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2. ON UNFAMILIAR MORAL TERRITORY ABOUT VARIANT EMBODIMENT, ENHANCEMENT AND NORMATIVITY

Interview with Jackie Leach Scully

Christoph Rehmann-Sutter: One of the recurrent topics in your work is the philosophical and ethical trouble that arises from the fact that we humans have bodies that vary to quite astonishing degrees, and at the same time we live within a culture that neglects this variability and instead cherishes an ideal of a human body. The body is mainstreamed by certain norms that we can talk about and that is important to reflect on because, as I understand you, enhancement as a biotechnological idea and strategy could not be understood without knowing about these normalization mechanisms. But before we go into the details of these mechanisms and their implications for ethics, I'd like to ask you why you see this as a problem at all. Is it not something that happens in every known society: that it has its ideals of a good or even better human body, one way or the other? People want these ideals as something to strive for in the way they work at their appearance. Look at beauty contests, the fashion business.

Jackie Leach Scully: Of course it's true that all cultures seem to have an idea of what kinds of body there ought to be, if I can put it like that. But I would be a lot more cautious about saying that all cultures, past and present, have the same *sort* of idea about it. I think we can very easily acknowledge that people in other societies might have, or have had, notions about physical beauty or desirability that are quite alien. What may be harder to grasp is that in other societies, the very concept of a physical ideal might have significantly different parameters: for instance it might come with weightings of obligation, pride, desire and so on that are quite unfamiliar to us, in our culture and our time.

CRS: Can you give an example?

JLS: I'm thinking here, for instance, of the way in which pre-modern European cultures seem to have been intensely oriented towards a sense that 'rightness' in the way a person lived was demonstrated through their place in the social structure, and also their place within a religious or spiritual structure, rather than through achievement of a physical ideal. I'm not of course suggesting that the medieval world didn't have physical ideals, but that the investment in them may have been more diffuse. Or to give a more contentious example: the extremely racialized bodily ideal of National Socialism; here, the body had an overtly political significance unlike anything we are used to today.

Clearly people do seem to accept (I'd hesitate to say 'want') that these bodily ideals are present and powerfully active in society. And of course, up to a point having something like this to aspire to is a positive thing: you'd have to be a real curmudgeon to argue that taking pleasure in one's appearance, at least to an extent, is something to be disapproved of! The important thing to hold onto, though, is that sense of 'to an extent': I'm suggesting there is a point beyond which an interest in one's appearance becomes disproportionate. It turns into vanity, which is an old fashioned and little used term, but one that I think is salient here.

So one problem, probably the one I'm most concerned about, is not that people have these interests and aspirations, but that they get out of hand. This is exacerbated when practical technologies become available for modifying/enhancing bodies, and those technologies are then directly and indirectly driven by powerful commercial forces. And on the whole, commercial forces are highly conservative: for obvious reasons, they have strong interests in ensuring that people end up wanting what they, the producers of body-modifying technologies of all kinds, can provide.

CRS: I know the topic of beauty remains a bit superficial philosophically, when we start from the fashion business, but it is still an evident social phenomenon that plays a big role in the lives of many people. What's the deeper meaning of beauty in your view?

JLS: I wouldn't want to describe 'beauty' in itself as superficial – after all, it's long been a legitimate topic for philosophers and artists, as well as fashion designers and engineers and scientists! And as you say, wanting to look beautiful or fashionable is a social phenomenon we can't ignore. It's also very complex: as I've mentioned already, there are social scientific questions to be asked about what constitutes beauty, how people know about that, how much deviation from the ideal will be tolerated, what are the normative limits of aspiring to our ideal, and so on. For me, the ethical issues are strongly tied up with the power of these social forces. I don't think that someone paying £10,000 to have their eyebags cut away is doing a grave moral wrong (though I would say they are doing *some* moral wrong, given that an investment of £10,000 could benefit a lot of people, for much longer than a facelift lasts, in poorer parts of the world). I have more serious questions about the moral culpability of the medical professionals, the media, advertising, and so on who put their lives to the service of convincing a person that the path to happiness is to have his eyes done.

