The Ethics of Reproduction

Baroness Ruth Deech DBE
Professor Rayna Rapp, NYU

24/2/2010

Baroness Deech

I am going to give you a lightning speed trot through the ethical issues that we face here in the UK, and indeed face all around the world, when science advances in this area, which is so intimate and so important.

Let me start by reminding you what an embryo is. You probably all know what it looks like, but I do get very angry when the newspapers write about these issues and illustrate work on embryos by showing a half-formed baby, which is a foetus. The embryo is that little cluster of cells, barely visible to the human eye, not at all the same as the foetus, which has started growing in the womb, and, after a few weeks, begins to look like a human being. Do not let the two get muddled up. I know that people who are pushing a particular agenda do tend to confuse the two.

Britain has led the world in many of the breakthroughs in this area, for instance the first ever In Vitro Fertilisation baby, Louise Brown, was born here in 1978. In Britain, whenever we have a problem in this country we set up an inquiry, whether it is the Iraq War or whether it is IVF babies or divorce or whatever it might be. So, after the birth of Louise Brown, the famous philosopher, Mary Warnock, chaired a committee on IVF, in 1984. She said it is important for the public to have a moral consensus. And so, the UK Fertilisation and Embryology Authority was set up by statute in 1990. It is almost unique in the world. It monitors all embryo research in all laboratories all over the country. It gives permission, or not, for new IVF to take place, new techniques. The members are appointed after a national advertisement. I was the Chairman from 1994 to 2002, and by law, the Chairman has to be a lay person, so that they do not seem partial.

The benefits of regulation are many: protection of the embryo, welfare of the child, and I think, above all, to my American audience, the control of market forces. As we will mention later in these slides, we do not buy or sell sperm and eggs. It is all very carefully controlled.

There are drawbacks, which are the realities of regulation, whereby we are constrained by law. You need money to do it. We are pushed and pulled by the media, and indeed the politicians, who are very jealous, so they want to get into the field themselves.

The HFEA has an ethical code. Human dignity has to be protected and the person's autonomy must be retained, that is deciding yourself what is going to happen to your own body, which means that everything must be done with consent. The welfare of the baby, nothing dangerous, respect for the status of the embryo, but also saving life through stem cells. There has been a great ethical breakthrough I think in stem cells, but what is important is to save life.

We are also allowed in this country, and actually carry out quite advanced embryo research, even though it is not for reproductive purposes, and that is what makes British ethics different from many other countries around the world. Our Parliament accepted, several years ago, that it is alright to do research on embryos which had been created for the purpose of research, on various topics, including serious diseases. Maybe not in my lifetime, but I do thing that, in years to come, there will be great advances in medicine because we are discovering how the human body starts, what it is made up of, what are the genes that may predispose to research.

But it was Americans who discovered stem cells - well, some say you do - James Thompson of Madison, Wisconsin, has a strong claim to being the first to discover stem cells. What are stem cells? Well, they are derived from early human embryos. That little clump of cells are the origin of everything, and stem cells are derived by coaxing them to grow. You can take the DNA from a person and you put it into egg - imagine that there is a chicken's egg, though of course it is a million times smaller, from which the yolk has been removed, and you can cause that egg to grow with the new DNA, without any use of male sperm, just by an electric shock - I have not got time to go into that either, but men, one day, might be replaced by a little electric shock. Some of us think that is not too bad news. Not me. You can cause that egg to grow, and you can create stem cells from it, which will not
be rejected by the human body because it has been grown from the stem cells of that body. You can do it from embryos also and from adults. Growing stem cells from adults is a lot less ethically controversial, but apparently, those adult stem cells are not nearly as useful as the embryonic ones are. So the purest of researchers will want to grow stem cells from an embryo, which has been created for that purpose, hence the ethical debates. Once you have got your stem cells growing, you can bank them and freeze them and use them for quite a long time.

What can you do with them? If you start growing stem cells from someone's body, you are, in essence, growing new bits of their body, and it might be that one day, when your heart is failing, your eyesight is failing, or perhaps everything is failing, you might be able to replace and get renewed bits of your body by growing stem cells and then organs from your own body - in other words, making your hair grow again, making your eye cells grow again etc. This is far-fetched, but not impossible. Remember, 100 years ago you could not have imagined having a heart transplant? So, 100 years from now, these amazing-sounding things are perhaps not impossible - they are working on it. There are people who say it is a waste of time and an ethical blot. I do not agree.

The Catholic Church, unsurprisingly, is against it because of the use of embryos. They say that life starts at conception, and you can be excommunicated for doing it. But, not everybody takes the same view. You may remember Christopher Reeve, a very brave actor who later became paralysed - he supported that research in the hope that it would help him. Sadly, it did not. Other supporters include Nancy Reagan, surprisingly, because her late husband had Alzheimer's, and also Michael Fox. The Jewish position is that healing is an obligation; you are a partner with God in trying to improve the human lot. Also, in a pragmatic way, and I am a pragmatist, not a philosopher, when you remember, in the States and in all sorts of countries that are very ethical about this, if you go in for In Vitro Fertilisation, it automatically involves leftover embryos which are allowed to perish. Is not it better to use them for healing purposes than to let them perish or to greatly constrain IVF so that there are none left over?

