

Reconstructing Geneticization: a Research Manifesto

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I. Introduction

Many commentators on the new genetics see geneticization and commercialization as related processes. They are the less desirable consequences of progress in biotechnology. Unavoidable and unwanted, they bring biotechnology into disrepute and turn public opinion against developments in genetics.

There is little difference between the ethical, legal and social concerns regarding commercialization and geneticization. Most of the critiques posit specific effects on individuals and communities, such as loss of opportunity to purchase insurance or to be employed, reduced tolerance for diversity in the range of human abilities and experiences, increased pressure to utilize genetic technologies resulting in reduced individual choice.¹

Clearly there are important issues with both of these processes: commercial involvement in academic science has led to conflicts of interest, and the definition of diseases in terms of genetics can produce anomalous situations. But it is too simplistic to see these processes as both irredeemably bad and, in the case of commercialization, this is acknowledged. Talk is not of banning commercial interest in genetic technologies, but of regulating it. Indeed, there are positive aspects to commercial involvement in biotechnology.

The aim of this article is to raise the level of debate that surrounds the concept of geneticization, to give a little more depth to it as a process and suggest future possibilities for research. Currently, the concept of geneticization does not allow a reasonable debate about the role of genetic explanations in medicine. Because it is constructed in a negative way, geneticization must be seen as contrary to the public interest and something to be discouraged. What is needed is a reformulation of the concept of geneticization that allows realistic and productive discussions, in the manner of the debates that surround commercialization.

A great deal of empirical work exists which documents the increase of commercial interest in life-science research and the relationship between academic and industrial researchers. Much of this is quantitative research, counting the

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¹M. Burgess, "Introduction" in B.M. Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville, Québec: Les Éditions Yvon Blais, 1998) at 340.

number of academic scientists who also hold positions in bioscience companies² or looking at how trade-secrecy inhibits academic publishing and skews research agendas.³ Looking ahead, it has been suggested that commercial involvement will lead to the premature entry of genetic tests into the market place “and the building of laboratory infrastructure arguably intensifies the need to create a market. Indeed, from the perspective of industry, any process which delays getting a service to market will likely be viewed as an unnecessary handicap.”⁴

Yet it is important to note the context within which this commercialization is taking place. It is easy to view academic scientists as the victims of powerful commercial concerns, struggling to make themselves heard above the clatter of money boxes. In truth, it is academic scientists who are in the vanguard of the commercialization of life-sciences: “the morality tale told about the corruption of science by industry is belied, or at least made more complex, by the overwhelming involvement of the field’s leaders in securing the bridgeheads.”⁵

This “morality tale” relies for much of its strength on the image of a “golden age” of science, where research was co-operative and non-competitive, funded by impartial government agencies. Like most golden age stories, it is in large part a myth, putting the academic life sciences “in a weak rhetorical position to weep over their lost honor.”⁶

Research into geneticization lacks such empirical foundations and the basis on which conclusions are drawn are far from convincing. What will follow is a discussion of geneticization, focussing on two articles which use it as a framework for analysis. This will be followed by suggestions for an alternative context for geneticization which may prove more productive for research.

²S. Krimsky, J.G. Ennis & R. Weissman, “Academic-Corporate Ties in Biotechnology: A Quantitative Study” (1991) 16:3 *Science, Technology & Human Values* 275.

³S. Krimsky, *Biotechnics and Society: The Rise of Industrial Genetics* (New York: Praeger, 1991) at 71.

⁴T. Caulfield & C. Feasby, “The Commercialization of Human Genetics in Canada: An Overview of Policy and Legal Issues” in Knoppers, ed., *supra* note 1 at 355.

⁵P. Rainbow, *Essays on the Anthropology of Reason* (Princeton, NJ: Princeton University Press, 1996) at 131.

⁶*Ibid.* at 137.

