Genetic Choices and Social Responsibility: Made-to-Measure Babies

Maria Casado

Today assisted reproduction allows us to intervene in the conception process, and new technologies make it possible to alter our genetic inheritance. Though the scope of this kind of intervention may now be limited , it is likely to be further extended in the near future. Speculation about the possibility of creating made-to-measure babies dates back to the early stages of the development of these technologies. The old dream of a future of healthier, more intelligent and more beautiful children has been given new life, but the same has happened with the nightmare of replicated dictators, armies of sub-human beings, stocks of spare organs...

Literature contributed to the creation of these spectres of the collective unconscious (from the alphas and epsilons of Aldous Huxley, to the extinction of women in Amin Maalouf's "The First Century after Beatrice"). Cinema, too, played its part (from "The Boys from Brazil" to "Blade Runner" or "Gattaca"). The media called up these frightening visions to create a spectacle for public consumption – just the opposite of the informed social debate needed to address the issues raised in the area of bioethics.

Leaving aside scenarios involving mass cloning or totalitarian political decisions, the possibility of choosing the characteristics of our children, it must be said, has always been enticing for humanity. In fact, parents generally wish to have an influence over their children: the process of socialisation and education is a manifestation of this wish. But the fact that the selection of genetic characteristics may act as a predetermining force on the unborn child raises concern. Legitimate matters of debate include whether we have a right to intervene in this way; or whether, in fact, we have an *obligation* to intervene in some cases (for example, to avoid the development of certain diseases). If risks are involved, particularly as a consequence of the fact that the techniques are new, are these risks acceptable confronted with the rights of the unborn child? To act responsibly as individuals and as a society, the costs and repercussions of decisions in this area must be considered in the context of their impact on the general welfare of society. Criteria must be established for the assessment of proposed interventions, and it must be determined who has to carry out these assessments: doctors, society, women, the companies and clinics using these techniques to earn a profit, or the public authorities.

There seems to be no end to the questions raised by the possibility of choosing genetic characteristics: will the new reproductive choices have an effect on human dignity? The right to life has been traditionally interpreted in a way that first brought it into conflict with the right to abortion: is it also relevant in the scope of pre-conception and preimplantation diagnosis? What is the appropriate position in relation to prenatal diagnosis and genetic counselling? Do new technical possibilities (rented wombs, insemination of single women, egg donations) alter the manner in which the right to create a family is to be interpreted? Will the medicalisation of decisions concerning women's bodies mean a setback for women's rights?

Will these techniques create new needs and new disappointments? Will enough information be available, and will consent be truly informed? And what of the rights of children – to an existence that is not predetermined, to a unique identity, to health and quality of life? How will we define standards of normality, and who will assume this responsibility? When these standards have been established, will the thin line they may imply lead to greater discrimination? Given the limited resources available for healthcare and its ever-growing costs, will it be possible to ensure equal access to healthcare services? The high costs involved in assisted reproduction and genetic technologies make it essential to set the priorities for the allocation of resources. The process of establishing these priorities must be transparent and democratic, and the outcome must be one that fully respects the principle of equitable access to these techniques.

The demand for the identity of those yet to be born not to be predetermined is regarded as the best foundation for the current ban on selection not specifically intended to prevent the development of disease. In other words, the purpose of intervention must be therapeutic. It is perhaps worth considering the role genes play in individual destiny. Are we simply the product of our genetic inheritance? If so, this implies the acceptance of a deterministic view of

life, and leaves little room for individual responsibility and freedom. Our genetic makeup does indeed have an influence on what we are, but environment and culture are also relevant. The experience of twins throughout history is a sufficient proof of this. In light of accumulated evidence, it seems reasonable to say that human beings are something more than biology, but controversy on this point underlies various forms of fundamentalism. Human dignity may be regarded as being able to freely develop one's own life and assume the corresponding responsibility. If the awareness that one is the result of genetic manipulation is an obstacle to this process, then such intervention will indeed constitute an affront to dignity. Our genetic profile, however, is not the only constraint on absolute liberty: economic limits can be an insurmountable barrier, for instance. Likewise, the social and geographical restrictions implicit in something as incidental as our place of birth may further limit our freedom.

Rational and informed debate should consider all of these issues before drawing any conclusions. Rights derive their force from the principle of human dignity. There is a cultural component in this principle that is marked by social evolution; it should not be turned into a taboo and used to silence debate. Dignity – a notion so often invoked – manifest itself in the ability to make rational choices, exercise the freedom which is rightfully ours as human beings, and assume the responsibility that derives from its exercise.

LEGAL CONTEXT

In Spain, there is specific, detailed legislation covering assisted reproduction: Laws 35/88 and 42/88 together with the numerous regulations governing their application, and Rulings 212/96 and 116/99 of the Constitutional Court. The laws seek to protect the rights of parents, children, donors of genetic material, and surrogate mothers. Greater emphasis is placed on protection of the child than on parental perspective, and the question of life expectations is addressed. The terms pre-embryo, embryo and foetus are defined; and, given that it is birth that determines legal personality, it should be highlighted that the embryo does not possess "rights". Only "persons" have rights: the embryo is a "legally protected entity", but cannot be regarded as a person and is not entitled to Fundamental Rights. The criminal code establishes various offences related to "genetic manipulation" and stresses the reason for its prohibition: to prevent "race selection". This leaves open to interpretation the question of whether such manipulation may be allowable for other purposes.

Comparative law takes a similar line, in accordance with guidelines established by the Council of Europe in 1978 and by numerous ad hoc committees. The Convention on Human Rights and Biomedicine, which came into force in Spain since January 2000, also regulates intervention that affects the human genome. It establishes that "an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants". The Council of Europe cites the reasons why it adopted this position limiting intervention. First, allowing genetic predetermination by a third party is regarded as a threat to human identity; second, human dignity may be in danger of being instrumentalised, and the individuals affected by these techniques could suffer various adverse health consequences or social difficulties. UNESCO also prohibits these practices in the Universal Declaration on the Human Genome and Human Rights.

In terms of legal decisions, it is interesting to note that the selection of sex (rejecting one sex for non-therapeutic reasons) is the only issue to have come before the courts in Spain. In the city of Mataró, the request of a mother who wished to have a daughter after having had five sons was rejected. The prohibition of sex selection for non-therapeutic purposes remains a source of controversy. Some have argued that this prohibition should be revoked, given that this type of selection would not be against the public interest and would pose no threat to personal dignity. On the other hand, choosing a child's sex is regarded as the first step toward a "slippery slope", which would, in the end, lead to made-to-measure babies.

Clearly, the free selection of the genetic characteristics of children is a highly problematic issue, whether examined from a legal, ethical, medical or sociological point of view. Accordingly, the general attitude that has held sway is a cautious one, and a generalised prohibition has been established. The current risks associated with genetic intervention of this kind seem to justify this level of restriction. The need for rational dialogue, however, remains. This is the only basis for agreement and for informed, autonomous decisions that can be revised when needed, and it is such decisions that are the essence of ethical (or in this case bioethical) behaviour.

KEYWORDS Reproduction. Council of Europe. Embryo. Foetus

ABSTRACT The current risks associated with genetic intervention seem to justify some level of restriction. The need for rational dialogue, however, remains.

Author's Address: **Maria Casado,** Obseratiori de Bioetica i Dret, Sax Cientific, Universitat Barcelona, Baldivi Reixac 4-6, 08028 Barcelona, SPAIN
E-mail: mariacasado@ub.edu

Human Ecology Special Issue No. **12:** 93-95 (2004)
Societal Responsibilities in Life Sciences
Charles Susanne, *Guest Editor*