It became a political issue in two American elections. John Kerry debated it with Bush, and lost. Bush, unsurprisingly, banned federal funding for stem cell research, but left private research unchecked, which I thought was unethical in itself. In other words, if you were a big pharmaceutical company, you could do it, but if you were at a university, you could not. Obama, who is not Bush, ended the Bush ban immediately, but put in new guidelines through the NIH. They are not actually as liberal as you might expect. Federal funding is allowed, but not for creating new embryos. It has still got to be on leftover In Vitro Fertilisation embryos, which have been created for a couple who wanted to reproduce, but not used, and embryo research, which I will come to in a minute. Pre-existing stem cells may be used if ethically obtained, but the old ones, I am told, are not much use. So there are new limitations on federal funding, but it is better than it was. Still not allowed to make cloned embryos, which, again, I will come to, but a step forward has been taken in the States, and because the states themselves have their own laws, California, as you might expect, did not bother with the Bush guidelines, but went ahead in 2004 with state funding for stem cell research, and they set up institutions which are really rather like British Human Fertilisation and Embryology Authority that I chaired - in some sense they copied it, rather.

Pre-implantation genetic diagnosis is the way of analysing an embryo produced in a laboratory. It is used quite often for couples who are not infertile, but, for various reasons, they need to have their embryos analysed to see if they are sick before using them. This is often the situation when you have an inherited disease in your family and you do not want your children to have it. You maybe already have a child with it. Instead of conceiving in the natural way, you can unite the egg and sperm in the laboratory, and when the little embryo has grown to the eight-cell size, you can remove one cell and test it for really quite a wide range of diseases. I used to worry that removing one-eighth of an embryo would somehow damage it, but apparently, it is alright, and they can test the cell for all sorts of inheritable diseases. This type of thing is growing. In Cyprus, for example, there is a very high rate of beta thalassaemia, an inherited disease. They have nearly managed to stamp it out in Cyprus by screening. You can test the embryo if you are worried about Down's Syndrome, and I am suggesting there that it may be more ethical to screen an embryo before you implant it, rather than waiting until the woman is pregnant, testing the foetus, and then having an abortion if it turns out to be affected. They have identified the breast and bowel cancer genes already. Every day brings news of more genes that can be identified and tested for, if you have them in your family and if you are prepared to take the much lower risk of actually getting pregnant but making sure that it is a healthy embryo.

A well-known case in this domain is the Hashmi family. The little boy suffered from an inherited disease, and the parents wanted not only to have a baby that was free of the disease, but they knew that, if they could have another child, whose tissue matched, whose bone marrow, whose blood matched that of Zain, they might be able to cure Zain. Under my chairmanship, the Human Fertilisation Authority gave permission for testing the embryo, not because they were infertile, but for testing it to make sure it was free of disease, but that also that embryo, if it became a baby, would have bone marrow and blood compatible with Zain. I am sorry to say that, after many attempts, the Hashmi family did not succeed, but we gave permission, which was
upheld in the courts, and it has succeeded in a handful cases, though sadly not in their case.

As I said, there are a number of diseases that you could screen out this way: in some communities, for example, sickle cell disease; in the Jewish community, Tay-Sacks disease. These diseases could be tackled, albeit expensively, by screening embryos before you put them in the body.

However, there are difficult issues. Disabled people say that it is ethically wrong to screen out embryos for disease. There is no such thing as disability, they say; there are abled and disabled people, but rather than getting rid, as they put it, of the disabled, society should adapt, that if we succeed in screening out lots of unhealthy embryos, society will move to a position whereby anyone who is born disabled, they will say, "Well, you never should have been born," and those who are already disabled will be treated badly. I do not think that is the case. Just because people are deaf or short-sighted etc., we help them and cure them. We do not say that they are unworthy and should not have been born. On the contrary, anti-discrimination laws, and I believe compassion, have increased in the last ten years, even though we have these new abilities.

I had a bit of an argument with the deaf lobby, who said that they should be able to choose an embryo that was deaf, deliberately. If you have two people with deaf genes in their family, in theory, you could produce embryos and choose one that carried the deaf gene. I did not think that should be allowed. I think you should do your best to ensure that every baby is born healthy and fully abled. Our new law in this country in 2008 has said that you can screen out an embryo which is unhealthy, but you cannot choose one deliberately that has a characteristic, whether it is deafness or a particular sex.

You cannot choose an embryo, in this country, because it is a boy or a girl. We had a famous case here of a family with four boys who wanted a girl. They finally had a little girl, naturally, but tragically, she died in a bonfire on Guy Fawkes Night, and they were desperate for another girl, by which time Mrs Masterton had had herself sterilised, thinking she had completed her family. We at the HFEA said that they could not choose to have a girl, because it seemed to us not right to be able to choose an embryo for its sex, that that was not a worthy ground on which to choose an embryo. What would it feel like for the four boys to realise the ends to which their parents were prepared to go to choose a girl rather than a boy? What would it mean in foreign countries, where we know they prefer boys to girls, and resort to all sorts of means to get rid of them? So we did not think it was right to choose a boy rather than a girl.

The same, apparently, happens in India, where they do not do PGD, but they have ultrasound scanning, and it is said that if a female shows up, the baby is aborted rather than give birth to a girl, because boys are preferred. We did not want to go along with that sort of attitude.

However, there are sometimes good medical reasons for choosing a boy rather than a girl, or a girl rather than a boy. As you know, men are the weaker sex, starting from the foetal stage. There are certain diseases that affect or are carried only by males. In such cases, we do give permission, for families that know they have a risk of that disease, to choose a girl embryo rather than a boy embryo. So, ethically, the situation is, yes to choosing for health; no to choosing on the grounds of gender. We say no to people who say "We want to balance our family," or who have religious or other reasons. I do not think there is such a thing as a balanced family. You have always got a father and a mother, so you have got balance there, but it is possible, and indeed, the most safe and successful way of choosing the sex of your child is through embryo analysis, but we do not allow that in this country. We think it is a bad idea. I have not got time, but I could tell you stories of other countries where they do allow it.