II. Geneticization

The term geneticization was coined by Abby Lippman in the early 1990s⁷ and has been adopted by a number of other authors (for example, Hubbard and Wald⁸) to describe “the ever growing tendency to distinguish people one from another on the basis of genetics; to define most disorders, behaviors and physiological variations as wholly or in part genetic in origin.”⁹ It operates at two levels, both as a way of thinking and as a way of doing¹⁰ and its paradigmatic expression is said to be the human genome project. In terms of intellectual predecessors, geneticization derives from the ideas of Ivan Illich¹¹ and Irving Kenneth Zola.¹² Their concepts of “medicalization” and “iatrogenesis” suggest that medical explanations are creeping into areas of social life where they do not belong (for example, in describing behaviors like alcoholism as a disease), and that doctors inadvertently cause as much ill-health as they try to cure. These ideas have received extensive and detailed criticism,¹³ yet they clearly influence the concept of geneticization. Lippman fears that because geneticization taps into “stereotypes and prejudices that are deeply rooted in North American society...it is likely to be even more problematic than earlier forms of medicalization.”¹⁴ Like medicalization, geneticization is a political tool, used to raise awareness and stimulate activism around particular technologies. “The process of geneticization is political because it redefines what we take to be significant differences between people and empowers new people and institutions to make these redefinitions.”¹⁵ But problems arise when this activist’s tool is adopted uncritically and used to analyse situations where it “seems to fit”. The current context within which the geneticization critique operates, the context of medicalization, is inherently critical. The way in which the concept of geneticization is constructed and the words which are used to describe it mean that it is difficult to use it in a neutral way. If “geneticization is a process of colonization with genetic technologies,”¹⁶ it is very hard, in these post-colonial times, to say anything good about it.

⁷A. Lippman, “Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequalities” (1991) 17 Am. J. Law & Med. 15.

⁸R. Hubbard & E. Wald, *Exploding the Gene Myth* (Boston: Beacon Press, 1992) at 65.

⁹A. Lippman, “The Politics of Health: Geneticization Versus Health Promotion” in Sherwin *et al* eds., *The Politics of Women’s Health: Exploring Agency and Autonomy* (Philadelphia: Temple University Press, 1998) 64 at 64.

¹⁰*Ibid.*

¹¹I. Illich, *Limits to Medicine: Medical Nemesis: the Expropriation of Health* (London: Penguin, 1990).

¹²I.K. Zola, “Medicine as an Institution of Social Control” (1972) 20 Sociology Rev. 487.

¹³D.F. Horrobin, *Medical Hubris: A Reply to Ivan Illich* (Edinburgh: Churchill Livingstone, 1972); J.J. Janzen, “Medicalization in Comparative Perspective” in M.W. de Vries, R.L. Berg & M. Lipkin eds., *The Use and Abuse of Medicine* (New York: Praeger, 1982) at 3.

¹⁴Lippman, *supra* note 9 at 70.

¹⁵*Ibid.* at 69.

¹⁶A. Lippman, “The Genetic Construction of Prenatal Testing: Choice, Consent or Conformity for Women?” in K.H. Rothenberg & E.J. Thomson, eds., *Women and Prenatal Testing: Facing the Challenges of Genetic Testing* (Columbus: Ohio State University Press, 1994) 9 at 13-14.

III. Geneticization in Context

In this section, I will discuss attempts to use geneticization to analyse two conditions: Breast Cancer and β -Thalassaemia. The aim is to show how the current critique, conceiving of geneticization as a form of medicalization, limits the possible discussions and hinders satisfying analysis.

BRCA1: Geneticization and the Individual

In their commentary on the breast cancer genes BRCA1 and 2, Sherwin and Simpson are clear about the negative impact that results from the use of such genetic information. They list “some of the facts about breast cancer which form the starting point of our investigation of the geneticization of a disease which threatens the lives and well-being of millions of women worldwide.”¹⁷ I wish to challenge the idea that this work provides evidence that breast cancer as a condition is currently subject to geneticization, and also suggest that the use of geneticization, as it is currently constructed, limits the kinds of debates that can be held about conditions and leads to inconsistencies in argument.

