## **Dispatch**

## On Bioethics and the Commodified Body: An Interview with Donna Dickenson

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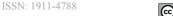
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An Emeritus Professor of Medical Ethics and Humanities at the University of London, Research Associate at the University of Oxford, and Visiting Fellow at the University of Bristol, Donna Dickenson is a trailblazer in thinking about the commodification of the body. In her 40 year career Dickenson has made many contributions to examining the intersections between the embodied subject, labour, gender, property and care including (among other publications) her books *Property in the Body: Feminist Perspectives* (2007) and *Body Shopping: The Economy Fuelled By Flesh and Blood* (2008).

In her keynote address to the 2015 symposium on *Consuming Intimacies: Bodies, Labour, Care, and Social Justice*, Dickenson spoke on "The Commodification of Women's Reproductive Tissue: The Lady Has Vanished and Is Still Missing," referencing her well-known, oft-cited article (Dickenson, 2006) on the absence of the women who provide eggs for the creation of embryonic stem cells from the stem cell debate. This keynote address provided critical insights about the ongoing utility of the term "commodification" to describe the systematic marketization of women's reproductive capacities and tissues, providing a corrective to the language of "choice" that focuses on the individual. Using the examples of the sale of eggs for *in vitro* fertilization and research, the banking of umbilical cord blood, international commercial surrogacy, and mitochondrial replacement techniques, Dickenson demonstrated how women's interests and voices continue to be largely absent from scholarship and debate over new technologies and treatments related to their reproductive bodies.

Following Dickenson's keynote address, Alana Cattapan (CIHR Postdoctoral Fellow in the Faculty of Medicine, Dalhousie University)

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interviewed her about the important contributions of her career, the challenges she has faced, and her thoughts about the future of scholarship on the commodification of the body.

Alana Cattapan (AC): Thank you so much for joining me. I want to hear first about one of your best known works, Body Shopping, which examines how the body has been, and continues to be, parceled into discrete parts and how this has been manifest in law. What was your inspiration for this work?

Donna Dickenson (DD): I started writing about eggs and sperm back in the 1990s, and at that point in the UK we were going through a number of consultations on the reimbursements. For egg donation, it was set at £15 now it's £750 - so it shows you how much things have changed. And I was taken with the idea that in a way, eggs and sperm are *not* our property. They are only *lent*, in a way as they are passed on to future generations. This is true for many other technologies, which we're now looking at, like human engineering and so forth. But it was these questions about the effects on future generations that interested me. I was also just interested in the disparity. At that point, men were being paid £15 for sperm donation, a very minimal amount. Women were not being paid anything, and were in fact not being repaid expenses, so they were in effect, paying to donate. And that didn't seem right. I wasn't at all convinced - I'm still not at all convinced that the road we've gone down in the UK is right either.

So that's how it started. But as you know, Body Shopping actually goes well beyond gametes and includes issues like private umbilical cord blood banking, which I think is another form of commercialization. It doesn't include surrogacy, but surrogacy will be included in a second edition of my Property in the Body book, which includes quite a wide range of other topics as well.

AC: What challenges did you face when you started doing this work, and which ones are you still working to overcome?

**DD:** I think one obstacle that you always encounter in bioethics is that people question the importance of the field, assuming that bioethics is not needed. You get the Steven Pinker phenomenon – that we had this summer – with his claim that there is one moral imperative for bioethicists: to get out of the way. I don't believe that this is true, and this claim relies on the assumption that science, whatever science can do, it should do.

There have been technologies in the last twenty years that bioethicists were told to stand back and simply let happen. The most obvious one was the stem-cell fraud of Hwang Woo-suk, a Korean professor who claimed to have created individual personalized stem cell lines. As you know, that was a

fraud, he hadn't in fact done so. At the time, a few of us were waving our arms around and saying, "Okay, we know that the technique that you're talking about, somatic cell nuclear transfer, requires human eggs. We also know that a similar technique, which was used to create Dolly the sheep, required huge numbers of sheep eggs to produce one Dolly. Something like 400." We knew that the figures he was quoting – of a very small number of egg donors to produce eleven cell lines – just couldn't be right. But nobody really wanted to know. Eventually, through a number of journalists' work, and a number of feminist groups' work, it did become known. And then there was a mad rush in the other direction.

The obstacle is that there's always that pressure not to say anything. Sometimes that pressure can be exerted on you from quite powerful forces. both commercial and university. Sometimes it can just be other bioethicists. Sometimes it can be scientists. I very rarely find that clinicians want us to step out of the way. I've worked with a lot of clinicians, and unless you're going to come in and tell them what to do (which is not how you go about working with clinicians), then usually they are also people with moral sensibilities. They like discussing these issues.