CRS: When you say the beauty of the body is a social phenomenon, what does that imply? There are norms involved, quite obviously. But there is also something else. Beauty is dependent on the kind of relationship. Somebody can find me beautiful, regardless of the norm I am fulfilling or not fulfilling. Other people would certainly find me unattractive. And this also happens to people with so-called disabilities. What I want to suggest is that beauty, attractiveness, as well as feelings of shame or pride, must somehow have to do with the sociality of our bodies – or the embodiment of our relationships. Is there an ethics within this? What is going on when somebody finds somebody else beautiful?

JLS: What we find beautiful, or even what we find normal, ugly, repellent, and so on, is a social but also a social-psychological and psychological phenomenon – and in many contexts a political one. To come anywhere near answering the question 'what is going on when we find another body beautiful?' would involve exploring all those domains, I think. Clearly there is something about fulfilling or not fulfilling norms that is, in a sense, superficial, because it can become irrelevant when set in the context of a particular relationship. ('She may not have been conventionally attractive, but she was beautiful to me' – that kind of thing.) I think you are right that what we experience aesthetically, if you like, is an embodied relationality. Where there is virtually no relationship to speak of, then perception is probably

more ‘objective’ in certain senses. There are some interesting points to explore here about the way in which our perception of deviations from a physical norm can be heightened or minimized, depending on our relationship to the person involved – that, psychoanalytically, our relationship is with an internal representation that reflects the ‘reality’ more or less well. I think that can actually take us somewhere quite ethically uncomfortable, if what it means is that in order to find a physically anomalous person acceptable, we unconsciously stop seeing the full extent of their unusual morphology. But that may be something that the human psychology of perception just does. The social aspects of physical norms and ideals (that is who gets to set them, how rigidly they are policed, and what sort of political and commercial interests underpin them) are more troubling because they are, in principle at least, contingent and open to change if they are ethically problematic. In which case, we have to acknowledge a moral responsibility to change them.

CRS: In your book ‘Disability Bioethics’ you write that we can ‘think through the variant body’. Can you explain the basic idea in this?

JLS: In that book I was using the idea to cover several slightly different ways in which we can usefully re-position the body in processes of ethical, and other, thinking. Perhaps the easiest or most trivial one is simply to take the body more seriously as the arena where moral good and moral harm are played out. It’s become almost a reflex today to criticize moral philosophy for being somehow disembodied – that in trying to make universal claims, its tendency is always to move away from the specifics of body and social embeddedness as rapidly as possible. This has become an almost boring point to make, and I think those of us who argue it tend to forget just how much ground there is still to be made up. To put this more concretely, medical and clinical ethics have always tended to prioritize instances of major decision making as being ‘real’ ethical issues and have paid less attention to the ethics of everyday interactions between particular bodies in a healthcare setting. The latter are a good deal less dramatic – courtesies of touch and recognition, for example, not mercy killing or abortion! But they are also harder, in the sense that they aren’t easily placed within existing ethical frameworks.

Another meaning of ‘thinking through the body’, which I elaborated in more detail, is to do with what the body means for how people think. Again, it’s a bit of a caricature, but there is a sense in which the model of the brain as the location of thinking so dominates our picture of ourselves that the bit below the skull becomes almost superfluous: a handy way of shifting the brain from place to place, and funnelling information about the world to the neurons, but not good for much else. Part of that is true: you don’t do a lot of higher order cognition with your little finger alone. But equally, it’s important not to lose sight of the way in which the higher processes of the brain (‘thinking’) are embedded within physiological systems that don’t just *influence* a function like perception: in a very real sense they are what *make perception happen*. And those physiological systems are distributed around the body (and also beyond it, once we take into account the effects that implements and technologies have on how the body interacts with the non-self world).