Sherwin and Simpson place our understanding of breast cancer within the “biomedical model” which they define as how “we understand disease as something that affects the body when some internal mechanism becomes disrupted either because of an inborn weakness or flaw or because of some sort of invading alien organism or hostile environment.”¹⁸

While they accept that there are some therapeutic benefits to the biomedical approach¹⁹ they are “concerned about the ways in which the public as well as the private focus on biomedical solutions tends to interfere with other types of approaches to this (and other) serious public health problem[s].”²⁰ They worry that “society has yet to respond with appropriate sorts of public health measures...most governments have not provided adequate resources to explore possible environmental, dietary, or social links.”²¹ This seems odd, since two paragraphs later they complain that “not only are women asked to pay worried and regular attention to their breasts, they are also advised to change lifelong eating habits, develop healthy exercise programs, learn stress management techniques.”²² It seems inconsistent to complain about governments’ failure to explore the environmental, dietary and social links with breast cancer, and then bemoan the fact that one needs to put into practice dietary, exercise and environmental changes to avoid breast cancer.

¹⁷S. Sherwin & C. Simpson, “Ethical Questions in the Pursuit of Genetic Information: Geneticization and BRCA1” in A. Thompson & R. Chadwick, eds., *Genetic Information: Acquisition, Access and Control* (New York: Kluwer Academic/Plenum Publishers, 1999) 121 at 121.

¹⁸*Ibid.*

¹⁹*Ibid.* at 122.

²⁰*Ibid.*

²¹*Ibid.*

²²*Ibid.*

What is also not explained is how these “external” options avoid reinforcing the biomedical model, which partly relies on the concept of “hostile environments”. The idea that environmental effects might cause breast cancer crops up elsewhere in this article²³ yet the authors fail to explain how, if their earlier definition of the biomedical model is accurate, their request for more research into the effect of environmental carcinogens is not strengthening it. This is a problem since “as long as health research is limited to the individualized focus of the biomedical model...the dominant approaches to breast cancer are unlikely to serve women’s interest well.”²⁴ One solution might be to say that by focussing on environmental factors, one is looking at people in a broad sweep, avoiding the individualization of the biomedical model. Yet, a population geneticist looking at the epidemiology of a particular genetic disease could make the same claim. In both cases, individuals are important as soon as one moves into the clinical setting. As soon as a doctor begins to talk to a patient, the disease becomes individualized. The difference between whether the disease concerned is known to be caused by an environmental factor (discovered by population scale searches for carcinogens) or a specific allele (discovered by population scale searches for a genetic marker) may still be important, but from the authors’ analysis, it is not clear how.

Another problem with this article’s stance on individualization is that it silences those people who have found benefit in the BRCA1 test. The authors claim that as a result of biomedicine’s individualization of breast cancer, “many women are easily frightened into a mind-set where they are preoccupied with monitoring their bodies for threatening signs of change.”²⁵ They suggest that introduction of the discourse of risk alienates women from the reality of their bodies:

Those with these mutated genes are told they are at “high risk” of developing breast cancer...what does the term “risk” mean? It represents a statistical difference, but not just any statistical variation. “Risk” is a heavily value-laden term; typically, it connotes fear or anxiety.²⁶

It is hard to incorporate this position with the views of some women who have had the BRCA1 test, and who have had to make decisions on that information. What Sherwin and Simpson fail to highlight is that many of these women know that they are already at risk:

I was a 41-year-old female in a family where four other women first had breast cancer in their mid-thirties to mid-forties.

²³*Ibid.* at 124-26 & 128.

²⁴*Ibid.* at 128.

²⁵*Ibid.* at 122.

²⁶*Ibid.* at 123-124.

Although I knew that a family history like mine was a risk factor for breast cancer, the source of risk was a nebulous “genetic predisposition” in my mind.²⁷

Family histories mean that a genetic test can actually be a solution. It is not that the BRCA1 and 2 tests are unproblematic.²⁸ The point is that the discourse of geneticization, as it is currently constructed, does not allow the voicing of such opinions. The failure of geneticization to acknowledge the hereditary nature of much family information has been noted before. Geneticization provides “an overly general description that obscures the fact that contemporary genetics discourse is a permutation of long-standing hereditarian discourses that reflect age-old recognitions by human beings that heredity plays a role in the characteristics of living things.”²⁹

Sherwin and Simpson might claim that those women who are helped by the BRCA1 test have “bought into” the geneticized nature of breast cancer. They do claim that “very little attention is paid to the psychological impact of finding out the status of ones genes”³⁰ – this is simply not true. Even the most cursory search of the Medline database³¹ produces over 100 references to psychological research into genetic testing for breast cancer. There are studies looking at women’s perception of risk,³² differences in opinion between patients and health professionals,³³ the impact of different therapies on women’s fears,³⁴ and even the differences in attitude between ethnic groups.³⁵ Some, or perhaps all of these studies might support Sherwin and Simpson’s position, but by not referring to any of this empirical work, they undermine the force of their argument. If what they mean is that “much research has been carried out, but it is ignored by policy makers” then this too is an empirical claim in need of evidence.

