

Letters

Genetic screening and ethics

SIR

Raanan Gillon (1) and David Shapiro (2) debate admirably some of the thorny bioethical issues potentially emanating from genetic screening, particularly in the context of the first report of the Nuffield Council on Bioethics. In the interest of widening public and academic debate of attendant issues from a broader perspective, encompassing international experiences with genetic testing, I wish to draw attention to a genetic screening law enacted, in September 1994, in the state of California (3).

In general, genetic screening in the United States has a highly controversial, and rather cryptic, past (4,5). Raanan Gillon's editorial (1) comments on contentious ethical issues in genetic screening residing in diverse realms, including: adequately informed consent; disclosure of results and confidentiality, and issues affecting employment and insurance. The experience to date of the United States with genetic screening, raises, similarly, a legion of issues, with tentacles reaching to privacy and confidentiality concerns, and possible discrimination in realms including employment and insurability (6).

The ongoing 'Human Genome Project' is a highly promising undertaking for biomedicine. As the constructing of the human gene map progresses, however, the many thorny issues and problems possibly associated with genetic screening will likely intensify, both in the United States and other countries (7). The legislative bill approved by the governor of California, in 1994, adds a major pillar towards the upholding of the foundation of state-based legislation affecting genetic screening, and is worthy of international examination (3).

As defined by the nascent California law, 'genetic characteristics' means

any 'scientifically or medically identifiable' gene or chromosome, or 'alteration' thereof, 'known' to be a 'cause' of disease or disorder, or determined to be 'associated' with a 'statistically increased risk' of development of a disease or disorder, and which is 'asymptomatic' of any disease or disorder.

An insurer requesting an applicant to take a genetic characteristic test must obtain the applicant's 'written informed consent'. The applicant must be provided with a description of the test to be performed, including its purpose, potential uses, and limitations. He or she must be aware of the meaning of the test's results. There must be procedures for notifying applicants of results; and the applicant must be informed that he has a right to confidential treatment of results.

The breadth of entities enmeshed in the webbing of the law is considerable. No life or disability insurer may require a genetic characteristic test if the test results would be used either 'exclusively or nonexclusively' for the purpose of determining eligibility for hospital, medical, or surgical insurance coverage, or eligibility for coverage under a non-profit hospital service plan or health care service plan. Neither a non-profit hospital service plan nor a self-insured employee welfare benefit plan may refuse to enrol any person or accept any person as a subscriber after appropriate application on the basis of a person's genetic characteristics which may, in some circumstances, be 'associated' with disability in that person or that person's offspring. Moreover, except as permitted otherwise by law, no admitted insurer, licensed to issue disability insurance policies for medical, hospital, and surgical expenses, may fail or refuse to accept an application for that insurance, fail or refuse to issue that insurance, cancel that insurance, charge a higher rate or premium for that insurance, or limit coverage

under that insurance, based on a person's genetic characteristics.

One viewpoint is that California has taken a vital step in an ethically proper direction by defining the onset of genetic disease as the start of symptoms, which may be of considerable import as genes are uncovered for cancer, heart disease and late-onset maladies such as Huntington's chorea (8). There is hope, as well, that the new law may encourage people to pursue gene tests without the accompanying fear of insurance loss. Others are less sanguine, though, and suspect that other forms of protection may be needed to ensure that the law is implemented properly (8).

Although California appears to have staked out the moral high ground in a State-rooted effort effectually to regulate screening for genetic characteristics, only time will tell whether the initiative will serve as a bellwether for other legislative initiatives, or whether it will prove, instead, to be a vestigial appendage of the body of laws affecting genetic screening. As worldwide lawmaking proceeds in the field of genetic screening, lawmakers, working in concert with bioethicists and policymakers, should remain properly mindful of the salient need adequately to guard the privacy and confidentiality of genetic data, and the need for autonomy as a shield against possible discrimination (9). Since this is an area of largely uncharted waters, circumspect navigation will be of utmost importance.

