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### **From Bioethics to Biopolitics: New Challenges, Emerging Responses\***

The chemical and physical inventor is always a Prometheus. There is no great invention, from fire to flying, which has not been hailed as an insult to some god. But if every physical and chemical invention is a blasphemy, every biological invention is a perversion.

J.B.S. Haldane, 1924 (quoted in Turney, 1998)

John B. S. Haldane wrote these words in 1924, at the time when, in the wake of the “rediscovery” of Mendel's work, the first projects were emerging that would shape the “new” life sciences of the 20<sup>th</sup> century. Haldane, one of the founders of modern evolutionary biology, was neither a sceptic nor a critic of science and of its potential dangers for the integrity and the well-being of humanity. On the contrary: his faith in the inherently progressive character of science was a crucial ingredient of his radical political outlook. He expected science to contribute to the eradication of hunger and poverty, of disease and war. Some of his proposals would certainly appear as bizarre nowadays, such as his commitment to the development of chemical weapons which would disable soldiers without killing them, thus effectively putting an end to the heavy costs of war in terms of human lives. This commitment included testing new types of chemical compounds on himself... (Gould, 2001).

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Haldane was writing after the first World War, in the wake of the recognition that scientific and technological development could be put to use to increase the scale and the sheer effectiveness of destruction and death. But Hiroshima, the Holocaust and the ecological crises were still to come and, like others in his time, Haldane felt he could still confidently speak out for the capacity of science to generate the solutions to the problems that science itself had helped to create.

As dated as Haldane's statement may look, though, and despite the provocative tone of his references to the “blasphemies” and to the “perversions” brought about by scientific innovation, it is also an acknowledgement that faith in scientific progress was (and is) far from universally shared. The Promethean ethos of the scientist clashed with the mix of awe, hope and concern (if not outright fear) that “common” people felt whenever science engaged in its project of understanding the world to be able to change and control it. Biology appeared as both the greatest challenge to the Promethean ethos and as the ultimate battleground over the conceptions of life, of nature and of humanity and the legitimacy of changing them through knowledge and technology, in the name of progress, health and the well-being of humanity. It has inspired a plethora of utopian and dystopian views of a future holding the capacity to control and manipulate “life itself”. Elsewhere, I have called this tension between hubris and awe, fascination and fear, utopian hopes and dystopian desperation, so-well captured both by the myths of Faust and Frankenstein and by contemporary science-fiction, the “Jurassic Park Syndrome” (Nunes, 2001a).

### **The “phylogenetic turn” and the molecular vision of life**

Haldane was writing at a time when the “new” life sciences were growing out of what has been described as the rediscovery of Mendel's work. As Moss (2003) has recently argued, this was a crucial boost to what he describes as the “phylogenetic turn” in biology, the move towards a focus on those features and processes of living organisms that were inherited or transmitted across generations and, in particular, on the units of heredity, which were to be called “genes”. This move amounted to pushing into the periphery of the discipline the approaches focusing on the organization and development of organisms over their life cycle. As early as 1923, Wilhelm Johannsen himself, the proponent of the concepts of “gene”, “genotype” and “phenotype”, stated his concern with the consequences of the focus of biological research on the units of heredity in the following terms:

But however far we may proceed in analysing the genotypes into separable genes or factors, it must always be borne in mind, that the characters of the organism — their phenotypical features — are the reaction of the genotype in toto. The Mendelian units as such, taken per se are powerless. (Johannsen, 1923, quoted in Moss, 2003: 1)

In spite of these reservations, research along the lines of the “phylogenetic turn” was to be generously funded by foundations (like the Rockefeller Foundation) and hosted by prestigious research institutions (like Caltech), and promoted as the cornerstone of a project of social control based on the premise that biology would hold the key to the understanding and shaping of human behaviour and thus of the means to eradicate disease, crime and, more generally, all kinds of behaviour defined as anti-social. Historians of the life sciences such as the late Lily Kay (1994) offered detailed historical accounts of the coming into being of what she described as the “molecular vision of life”, which flourished in the United States and, though following different paths and chronologies (Gaudillière, 2002), in several European countries.