I started to puzzle about this really because of the observation that sometimes, people with the kind of variant body that we called disabled could hold ethical opinions that were different from those held by standard model, or non-disabled people. I want to be careful here to say

that it wasn't that these opinions were radically distinctive or ubiquitous, but that in certain cases there were quite marked differences in priorities, values and judgments. I felt it was too easy to respond dismissively with 'oh, they would say that in their position', or slightly more positively with 'their experiences have led them to think that'. I wanted to join the dots a bit more fully: what, exactly, is it about experience that leads people to think differently? In what way does the experience, as it were, get inside someone's head? (And there of course I am doing precisely what I've just criticized philosophy for doing, that is arguing as if all the thinking goes on between a person's ears!) Clearly this is a general point about epistemology and ethics. I was interested in disentangling the different ways in which a disabled person's distinctive embodied experience – distinctive because she has a variant and not a standard body – could be part of her ethical perception and judgment.

In the end I drew on a cross-disciplinary set of ideas, ranging from the phenomenology of Merleau-Ponty and others, through work in cognitive neuroscience on embodied and distributed cognition, to the anthropologist Pierre Bourdieu's writing about habitus. All of these are struggling with approximately the same question: how does who you are, physically and socially, affect how you think? It's an extraordinarily difficult area because we lack the analytical methodologies and techniques needed to join those dots; we can only come at the question indirectly.

CRS: I understand that this set of ideas originates from your work about disability. When we now consider biomedical interventions, such as genetic ones, which are usually classified as 'enhancements' (in the sense that they go beyond restoring some dysfunction or loss of function), what are the implications of thinking through the body?

JLS: The implication would be that such interventions, by changing the nature of the body and therefore modifying its interaction with the world, could change the way in which that person thought. I'm not being specific here about how thinking might change, or how much; as I've just indicated, there is very little useful data to support claims of that order. And if any differences are subtle, how would they be detected? This would be a particular feature for genetic enhancements which, if they were germline modifications, or were introduced in utero or very early in life, would then be that individual's norm. The effects of interventions later in the individual's life, or of non-genetic enhancements – pharmacological, sensory, involving a prosthesis and so on -- might be easier to track. But still there would remain the issue of knowing what sort of effect to look for, and where.

I realise this description makes ethical perception and judgment sound more mechanistic than I would want to. And I'd also want to say that I'm not assuming that altered thinking through a variant body as a result of biomedical intervention is necessarily something to be deplored or feared. I *am* saying it's an area worth exploring, particularly because it could mean that enhancements come with a cost (physical, cognitive, emotional, social) to the individual. Much of the ethics of enhancement so far has worked from the premise that, as long as the technology doesn't inadvertently harm the individual, then by definition an enhancement must benefit *her* even if there are ethical costs to society, for example through the distortion of healthcare provision, through increased expectations or by exacerbating social divisions. But if enhanced bodies have more diverse effects on the individual than straightforwardly improving a function, then there are also likely to be ethical costs to the

individual – and that would change the balance when weighing up harms and benefits of the intervention.

CRS: This is a very important concern, which is rarely seen in ethical discussions of enhancement technologies. We normally just take for granted that people with improved bodies would make their ethical judgments in the same way that we, the non-improved humans, make them when we evaluate what will be an improvement and what would be harmful or risky. If I understand you correctly, you hold that the improvement of body functions, such as amplification of cognitive power, or postponing the process of aging, could possibly affect the moral world of these individuals. This follows from your reading of Merleau-Ponty and other phenomenologists. And because we cannot foresee in what way an enhanced person's ethical perception and judgment will change, we, the non-affected, therefore cannot make a reliable moral assessment of the value of such a change for them. Hence, improvement must be conceptualized in a radically perspectival way. It matters for whom something is supposed to be an improvement, because their bodies may differ. And in regard to plans to change embodiment 'for the better' we cannot foresee how those affected will in fact evaluate the changes in their bodies, and whether they will indeed be betterments for them. This makes an ethical assessment of enhancement technologies quite difficult, if not impossible. And those who 'live' the change don't know how it would be to live as another embodiment. For them it is just the norm, as you say. They will adapt to their embodiment.