We do not have an age limit on In Vitro Fertilisation treatment in this country. Women of sixty and over have been treated. We do have a principle about the welfare of the baby before the person is treated, but there are quite a few cases where women of over sixty have been treated. We have a case in this country of a woman who said she was 55, and I took one look and I thought that it was a bad idea, and in fact it turned out that she had lied and she was in fact 65. She gave birth to twins, and sadly, she fulfilled all the terrible predictions of people who do not think that older women should be treated. She died when they were two. Of course, the argument has always been you do not want to treat old women because they may die, leaving the children without parents, but when a man of 60, 65, 70, 75, nay 80, gives birth, we all say, "Wow! Good for him!" So I am not so sure about the ethics of this. Nature must have a reason for the menopause, which stops women having children naturally, but it is hard to argue that you should not treat a woman of sixty if a man of sixty is able and does bring about birth. This is a very difficult question. You feel instinctively that it is wrong, and yet it is hard to say why if we are applying the same reasons to men as we do to women.

Another interesting issue started with young cancer patients. Imagine having cancer when you are 30 or 35. You are going to
have chemotherapy, radiotherapy, which will adversely affect, probably destroy, your reproductive capacity. If there is time, and
the treatment is starting in a few weeks, it is possible to remove eggs from a woman cancer patient and freeze them, before
she is treated, so those eggs are in good condition, then she has her treatment, hopefully she survives, she can then take
back her eggs from the freezer and use them to give birth, one hopes, though the success rate of defrosting eggs is not very
good.

Having allowed cancer patients to do it, logically, we at the HFEA had to allow career women to do the same, because you
cannot say that only sick patients can do this because it is very hard to define. So, in theory, and I am not recommending it but
it is possible, if you are 30 or 35, and Mr Reasonably Okay or Mr He Will Do are unacceptable to you and you are holding on for
Mr Right, you run a severe risk that your eggs will die before he appears. Not very many women do it, and I am not saying I
recommend it, but women of 30, 35, do freeze their eggs, go back to work, become a judge or a captain of industry, and then,
later on, if they find the right man, the eggs are still okay, or you could look for donor sperm. I suspect that this will grow. As
men's willingness to commitment in marriage diminishes, the prospect of freezing your own eggs and therefore preserving your
fertility, like that of a man, may well increase.

You can also - and I disapproved of this, and I fought it all the way to the Court of Appeal - take sperm from a dead man and
become pregnant by your dead husband. I think it is alright if he consents, but I and my whole committee objected to this lady,
whose husband suddenly died from meningitis, and she asked the hospital to remove his sperm, just before he died and just
after he died. He had no idea what was happening, and I do not think that is right; I regarded it as a sort of rape on the death
bed. I think it is alright if you consent, but not if you do not know about it, because it is not just taking an organ - it is doing
something that affects future generations. She won her case in the Court of Appeal on rather odd grounds, that she could take
it abroad to Europe, because, in Europe, you are allowed to do this sometimes, and you can travel with medical necessaries, but
I did not think that it was a good idea.

We changed our law recently in Britain - it has become even more liberal. We now allow, by the law of 2008, mixing of animals
and humans for research purposes. You can mix human DNA with an animal egg, or the other way round, or you can fuse, let
us say, the sperm of an animal with the egg of a woman, for research purposes. I hasten to add, not for giving birth to any sort
of monster - that certainly is not allowed. But, for research purposes, you can do this. This was hotly fought over in Britain, but
it did succeed.

We also now allow the registration of two mothers on a birth certificate, where a woman has given birth by IVF or whatever
means, but she is living with another woman. I have problems with that, because I think a birth certificate should tell the
biological truth or else it should say nothing, and I think to go through life with two women on your birth certificate may cause
problems.

But we do allow the mixing of animal and humans. It is not that new, in that, under the old law, it was always possible to test the
viability of human sperm on animal eggs. There is one animal whose eggs have always responded rather sensitively to male
sperm, and has been used for many years to test the viability of male sperm. When I ask my girlfriends which animal it is they
think is most allied to male sperm, they tend to say rat or a weasel, but actually, it is a hamster. But in future, research will be
permitted mixing humans and animals, but I assure you under very strict guidelines for research.

At this point in my talk I become a bit critical of the States. I have not got time to go into it, but there is much less regulation
there than here. I am sure you read about Nadya Suleman, who gave birth to octuplets. She already had a few children. She
gave birth to octuplets in 2009. Probably six embryos were implanted, and two became twins. That is not allowed in this
country. If any doctor had done that, he would have been disciplined and probably struck off. We insist on two embryos, not
more, precisely because of these dangers. Even so, it has not been really tackled. There was a bill in Georgia to limit it, but it
has not passed. In this country, only two embryos may be used for women under forty, possibly three if you are over forty, in
order to avoid the dangers and risks of multiple births. We have managed to cut the triplet rate. Twins and triplets, these days,
in Britain, people assume they are IVF, and they are not a very good idea because they are really quite risky.

