the form of gaining as much knowledge as possible about the disease and applying it to oneself or to the person for whom one cares, with the aim of optimizing health and improving the quality of life. This applies to such things as dental care for persons affected by HD, the use of feeding tubes to prevent the deterioration of a person with HD in advanced stages who has difficulty swallowing, the alleviation of muscle pains caused by

the choreic movements, learning about the side-effects of the medication one is prescribed.

Further, the relations with professional expertise are increasingly conducted at a distance. In the first place, relations are distanced though the medium of hypertext which makes it easier to access medical information. The Internet becomes a source for informing oneself about the nature of the disease and various resources for coping with it. In a second sense, relations are at a distance, in that professional experts are no longer considered as the sole repository or mediator of knowledge, with whom one enters a passive relationship. Knowledge comes to be regarded as residing in multiple sites, which are to be actively sought and assimilated for purposes of the care of the self and the care of others. Somatic individuals, in this case those genetically at risk, engage with this knowledge as interested and avid consumers, aware of the range of knowledge products on the market, and demanding that their choice is constantly expanded. Within this configuration, geneticists and clinical researchers are assigned the responsibility and duty to produce new forms of knowledge that are available and applicable to persons suffering from this disease. The responsible-genetic subject becomes active in the shaping of the enterprise of science. This takes the form of placing one's hope in finding a cure for HD. It entails posting promising new research findings in the webforum. Materially, it often implies donating parts of one's income towards finding a cure for HD, engaging in various fundraising activities to support the search for a cure, and a willingness to take part in experimental clinical trials for potential therapies to cure HD. People do not passively await the development of new treatments: they come to have an active stake in the development of biomedicine (Rabinow 1999; Rabeharisoa and Callon 1998).

Increasingly, those at risk constitute their own forms of expertise, through support groups for those at risk or affected by HD (cf. Levi 2000; Moore and Valverde 2000, both in this issue). Group talk is encouraged as a means of coping with one's HD status. The Huntington's Disease Society of America (HDSA) and its affiliated HD societies are seen as sources of information, and of useful pamphlets that can be used as guides to living and coping with HD, ranging from information on juvenile HD to insurance to genetic testing. In this context, the role of genetic counselling is redefined. The genetic counselling session is seen as beneficial in terms of helping individuals cope with the predictive testing process and the experience of being genetically at risk or presymptomatic. The genetic counselling session is valued not so much for reproductive advice, but in terms of providing the coping skills necessary for coming to know the truth about one's genetic self.

Risky genes and life strategies

The intersection of subjectification in terms of genetic risk with contemporary responsible, choosing personhood suggests novel ways of thinking about and

acting upon our lives in the present in relation to some future goals. The concept of life-strategies attempts to give a name to the variable and multiple strategies that individuals formulate in relation to particular directions that they would like their life to take. Life strategies are formulated in a complex field of ongoing ethical problematization of how one should conduct one's life. Only a finite set of forms of life are at our disposal: the practices and techniques that we have to shape the self and mould our lives are contoured by dominant cultural practices and are historically specific. Predictive genetic testing, genetic counselling, the disclosure of the self in the webforum, planning methods and religious practices thus interact in the formulation of life strategies. Individuals act upon the inscriptions of clinical risk which mark their bodies and define them as particular kinds of subjects. In the debates on the webforum, life is considered in temporal terms, as formed of stages when one would like to accomplish certain objectives or in the sense of what to do with the time remaining on this earth. Thus, the formulation of life strategies in relation to the governance of genetic risks merges and combines with other life projects, such as the crafting of a unique identity, concern with health, diet and the management of our relations with others. The formulation of life strategies should be seen as projects that are composed not in isolation, but rather in conjunction with a range of authorities that are folded into the self, such as genetic counsellors, psychologists, support groups, Internet discussion groups, advice columns, television programmes and conversations with friends and family members. A plurality of strategies emerge and are crystallized in negotiation and conflict with the self and with significant others who take it upon themselves to act upon their individual and joint conduct in relation to some future goals. Individuals and their families have taken unto themselves the responsibility for the government of their risky genes, in relation not merely to a secular norm of immediate health, but an obligation to one's kin, to those one loves, and to the future.