There are some difficult questions in that. The first one is obvious: How should we, as non-altered people, judge that the different moral perception and judgment of a person with altered embodiment is in any way worse or deficient? It will be just different from ours. What right do we have to say that their adapted moral perception, or their feeling of being 'right' as they are, is problematic?

JLS: That is simultaneously a very trivial and a very profound question! You're right in the sense that if the moral perception or judgment of a person with a variant embodiment is in some way different from ours, there is no a priori reason to evaluate it as a worse or less adequate judgment than ours. It is, as you say, just different. But in reality, there are many situations in which we don't simply stand back from those judgments and say, well OK, your viewpoint is just different. We make evaluations of different perspectives: are they reasonable? Are they coherent with other stances and values? Are they something we can tolerate under the broad umbrella of whatever a modern, democratic and pluralist society can live with? Or do they just go too far? And why are these areas of judgments, specifically, and not others, under scrutiny as to their acceptability?

From that point of view, such questions feed into a very large debate about the parameters of shared moral understandings in societies that are increasingly socially, ethnically and culturally diverse, and where alternative moral understandings to the mainstream ones are becoming more prominent – one might say, gaining in political and moral confidence. So on a theoretical level these debates are far from new. What *is* new is the possibility that, as well as different moral understandings arising out of distinctive cultural, religious or ethnic milieus – the sort of groupings that have long been considered to constitute discrete individual and political identities – they may also be generated by more contested sites of difference to do

with the body and embodied experience. The question then becomes, how do we identify and evaluate these judgments?

In this context it is important to understand, as far as is possible, what particular acts and practices mean for different groups, and not to assume that meanings can be extrapolated in a facile way from one group to another. To return to the example that I have been looking at, on and off, for some years: when signing Deaf people indicate that they might, conceivably, wish to use assisted reproductive technologies to ‘select for’ deaf children (or at least not to select against them), we need to have a view of the full context within which such an evaluation might be made – the context of a flourishing signing Deaf community, for example – in order to tell whether that decision is in itself consistent with the prioritization of the child’s welfare or not. Deaf and hearing people will not disagree with each other about whether a child’s welfare should take priority. But where they may differ (and this is what is affected most strongly by their differently embodied experiences) is how ‘the good of the child’ may be acted out. As a result, the Deaf community can see a preference for a deaf child, or at least the absence of a preference for a hearing child, as fully in line with the desire to protect the best interests of the child, the parents, and the community as a whole; where the hearing world are likely to perceive this choice as actually harming the child’s best interests.

Ultimately this means I think that acquiring baseline empirical knowledge becomes an ethical requirement. To understand whether a ‘different’ moral evaluation is ‘different but understandable’ or whether it means ‘this is beyond the limits of what is comprehensible within the common moral framework’, we need to have a clearer knowledge of what various bioethical decisions actually mean to different actors in different contexts.

CRS: Even if we agree with your argument about variant embodiment in principle, aren’t there nonetheless some differences to take into account? Obviously not all body changes will be equivalent. Can we differentiate between ethically neutral and possible non-neutral body changes with regard to changes in moral perception? One that could fall under the ‘neutral’ category and will probably – but yes, that is still a question – not change ethical thinking of the person concerned, could be the improvement of resistance to diseases. If we could add some extra genes to our children that make them considerably less susceptible to cancer throughout their lives, much less than today’s average cancer susceptibility, this would count as an enhancement. Their bodies would be stronger, more resilient. But the changes would not alter everyday life. But if somebody were to get a neuro-implant that enabled her to instantly memorize everything that she reads, it would affect everyday life, and very likely also ethical judgment. This would be an example of a non-neutral body change that may affect moral perception.