The attitudes in America to regulation of this field struck me as rather similar to the arguments that Americans have had over
Obama's plans to introduce more medical insurance in the States. Although you know it is a good idea, your libertarian instincts
fight against it. I think it is a pity. There is nothing to fear in the NHS, and maybe the Americans who have been in Britain long
enough will know that, but the American attitude is very much of this is all a business between me and my doctor, no one else
should interfere. The ethical arguments are the welfare of the baby, which we try very hard to protect, and on the other hand,
does a woman have a right to be a mother? I would say no. Maybe she has a right to try, and even that is limited.
And again - I am putting it very crudely - we tend to look at American medicine and say, well, it is very successful, but it is
everything that money can buy, whereas here, we still, rightly or wrongly - quite often wrongly, I know - control medicine in the
interests of the community. We do not commodify it. We try to make it dignified. But I think this will be the subject of Reyna's
lecture.

Another example of how different it is between Britain and America is that the British do not pay anything, other than expenses,
for eggs and sperm. Children conceived after 2005 have not been able to know who their fathers are. They may, in about
2023, be able to find out. But sometimes, when I have the odd few minutes, I enjoy looking at American websites - California
Cryobank and so on, and you can log on and it says "What would you like the father of your baby to look like?" and you can tick
blond, dark, old, young, and they advertise these men's sperm - PhD Berkeley, basketball champion, IQ of 150, etc. We do not
like that. We think its commodifying. But apparently, you can do that sort of thing, and of course, women offer to sell their eggs
too, for a large sum that will fund their studies. That has not caught on in this country. We do have debates about it. Some
people say, "Well, why shouldn't a woman sell her eggs? What's wrong with it? It's a valuable commodity, and if she's tested and
she's healthy, why not?" But that is touching on the very different attitudes taken by Americans and by the British, if I can so
crudely stigmatise or describe American attitudes and British.

On a campus noticeboard in the States, it is not unheard of to see a notice up from somebody who wants an egg donor. One I
found asked for "a University of Pennsylvania student, Caucasian" - I think you would be had up for racism in Britain if you put
that - "athletic, 5-7 to 5-11, German, English, Eastern European or Irish" - in other words very Caucasian - "very attractive and
pretty, kind and fun personality, please consider being our egg donor." At the bottom of the paper they had slips one could tear
off with the address to which you would have to send a picture. Every single word of that would not be allowed in this country.
The downside is you would be lucky to find an egg donor at all, because they only get expenses. It is not an easy procedure.
But I think that shows, in stark contrast, the difference between possibly over-regulation in this country and possibly under-
regulation in the States.

I will stop there and hand over to Rayna, who I am sure will take this to a much deeper level. Thank you very much.

Professor Reyna Rapp

Professor Deech has spoken about the science, ethics and social policy implications that accompany this expanding set of
reproductive technologies. But let me start by saying, as an anthropologist, I backed into this topic of what were then dubbed the new
reproductive technologies, studying them throughout the conundrum of my own pregnancies. The first lesson of this talk is
that you should never let hyper-educated women apply for grants because they tend to study exactly the social dilemmas in
which they find themselves, and so I did, as an older woman, study amniocentesis. I spent countless days in hospitals, in
clinics, at home with families, in medical archives and records, interviewing genetic counsellors and geneticists, trying to
understand how a new technology became the controversial topic they are today and who would accept and who would not accept
it, and what they thought about it, what women of diverse class - social, ethnic, religious, national origin - understood about the
technology and what their aspirations for what it meant to have a healthy pregnancy or a healthy foetus really were. The result
was the book, "Testing Women, Testing the Foetus," which came out a little over a decade ago now.

Lest I thought I was doing anything particularly original, all around me, other anthropologists and sociologists, many influenced,
as I was, by the women's health movement, and moving into fields like the medical social sciences to study the impacts of these
technologies, and then the anthropological study of medicine, science and technology, many others were also exploring the
new reproductive technologies, which quickly become dubbed the assistive reproductive technologies, that is they were
already grounded enough not to be considered new, and that happened at a very quite rate.

Since the first baby born by In Vitro Fertilisation in Great Britain, more than three million births through assistive reproductive
technology have been reported around the world, from North America, Europe, the Middle East, China, India, South-East Asia,
Africa and Latin America. Nor is it surprising, given the flourishing fertility industry in the industrial north, to see high-tech fertility
clinics opening, even in very low resource areas or alongside overburdened and under-funded primary healthcare systems.
With revenues of over $4 billion a year in the US alone, fertility is big business. Entrepreneurs, both within and outside of what
was once euphemistically called "the developing world", look to it as the promising new edge of an ever-expanding assistive
reproductive technology market.

While the rapid spread of assistive reproductive technologies signals the most dramatic of reproductive transformations, it is
hardly alone. As many have noted, we find ourselves in an age of many forms of highly selective and exquisitely stratified
globalisation. Not only can India or Thailand attempt to regulate reproductive services that will make their economies user-friendly for consumers travelling from expensive to cheaper zones of In Vitro Fertilisation, treatment, surrogacy or egg purchase, all those things are available on the web and internationally. We also see a rise in international adoptions, female labour migration and multiple births. This last set are better regulated in Northern Europe, and increasingly, in the EU and the UK, but not at all regulated in the Wild West of fertility services in America, and so I am glad that Baroness Deech mentioned the "octo-mom". She is going to weave in and out of my talk.

The American Society of Reproductive Medicine and the Society for Assistive Reproductive Technologies, that is the professional organisations themselves, recommended only in October of last year, that there should be a sliding scale of the number of embryos put back in - it is fine to do one or two if you are younger, but if you are older, they are going to put in three or four for you, on the hopes that one will take. While, statistically, that may work out very well, I absolutely agree that there is a very big set of ethical issues about the health and fragility and protection of those embryos and what happens to them if three or four actually do take root and come to fruition and are therefore born probably at very low birth weights - a problem I am going to talk about in a moment.