²⁷T. Marteau & M. Richards, eds., *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge: Cambridge University Press, 1996) at 31-32.

²⁸I have written elsewhere about the unethical way in which such tests have been marketed. R. Chadwick & A.M. Hedgecoe, “Commercial Exploitation of the Human Genome” in Harris & Burley, eds., *A Companion to Genetics: Philosophy and the Genetic Revolution* (Oxford: Basil Blackwell, forthcoming).

²⁹C. Condit & M. Williams, “Audience Responses to the Discourse of Medical Genetics: Evidence Against the Critique of Medicalization” (1997) 9:3 *Health Communication* 219 at 220.

³⁰Sherwin & Simpson, *supra* note 17 at 126.

³¹Using search terms “psychological,” “genetic” and “breast.”

³²M. Watson *et al.*, “Family History of Breast Cancer: What do Women Understand and Recall about their Genetic Risk?” (1998) 35:9 *J. Med. Genet.* 731; A.P. Polednak, D.S. Lane & M.A. Burg, “Risk Perception, Family History, and Use of Breast Cancer Screening Tests” (1991) 15:4 *Cancer Detect. & Prev.* 257.

³³G. Geller, *et al.*, “Decision-making About Breast Cancer Susceptibility Testing: How Similar are the Attitudes of Physicians, Nurse Practitioners, and At-Risk Women?” (1998) 16:8 *J. Clin. Oncol.* 2868.

³⁴M.J. Massie, P.R. Muskin & D.E. Stewart, “Psychotherapy with a Woman at High Risk for Developing Breast Cancer” (1998) 20:3 *Gen. Hosp. Psychiatry* 189; M.J. Esplen, “A Group Therapy Approach to Facilitate Integration of Risk Information for Women at Risk for Breast Cancer” (1998) 43:3 *Can. J. Psychiatry* 375.

³⁵C. Hughes *et al.*, “Ethnic Differences in Knowledge and Attitudes about BRCA1 Testing in Women at Increased Risk” (1998) 32:1-2 *Patient Education & Counseling* 51.

Another example of an unsupported claim is: “research funds, both private and public, are primarily directed towards developing further technologies that will bring increased profits to industry.”³⁶ This is exactly the kind of statement that requires a reference if it is to be anything other than an expression of opinion. What are the figures for this funding? What is the ratio of public to private? How has it changed over time? The geneticization critique does not make use of this kind of information (present in discussions of commercialization). It is a poor analytic tool in any adequate sense of the word. The ill-defined, unempirical nature of geneticization as a concept does a disservice to the ideas and motivations that underlie it. There is a need for detailed and rigorous analysis of the way in which genetics affects our conceptions of disease and illness, but the extreme, value-laden way in which geneticization is currently constructed makes this harder to do.

The clearest example of this is the idea that this article illustrates the geneticization of breast cancer as a disease, rather than the specific, familial version that affects a small percentage of women. The authors’ own definition of geneticization states “geneticization is the attitude that the differences among people can be reduced to differences in their genetic makeup; it assumes that most disorders are largely attributable to genetics.”³⁷

The authors do not show how attitudes towards women with breast cancer (as a whole) have been reduced to genetic differences. Possible evidence of this (newspaper content analysis, reader reception, interviews or focus groups for example) is not cited. Nor in this article do they present evidence that any other disorder is “largely attributable to genetics.” Breast cancer may be undergoing geneticization, but unless empirical evidence is presented, how are we to know? These problems stem directly from the medicalization context from which geneticization is derived. Sherwin and Simpson are limited by their analytic framework because their core concept of geneticization is inherently critical of and negative towards genetic technologies; there is no way for them to incorporate alternative positive viewpoints.