JLS: That’s an interesting question. Of course, not all body changes are equivalent in any sense, and certainly not in the sense of affecting moral perception. I’m interested by the example of the ‘neutral’ category that you give, though, because in fact one can imagine this actually having profound non-neutral consequences for moral understanding. For instance, improved resistance to disease might have the consequence of making people feel less empathy with those who do still show vulnerability to disease. It’s quite imaginable that in such a case, the enhanced person would not feel that she or he has experienced astounding privilege, but rather that people still subject to cancer or other kinds of disease are just weak,

repellent, to be shunned. (It would be nice to imagine that kind of constitutional superiority going hand in hand with increased compassion and sense of gratitude for the luck one has experienced, but unfortunately social-historical precedents don't give much cause for optimism here.) So in a sense, this kind of enhancement would actually have very profound impacts on areas of everyday life that don't have anything to do, directly, with cancer.

I agree that the neuro-implant case would have more immediate and direct consequences for everyday interactions, with animate and inanimate others, that inform subjectivity. I'm not sure, though, that the situation you describe would necessarily give rise to much more radical changes in moral perception or judgment than having significantly enhanced disease resistance.

One of the messages of 'Disability Bioethics' was about how bad we are, collectively, at predicting what the significant consequences of a new technology are going to be. In that book I was thinking specifically about predicting what were the likely consequences of a disabled embodiment on moral understanding, and also the possible consequences of a biomedical intervention or assistive technology on the life of a disabled person. However, the idea can be applied more generally than that; and the conclusion, more generally, must be that there is an absolute necessity for empirical and experiential research into the real effects of such modifications. We can make all the predictions in advance that we like, but a growing track record of experience with a range of new social technologies suggests that the real changes, problems and challenges are likely to be both more mundane than expected, and unpredictable. In the face of that kind of dilemma we need to swallow a large dose of epistemic humility, and explore the empirical reality of embodied moral understanding.

CRS: Let me ask you one key philosophical question, just to clarify how we think: Do you suggest that we should believe in a form of embodied relativism? Or are there still reasons to believe that some basic ethical concerns, for instance the ideas of injustice, discrimination, or exploitation, must be universal, regardless of the kind of bodies we have? – In an enhancement world we could end up in a situation like Deckard in Ridley Scott's movie 'Blade Runner', who falls in love with a replicant but is supposed to hunt her down and kill her. The language of the emotions clearly tells him that this would be a bloody form of discrimination, regardless of her ontological status as artificial. You just need to replace 'replicants' with 'improveds', and you can pose the same question. Don't we have strong reasons to defend a universalist approach when it comes to oppression?

JLS: I'm quite sure I'm neither advocating nor diagnosing the kind of relativism you are indicating here, embodied or otherwise. First, there are some very basic ethical concerns and concepts that are clearly shared within many societies, and may well be universal: these are things of the order you mention, such as a concept of (and rejection of) injustice, the idea of discrimination, giving special weight to the welfare of children, protecting the vulnerable, and so on. The important point here is that although the outlines of these concepts are shared, ideas about how they are operationalized – that is, what acts and choices constitute discrimination, against whom, and so on – may not be. That level of idea works much more, I think, on the level of moral intuitions that are acquired through socialization processes of various kinds, within the family, school, and wider community.

In ‘Disability Bioethics’ I was suggesting that a person’s embodiment might contribute in a variety of ways to the formation of their moral intuitions. I considered that this might happen in terms of the *kinds of experiences* they had: that some might be distinctive, or have distinctive features, as a result of having a particular embodiment. An obvious example here would be pregnancy as a function of gendered embodiment, but there would be others that derive from having a disabled embodiment – having a prosthesis fitted, for example. These sorts of differences are fairly easy to see. Less obvious perhaps is the possible contribution of embodiment to the *meaning people make* of experiences, even ones that are shared. For example, that the meaning of testing for anomalies during pregnancy might be different for a disabled than for a non-disabled woman. I don’t suggest here that the moral meanings of this experience would necessarily be absolutely different for a disabled woman, and certainly not that a disabled woman’s moral understandings in general would be radically unlike those of a non-disabled woman. It was simply the claim that such embodied experiences generate a sense of what is obviously right or obviously wrong, the intuitive responses that people will then go on and produce better or worse justifications for, if pushed.