References

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Szasz and psychiatric abuse

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Thomas Szasz exhorts us (1): 'Psychiatric abuse ... is related not to the misuse of psychiatric diagnoses, but to the political power intrinsic to the social role of the psychiatrist ... a scientific classification is not sufficient to protect from abuse ... the crucial issue is not subjectivity versus objectivity, but coercion versus cooperation, wielding power versus not wielding power ... the scientific or unscientific character of psychiatry has nothing to do with its abuse'. Dr Szasz then goes on to argue his usually brilliant case for institutionalized psychiatric power being the *caput Nili* of psychiatric abuse.

While I would not care to argue which is the more serious flaw, I think Dr Szasz could be construed with these statements to be denigrating the role which poor science, even pseudoscience, plays in propagating psychiatric abuse. After all, there are therapists practising 'past-lives therapy' and 'alien-abduction therapy'. A little less sensational but more damaging is the epidemic of 'repressed memories' of child abuse. The False Memory

Syndrome Foundation knows of ten thousand families that have been damaged by therapists using this concept. This tragedy has occurred despite the fact that there have been a number of reviews (2) of the concept of repression that conclude that its existence is based on a very shaky scientific foundation. These poorly founded hypotheses, and sometimes quackeries, I admit, are not unrelated to psychiatric power. It could be argued that the only reason therapists get away with it is because the psychiatric establishment, with which all therapists are at least loosely connected, has unassailable power to do most anything it wants. At least it was unassailable until Dr Szasz's devastating critiques. The fact, however, that psychiatry has clung to Freudian concepts despite a profound lack of scientific evidence points up the shoddy science problem in psychiatry as an independent cause of psychiatric abuse.

Let us imagine for a moment a Szaszian world in which psychiatry has been completely written off the law books. There is no such thing as a civil commitment or an insanity verdict. All therapy is contractual and autonomous; the prescription of drugs is left to 'medical doctors'. 'Mental illness' and diagnosis have been replaced by counselling for 'problems in living'. Psychiatrists have no more social influence than say, chemists. Will this result in the elimination of psychiatric abuse? The psychiatrist, still a scientist or expert of some sort (perhaps in interpersonal relationships), will still be suggesting solutions to the client's problem. Courts will still call upon them for expert testimony, just as they do criminologists, anthropologists, etc. Are these new world order psychiatrists going to make unfounded, if not ludicrous, assertions to their clients or to the courts? Any expert can cause serious problems by offering hairbrained advice. This is why we had a man imprisoned for years in San Diego after four-year-olds testified that he carved up an elephant and a giraffe in a church. Therapists testified that the children were credible.

Dr Szasz's admonition about diagnoses not being diseases continues to be penetrating and topical in this age of the Menendez brothers and similar court cases. But a diagnosis might be considered a *theory*. Multiple Personality Disorder, for instance, is a theory to explain an individual's quixotic behaviour. We can agree that it is not a disease but some other class

of phenomena even if it turns out to be essentially well founded, but being well founded is a matter of empirical test. The problem with MPD is twofold: psychiatry has appropriated the alleged condition as another example of a 'mental illness', and it has never been subjected to adequate empirical testing. What would such a test look like? For openers, the patient would have to be questioned carefully, in the manner of a police investigator, to ensure that the individual tells a consistent story. Sybil should be easy to trip up, unless, of course, she is telling an accurate story.

Dr Szasz is correct, of course, in his warning that being scientific is not a guarantee of fairness. He gives us the example of slave owners classifying certain persons as Negroes. Dr Szasz says it was scientific but not fair. Other examples come to mind: Nazi Germany, and arguably Skinner's *Walden Two* society. It is a point well taken. In defence of science, however, I must point out that a simple colour classification such as the slave owners' system is not *very* scientific. Had they conferred with a real scientist, perhaps Mendel or Darwin, they might have seen that interbreeding and other factors make 'race' a more complicated issue than mere skin colour. The colour classification system was perhaps passably taxonomic, but it was driven mainly by mores.

To sum it up, while the thrust of Dr Szasz's argument about psychiatric power continues, in my view, to be an invaluable contribution, I think he should not slight the problem of substandard science in psychiatry.

References

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