β-Thalassaemia: Geneticization and Autonomy

In their 1998 article “Geneticization: The Cyprus paradigm,” Hoedemaekers and ten Have analyse the discourse surrounding screening programmes for β-thalassaemia.³⁸ This recessive blood disorder is very common in Cyprus, where over the past 20 years an extensive screening programme of testing and counselling for the disease has developed. Hoedemaekers and ten Have’s analysis has the advantage over broader discussions of geneticization³⁹ in that their focus on a single

³⁶Sherwin & Simpson, *supra* note 17 at 123.

³⁷*Ibid.*

³⁸R. Hoedemaekers & H. ten Have, “Geneticization: The Cyprus Paradigm” (1998) 23:3 J. Med. & Philos. 274.

³⁹For example, D. Nelkin & M.S. Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: Freeman, 1995).

case study allows detailed analysis. Their central claim is that the growth of the β -thalassaemia screening programme in Cyprus has been achieved through overriding and manipulating public opinion towards the disease. I suggest that starting from the perspective of geneticization critique, this is the only conclusion one could draw. The concept of geneticization, as currently constructed, does not allow that genuinely autonomous decisions are possible with regard to genetic tests.

Hoedemaekers and ten Have split the history of β -thalassaemia screening in Cyprus into four parts, with the post-1960s period characterized by the classification of β -thalassaemia as a genetic disease and the introduction of selective abortion as an option for parents.⁴⁰ They describe how public education programmes were set up and how the screening programme was justified in terms of the disease burden on a small society and the impact of β -thalassaemia on families.⁴¹ They suggest that a new form of medicine, “genetic medicine,” has gained dominance, with an assumption that its goal is the prevention of new β -thalassaemia patients. This assumption “finds expression in educational strategies which challenge the notion of voluntariness.”⁴² Hoedemaekers and ten Have question whether Cypriot couples really make voluntary decisions regarding prenatal screening and selective abortion. They suggest that far from making these decisions free from external influence, parents in Cyprus are subject to “considerable social pressure”⁴³ in the form of education about the disease. This “sensitization is a form of (subtle) persuasion, propaganda, or manipulation, with free choice and alleviation of suffering as ‘hidden persuaders.’”⁴⁴ When parents are presented with the option of “preventing a future sufferer” (i.e. selective abortion), the authors ask “what choice do the parents really have? Can we expect them to act autonomously after having been conditioned to avoid a thalassaemic child, either by prevention of conception or by prevention of birth?”⁴⁵

It is not clear what the answer to this question is. The authors themselves do not answer directly, perhaps because there is no evidence to allow an unequivocal reply. They have presented evidence that a β -thalassaemia education programme was mounted in Cyprus. Couples have increased knowledge about the disease, and the option of selective abortion has been taken up by prospective parents (no numbers are mentioned, but no new β -thalassaemia cases have been born in Cyprus since 1982).⁴⁶ The health professionals claim that these couples are making free, autonomous decisions on the basis of this information, but, if one starts from the position of the geneticization critique, then these decisions cannot be free and autonomous: the education programmes must be “propaganda.” Geneticization is an inherently negative process which occurs “institutionally, when genetic expertise is required to deal with problems...[and]...culturally, when genetic knowledge and

⁴⁰Hoedemaekers & ten Have,*supra* note 38 at 277.

⁴¹*Ibid.* at 278.

⁴²*Ibid.* at 279.

⁴³*Ibid.* at 280.

⁴⁴*Ibid.*

⁴⁵*Ibid.*

⁴⁶*Ibid.* at 276.

technology led to changing individual and social attitudes towards reproduction.”⁴⁷ The geneticization critique cannot accept that these attitudes are not coerced. They have to be the result of “manipulation” and “hidden persuaders.”

The authors complain about health professionals’ paternalism but have problems explaining doctors’ insistence on patients taking responsibility for their own reproductive decisions which “seems somewhat inconsistent.”⁴⁸ Their solution to this lies in both the general increased emphasis on patient autonomy in Western medicine, and the responsibility that professionals have for policy decisions which reinforce their paternalistic position. They then present examples of how healthcare professionals really do feel responsible for reproductive decisions, none of which are referenced, yet which are presented as empirical evidence. This is typical of the discussions around geneticization; claims are made supported by examples which may or may not be true, since no references are supplied for this section to allow readers to make up their own minds. The authors then confusingly use the fact that individuals (i.e. patients) “are now held responsible for *any* decision with regard to the use of these genetic technologies”⁴⁹ as an example of how “public health authorities and screeners cannot avoid responsibility.”⁵⁰ The authors seem to be implying that genetic technologies have lead health professionals to be more paternalistic by allowing individuals to exercise more of their autonomy. This position is not necessarily inconsistent, but requires more detailed explanation to pick apart the separate threads than is provided here.

