

**Looking to the Past: Soma, Magical Thinking and the
Implications of the New Genetics**
**Commentary on Stowe et al., Journal on Developmental
Disabilities, 13(2), 2007**

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Matthew Stowe, Rutherford Turnbull, Suzanne Schrandt, and Jennifer Rack (this issue) are to be commended for their wide-ranging and thought-provoking discussion of many key ethical, social, and politico-legal issues arising out of contemporary work on the sequencing of the human genome and the associated technological and therapeutic innovations that are promised (threatened?) by it. For those of us outside of the United States, much of their discussion of the legal implications can be of little immediate practical relevance - although, it is to be hoped that legislators in Australasia may learn from the experience of the North American jurisdictions discussed. This is not in any way a criticism of their paper, because clearly the issues of individual privacy, confidentiality of genetic data, personal autonomy, and so on transcend legislatures.

These issues are not those to which I wish to respond, however. Here I would simply like to add a further voice to their call for public debate about the issues raised by the Human Genome Project (HGP) and associated technologies (henceforth HGP for short) to be explicitly informed by an appreciation of medicine particularly, and the biological sciences more generally, as essentially social and political activities. That is to say, it is my belief – and this is alluded to by Stowe et al. – that we live in a world where much (too much?) credence is given to the pronouncements of big-S science and, further, one in which the interests of those who retail the products of the biological sciences are, not infrequently, inimical to the common good. I will return to this briefly below.

Given that we often seem to forget this, I was pleased to see the authors begin their paper by asking "the leadership of the disability field [to] remember that in fashioning a brave new world, they are compelled to take into account science, policy (both exceptional and generic), history and its lessons, and ethics and its precepts" (this issue, p. 1). It is not common, certainly in Australia, for students in the disciplines that do so much to shape the lives of people with disabilities (e.g., psychology, psychiatry, the allied health professions such as nursing, or even students in dedicated disability studies degrees) to be required to develop a detailed understanding of

science in the social context, nor even of the history of medicine (to use medicine as a shorthand term for "therapeutic" interventions of all stripes). I have lamented this absence before (Hansen, McHoul, & Rapley, 2003), but Stowe et al. provide us with a timely reminder that, as George Santayana (1905) observed, "those who cannot remember the past are condemned to repeat it" (p. 284). Needless to say, this places an extremely serious responsibility upon those of us who are currently engaged in educating the next generation of leadership in the disability field to erase the possibility of forgetting what they describe, aptly, as the "dark history" of medical progress. And this also demands that we, as academics, cast a critical eye over the hyperbole surrounding the entire HGP endeavour. We should not forget – nor allow our students to forget – that genes code for proteins. That is to say genes do not code for being unhappy, washing one's hands a hundred times a day, having "an anti-social personality," claiming to be Napoleon Bonaparte, nor hearing voices no matter how many times members of the American Psychiatric Association say that they do.

Indeed, as Stowe et al. so accurately note, "the blotches on the record of medical accomplishment are rarely acknowledged and are all too often glossed over as 'bad science' conducted by a few, isolated 'bad people'" (this issue, p.3). To this I might add that the fictitious "disorders" that medicine has but only relatively recently abandoned (masturbatory insanity, moral imbecility, dysæsthesia æthiopiæ, drapetomania, dementia præcox, homosexuality-as-mental-illness, etc.) are also usually glossed over in a Whig history of inevitable progress. As conveniently forgotten is Cyril Burt's fraudulent "discovery" of the hereditability of the IQ and the appalling racism of the so-called "Bell Curve" controversy. In the place of these misguided efforts, by bad people, we are assured, now we have serious science – the MRI scanners, CAT scanners, PET scanners, and sundry other machines that go "ping." Unlike the dark ages of pre-modern science, we know that much human disability is a matter of the brain, particularly of its "chemistry," and no doubt soon we will find the gene for "it" (insert deviance/impairment of choice). Indeed (and sadly), Stowe et al. make this very point when they argue that "chemistry has contributed greatly to how policy makers and the public generally define and regard other types of disability (particularly mental-emotional disabilities)" (this issue, p. 55).

And it is here that their otherwise acute critical faculties desert them, and this lacuna in their paper acts to sharpen their point about the crucial role that public education around the HGP must play. It is indeed true that "chemistry has contributed greatly to how policy makers and the public generally define and regard other types of disability (particularly mental-

emotional disabilities)" (this issue, p. 55). That "depression" is "caused by a chemical imbalance in the brain" is the part-and-parcel of contemporary western common sense, but it is not chemists who have propagated the soma story. Rather, it is a disconcerting alliance between institutional psychiatry (particularly in the U.S.A.) and the retailers of the molecules produced by chemists (the pharmaceutical industry), and this alliance is committed to precisely the biological reductionism and determinism that Stowe et al. (this issue) so commendably warn us against earlier in their paper. The version of human experience propounded by what David Healy calls "Big Pharma" and its allies in the various human services industries (Healy, 2004) is designed to leave open only soma (under various brand names like Prozac™, Effexor™, Luvox™, etc.) as the logical therapeutic response. That there is not a shred of scientific evidence for the "depression-is-caused-by-a-chemical-imbalance-in-the-brain" story has not prevented it from being widely accepted by the vox pop and as importantly as Stowe et al. note, policy makers too. The probability of a similarly "dumbed down" story being sold about "genes" (given that neither the public nor the legislature can be expected to know much more about genetics than they do about biochemistry) is strong.

What I believe Stowe et al.'s timely paper tells us most crucially is that we must be constantly alert to the very dark side of science and, increasingly, alert to the yet darker side of the commercialization of the products of science. Much of the academic literature in psychiatry and psychopharmacology is now ghost written by copy agencies with a particular line to sell (Healy, 2004); much of the academic literature in clinical psychology takes a determinedly anti-environmentalist approach to human distress and disability (Boyle, 2002); and a great proportion of the sociological/disability studies literature eschews interactional understandings of disability in favour of deficit-finding, individualized approaches (Rapley, 2004).

Let us hope, then, that if we adopt a sceptical, critical, and historically-informed approach to the new genetics, that we can avoid the many perils that Stowe et al. have identified. The appeal of magical thinking and the quasi-religious promises of soma are, it appears, all too compelling. It is the job of academia to enable the communication, realistically, comprehensibly, and truthfully, of the many potential benefits – and many potential harms – of the HGP to people with disabilities, the public at large, and the legislature. Stowe et al. are to be congratulated for mapping out much of the ground upon which that endeavour must proceed.

References

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