

The making of a human being

The growing mastery of techniques for medically assisted reproduction, combined with advances in genetics, points to the possibility, in the near future, of making children on demand.

By Emmanuel Thévenon, journalist

On February 24th, 2002, the first French test-tube baby, Amandine, celebrated her twentieth birthday. What was, at the time, a technical feat has since then become considerably widespread: in order to enable infertile couples to have a child, ten thousand babies conceived by in vitro fertilisation (IVF) are born every year in France, and a million throughout the world. Until 1992, **IVF consisted of putting an ovum in contact with sperm, before transplanting the resulting embryo into the womb of the mother-to-be. Since then, ICSI (Intracytoplasmic Sperm Injection) has been used to inject the sperm directly into the ovocyte. The advantages of ICSI is that it gives the majority of infertile men the chance to have children.**

Like every new technology, IVF, and more generally, Medically Assisted Reproduction (MAR), has given rise to abuses in some countries: post mortem fertilisation, traffic in oocytes, wombs "for hire"¹... The most striking example is undoubtedly the case of a sixty-two year old Frenchwoman who gave birth in May 2001. Nine months earlier, she had had implanted abroad an egg, from an American donor, fertilised in vitro by the sperm of her own brother, aged fifty two. This "social incest" profoundly shocked Professor Axel Kahn, member of the Comité consultatif national d'éthique (CCNE)² [French national consultative committee on ethics]: "The most important thing," he pointed out indignantly, "is that doctors were involved in this process, and they did it because they were paid handsomely."

From selection to discrimination

The recent links between MAR and genetics, along with an increasing level of competition between biotechnology firms, might be a source of new abuses, but on an altogether different scale. ICSI already allows, at least in Great Britain and the United States, the sex of a baby to be chosen (with an 80% success rate). This decision, if it were to become widespread, might badly affect the balance of sexes in countries where, because of the social discrimination that affects women and the declared inferiority of the female sex, the birth of a girl is considered a tragedy.

"Prenatal" diagnosis, involving tapping the amniotic fluid, can avoid the passing on of certain particularly serious illnesses as it enables the use of therapeutic abortion. "But," observes Professor Jacques Milliez, head of the obstetrics and gynaecology department at the Hôpital Saint-Antoine in Paris, "the spread of trisomy 21 screening to all pregnant women might be the first step towards a hunt for the bad gene, towards an organised health policy aimed at eradicating a human group, people with Down's Syndrome."

This step is in the process of being blithely taken with "preimplantation genetic diagnosis" (PGD). Its aim is to discard any embryos that carry genetic disease and transplant the "best one" into the mother's womb. The technique - restricted in France to detecting only one serious pathology - enabled the birth in France, in November 2000, of a baby lacking the gene for an enzymatic disease from which the first three children of the family had died. But some North American in vitro fertilisation centres are already offering "convenience" PGD concerning around fifty genetic abnormalities as well as genetic predisposition to diabetes, high blood

pressure or breast cancer. "It is no longer a compassionate alternative to foetal euthanasia," protests Professor Jacques Milliez, "but a first step on the road to seeking the perfect child."

Another possibility being explored for therapeutic purposes and which results from bringing together PGD and cell therapy, the conception of babies designed for therapeutic purposes. An embryo unaffected by a disease carried by one of the children of the couple is chosen for implantation. When the child is born, the stem cells are taken from the umbilical cord then transfused to the sick child in order to repair its damaged organism. Thus in the United States a child suffering from Fanconi's anaemia, a seriously progressive disease of the blood, has been cured. But what would the perception have been of the new-born child if the cell transplant had sadly not worked. A failed product?

The end of the sexual dimension of reproduction?

And what if men were to become unnecessary for reproduction? An Australian team has managed to fertilise mice in vitro by using, instead of sperm, non-sexual cells, which therefore do not come from the reproductive organs. All that remains to do is implant them in a surrogate mother in order to obtain offspring. If the operation proves effective, it might enable a totally infertile father to reproduce without having to resort to donated sperm. Or be offered to couples of gay women wanting to have a biological child, which would undoubtedly give rise to much controversy.