Perhaps things would be clearer if Hoedemaekers and ten Have had offered up a definition of what they regard as an “autonomous” decision in the first place. They suggest that patients cannot make such a decision, since they have been exposed to information and education about β -thalassaemia. However, it hardly makes sense to say that one can only make a real autonomous decision if one is ignorant of the details of a disease, and of course Hoedemaekers and ten Have are not implying this. Their position suggests that if the patients had the right information about β -thalassaemia, then they would be able to exercise their autonomy. The problem is knowing which information or education is right, and how any information Hoedemaekers and ten Have might supply to patients would differ from that currently provided. The authors do not deny that β -thalassaemia is caused by a genetic defect, that it runs in families, and that the test for the gene concerned is accurate. The “propaganda” element seems to lie in the offering of screening and selective abortion, and it is this that underpins the inconsistencies in their argument.

The authors are clearly uncomfortable with the availability of selective abortion in a medical setting. They suggest that, “[w]ith the advent of these technologies another step has been taken on the way to institutionalization of

⁴⁷*Ibid.* at 275.

⁴⁸*Ibid.* at 280.

⁴⁹*Ibid.* at 281.

⁵⁰*Ibid.*

abortion,”⁵¹ and that the “integration [of abortion] into medical practice can be seen as another phase in the slowly changing attitudes towards abortion. Its exceptional character is disappearing.”⁵² This change in attitude towards abortion is partly explained by developments in society,⁵³ both an “increased emphasis on self-determination...[and]...less and less inclination to accept suffering passively if it can be controlled or alleviated in some way.”⁵⁴ The authors’ attitude towards abortion is clear in the statement that “[T]he grief and suffering caused by termination of pregnancy is apparently believed to be less intense than the grief of having no children.”⁵⁵ Yet they present no evidence either way. From their position, coloured by the assumptions that underpin the geneticization critique, it is inconceivable that choosing to not have children could be harder than opting for a termination. Personally I suspect that it depends upon the people concerned and their situation, yet the geneticization critique cannot allow that abortion could be the better decision. One solution to a problem where the “right” answer is so dependent upon how individuals feel is to allow individuals to make these decisions themselves, but it is precisely the possibility of this autonomy that Hoedemaekers and ten Have are disputing.

Their conservative agenda is apparent when they complain about how respecting autonomy allows the possibility of mistakes being made:

The great emphasis on autonomous decision-making and free choice with respect to selective abortion creates...at least the *possibility* that immoral choices can be made. Within the limits of abortion legislation a kind of moral vacuum is created where parents are allowed to take the decision that fit in with their beliefs, attitudes and value-system.⁵⁶

Autonomous decision making, which they earlier claimed to be defending against paternalistic healthcare professionals, is now a “moral vacuum.” It is odd that allowing people to make decisions that “fit in with their beliefs, attitudes and value-system” is somehow regrettable. The authors then claim that “[t]his moral position seems characteristic of the domain of genetic screening and counselling, but is, of course, not universally practised in other societal domains. In everyday life we are usually *not* allowed freely to pursue our own value-systems.”⁵⁷

Such a claim seems to me false. The basis of western liberal democracies is the fact that we are allowed (within limits) to pursue our own value-systems, be they religious, political or ethical. It seems that at its heart, Hoedemaekers and ten Have’s position is not opposed to the directive nature of the healthcare professionals’ imputed paternalism. In fact, they seem to be proposing a form of

⁵¹*Ibid.* at 281-282.

⁵²*Ibid.* at 282.

⁵³*Ibid.* at 283.

⁵⁴*Ibid.*

⁵⁵*Ibid.*

⁵⁶*Ibid.* at 285.