So I was making what I think is the fairly uncontentious claim that, within a framework of basic ethical values and beliefs that is generalizable across a society, and may even be universalizable across all societies, there are differences in how those values and beliefs are considered to be lived out; and that it’s within this kind of moral register that disabled or enhanced embodiment may make a difference. It’s less of a normative argument about relativism or universalism than a hypothesis about where differences in moral intuitions might come from – and especially a pointer to the neglect of the body as a possible source of difference.

CRS: Yes, I can better see your point, and I enthusiastically agree about the importance of the body. But let me press you a bit on this. I still ask myself, how the different embodiments can matter, how they enter the moral worlds. How can we distinguish between values, which may be roughly the same across all societies, even universal, and the differences in how those values and beliefs are considered to be lived out, or the moral intuitions that different people with different bodies develop? Both are kinds of values, both are socially and culturally formed. And both are necessary in order to fight oppression and injustice. I don’t see how universal values can work without the feelings and intuitions that support them.

JLS: I think your second point is the key one here. I would agree that widespread or even global moral values, and more parochial ones, are socially and culturally formed; but clearly the register, if you can put it that way, is different. As I said before I think there are very fundamental beliefs about moral behavior that are culturally widespread: I can’t think of a culture that endorses indiscriminate killing for example, or that doesn’t hold the welfare of the child to be a good thing. Those are socially formed in the sense that the ideas of ‘indiscriminate’ and ‘killing’ and ‘child’ are social ideas. (It’s true that the concepts of killing and of the child both entail a material or biological reality, but distinguishing between killing and death, and defining when a child turns into an adult, are social moves.) I don’t want here to enter into a debate about where those very fundamental ideas come from, to what extent they are hard-wired, or are behaviors that have been selected for because they promote the survival or flourishing of individuals within groups, or because they have some metaphysical

origin. Whatever the origin of these values, they are of course held in place by the associated behaviors and intuitions. But I think they can be distinguished, albeit imperfectly, from the working-out of particular ‘good ways of being’ that embody those fundamental values in actual lives. Intuitions derived from fundamental shared moral values are what make certain practices, and not others, carry a degree of plausibility as a way for members of a society to live. It’s complicated of course, because over time as practices turn into habits and traditions, they too become part of the intuitive texture of moral life.

How different embodiments then matter is the question I tried to explore in ‘Disability Bioethics’. One of the conclusions I came to was that because there are multiple ways in which embodiment might, in principle, modulate moral evaluations, we need a similarly diverse investigative approach – examining how bodies affect social interactions (we know a bit about that), the psychological processes through which social interactions might shape consciously held moral opinions (we know rather less here) and also unconsciously held ones (almost nothing known), and how variant motor, sensory and perceptual possibilities – including those that involve assistive devices and extensions – can alter moral cognition). All of which is to say that, at the moment, people like me can devise all sorts of fancy theories about how embodiment might affect moral understanding, but don’t have much in the way of empirical data with which to test out theory!

CRS: Let us now turn to a different topic: the side effects of regulation. I am thinking of pressures that can be exerted on individuals and societies by moral or legal norms to regulate enhancement. In a paper of 2001 on human genome alteration, or ‘gene therapy’, which we both co-authored, we claimed that it is unwise to regulate this field by a rule that allows therapies and bans enhancements, if the latter category is defined on the basis of a distinction between the species-typical or normal human functioning and other functional states that are beyond, above the normal. It is unwise, we said, because it will have discriminatory side effects for those who actually live with variant bodies. Is that still today a valid criticism in your view? And could you explain how you think that argument should be made?

JLS: Things have clearly moved on since then – not least because developments in the life sciences, like work on neuropharmacology, mean that the drawing of a bright line between therapy and enhancement is considerably less plausible. Back in 2001, most of the debates around the ethics of enhancement started from the premise that we could distinguish clearly and straightforwardly between two classes of intervention. When we wrote that paper, what we were particularly concerned about was that enhancing and therapeutic interventions were being defined specifically in terms of their relationship to normality – so that therapy was restoration to the normal range of human form and functioning, while enhancement was going beyond that – and as a result we thought that if these interventions were then going to be regulated, something like a definition of human normality would begin to enter into law. And this would be virtually unprecedented, at least in terms of the scope and level of detail necessary to craft such a policy.