Nor is there any need for sperm with reproductive cloning, which consists of transferring the nucleus of a non-sexual cell into an ovum that has had its own nucleus removed. On April 6th, 2002, the Italian gynaecologist Antinori announced that a first cloned human baby was on the way. According to him, there is no shortage of clients: couples infertile due to the absence of gametes and homosexual couples who want a baby that shares the genetic heritage of one of them; single people; people unable to come to terms with the death of their child... The highly sceptical scientific community reminds us that it was necessary to restart the experiment 277 times before Dolly, the obese cloned sheep who is now showing signs of premature ageing, was produced...

The theoretically possible birth of a clone would drastically change the way we see man and humanity, as well as our identity and the family. Because a child produced by this method would be neither son nor daughter, but the twin of the parent who donated the nucleus. In an article published recently in the newspaper Libération, Dominique Boulier, professor at the University of Technology in Compiègne, sounded the alarm: "The human child would now be a product to be ordered at will from super-technicians, according to the requested format and characteristics, complete with quality assurance.(...) How far can we try to wrench ourselves free from our sexual marking and from the biological conditions of reproduction without lapsing into madness?"

Interview with the biologist Jacques Testart, director of research at the Inserm [1] and chairman of the French Commission for sustainable development
"In a few years time, producing a child in a random way will be considered shocking"

Demonstration of handicapped people and their families in France at the time of the Perruche case in 2000, to oppose the idea of compensating children for being born, when their birth could have been avoided if the handicap had been detected during the pregnancy.

Label France: What fears do the current directions of scientific research inspire in you?

Jacques Testart: I think that there is much talk in the media concerning bogus threats, such as reproductive cloning. Even if a human clone were manufactured tomorrow, the technique for this would remain at the crude stage for a long time, as it runs so counter to our ethical, philosophical and cultural principles. On the other hand, certain politicians, researchers or industrialists are using the bogey of reproductive cloning to conceal other much more imminent dangers, such as the selection of embryos. The technique, which might soon become a mass phenomenon, is reviving the old fantasy of eliminating handicapped people, a recurrent theme since the dawn of humanity.

Genetic probes, "biochips", now make it possible for the genome of an embryo to be quickly established, and therefore any hereditary defects it might carry to be determined. An English laboratory is already offering this service in a day for a thousand dollars. Tomorrow, it will cost ten dollars and be done within the hour!

LF: Before selecting embryos, we still need to be able to produce them in great numbers...

JT: In this field, it is not the sperm that pose a problem, since a man normally produces 200 million of them per day and just one is enough for fertilisation. No, the key to the problem is the eggs. Women produce only one of these per month naturally and hormonal stimulation can only increase this number by ten, which is still too few to put in place a genuine selection of embryos.

But new techniques are being developed: we know that a small piece of ovary contains thousands of cells (oocytes) which can, in vitro, develop into one to two hundred eggs. The ideal thing would even be to operate on the five-month old foetus which contains no less than five million of these cells! It might well be possible, during a minor surgical operation, to take from a little girl a tiny piece of ovary, then freeze it. Later, when she wanted a child, she and her partner would go to the laboratory which would ask them to choose from among the genetic profile of tens or hundreds of embryos created for the occasion, the one they wished to keep. They could even choose the sex. There will never be the perfect baby, but there will all the same be those better off biologically than others...

LF: Is there a market for this?

JT: An enormous one. Since it will concern all conceptions in developed countries. Imagine the number of probes and in vitro fertilisations that that represents! For the moment, people say they still prefer to leave it to chance, because the technique is not convincing. But they are already beginning to become familiarised with the idea.

In ten, twenty, thirty years, it will have become shocking to have made a child in a random way in a modern and scientific society, and not to have taken the best precautions. It is even likely that the public welfare service will no longer reimburse the costs of pregnancy to people who have not undergone these tests. And we shall arrive at a crazy situation in which a virtual elite, limited to the rich countries, will carry the "qualities" of the human species. What is most alarming about current advances is the ease with which they are winning minds over to the idea that the human being is purely a product of his or her genes.

LF: What barriers could be put up to contain this type of abuse??