⁵⁷*Ibid.*

paternalism of their own, objecting to the decisions patients are being directed to make, rather than the fact that they are being directed at all. This confused position is a direct result of the use of geneticization in this analysis. Because of the critical nature of this position, the authors have to contort themselves into criticising the healthcare professionals' undermining of autonomy. At the same time they themselves object to the role of autonomy in medical decision making.

Both these articles highlight the role of geneticization as a "broad church," incorporating both radical feminist and more traditional conservative perspectives. They also demonstrate the kinds of non-empirical arguments that are used in discussions surrounding geneticization. Clearly there is a need to reconstruct the concept of geneticization if it is to be of use in the analysis of health care issues.

IV. Shifting Contexts: Molecularization

As I have already suggested, many of the problems of the geneticization critique stem from the fact that it is derived from and still rooted in the ideas of medicalization. The critical voice of Illich can clearly still be heard in the writings of Lippman, Sherwin and others, yet the need is now for an analytic concept rather than an activist's rallying cry. It is not that geneticization cannot be used to criticise developments in science and technology, but its current construction, where genetic technologies are *a priori* wrong, prevents researchers from carrying out coherent, accurate analysis. One solution is to take geneticization out of the context of medicalization, and shift it towards the idea of molecularization. This has the double advantage of giving a degree of historical background (which geneticization currently lacks) and providing a more neutral perspective than medicalization.

The concept of molecularization has been used by a number of historical authors (for example Feldman and Tauber in their discussion of sickle cell anaemia).⁵⁸ De Chadarevian and Kamminga define it as "[t]he identification, production, circulation and uses of molecules in biological research and in the explanation and treatment of diseases."⁵⁹ Seen in this light, geneticization is merely the latest sub-set in a historical process which has taken place over the past 100 years. Molecularization has many similarities to geneticization; it works at two levels, the physical and the conceptual:

The concept of molecularization...might be seen as having two distinct layers of meaning. First, it is a technical process, in which the complex, refractory stuff of biological reality is broken down into discrete molecular constituents...But secondly, molecularization is also a social and cultural phenomenon, evident in the emergence of a wide range of

⁵⁸D. Feldman. & A. Tauber, "Sickle Cell Anemia: Reexamining the First 'Molecular Disease'" (1997) 71:4 Bull. Hist. Med. 623.

⁵⁹S. de Chadarevian & H. Kamminga, eds., *Molecularizing Biology and Medicine: New Practices and Alliances, 1910s-1970s* (Amsterdam: Harwood, 1998) at 1.

institutions committed to furthering the process of molecularization in its narrower technical sense.⁶⁰

Like geneticization, molecularization has strong links with industry and how it funds research:

Molecularization, in the laboratory and the clinic, also had important industrial dimensions. Industries were crucially involved in the production and circulation of standardized molecular reagents and drugs, as well as in the commercialization of instruments for the representation, measurement and analysis of molecules. Commercial interests often promoted molecular approaches.⁶¹

The historical perspective on molecularization allows one to step back and see this process in its broader context. It is less overtly critical than the discussions of geneticization although it by no means avoids commenting on the awkward and controversial aspects of molecular science.⁶²

To illustrate how the context of molecularization can “fill out” discussions surrounding the role of genetics in disease, let us return to the case of the BRCA1. Sherwin and Simpson’s discussion revolved around the idea that the discovery of these genes was a watershed in the way in which we view breast cancer, and medicine as a whole. They suggest the use of genetic tests for breast cancer, although in keeping with the traditions of the western biomedical model, is a new and unwelcome development in the individualization of this disease. However, the “genetic model” of cancer is not the first time cancer medicine has focussed on the individual and adopted molecular technologies. In his discussion of concepts of viral causation in cancer and their replacement with genetic explanations, Jean-Paul Gaudillière claims that there is more that unites these different approaches than divides them:

By the 1980s...after 30 years of a prosperous life, cancer viruses and cancer vaccines quietly left the stage to be replaced by molecular genetics and the promises of recombinant DNA and modern biotechnology....[But] the “recombinant DNA revolution” of the 1980s was only the most recent among the molecularizations of cancer etiology. Molecularization was not a single process but a series of retrospectively unified “molecularization practices” which emerged in different places at different times.⁶³

⁶⁰S. Sturdy, “Reflections: Molecularization, Standardization and the History of Science” in de Chadarevian & Kamminga, *ibid.* at 273.