According to Kay (1994: 3-5), the main features of the “molecular vision of life” were the following:

- the stress on continuity — rather than diversity — of life phenomena (e.g., DNA as the shared building blocks of life); this was illustrated in recent times in an exemplary way by Craig Venter at the White House Press Briefing to present the first draft of the Human Genome, in June 2000, when he stated that “our work previously has shown with the close to 24 genomes that we've done both at Tigr and celera, is that having one genetic code is important, but it's not all that useful. And it's only through comparative genomics — having both human and mouse, dog, chimpanzee, rat, other species to layer on top of the human — will we only then be able to truly begin to interpret the genetic code” (U.S. Newswire 202-347-2770/06/26);
- the choice of “minimalist” levels of analysis, materialized in the choice of “simple” biological systems as models; as Cook-Deegan (1994: 48) recalled, the early strategy of molecular biology was not based on abandoning human genetics of “higher” organisms altogether, but on concentrating on the understanding of basic processes by studying those organisms which were simpler and allowed a clearer access to the processes of interest;

- reduction of “life” to physicochemical phenomena, excluding the study of emergence and complexity; in this way, interest is focused on “bottom-up” effects, not on top-down or interactive processes involving different scales of phenomena;
- the use of methods from a diversity of disciplines;
- the empirical and analytical focus on macromolecules (DNA, RNA, proteins);
- the focus on life phenomena at the intracellular or subcellular level;
- the development of new technologies for research;
- the organization of research by teams, with tasks defined around the use of a specific instrument or set of instruments; the value assigned to cooperation.

An interesting feature of the emergent field of molecular biology was its loosening of the grip of medicine and of medical concerns in defining research priorities and objects. The link was still there, but it was based on a considerable autonomy of the two fields (which allowed molecular genetics to concentrate on “simpler” organisms) until the emergence of medical genetics and, in particular, the explicit convergence advocated by the promoters and supporters of the project of mapping the human genome. At that point, medical concerns were again systematically mentioned as a reason for funding and development of research programs (in fact, this is the almost exclusive public justification for research on the genome). As Cook-Deegan (1994: 47) nicely put it, “the impetus for DNA sequencing arose from those who contemplated the structural study of DNA, not from classical genetics and the study of inherited characters. The confluence of structural and classical genetics was delayed, but it was inevitable.” And, we might add, so was delayed the need to tackle the ethical and political issues raised by the new biology. As long as the latter could be seen as a “confined” form of scientific activity, its regulation could be seen as being within the reach of the practices of self-regulation of the scientific community. Ethical issues became paramount, however, when the potential of the new biology for transforming the characteristics of living entities became apparent, on the one hand, and when the uncertainties associated with the use and outcomes of the techniques based on these capacities were acknowledged, on the other. I shall come back to this later.

### **The “new epigenetics”**

The current strengths and predicaments of the life sciences have to be understood in relation to the crucial redefinition of the link between representing or inscribing (i.e., generating objects of knowledge through research activities) and intervening — i.e., manipulating living matter to produce new entities (Hacking, 1982; Latour and Woolgar, 1986). The motto of the “new” biology could well be “no representation without intervention”. Objects are created and changed in the very operation of representing or inscribing them. Biology thus appears as a form of ontological politics (Mol, 1999). This raises new problems on the dynamics of inter-scale processes following interventions at the molecular level. The precision of laboratory-based intervention seems to be linked to an increase in uncertainty and contingency at supra-molecular levels. This has become one of the central concerns in the regulation of the new biology and biotechnology, even when it is not openly acknowledged as such.<sup>1</sup>

Over the last two decades, debates within biology — be they prompted by the discussion of empirical research or of surveys of research fields or, in a more explicit and elaborate way, in debates within the field of the philosophy of biology — have focused on what genes can and cannot do, and on the interaction of different levels of biological organization, of organisms and environments. The responses given by biologists to these questions had important consequences for the way research was carried out and for a critical assessment of the way different narratives and metaphors of life processes contributed to the shaping of research and of the consequences of the modes of intervention associated with that research.<sup>2</sup> Developmental biology and the biology of reproduction thus continued their exploration of ontogeny, of the coming into existence and the development of organisms, through an incorporation and critical assessment of molecular genetics.