JT: We have proposed to our French and international colleagues that they undertake to comply with a clause that exists only in current French law: that diagnosis should only concern a gene abnormality in each of the embryos conceived by a couple "at risk". The majority of practitioners contacted rejected this proposal. Some of them, especially on the other side of the Atlantic,

even criticised us for seeking to undermine democracy and the "freedom of couples"! The die is cast. "Bioethics" is now just a line taken to get people used to the technical realities.

Interview conducted by E. Thévenon

Interview with Noëlle Lenoir [2], Minister of state in charge of European Affairs
"It is possible to reconcile research with our ethical values"

Label France: Are not ethics an obstacle to the development of scientific research and biotechnology companies?

Noëlle Lenoir: The position of Europe, which is trying to reconcile the free market and ethics, does not seem to be acting as a brake on progress and industrial development. The affirmation of "fundamental ethical principles", an expression that is used in many EU texts, is a sign of Europe's special sensitivity about the life sciences. Far from opposing the very principle of such an activity, it sets safeguards for it, which reflect our cultural and political identity and allow its expansion to be controlled.

LF: What problems are posed by the lack of status for the human embryo in the European Union?

NL: In spite of the human embryo's lack of status within the European Union and the diversity of the current laws in force in the member States, particularly with regard to the moment at which a human being emerges, regulations do exist at European level which control research on the embryo and prohibit, for example, the patentability of inventions including the industrial or commercial use of human embryos. Furthermore, the Council of Europe Convention on Human Rights and Biomedicine, signed in Oviedo in 1997, bans the formation of human embryos solely for the purposes of research and requires adequate protection of the embryo by law. Thus, research on the embryo, which offers promising medical prospects, can continue to advance, provided that it is supervised and complies strictly with ethical principles.

LF: What do you think of the possible adoption of a United Nations resolution banning human cloning?

NL: France and Germany are proposing to the international community that human reproductive cloning be banned by means of a binding legal instrument rather than by a simple resolution, as is the case at present with UNESCO's universal declaration on the human genome. It is, in fact, urgent for effective action to be taken in this field, bearing in mind the announcements, made by certain irresponsible doctors, of the imminent births of cloned babies. It is our duty to prevent such practices that are prejudicial to human dignity. And indeed the Charter of Fundamental Rights and Citizens, which France is demanding to be integrated into the future European Constitution, categorically prohibits human reproductive cloning, and what becomes established in Europe should become the world standard.

There is room for optimism as there is a consensus within the international community, regardless of philosophical or religious convictions, in favour of the prohibition of human reproductive cloning.

LF: Is the Europe of bioethics not moving forward in a disorganised manner?

NL: It is true that there is not always a convergence of views among the members of the European Union. Our common culture, summed up by the principles of "respect for the fundamental right to human dignity and personal integrity", should however help bring these points of view closer. The Charter of Fundamental Rights clearly sets out the principles of European bioethics which should then be stated in national legislations. Proof indeed that this

impression of a disorganised manner among Europeans can be considerably moderated. It is perfectly possible to reconcile the promotion of European research and biotechnology with our common ethical values.

Interview conducted by E. Thévenon

For further information

Au Bazar du vivant (In the bazaar of life), by Jacques Testart and Christian Godin, pub. Editions du Seuil, Paris, 2001.

Et l'homme dans tout ça ? (And man in all of this?), by Axel Kahn, pub. Nil, Paris, 2001.

Des hommes probables: de la procréation aléatoire à la reproduction normative (Probable people: from random procreation to standardised reproduction), by Jacques Testart, pub. Editions du Seuil, Paris, 1999.

[1] Institut National de la Santé et de la Recherche Médicale (French national institute for health and medical research)

[2] Noëlle Lenoir has held the following positions among others: • Head of mission related to the law on bioethics and life sciences for the Prime Minister (1990-1991). • Chairwoman of Unesco's International Bioethics Committee (1992-1998). • Member (1992), then Chairwoman (1994-2002) of the European Group on Ethics in Science and New Technologies at the European Commission. • Lecturer on bioethics law at the University of Columbia in the United States (2001). • Responsible for teaching "Bioethics and Human Rights" at the Faculty of Law of the University of Paris II (2000- 2002).

http://www.diplomatie.gouv.fr/en/article-imprim.php3?id_article=4788