Conclusions

We have argued that the critics of biological determinism, genetic reductionism, geneticism and the like have considerably oversimplified the shifts in forms of personhood associated with the rise of ideas and practices of genetic risk. We find little evidence that modern genetic biomedicine dreams of the reduction of the sick person to a passive body-machine that is merely to be the object of a dominating medical expertise. And, even if these dreams are dreamt, we can see that the genetic subjects that inhabit our contemporary complex and contested reality are very different. Genetic forms of thought have become intertwined within ethical problematizations of how to conduct one's life, formulate objectives and plan for the future in relation to genetic risk. In these life strategies, genetic forms of personhood make productive alliances and combinations with forms of selfhood that construct the subject as autonomous, prudent, responsible and self-actualizing. And a new relation to expertise has developed, in which,

at least for some, biomedical expertise is increasingly placed in the position of a resource to be drawn on in life planning, rather than as a master discourse in arbitrating forms of life or decisions as to procreation in the light of risk. This expertise is located alongside other forms of expertise, notably that developed in the virtual communities of 'at risk' persons themselves and their families and allies – the virtual community of the HD webforum here stands as an exemplar of the growing array of virtual communities of somatic individuals organizing key axes of their forms of life around their sickly, risky, improvable or manipulable corporeality.

Further, we suggest that genetic forms of thought and practice are elements within a much wider somatization of individuality, which is linked to a reshaping of the psychological space that gradually opened up between the body and its organs and the person and his or her conduct since the eighteenth century.¹² The psy-shaped space that inhabits the human being is losing its depth – that depth that once had to be mined and interpreted. The psyche is becoming flattened out and mapped onto the corporeal space of the brain itself. Such technological developments as neurochemistry, with its models of neurotransmitter action underlying mood and affect and brain scanning, with its apparent localization of particular feelings and perceptions in real time, appear to establish direct and 'superficial' empirical and observable relations between the physiological and the ethical: between the brain and all that makes a person human. Not that the experts of psy have been made redundant – in this new distribution of personhood, they have a new vocation: managing the ways in which the somatic individual conducts him or herself in relation to their particular risks and habits.

More fundamentally, criticisms posed in terms of biological and genetic determinism fail to recognize a rather significant change that is occurring in conceptions of life itself.¹³ The explanatory form of the genetics they criticize is that of a depth ontology. They believe that biologists construe the genetic code as a deep inner truth, the cause of sickness or health, merely expressed in the surface of corporeality, conduct, character, etc. Explanatory structures that operate in terms of depths and surfaces clearly characterize much 'modern' thought – political economy with its arguments about the hidden hand of the market or the causal powers of the mode of extraction of surplus value; the depth ontologies of the human subject associated with psychoanalysis and all the dynamic psychologies. We would not wish to deny that such explanatory forms are also prevalent in biological thought, especially in its semi-popular forms (such as Richard Dawkins or the writings of the socio-biologists). The spontaneous philosophy of the biologist is undoubtedly 'modern' in this sense – reflecting on their practice and representing it to others, they tend to ascribe a deep ontological reality to their concepts and portray them as the hidden truths that produce and determine a realm of observable effects. But, as a whole tradition of philosophers of science from Bachelard onwards has taught us, one should not mistake the spontaneous philosophy of the scientist for the operative epistemology or ontology of scientific activity. In this sense, despite popular and pseudo-philosophical

accounts, we suggest that contemporary genetics is beginning to operate in a 'flattened' world, a world of surfaces rather than depths. In the developing explanatory schemas of post-genomics, the genetic code is no longer thought of as a deep structure that causes or determines, but rather as only one set of relays in complex, ramifying and non-hierarchical networks, filiations and connections (cf. Deleuze and Guattari 1988). We do not argue that the metaphysics of the gene has been abandoned. But we do suggest that such an ontology is not unchallenged, and that these challenges and alternatives will accumulate over the next decade. Perhaps, that is to say, we need to analyse the way that genetics and genetic risk might figure in the forms of personhood associated with a post-ontological conception of life, a vitality not of depths and determinations but of surfaces and associations.