The dominance of the “phylogenetic turn” (Moss, 2003) was thus openly challenged by new moves towards a “new epigenetics”. Approaches broadly described as evo-devo (evolutionary developmental biology) and developmental systems theory (DST) engaged with the complexity of ontogeny through a criticism of the limits of and the problems raised

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<sup>1</sup> On the history of the regulation of molecular biological research and biotechnology, see Wright, 1994, Gottweis, 1998, and Nunes, 2001a. The debate on the ethical, legal, social and political issues related to the Human Genome Project has been the object of a number of collective volumes, including Kevles and Hood, 1992, and Sloan, 2000. For an insider’s view of the early stages of the project, see Cook-Deegan, 1994.

<sup>2</sup> There is a growing body of work on these themes, including Keller, 1995, 2000, 2002, and Kay, 2000. See also the references in note 3. For a fascinating discussion of stem cells as “autopoietic densities” which extends towards new directions some of the concerns of this line of work, see M. Ramalho-Santos, 2003.

by the reliance on the metaphors of information and code around which molecular genetics had been built.<sup>3</sup>

This complexity has led to the explicit recognition of uncertainty regarding the consequences of some interventions in life processes by supporters and practitioners of cutting-edge research themselves. Uncertainty is not just the consequence of technical limitations which would eventually be overcome; it is also a constitutive property of the always partial knowledge of the complex processes of life. Hence the efforts by many of these researchers to critically assess the current objectives and modes of research in the life sciences and biotechnology, and to search for more precautionary and socially and ethically accountable ways of exploring the potentials, promises and uncertainties of the “new” biology.<sup>4</sup>

### **The debates over reprogenetics**

Ethical, political and social concerns have been growing in pace with developments in biological research and biotechnology, such as the launching of the projects aimed at the mapping of the Human Genome in the late 1980s, the move in plant and agricultural biotechnology from the (literally, in the physical and biological senses) confined setting of the laboratory to “open air” trials and to the uses of genetically modified organisms in agriculture and the food industry, the protection of biodiversity and of access to its resources, the property rights over and the patenting of life and, more recently, xenotransplants, cloning, the derivation of human embryonic stem cells and, more generally, the whole field of “reprogenetics”, of the coupling of “genetic, nuclear transfer and stem cell technologies” which “will potentially provide powerful tools for preimplantation genetic profiling, H(uman) E(mbryonic) S(tem) cell alteration, and germ line therapy” (McLean, 2001: 205, note 1). The field of the life sciences has been prodigal in delivering promissory notes which would justify both the legitimacy and ethical status of research and the need for generous funding by public bodies.

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<sup>3</sup> For recent overviews and debates on evo-devo and Developmental Systems Theory, see Hall and Olson, 2003; Oyama, 2000a, b; Oyama *et al*, 2001; Moss, 2003. Related arguments can be found in Kupiec and Sonigo (2000), Sonigo and Stengers (2003) and Lewontin (2000). For a DST-inspired study of the construction of the sexed body by a feminist biologist, see Fausto-Sterling, 2000. The book, which won the Robert K. Merton Award of the American Sociological Association, is a fascinating example of the interest and potential of approaches like DST to emerging themes at the intersection of the life and social sciences.

<sup>4</sup> For an excellent discussion of these issues in relation to the consequences and implications of the use of different methods of assisted reproduction, see J. Ramalho-Santos, 2003.

Regenerative medicine and reproductive freedom and control have thus been added to the promissory notes of predictive medicine and of putting an end to hunger in the world through biotechnology. Whether the life sciences will be able to deliver what they promise is, of course, an open question. But what is at stake in many of the current controversies is a lot more than the fulfilment of scientific-technical promises.