Sweden, notably, actually was the first European country to regulate the embryo transfer question, and they only allow single embryo transfer, and they have seen a huge decrease in the use of their NICUs, Neonatal Intensive Care Units, in birth of multiples, unlike what is going on in many parts of the world where you have seen these things go on. Of course, in the USA, the octo-mom story filled our headlines and datelines for months on end last year. Those general guidelines and regulations increasingly in place throughout Europe and the UK should be considered in terms of other globalising changes.

We know that birth rates in general are coming down, even in the high fertility parts of the world, and we expect them to come down even further over the next twenty years. At the same time, inter-country adoption is on its way up. The US, of course, has got the lion's share, but, in Europe, Norway is, by proportion of population, the highest inter-country adopting nation. So what you are really seeing is that, as the age of marriage goes up, and age of first birth goes up, and infertility goes up, what you also see is more adoption, which is, after all, a technology of reproduction as well.

Likewise, the number of assistive reproductive cycles reported in the US has gone up, although we have got this information mainly from the fertility professional organisations themselves. We do not have good Government regulation, which is exactly what you were talking about.

Likewise, twins by country have gone up because of this shift toward an older age, at which twins are more likely, but especially because of assistive reproductive technology.

Because of the velocity with which this technology is moving, it is hard for the research into things such as the effects of multiple births to keep up to date, and so we have to admit how very little we understand about how much multiplicity is going on. Again, in the EU, you may give us a light touch about that, starting a commission of inquiry, but there is a consciousness that has been studied throughout the EU, and in the UK itself specifically, about the impact of having multiples, and in the United States, that is considered basic journalism - that is, nobody takes it very seriously yet, but they certainly ought to.

I should say that when we speak of egg donations, the word "donation" may itself be a bit of screen, because often we are talking about the sale of eggs, even though, as Baroness Deech pointed out, that is not legal in many countries - certainly not legal here, but it is legal in the United States and in many other countries as well. But we will come back to this.

Anthropologists have, of course, been observing this worldwide picture, these changing upward trends in marriage age and increased use of adoption and more infertility and more assistive reproductive technology as well, asking a lot of questions and analysing what happens on the ground, for there is often a large lived and existential gap between a declared social policy, advertised and regulated, or unregulated, services, and the experiences of those who would use or are sometimes used by the assistive reproductive technologies themselves.

I am going to give you some examples from a book called "Assisting Reproduction Testing Genes". It is a book that really takes mostly the developing world as its focus, and has a collection of articles that are quite interesting about how people respond and how those technologies are put into play in different parts of the world, because, certainly, all involve simultaneous entanglement, not only with the medical system of a given nation or a region, but also, with the gender, kinship, religious and governmental regulation, at both the local and the international level. So what I am saying is that there is a much more complicated social picture here of where it is that people are using the assistive reproductive technologies and how they understand them.
Let me begin with a couple of examples. I will start with German Turks and their use of IVF. In Germany, infertile German Turkish couples reap the benefits of IVF, but are often subjected to public stigma, labelled as over-populators, in need of contraception, and sycophants on the German national health system, so there is a real kind of racialised, ethnic labelling that goes on, even though they do have access, and often very human access, within the medical system. Statistically, they are far from over-users of the system. Like many people in the lower socio-economic sectors, German Turks have higher rates of infertility, including infertility caused by tubal factors, which itself is a kind of an archaeology in the body, in which you can see that a woman had an infection that could have probably been cured medically but instead she scarred a tube to the point where it became dysfunction. German Turks enter the infertility treatment sector with considerable hesitation, yet fertility and family formation among German Turks are highly valued. Turkish couples resist being labelled over-populators, for example, describing German couples as colder, less committed to their children than Turks consider themselves to be. Germans have lower birth rates and are imagined to be less persistent in seeking rigorous fertility treatment. I am not saying that that is the case - I am just saying that they have a kind of resistant stereotype that they kind of push back with, in this case.

In Ecuador, to take another example, women and their supporters who need to pursue IVF are suspicious of costly and anonymously purchased eggs. They rely on familial egg donation, where multiple forms of reciprocity, including repayment of prior economic loans in precious gametes, embed concepts of modernity and responsibility. Thus, an existent and highly resilient form of kinship reciprocity, in which people would automatically give things to one another on the basis of family ties of affection, extends to the use of gametes, so that female kin will give eggs to one another, which is, as you indicated, a very difficult process, but they will go through it. This has a double defect here. On the one hand, it shows a kind of kinship responsibility and a kind of a belief in and use of the technologies of modernity, even while it escapes at least part of the market forces, because you are going to pay for the IVF but you are not going to pay for the eggs.

Another important example involves Shia Iran, on the cutting edge of gamete and embryo donation for the Middle Eastern region. There, a potent combination of religious deliberation and pronouncement, biomedical expertise and authority, and the ongoing importance of kinship, knowledge and reciprocity, make temporary marriage an important institution for fertility treatment. The institution of mu’tah, or temporary marriage, is a key to securing egg donations because, in principle, under Shia regulation and not necessarily under Sunni at all, you can have a temporary marriage in which a man can contract with a woman to be married for a certain period of time. In this case, often it is used to purchase eggs, but to use this institution, which is completely legitimate from a religious point of view, in order to get eggs that will help with an infertility problem in the primary marriage. When things go wrong sometimes, a temporary wife, who was hired for egg donation, may end up as a household servant and be available for subsequent or a prior egg donation, or she may in fact become a second wife in a more full sense, and her fertility contribute to the larger kind of lineage problem. Most donations remain halal, that is religiously acceptable, through the use of siblings and other approved kinship donation. This has obvious lineage advantages, but may lead to psychosocial complications, not least of all for the clinic staff, who need to be flexible in counselling intake and procedure. They find themselves often facing a kinship battle. They may find themselves in a situation in which not only religious authority but also the wishes of senior kin need to be respected. Many clinics now require that couples in potential treatment sort out the legal, social and financial arrangements they have with kindred gamete donors with their own local religious authority before they are accepted for treatment. So there is a kind of negotiated process that is very much a public one that is understood in the relations between medicine and religion in Iran.