Notes

- 1 While the paper is jointly written, the account of the history of genetic counselling and the analysis of the ethical and life strategy issues in the Huntington's Disease Webforum are primarily the responsibility of CN who acknowledges the support of the Wellcome Trust's Biomedical Ethics Programme for the doctoral research which this draws upon.
- 2 The prime example here is the development of a population-wide database in Iceland, which is being undertaken by a private company, deCODE Genetics, under legal provisions enacted by the Icelandic parliament – good information on this ongoing project can be found at <http://sunsite.berkeley.edu/biotech/iceland/>.
- 3 Of course, less widely noted is the obverse possibility that, as some conditions such as heart disease or lung cancer come to be accounted for genetically, and as genetic diagnostic tests become available, those not carrying the genetic markers of risk may be free to eat, drink and smoke their way to a happy old age!
- 4 Nancy Wexler's work on genetic linkages in a community of Venezuelan families with a very high incidence of Huntington's Disease, which led to the location of its genetic basis to the short arm of chromosome 4, is an exemplar here – best described by Alice Wexler (1996).
- 5 Novelty seeking was linked to variations in the D4DR site on the short arm of chromosome 11; bipolar affective disorder was linked to specific DNA markers on chromosome 11 in the Old Order Amish, although the correlation later proved to be false – for a popular account, see Ridley (1999).
- 6 For further examples, see the website of the Genetic Alliance which 'fosters a dynamic coalition of consumers and professionals to promote the interests of children, adults and families living with genetic conditions. For twelve years the Alliance has brought together support groups, consumers and health care professionals, creating partnership solutions to common concerns about access and availability of quality genetics services. Currently numbering 287 support groups and 214 consumers and professional members, the Alliance was founded in 1986 – propelled by the energy of the self-help and support group movements' (<http://www.geneticalliance.org/allianceinfo.html>).
- 7 For a discussion of the rise and fall of the XYY paradigm, see Saulitis (1979); the role of recent biological developments in strategies of crime control is discussed in Rose (2000a).
- 8 Actually, this debate may have paradoxical effects. Some suggest that, far from leading to wholesale genetic discrimination, it will reveal the superiority of a national, compulsory scheme of health care funded through taxation over all individual and group-based

schemes: as it becomes possible to predict those who may have an increased likelihood to develop Alzheimer's or Parkinson's disease, as there are increased pressures to exclude those at high risk from cover by fiat or by the costs of purchase, as individuals at no or low risk begin to exit the private insurance system rather than subsidize those at high risk, the strategy of pooling of risk across a national population will begin to seem attractive to those who wish to be insured without a knowledge of what the future might hold for them, to governments seeking to maximize cover because of fears about the implications of any public safety-net system being overwhelmed by demands from those deemed uninsurable in the private sector, and to the insurers themselves, on the basis that there can be no individual risk classification without access to full predictive information.

9 Goffman (1968) provides a classic analysis of the management of 'spoiled identities' in an earlier age of personhood: a comparison with the present examples is instructive.

10 The data for this section of the paper are derived from a study that CN conducted of an HD webforum that was downloaded from Massachusetts General Hospital webforum dedicated to promoting discussion among persons affected by a range of neurological disorders. The study covers a period of two years ranging from 6 May 1995 to 27 January 1997.

11 Huntington's Disease is a late onset genetic disorder characterized by progressive neurological deterioration, which results in choreic movements, mood swings, and depression for which treatment is solely palliative. Long known to run in families, and roughly mapped in 1983, the gene itself and the mutation involved were identified in 1993, and direct mutation DNA tests have been developed which can predict with virtual certainty whether an individual will develop the disease, and also give some indication of the likely age and severity of onset.

12 In thinking further about this issue, we might usefully take our cue from Foucault's suggestion that one can characterize different modes of individuating illness and health by analysing the spatializations of illness across a variety of domains: 'the order of the solid visible body is only one way – in all likelihood neither the first nor the most fundamental – in which one spatializes disease' (Foucault 1973: 3). There have been, and will be, other distributions not merely of illness, but of life itself.

13 Our thinking on this issue was clarified by Scott Lash, in 'Technological Forms of Life', his inaugural lecture for a Chair in the Department of Sociology at Goldsmiths College, University of London, delivered on 22 February 2000.

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