Questions arise that have to do with deeply rooted cultural, social and moral faultlines and conflicts: are the new lines of research morally acceptable to those who are funding them and who will have to live with both the beneficial and harmful consequences of this research? How are they changing our concepts of family, procreation, parenthood and kinship? Should public funds be awarded for research that is controversial and likely to be morally questionable for a considerable part of the population? Should private entities be allowed to carry out this kind of research — or, in other words, is the public/private divide relevant when these issues are at stake? Do the research orientations under discussion correspond to collectively defined priorities in the allocation of intellectual and material resources defined according to criteria of justice? Who is entitled to discuss these matters and make decisions on them? These questions frame a discussion that is exemplary of the intermingling of the scientific, the political, the social, the economic, the cultural, the legal and the ethical which is a defining feature of the objects and practices of the life sciences.<sup>5</sup>

The recent development of stem cell research and cloning and, more generally, of what is now described as rerogenetics and regenerative medicine raise particularly thorny ethical questions, such as:

- the status of the embryo as a moral entity
- the totipotency of the embryo vs the pluripotency of embryonic stem-cells and the implications of the acceptance of this difference for the acceptability of research using human embryos

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<sup>5</sup> An accessible introduction to the state of the art in rerogenetics is Testart, 2003. Two useful overviews of the debates can be found in McGee, 2000, and Holland, Lebacqz and Zoloth, 2001, and, for earlier debates on the regulation of embryo research, Mulkay, 1997, Steinberg, 1997 and Kirejczyk, 1999. Feuillet-le-Mintier (1999) includes interesting contributions and insights on the controversies surrounding the regulation of research in the life sciences and of biomedical practice based on an assessment of the effects of so-called “bioethical” legislation in France. For social scientific approaches to the field of reproduction which are of obvious relevance to the debates on rerogenetics, see Franklin and Ragoné, 1998.

- the issue of deriving vs creating fetal tissues for research the relationships between the sources of embryo tissues (abortion, IVF, somatic cell nuclear transfer) and research
- the legitimacy of creating hybrids of human/non-human cell lines
- the public/private distinction in funding and regulation
- the acceptability of public funding of human embryonic stem-cell research

To these one may add questions on the very definition of the need, desirability or priority of these directions of research when placed alongside pressing needs for the promotion and enactment of the reproductive rights of women, health care, public health campaigns, particularly for the poor, marginalized and excluded and disabled people and for populations of the Southern hemisphere, and the need to address emerging issues such as the reproductive rights of LGBTs (lesbians, gays, bisexuals and transsexuals) and their access to the new technologies of medically assisted reproduction. Problems concerning the distribution of benefits and hazards associated with the new technologies and the new forms of inequality that may arise from them in terms of access or new forms of discrimination based on biological “fitness” require as well that issues of justice be brought into the discussion. Besides the problem of who is to be admitted to the definition of the issues at stake and to debate and deliberation (and who is to decide on criteria of participation), there have been criticisms of the focus on the moral status of the embryo, for instance, and the relative neglect of discussing them in relations to the status of women. It is important to follow the rhetorical shaping of these debates, namely the extent to which it is possible for participants to agree on the *topoi*, the commonplaces that provide some shared ground for agreeing and disagreeing, as well as the arguments brought forward by different participants, to state their points of disagreement. It should be noticed, however, that whereas some of these problems are likely to be the object of debate and deliberation, others seem to be intractable ethical issues.

### **The limits of actually existing regulation**

The response to this new situation in most Western countries was the emergence of bioethics as a field which deals with the ethical, legal and social implications of research and technological development in the life sciences. The last two decades witnessed a mushrooming of committees and councils devoted to the debate of and deliberation on these implications. Their role is usually a reactive and advisory one — responding to issues raised either by scientists, government or parliament or citizens —, and they tend to be composed mostly of scientists and experts in areas considered to be relevant for the debate. In other words, they enact what Luigi Pellizzoni (2003) defines as “excluding by composing”.