In India, embryo donation and surrogacy are both big business. Indian Government regulators and business investors tend to profit from the ease with which clinics can work with gametes, embryo and human foetal tissue, when contrasted with the fraught moral status such embryonic entities hold in Euro-American discourse and practice, and that label of embryonic entities is one that was used by anthropologist researcher Aditya Bharadwaj to describe the Indian situation, where he has done a huge amount of research. In both elite private and newly emergent public infertility treatment programmes, women in treatment are targeted for their spare embryos as donations. While a rhetoric of generosity towards national research programmes is stressed, the Indian Government is also attempting to create a scientific business fusion, in which India emerges as a key competitive site where human embryonic stem cells, that Professor Deech talked about, where that kind of knowledge and research can rapidly emerge, and they are betting that they are going to actually become, again, a lower cost arena in which this highly technical medical innovation may take place, hoping to use their own population to do so.

In the present era, India has also become a major site of medical tourism, that is, people travelling to get medical services at lower cost from their home countries, especially here the US is a particular place that should be highlighted.

The US sociologist Arlie Hochschild recently published a story in the American Prospect magazine entitled “Childbirth at the
Global Crossroads. There, she quoted compelling accounts of the poverty and kinship support which condition the decision of women to enter several gestational surrogacy programmes - that is, she went around to the programmes and got access and interviewed the women who were in them, who were acting as gestational surrogates. In such programmes, surrogates must abide by stringent rules that are user-friendly for commissioner Westeners and upper class Indians, while separating the surrogates, for long periods of time for medical and nutritional surveillance, from their own families. As one mother-in-law, who, along with her son, was taking care of her son and daughter-in-law's children while the daughter-in-law was acting as a surrogate gestator, getting paid to have a surrogate pregnancy for another couple, put it, "Yes, we take care of the other children. We agreed to this because she brings in so much money, much more than his work as a food vendor could ever hope to do." So I think we have to take a very strong account of the financial kind of pressures on people to do that kind of selling and renting of parties of their bodies and times in their body. As Hochschild goes on to point out, "Right now, international surrogacy is a highly complex legal patchwork." Surrogacy is banned in China and much of Europe. It is legal but regulated in New Zealand and Great Britain. Only 17 out of the 50 of the United States have laws on the books. It is legal in Florida and banned in New York. In India, commercial surrogacy is legal, but unregulated, although a 135 page regulatory law has been long in the works and it is making its way through the parliamentary process. Many Indian commentators have criticised the potential lies aimed towards wealthy national and international consumers, and insufficiently protective of the rights of the overwhelmingly poor gestators, who I have just described to you.

At the same time, gestational surrogacy is booming in Israel, where traditional surrogacy is banned, as Jewish women cannot contribute their own eggs to another couple without violating Halachic law - that is, in principle, if you have assisted insemination of your own eggs and therefore become a traditional surrogate, that is, it is your egg that you are gestating along with the sperm with the contracting father, you are committing adultery, according to Halachic law. So instead, they find it easier to actually purchase eggs, often outside the country. Because of this, places such as Romania, Italy and Russia have become very large sources of eggs for Israeli couples. Then the couple do this kind of total surrogacy in Israel, where you can have the baby under religious law - it is absolutely fine.

Surrogacy is, however, banned in the Muslim Middle East and in Vietnam. In all these cases and more, we witness what Marsha Inhorn and Daphna Birenbaum-Carmeli, the editors of this book, describe in their new edited collection "Assisting Reproduction, Testing Genes", as the destabilisations of late modernity, that is, the rapidly evolving reproductive technologies are destabilising on many fronts, the taken for granted relations between sex and reproduction, between nature and culture, muddling lines between gift and commodity, informal and formal labour, biology and sociality, heterosexuality and homosexuality, the local and the global, and of course the secular and the sacred. So, we are in the middle of a symbolic thicket here, in which people really have to use the resources they have to understand what parts of these technologies make sense to them, and what parts of them just feel too far into the way their understandings of what constitutes a foetus, a pregnancy, gender relations, kinship relations, religious authority, and the like, proceed.

Birenbaum-Carmeli and Inhom note that gender relations, in particular, are brought into stark view by these technologies, for women bear the physiological burden of most interventions, although the social and psychological consequences of male infertility have also been publicised and are increasingly medicalised with the advent of ICSI, which stands for Intra-Cytoplasmic Sperm Injection. Basically, it is a way of taking sperm, and again, highly medicalised and a highly rigorous procedure, not an easy one that one would undergo lightly, to get sperm from somebody who is producing very few or no sperm that can be used in fertilisation directly, so they are able to take it out for him and then use the in vitro Petri dish fertilisation process to make an embryo and then hopefully a foetus.

As Marsha Inhorn observes about infertility treatment in the Muslim world, where services are now offered in many countries, it is not unusual for couples who can afford it to travel from majority Sunni to minority Shia locations. Shia are more traditionally flexible in terms of their theology and how much you can interpret. It is much more the case that your local imam can make a fatwa which will tell you what is permitted and not permitted, which gives enormous room for negotiation, and many Sunni countries do not permit this.