Our job then, is to help elucidate bioethical issues. It might be that we can provide legal advice or provide some facts that maybe they don't know. In the area of body shopping, that does happen quite a lot because of the ambivalent position of the body in the common law. People don't always know that, they think you own your body. Sometimes we can provide right answers. Mostly our job is to help elucidate and sometimes it is to say "slow down" or "let's talk this through." And it may be that we will decide that science should proceed. But to just say that bioethicists should get out of the way totally abdicates our responsibility.

AC: The commercialization of the body has changed a lot since you started working in the field, and as you just described, it continues to change. What do you think are the major developments in the commercialization of the body in the last decade or so since *Body Shopping* was first published?

**DD:** There have been major developments in both directions in favor of commodification and against commodification.

I think the main development against commodification has been the Myriad Genetics case on patenting of the human genome, which was contested all the way from district court to Supreme Court in the US. And while it doesn't directly affect Canadian jurisprudence, or English jurisprudence (because we're both common-law jurisdictions), I think that the principles would hold. This has put a major brake on the phenomenon [of gene patenting], which was galloping along. In 2005, one in five human genes was the subject of a private patent. People always find this difficult to believe. They say, "You mean the genetic test was the subject of the patent," and I say, "No, the gene itself was the subject of the patent." Meaning that no

one could invent around it unless they had a license from the patent holder, which is rarely going to be of any interest of the patent holder to grant. When the Myriad Genetics case was decided, basically it overthrew 31/32 of the patents that were held on this particular breast cancer gene, well, two genes (BRCA1 and BRCA2). This then set a precedent for all of those other private patents. While some of them still hold - because it may take individual actions to overturn them - the decision in Myriad Genetics will be a deterrent, at the very least, for other companies or universities or researchers from taking out more patents. And it will probably result in patents being scaled back. So I think that's a really major development.

On the other side. I think we have had more commodification of surrogacy. We have had more commodification of eggs and sperm, particularly eggs. We've had the development of quite a differentiated market in eggs. differentiated by phenotype. You know what the stereotypes are: tall, blonde, musical, athletic, intelligent students. This is now being carried out on a global scale. You have advertisements in American college newspapers calling on young women to travel abroad. The one I like best – I don't know about best – but one really striking one is an advertisement that appeared in a US college newspaper that exclaimed, "Girls! Sell your eggs and enjoy the nightlife of Chennai!" When you've been going through ovarian hyperstimulation, you're not going to be in any mood to enjoy any nightlife. And it's trivializing of the time that goes into egg provision: sixty hours or so of ovarian stimulation that must be put in before you can "harvest" eggs. Not to mention the risks, which are quite major. I'm concerned about those developments.

**AC:** I think that one of the most important insights that your recent work has offered, at least for me, are the complex ways that neoliberal capitalism and the use of biotechnologies speak to one another. And I know that you recommend state regulation of biotechnologies as a means to guard against corporate ownership of the body and its tissues. What countries and laws are doing a good job of regulating this field?

**DD:** Just to take you back a minute, I'm not saying that we *should* always regulate but I'm saying that the possibility should always be on the table. The neoliberal approach would be to say the possibility should rarely be on the table. The presumption should be against regulation. And I'm saying the opposite. The presumption should be in favor, because these are matters that affect the common good. And therefore there is a job for government here.

As to countries that are doing it well... I think Thailand was very interesting. There was a scandal in the previous year involving a surrogate pregnancy where the commissioning couple were paying extra for twins, and one of the twins had Down syndrome. The commissioning couple withdrew the extra payment for the second twin. They refused to take him. The birth mother took care of him, but she was not compensated for it. This case

demonstrated very clearly that surrogacy is about the sale of a child, and not about the pregnancy. The commissioning couple was willing to pay for the child who wasn't, as they saw it, "damaged goods." And that, to me, shows that it is baby selling, which is my view of it. Thailand has now passed legislation against commercial surrogacy, particularly against international commercial surrogacy, which had been quite a busy business there. They passed this law, which I think is actually pretty brave, given the momentum that has been going in favour of commercial surrogacy elsewhere.

France has traditionally been quite strong on regulating commercial surrogacy, on regulating egg sale, and most of the reproductive "services." However, their most recent report on private umbilical cord blood banking and public umbilical blood cord banking, to my mind, went in the wrong direction. They are strongly encouraging women to donate cord blood in the name of the patrimony, even though donating cord blood can be a hazardous procedure. So I would have said France, but I'm less certain now.

AC: If you remember, last October [2014], when Apple and Facebook announced that they'd be paying for egg freezing, claims that the technology is liberating and allows women to choose when to become mothers was repeated in the media again and again. And we also saw counter narratives that framing egg freezing in this way privileged one sort of choice over broader reproductive autonomy, that is, real, meaningful decision making about when and how to become a parent that might be enabled in other ways.