The performance of bioethics committees and councils thus falls short of what is required of a democratic politics of life, of what, following Michel Foucault's lead, I shall call a biopolitics for the era of the genome, of biodiversity and of biotechnology. Susan Kelly's (2003) analysis of bioethics bodies in the US suggests an interesting path towards this kind of research, based on the examination of the performance of bioethics bodies as boundary organizations, in terms of how they relate to scientific or broader expert authority, of how they contribute to broad public debate on the life sciences and their implications for public policy and society and how they contribute to the building of consensus on ethical and policy issues. But this is just half of the broader task of exploring what I shall call, following my colleague Boaventura de Sousa Santos, the *absences* — through ignoring, silencing, marginalizing or otherwise suppressing alternative or dissenting views — and *emergences* — of discourses, collective actors and identities, forms of knowledge and experience — in the debate on the life sciences and biotechnology (Santos, 2003a).

Ethical discussions have mostly been focused on the definition of what is and what is not acceptable in terms of research initiatives and research practices, and they raise the problem of how to make the protection of human dignity and of the integrity of life compatible with freedom of scientific research. These discussions, however, meet with difficulties associated with recent developments in the organization of scientific research, namely the new types of relationships between scientific research institutions, public institutions and private industry. This has entailed a whole new set of problems centred on issues of intellectual property, of publication policies, of ethical vigilance, of financial interests, of how to regulate this rapidly changing field. The redefinition of the map of the relationships between business, States and scientific institutions has at its centre a number of crucial issues, of which that of ownership of the results of research is the main one. This, in turn, leads to growing concerns with the possible uses of this kind of knowledge in ways that

may threaten the rights and liberties of citizens. Ethical issues thus have become central political concerns. The life sciences have brought to the concept of risk society new and unsuspected meanings, and have moved forward the debate on the notion of precaution as the cornerstone of public policies targeted at this field.

The conditions under which new knowledge and technology may be produced, the circumstances requiring consent for the use of biological materials or biological information, the purposes to which the information and the materials may be used, these are all issues which, in one form or another, have been the object of regulation by international conventions and declarations, by European Union directives or by national legislations. But there are still questions as to how appropriate and effective current means of regulation are. What is to be regulated, how and by whom is a controversial matter, and the different modes of regulation which have been designed and implemented, since the advent of recombinant DNA in the 1970's, undoubtedly require a great deal of rethinking and reinvention. And one should always keep in mind how the different temporalities of scientific research and innovation and of ethical, legal and political deliberation raise serious problems for these modes of regulation.

### **Steps towards a democratic biopolitics**

Since more conventional modes of regulating scientific research and technological development are no longer adequate (be it through the self-regulation of scientists or of the medical profession, or more traditional modes of decision based on scientific advice), solutions were sought in the creation of the field of bioethics and in its particular brand of boundary organizations, on the one hand, and of a range of consulting and deliberative experiments, on the other, all based on the idea of seeking for consensus and on what Pellizoni (2003) called excluding by composing and excluding by decomposing, respectively. Both have been recognized to have problems, but I would like to focus on a different issue: the need to broaden the discussion from the actual responses to the problems to the mode of selecting and framing issues and organizing the debate and deliberation, and of their influence on decision-making by governments, parliaments and regulatory bodies. This is based on the idea of moving from bioethics to biopolitics — possibly through a change in the very concept of ethics, following the lead of the liberation philosopher Enrique Dussel (1998) — and exploring the ways in which the agonistic features of the issues are to be dealt with, in such a way that, on the one hand, appropriate, inclusionary spaces for

confrontation and debate are created and allowed to proliferate and, on the other hand, these emerging public spheres are articulated with institutionalized modes of democratic decision-making, within the democratic state (Hermitte, 2003).<sup>6</sup>

I mentioned earlier the need for an identification of the absences and emergences of discourses, collective actors and identities, forms of knowledge and experience in the debate on the life sciences and biotechnology. This move would require the following:

- the recognition of a broad range of actors, issues, forms of knowledge and legitimate forms of expression and of the need for different forms of hybrid fora to allow public voice to all those involved or with a stake in the issues being debated (includes recognition of the legitimacy of protest and other forms of citizen mobilization);
- inclusiveness, that is, the definition of procedures which allow all the actors with a stake in the issues being debated to have a voice; this will require iterative modes of redefining who is to be included, so as to minimize the exclusion or silencing of actors or positions (in the line of what is proposed by Latour, 1999);
- recognition of the agonistic character of the issues and of the impossibility of achieving a stable consensus, namely on intractable problems of ethics or conflicting or diverging notions of justice; all spaces of debate should thus be seen as agonistic spaces;
- this, in turn, calls for a “Deweyan” move beyond the focus on intractable moral issues towards a more bounded and situated definition of problems, allowing for “action with measure” (precautionary action) and for workable compromises, as Pellizzoni suggests (2003);
- creation of spaces for public debate not bound by a top-down definition of the problems and allowing participants to define the terms and languages in which the debate is to proceed (something like the *subaltern public spheres* advocated by Boaventura de Sousa Santos);

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<sup>6</sup> This admittedly sketchy approach to a democratic biopolitics is heavily indebted to the work of Santos (2003b), Callon et al (2001), Barry (2001), Hermitte (2003), Latour (1999), Pellizzoni (2003), Irwin (1995, 2001), Elam and Bertilsson (2003), Stengers (1997) and, more generally, to ongoing debates on democracy, participation and (scientific and technical) citizenship.

- creation of spaces where citizens, stakeholders, experts and decision-makers can meet, debate and deliberate — what some Brazilian social scientists and political theorists call *non-State public spheres*<sup>7</sup> —; this, in turn, would make room for experiments in the articulation of participatory initiatives and of representative democracy, in order to generate decisions legitimated by broad public participation;<sup>8</sup>
- use of information and communication technologies as a means of fostering and reinforcing multi-site real-time debate and deliberation;
- recognition of the diversity of scales and spaces involved, and thus the rethinking of the role of the State and of supranational or international organizations or agencies and of transnational NGOs in monitoring and enforcing compliance with regulatory frameworks.

The criteria for assessing the effectiveness of these experiences, in turn, should include:

- the empowerment of citizens (voice, capacity for setting up demonstrations, capacity to influence policy-making);
- composition of new common worlds and of new collective identities (Callon et al, 2001; Latour, 1999; Barry, 2001);
- regulatory outcomes;
- distribution/redistribution of costs and benefits of action according to criteria of social, cognitive and environmental justice.

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<sup>7</sup> See the contributions to Fischer and Moll (2000). This concept was proposed by former mayor of Porto Alegre Tarso Genro in relation to the experiences of institutional design associated with participatory budgeting. In spite of the controversy the concept has generated, it seems to capture some of the innovative features of emerging public spheres (see Avritzer and Navarro, 2002, for a more detailed discussion grounded in a set of empirical studies of experiences in local democracy). There is some obvious convergence between this concept and that of hybrid forum, proposed by Michel Callon.

<sup>8</sup> For a fuller discussion of this point, see Nunes, 2003. Some experiences of participatory technology assessment, such as citizen juries and consensus conferences (Joss and Belucci, 2002) and of therapeutic activism, related to AIDS, breast cancer and other conditions (Rabeharisoa, 2002; Barbot, 2002; Epstein, 1996), as well as the diversity of hybrid for a and participatory experiences discussed by Callon et al (2001), Jamison (1998) and Sclove (1995) all provide interesting resources for the design of different forms of non-State public spheres. On the articulation of participatory and representative democracy see the contributions to Santos (2002) and Avritzer and Navarro (2002).

These are the issues that social scientists will have to take up in order to make sense of the changing features of contemporary societies grappling with the challenges of the life sciences. Social scientists are particularly well placed for the mapping of the agonistic spaces, of the emerging forms of hybrid fora and non-State public spheres and subaltern public spheres, but also, in an action-research mode and as an actor in the process, for contributing to a performative politics of articulation (Laclau and Mouffe, 2001; Nunes, 2001b, 2003) of the aims, languages and modes of public intervention enacted by “traditional” and emerging collective actors, without falling prey to the temptation to impose their own normative views or to claim an epistemic privilege for sociological knowledge. Both the normative and knowledge claims of social scientists will have to be argued for as part of the collective tasks of active citizenship.

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