At the same time, gender relations are up for grabs as reproductive life is quite time-sensitive with differing implications in varied local moral worlds. Being an old mother may lead to serious stigma, but almost never as much stigma as being childless in the first place. Being a husband or a father whose wife is treated by ICSI may also lead to taking a second younger wife as a more reliable baby-producing route than playing with the IVF odds, which decrease as women grow older, even if the initial reproductive problem was unambiguously male. That is, the man may be the infertile part of the couple, the wife may try everything and not get pregnant. Later along the way, 10 or 15 years into that marriage, along comes ICSI, they can then try
again, but the wife is 10 or 15 years older, and her chances of succeeding are not necessarily great, so therefore the possibility of taking a second wife looms large and it becomes almost a gender irony in this situation, once you have disrupted things through medical intervention.

At the same time, Marsha Inhorn believes that the social and psychological sorrows of infertility have actually incubated a profound sense of companionate marriage among many who endure them. A wife or husband who remains loyal to an infertile partner, or accompanies them through unsuccessful treatment, is forced to focus on the value of the marriage itself, as its reproductive importance can no longer be assumed. So she is seeing both things happening in the Muslim Middle East, that is, she has done a huge amount of work on many fertility clinics in four or five different Middle Eastern countries and what she is saying is that, yes, there is this tremendous time pressure and sensitivity and the taking of second wives to make IVF work for guys who can now do ICSI, and at the same time, there is more acceptance of a companionate marriage and the value of the people who are loyal to one another, despite the fact of their infertility, which has enormous stigma in the local culture.

Accompanying these reports, feminist bio-ethicists are now exploring the umbrella of human rights. Just as the women's health movement, in all of its international diversity, shifted strategically to the use of human rights discourse to intervene in international tribunals, national regulations, and UN frameworks and conventions in the 1990s, so too feminists within bio-ethics are now considering what strategy might be best to bring their concerns with the protection rights and limits on the exploitation of women as gamete donors and surrogate gestators under emergent conditions of rapid commercialisations.

"Informed Consent" is an enormously important document, and I know we have not had time to talk about that. It comes out of the Nuremberg trials. It has a history of its own, but the idea of having to make sure that a patient understands what is voluntary, that they can withdraw, what are the risks and the benefits involved in those procedures that they sign up for, this is tremendously important, and I really want to stress that. But at the same time, if all the burdens of egg and embryo donation, which is overwhelmingly to say sales in terms of the larger global picture, and surrogacy are left to the signatory exchange, the encompassing world of profound inequality, in which social justice and injustice, poverty and development, and of course patriarchal punishment exist, will continue to flourish in the regulatory shadows that have been left behind. So we need more than just informed consent is what I am saying here.

Two concepts, drawn from my earlier work, may be helpful in sorting through many of the compelling reports I have just run through as examples. They are: stratified reproduction; and moral pioneers. Let me talk about stratified reproduction for one minute first.

Stratified reproduction just means, the whys and hows and wherefores of the consequences of reproductive aspirations, practices and outcomes in which one group of people's reproduction is valorised and another is despised or unsupported. So, not all of us are equally considered worthy of being parents in the first place, and that is something that leads into a very eugenic past, and a not so past as well.

I have cited many examples earlier which recall Hochschild's report on gestational surrogacy in India or the hiring of a poor world woman as a temporary wife and egg donor in Shia Iran. Stratification is central to the analysis of the legal scholar Lisa Ekimoto, who writes about worldwide egg procurement, human egg procurement, under conditions which are potentially economically coercive, and the invisibility of the powers of the market in favour of the sympathy many feel for people suffering with infertility - it really is a suffering. Or legal scholar Dorothy Roberts' concern with African American surrogate gestators, who are deemed appropriate womb-renters and nannies of course in the USA, but often the object of public opprobrium as mothers themselves - that is, they are good enough to take care of and gestate children of the upper middle class, but they are not good enough to be mothers themselves.

The second concept I want to talk briefly about is moral pioneers, which really just means that decisions get made not simply on the basis of rational or ethical debate, but also within local gender, generational, class and caste relations, all of which provide a kind of optic through which innovative technologies get viewed and assessed. The example I drew from Elizabeth Roberts' research on Ecuadorian gamete donation among sisters and other female kin surely illustrates this concept, that is, they took the situation of a new technology into their own hands and used an old technology, which is kind of reciprocity and borrowing, in order to just extend it to the gametes themselves. So does Lisa Vanderlinden's report on German-Turkish infertility treatment, and the corpus of Marsha Inhorn's scholarship on reconciling kinship, desire, religious authority, and regional medical marketplaces in the Muslim world of infertility treatment.

How do individuals, couples or families and kinship networks come to decisions to use or limit the use of assistive reproductive
In the USA, we have evidence of moral pioneering as genetic testing technology rapidly moves forward. For example, I have worked as a consultant on a project which is run by a psychologist named Lisa Ruben about what happens when women who have already been tested positive for BARC1 and CA2 genes, that is they confer a heightened risk of familial forms of breast cancer, at a younger age as well, what happens when they are offered prenatal genetic diagnosis. This test would mean doing IVF, taking out you eggs, taking out your partner's sperm, putting them together in a Petri dish, and then testing the embryos in the way that Professor Deech was talking about, so that you might know whether the risk you have for your genetic makeup, which is going to heighten the chances that you are going to get breast cancer. The question for them would be: do you want the same thing for your offspring? Do you want to only put back in embryos which are without that genetic makeup or do you want that genetic makeup as well? So, they are asked a lot of questions about this, and the answers have been very interesting. Many of these women, who tend to be very well-educated if they are part of this process in the first place and have gone for genetic testing in the first place. Many women say no, they do not want to play God - and notice that language - it is very hard to convey to a British or any other audience the deep religiosity of much of the US discussion about these topics and the way in which they come down the pike at us. Many said they did not want to play God with genetic choices, and even those who were more positive - that is, they said they would use prenatal genetic diagnosis - also expected science to provide the cure for breast cancer by the time their impending offspring might need it. Maybe it is the combination of the two - that is, maybe there is a kind of a true belief in science and in the possibility that science is going to solve the problem of breast cancer - which enables them to say no to its use in the first place, effectively saying “I can wait and play my chances because science will come forward in the end.” So that is a certain kind of moral pioneering.