We also argued that it would entrench a very narrow view of human normality, and that this could be damaging to people with variant embodiment – that is, with body forms or functions that fall outside the species-typical range, some of which are identified as impairments. The harm would result from the way in which such an entrenchment ignored the

possibility that an intervention which would be considered therapeutic by non-disabled people – restoring them to a norm – might be experienced by disabled people as enhancing – as taking them beyond a state of form or functioning that is their norm. This perspective would have to be ignored, in order for the intervention to be considered a therapy and therefore be legal; but doing so would effectively be saying that disabled people’s capacities for self-definition and self-determination are not to be taken seriously. (Doing so would be depressingly in keeping with a history in which disabled people’s rights to self-determination have been systematically ignored, but historical precedent is hardly a point in its favor.)

Today we have moved to a general recognition that many biomedical or biotechnological interventions don’t fall cleanly within the categories of enhancement or therapy. There are too many cases in which interventions could both ‘take the individual beyond normal’ and ‘restore to some kind of normal’; for instance, a pharmaceutical developed to ameliorate the memory loss of dementia could also, at different dosages, enhance the capacities of someone with standard memory. If there were no differences between the two ‘therapeutic’ and ‘enhancing’ uses in terms of harmful side effects, it would be difficult to argue that one use is permissible but the other isn’t, without also arguing more generally that the statistically normal range of body forms and capacities should be normative. There are ways of arguing for this, of course, but I think it’s clear that neither they, nor the transhumanists’ arguments in favor of a much more liberal line on the transformability of the human body, are universally compelling at the moment. If they were we wouldn’t still be debating them so much.

One thing it is important to keep in mind (and is sometimes hard to remember for those of us who spend so much time discussing these issues) is that we are, socially and culturally, on unfamiliar moral territory here. Until very recently, individuals or societies have had few means available to control the kinds of bodies that they or others have. Societies have always had opinions about how much physical or behavioral variation is tolerable, and what constitutes an impairment, but actually enforcing those opinions has been restricted to crude methods, like infanticide or the social ostracism of disabled people, which over time have become increasingly unacceptable. What we have now is a situation of growing technical ability to select for the phenotypes we want by prenatal, preimplantation or preconception interventions, or to change the capacities of existing bodies by pharmacological, neuroprosthetic or other means. And this, I’d suggest, puts the societies that have access to those technologies in the potentially dangerous position of being able to act on historical assumptions and prejudices about bodily variation that have never really been subjected to proper scrutiny.

It’s a fascinating historical moment. These selective and manipulative technologies are coming onstream in a social and political context which in some ways is more accepting than ever before of diversity in general, and of disabled people, and where disabled people are beginning to have a global political voice as well. Yet at the same time, as we discussed earlier, the cultural context is one in which the pressure to conform to particular standards of physical appearance and behavior is mediated through extraordinarily effective commercial, governmental and bureaucratic agencies. Future forms of bodies, and the kinds of lives that can be lived by them, will be determined by the bioethical deliberations going on today, because they will lead to policy decisions and to the creation of a cultural atmosphere that is more or less hospitable to diversity; and that’s why it’s so important that we engage in these deliberations with care.

The interview was conducted via email in 2012. Jackie Leach Scully refers to her book *Disability Bioethics. Moral Bodies, Moral Difference*, which appeared in 2008 in Lanham from Rowman & Littlefield. The article by Scully and Rehmann-Sutter mentioned is “When Norms Normalize. The Case of Genetic Enhancement” (*Human Gene Therapy* 12, 2001, pp. 87-96. In 2002, Scully’s Swarthmore Lecture appeared as a book entitled *Playing in the presence: genetics, ethics and spirituality* (at Quaker Books, London).