But this is an old argument - choice versus autonomy - that has been raised previously in relation to egg donation, surrogacy, genetic testing, and a wide variety of other biotechnologies. So we don't need to rehash the argument, but have you seen a change over the course of your career in the ways that this dichotomy – choice versus autonomy – has been presented in relation to reproductive biotechnologies?

**DD:** I think if anything, certainly in the UK, it's even *more* dominant, and it's dominant in new fields. For example, the competing narratives of choice and autonomy are apparent in discussion of the enhancement technologies, both chemical and genetic. The argument that's being made is that you have the right to be the best person you possibly can be, and the best person you can be is going to be the enhanced person. It's a very simplistic view of what makes you more autonomous. And certainly, a simplistic view of what makes further generations more autonomous. And in terms of CRISPR [a new genome-editing technology] engineering, you know, you're then talking about removing autonomy of a future generation. And yet it's presented as enhancing the autonomy of current generations.

The autonomy arguments about extending new reproductive technologies to "non-standard" families - gay couples, for example - is an autonomybased argument, but it masquerades as a family-based argument. You could see it that way, and I'm certainly not denying that the desire to have children is extremely important, and being frustrated in that desire can be really devastating. I'm certainly not denying any of that. But to see it *only* in terms of the autonomy of the commissioning couple and not the autonomy of the surrogate, and to end the discussion of the autonomy of the surrogate with the argument that she chose to do it, is really just not good enough.

What you need is a more evolved analysis of the possibility of exploitation. And I have tried to do that with some of my recent work. Whereas exploitation is viewed as a propaganda term, choice is viewed as a factual term. Now to my mind, it's the other way around. I think choice is a propaganda term. I think the argument that whatever we do we have *chosen* to do is probably false, and it is bad philosophy. We need to develop an analysis of some counter terms, such as exploitation. Relational autonomy is another, which feminism in the early 1990s was certainly very interested in developing, particularly in relation to surrogacy, and that's fine. I think we face so much pressure to accept the choice argument, and I don't think that has gone away.

If anything, it is important to consider that we do have neoliberal governments in many Western countries, certainly in England. Notice that I do not say the UK because Scotland doesn't (well done Scotland), but England and Wales most certainly do. And Canada. I think there have been political pressures as well that have ratified and strengthened the neoliberal doctrines about choice, and I think you know it's a more difficult road to hoe for young scholars and I hope people will do that.

**AC:** You mentioned that you're working on a new edition of *Property in the* Body that will include work on surrogacy, which I am personally excited about. Can you speak more to the things that are coming up next for you and the kinds of technologies and interventions that you're thinking about?

**DD:** I also wrote a book two years ago called *Me Medicine vs. We Medicine* [Dickenson, 2013]. I'm still doing quite a lot of work in that area. It's about personalized medicine, which is sometimes called "stratified medicine" or "precision medicine." I thought all medicine was precision medicine, but I guess not. The idea, then, is that what is "personalized medicine" very much depends on the discourses of autonomy and choice, using those terms as favourable, and the idea that personalizing medicine involves more choice over what drugs you would use or what treatments you would have based on your own genetic profile, your individual genetic profile.

You can see the same common threads among various technologies, such as private umbilical cord blood banking, which I have dealt with in Body Shopping and Property in the Body. I also dealt with this in Me Medicine because that is a personalized technology, but personalized for the baby. So

<sup>&</sup>lt;sup>1</sup> This interview took place in October 2015, just prior to the election of Justin Trudeau's Liberal

umbilical cord blood collection is sold on the basis of being uniquely personalized, the cord blood is personalized to the baby's own genetic profile. So some of those areas are the same.

I also wanted to move into a discussion about the commons, genetic commons, and the idea of the commons in biotechnology. Some of that has already been done by other scholars, for example in James Boyle's *Shamans*, Software, and Spleens [1996] which draws a parallel between the enclosure of the commons in England and the clearances in Scotland to the modern enclosure of the genetic commons through the kinds of patents that we were talking about earlier. I think that's a really powerful metaphor, but I think that it's also interesting that we have seen movement towards a charitable trust model, like the one which has been developed by David Winickoff at Berkeley, to treat research subjects as if they were the commoners really, as if they had certain rights in the resource of the research and the work of any biobanks. And beyond that, to give them rights similar to those that would be held by the trustees of a charitable trust. And he, Winickoff, has worked out quite specific rights, what those would be, and they're very practical. I think it's nice that we've got some development against the mentality of individualism in terms of broadening who stands to benefit from the genetic commons, which differs from this rather amorphous idea that well, science will automatically benefit humanity.