Here, in the UK, Monica Conrad's "Narrating the New Predictive Genetics" reports on families who have near relatives with Huntington Disease, a neurological wasting disease which is inevitably fatal. People make exquisitely thoughtful decisions about which grown children and other near relatives can be relied on to understand a diagnosis and to consider testing for themselves, and from whom they consider that this new kind of genetic status should be keep secret.

Margaret Locke, a Brit who lives in Canada, arguably the North American doyen of medical anthropology, has done really wonderful research on Alzheimer's disease, which also fits into this concept of moral pioneering. There, she labels current genetic testing for near relatives of people with Alzheimer's disease, in terms of the eclipse of the gene and the return of divination, and what she means that there are many different factors which contribute to a change that may have something to do with Alzheimer's disease. When they went after it, the scientists first thought they'd get a very simple answer, but it became much more complicated than that. Basically, some forms of the factors that you may be carrying confer heightened risk if you are the child of somebody with Alzheimer's. Some of them confer a heightened protection as well, and it is possible to get Alzheimer's without the heightened risk genes and to not get it with the heightened risk genes, so it is a very complicated situation. Under those circumstances, people often prefer not to go any further with the testing. They do not really want to know very much, and they do not necessarily remember it or recommend it to others in their family, precisely because the results are so ambiguous in the first place.

Whatever their reasons, these are all instances of moral pioneering for individuals and their familial networks of affect, hope and despair, for they must ultimately make choices to use or forego technologies whose information is presented as neutrally as possible, but whose psychosocial burdens are intense and intensely new. Here, gender, generation, racial/ethnic class, educational attainment, and much more, will all play a role in how a person in her embedded network seeks, receives and uses new biological, biomedical information.

We also see these quite philosophical sets of problems at work, as we read recent anthropological reports concerning ramped up programmes in newborn screening in the US. Sociologist Rachel Gallab writes quite movingly, for example, about falling in love with your baby, except when there has been so much newborn screening that you are likely to get a diagnosis of something that your child is carrying the genetic makeup for, but whose implications you do not really know very much about.

Cystic fibrosis comes to mind, which is a relatively common form of a single gene disorder. But with cystic fibrosis, you can have cases which are sub-clinical - you may not know until you try to go and have a baby yourself that your fertility is impaired because you have sub-clinical cystic fibrosis. You may have a whopping big case of it, but it may not come on until you are five or six. So what does it mean to teach a parent that they have got a kid with a CF gene, but they have also got a newborn baby, and she has really tried to follow through to say what are the implications of this for families who need to learn how to take care of their baby, but in fact, are already having a medicalised experience by the time the newborn comes home from the hospital.
Let me just give you one more example, which comes from my own work, and that is, what I have been working on recently has to do with the rise of children who are diagnosed with having disabilities in the schools system. About 15% of our school population now gets special educational services. I know the rates are rising here in the UK as well. The weights of children who are born after multiple pregnancies and even after single embryo transfer with IVF have knocked up the rates of children who come out at low birth weight - low birth weight babies are at much greater risk of using special educational services later on. They have mild cognitive impairments. About 25% of the kids who are coming out of IVF have mild cognitive impairments, as best we can tell in the United States, and what that means is that there is a huge transformation in what it takes to raise a child. The niche of reproduction, I would argue, along with my colleague Fay Ginsburg, is no longer something that is contained simply at the moment of conception and pregnancy. In all of these examples, what I am trying to talk about is that the niche of reproduction itself is expanding and we have a huge sense of it as including not only neonatal screening but also testing for later onset diseases and what kind of reproductive decisions those will bring you to later on.

What is the link between the kind of science that we have been talking about and these kinds of kinship and later onset and parenting decisions I am talking about? As the capitalisation of the Life Sciences expands apace, the aspirations for parenthood, childhood, safe help, and full inclusion link us all across many sites in the globe. These are the felicitous words of sociologist Arlie Hochschild:

"person to person, family to family, the first world is linked to the third world, through the food we eat, the clothes we wear, the care we receive. That Pilipino nanny who cares for the American child leaves her own child in the care of her mother and another nanny. In turn, that nanny leaves her younger children in the care of an eldest daughter. That daughter may be gestating for a couple from the West who has contracted for her surrogacy. Our scientific investigations and regulatory processes in the world of assisted reproduction are dizzying in their velocity of change, yet they are clearly works in progress, taken up, transformed and reformulated in exquisitely specific locations in a global marketplace. These may have unintended consequences on our gender, generational and kinship relations, to say nothing of our public institutions."

That was really the educational part I was trying to index. And I would add that, in all these social locations, reproductive technologies also serve as a kind of an optical technology, focusing our attention on making those bonds and changes more visible.

©Baroness Ruth Deech & Professor Rayna Rapp, Gresham College 2010