⁶¹de Chadarevian & Kamminga, *ibid.* at 10.

⁶²D.B. Paul & P.J. Edelson, “The Struggle Over Metabolic Screening” in de Chadarevian & Kamminga, *ibid.* at 203.

⁶³J.P. Gaudillière, “The Molecularization of Cancer Etiology in the Postwar United States: Instruments, Politics and Management” in de Chadarevian & Kamminga, eds., *ibid.* at 165 and 163.

Seen in this light, the emergence of tests for the BRCA1 and 2 genes is not the revolutionary break that it has been presented as, but more the latest part of a steady process of molecularization. This may not satisfy the critics. The fact that the “geneticization of breast cancer” can now be set in a richer historical context may not be of interest to those who feel that geneticization is by definition wrong. What it should do, though, is suggest that it is possible to reformulate the concept of geneticization in such a way as to be of use in the analysis of science and technology.

In the case of β -thalassemia, the context of molecularization would blur the differences between the historical phases suggested by Hoedemaekers & ten Have. The third phase that took place in the 1950s when “molecular research revealed that a defect in the formation of globin was the cause of the symptoms”⁶⁴ would be harder to distinguish from the fourth, genetic phase. Emphasis upon the role of genetic technologies in screening populations would be placed in some form of historical context. From Hoedemaekers & ten Have’s paper there were clearly screening programmes already in place in Cyprus before the actual genetic defect was identified. By using molecularization, critics will have to specify whether the practices brought in with genetic technologies are different in kind from molecular screening; and the assumption that genetic technologies are inherently unwelcome will be harder to make.

V. Conclusion

I have tried to show that the current concept of geneticization, however useful in raising political awareness and activism, is lacking as a serious analytic tool. Situated in the context of molecularization, it lacks the empirical grounding and clarity of discourse that I suggest is present in discussions of commercialisation. Geneticization can become a useful tool, but what is needed is a more neutral attitude towards this process. In the same way that it is now possible to debate the merits of commercialization, with at least two perspectives on this process, so we need to be able to suggest that geneticization is not always a bad thing.

I propose that researchers interested in using the concept of geneticization, be they philosophers, social scientists, lawyers, or policy experts, first look at the concept of commercialization. Here there is evidence of the role that commercial interests play in the life sciences. There are quantitative surveys but also interviews with scientists and academic administrators and detailed analyses of case studies. Geneticization researchers should decide whether they can present evidence supporting statements to the effect that “modern medicine is subject to geneticization” or “breast cancer is an example of geneticization.” While geneticization is hard to dissect in quantitative terms, it is not enough to make sweeping claims about changes in society and then fail to provide adequate

⁶⁴Hoedemaekers & ten Have, *supra* note 38 at 277.

comparisons for the audience.⁶⁵ It may be true that “the cultural meanings attached to the gene are shaping employment practices, educational policies, and decisions in the courts,”⁶⁶ but to simply claim this is not enough. We need to understand what employment practices were before the gene entered our cultural life, and whether educational policy-makers have ever used heredity as the basis of decisions before. Describing genes as “blueprints” does not necessarily reinforce genetic determinism in the public mind.⁶⁷ As I have already stated, it is not that we should avoid criticism of genetic technologies, nor blind ourselves to the problems that arise. It’s just that going into such analysis with the prior assumption that the use of genetic explanations and technologies is inherently bad, prevents a balanced discussion of the pros and cons and an accurate picture of how the process of geneticization takes place.

We may be living through a revolution in how we see the world, but if so, we need evidence of it.

⁶⁵C. Condit, N. Ofulue & K. Sheedy, “Determinism and Mass Media Portrayals of Genetics” (1997) 62 *Am. J. Hum. Genet.* 979.

⁶⁶D. Nelkin & M.S. Lindee, “Letter: Media Portrayals of Genetics” (1998) 63 *Am. J. Hum. Genet.* 662 at 662.

⁶⁷C. Condit, “How the Public Understands Genetics: Non-Deterministic and Non-Discriminatory Interpretations of the ‘Blueprint’ Metaphor” (1999) 8 *Public Understanding of Science* 169.