It is important to consider exactly how, exactly who, and exactly when benefits will accrue. The people who are contributing research materials, they might not necessarily want or deserve financial remuneration, but they might still have some other rights. For example, they might have the right to control some uses of the tissue, so that people can object to their being used for cosmetics, or other purposes that they see as trivial. I think I wanted to expand on these ideas in Me Medicine to look more at the commons, and I did do that in the final chapter. And I brought in the idea of "we medicine," that is, medicine like public health medicine or vaccinations that have a public benefit in mind rather than personal private medicine. And I'm still working in that area. It seems to be an encouraging sort of area, an important sort of area.

AC: This may be a selfish question, but I think that it's always useful to know when you're talking to senior scholars in the field, what pieces of advice you wished you had when you were starting out. What advice would you give to young scholars working in bioethics and on biotechnologies?

**DD:** I was very lucky in that I was working at Imperial College School of Medicine, I had a number of colleagues who were keen to work with ethicists. I was also sort of the clinical ethics person at a psychiatric hospital in Oxford, and I was able to work with a lot of clinicians there. And I've worked with a number of reproductive medicine clinicians and other contacts. I've always found clinicians to be generous with their time and their

knowledge. At that point, I don't think I knew very much about medicine. But they were willing to tell me what I should be reading and I did go out and read it and we worked together. And anything that I got wrong, they would put me right, which is what you want. I think clinicians find it really annoying when philosophers come in and start throwing their weight around without knowing their medicine, and rightly so. I think you should know as much you can about the subject you're collaborating with the clinician on.

When I was collaborating with a renal surgeon on a transplant committee at St. Mary's in London, we had a decision to make on the clinical ethics committee there about hand transplants. We were asked to approve the first human hand transplant. I didn't know anything about hand transplants, so there was a very quick learning curve there. But my colleague, the renal surgeon, was very helpful. We were able to make an informed decision, which was to go beyond the autonomy of the patient. He turned out actually to have mental health issues. We asked for a psychiatric referral, the team decided to go elsewhere, someplace that wasn't going to be quite so demanding, although where they finally went they had an ethics committee and went through the proper procedures.

So, I would advise to really use clinicians' knowledge, and to collaborate with as many clinicians as you can. I also think that this helps you to get around the problem we were talking about earlier, which is the idea that bioethicists should just get out of the way. If you don't know your medicine, then you'll be much more vulnerable to that argument. If you do know your medicine, then there may be cases when you can actually say, as some of us feminist scholars did [...] "look, we've read the Dolly papers, we know how many ova that took, we know it took 400 initially and then after enucleation, it took 267, and you produced one Dolly. And your technology is so similar, even though you're not cloning an individual, but nevertheless using the same technology to clone a cell line." And when you can make that sort of argument, then you're on much stronger ground. So you need to know your philosophy, law, and clinical or research medicine.

AC: This is my last question. We're here at the Social Justice Research Institute at Brock University, and your work has really been about social justice in a number of ways. So if your work could lead to one concrete social justice intervention or outcome, what would you like that to be?

**DD:** Wow. That's a very tough one....

**AC:** You can have two...

**DD:** Can I have big one and a slightly smaller one?

I would like to see this idea of the commons get more traction. That's the slightly smaller one.

And I would like to see the idea of the bundle concept in property used more. That is, in the common law, as you know, we have the notion that property is not unitary. Property is a bundle of rights: the right to own an object, to manage the use of an object, to perhaps derive income from an object, to prevent others from access to the object. These are separate rights.

We can see these differentiated rights, for example, in the case of the vote. I have the right to manage my vote, which you could construe as the right to give my vote to the candidate I please. But I do not have the right to sell my vote, and I don't even have the right to give it to another person. So, property in our law is differentiated.

Now, I'm very keen to use the concept of property as a differentiated bundle in order to prevent incursions by biotechnology companies, or researchers, such as the patent rush that we were talking about before. Sometimes when I say that we might try viewing the genome as property, people claim that doing so would be commercializing it. And to that I say, step back, thinking about the genome as property could be a means to prevent commercialization. For example, you could say that a private company might have the right to work on a gene, but not necessarily a right to all the revenue from any invention deriving from it; rather, perhaps there should be benefit sharing. Some of it might go to the group that has been the research subject. And we've seen that with something like the PXE group where a particular gene was patented and the group whose children have this gene have worked in collaboration with a biotech firm (I'm not against biotech firms as such). And what they've developed is a really good model because the biotech firm comes in and sponsors further research with the profits, so a certain percentage of the profits have to go to further research on PXE. Of course then, they get the benefit of the cooperation with the patient group and the access to research subjects and biobanks. So, it seems to me you could have a really good collaboration in many areas. We don't have to be looking at regulating with an iron hand all the time. We could be looking at encouraging collaborations and I think we can do that if we bear in mind that we have an advantage in our law in that property is not unitary. It's more unitary in the civil law jurisdictions, but even they have ways around it. But in common law jurisdictions we have this resource of property as a bundle. And I would really like to see us use it more.

**AC:** Thank you so much for speaking with me today.

**DD:** Thank you for having me.

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