

Baylis Interview Transcript:

Russell: Hi, I'm **Camisha Russell**, Assistant Professor of Philosophy at the University of Oregon and Co-Editor in Chief of *Hypatia*. I'm joined by **Caroline Lundquist**, University of Oregon Ethics Instructor and Co-Managing Editor of *Hypatia*.

Our guest, **Françoise Baylis**, joins us today as the 2020-21 Wayne Morse Chair, which would normally have put her in residence here at the University of Oregon. Dr. Baylis is a bioethicist and university research professor at Dalhousie University, Nova Scotia. A philosopher whose innovative research in bioethics lies at the intersection of policy and practice, she challenges readers to think broadly and deeply about the direction of health, science and biotechnology. Her work aims to move the limits of mainstream bioethics and develop more effective ways to understand and tackle public policy challenge. These goals are nowhere more evident than in her 2019 book, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing*, published by Harvard University Press. It is on this book that we will be focusing today.

Welcome, Dr. Baylis.

Baylis: Hello.

Russell: For the sake of the audience, who might not have read this book – yet – could you take a moment to describe what this book is about and why you wrote it? And, within that, I would love to hear you say a bit about the decision to write such a publicly accessible text and how you went about it?

Baylis: I've been working my whole career on issues to do with the manipulation of the human embryo. In fact, that's what my thesis was on many, many years ago. And I've actually just kind of followed the different technologies, over time, that have involved manipulating the human embryo. So not surprisingly, I've worked on issues to do with in-vitro fertilization, pre-implantation genetic diagnosis, human cloning, stem cell research. And lo and behold, one day comes along the technology of CRISPR. And so just in terms of it being sort of within the purview of the kind of work I was already doing, it was one of the technologies that came along. But that didn't mean I had to write a book about it. I don't think that I would have done that honestly, but for the fact that I was named in 2015 to the organizing committee for the first international summit on human genome editing and that whole experience raised a number of additional questions for me in terms of how power moves in this arena. And I think it was just really explicit in that context. So, I do recall that when I was first asked if I would become a member of that committee I said, "Is this going to be another Asilomar?" and I sort of had the thought that maybe that wasn't something that I was well suited to participate in. And I was assured that this would be different, that the public was going to be involved, it's going to be an open meeting, and not just open to the public, but open to the media. And that there really was this desire to bring to the fore a number of important ethical questions with respect to this controversial science.

Now just to remind everybody, the controversial science at that time was that a Chinese researcher had taken a human embryo, what was called a non-viable human embryo, meaning that it could not, even if transferred to a uterus, go on to become a human child. So, he had taken non-viable human embryos, manipulated them in the lab using this technology called CRISPR to make

genetic modifications, he had studied that and then had discarded the embryos. So, what you had was a basic science work but very quickly a broad community of scientists saying this was deeply problematic, it required careful reflection, and within the scientific community, the beginnings, if you will, of a little bit of polarization. Some scientists calling explicitly for a moratorium and other scientists saying we needed to proceed with prudence. And so, I was really quite interested to see from the very sort of early stages of discussion and debate about how the science might be used that we were seeing different scientists position themselves differently.

Now there's all kinds of interesting things that could be said about that in terms of why that happened and what the motivations were, and I think they're probably very complicated. But that's how I became sort of more intimately involved in policy initiatives around the science and a real desire to bring ethical issues to the fore. From my perspective, the first meeting was a little bit of a disappointment because I think the content of that meeting very much skewed towards the science questions. And I think that's not surprising—the majority of the planning committee were scientists and I also think that there's kind of a comfort level around the science because you feel like you're dealing with facts of some kind. And I will say that it's a context within which the fact-value distinction is quite robust in the minds of some and so we're looking for the facts. I think it speaks to a comfort level and also intrigue because the science is knowable—What's possible? Where can we go? —but I don't think it actually addressed enough of the ethical issues.

All of that to say that shortly after that, I was continuing to do the kind of work that I normally do which involves writing and attending conferences, and I was actually approached by the press: “Would I do an authored book on this topic?” And from the beginning, the idea was that this would be a book that would be accessible to the public. Now that may seem unusual because it's an academic press of some renown, but that was clear from the beginning that if I took on this project, it was going to be a book that would be accessible to the general public. Now I want to say a big caveat there: I understand I have not reached the general public in the true sense of that word. I think I have reached a non-academic audience, these might be people who would read *The New York Times*, *The Washington Post*, *The Boston Globe*, things like that. So, I do think that I achieved some of what I was hoping for, but I don't think I could have with this vehicle, reached as broad an audience as I think still needs to be reached. I see this as one contribution to that effort to make the issues available for a broader discussion and debate.

Russell: What are some of the more common misconceptions surrounding gene editing, and CRISPR in particular? Based on your research, what is the most problematic misconception about gene editing?

Baylis: I think the obvious problem is, for many people it kind of lends a sort of credence to “our genes are us.” And I do think that there's very real worry. And I have written about in a number of other contexts. I've written about how it is that we know about gene environment interaction and yet we behave as if that were not true? In that context, I'm reminded about all the news headlines—the gene for this, the gene for that. Most recently, a cousin of mine who lives in England, sent me a newspaper article that they have now found a gene for people who like to do bargain hunting and she said, “Oh, I guess that's our familial relationship; we both have that gene.” And I'm thinking, how would it ever occur to anybody to think that there would be such a gene? But of course, it turns out that somebody did a study of twins—because I actually did try to find out where would this belief come from—and they noticed certain kinds of behaviors and were willing to admit that maybe it has something to do with environment (i.e., the family in which they

were brought up and the kinds of values and practices, etc.). But there was this real sense that because they had studied twins in this particular context as opposed to siblings, as opposed to friends, that they could make these sorts of assertions. So, I think in a contemporary context, the gene is still mysterious, the gene is still in some sense thought to be very powerful, and I think that that continues to be a real challenge to any kind of conversation about CRISPR technology.

And I say that even with respect to my book. The focus of my book is on the gene and how it moves—how it moves not only through the body but through conversation, through society, through politics. And in a number of places, I am very careful to make comments about gene environment interaction and to say that it isn't always just the gene. But I think sometimes, it's relatively easy for people to miss those comments along the way, and to see this as, perhaps at times, lending some credence to clearly false beliefs around genetic determinism. I think that's always going to be one of the struggles when you're writing about genetic technologies, partly because of the way in which you focus on one facet of a particular problem.

Russell: If you could change anything about the book or clarify any of its ideas, based on its reception, what would it be?

Baylis: Well, I think I might try to make the issue around gene environment interaction more explicit. I know that I talk about it when I talk, for example, about enhancements and I try to say look, you could have the best project in the world and think that if you tinkered with all these genes, you will get this “product” that you're looking for. And I spend quite a bit of time saying that it doesn't work that way. But I think that there are probably ways in which I could have made that maybe a little bit stronger, or maybe drag them through the book a little bit more clearly for people to see. So, I think that's one thing I would like to do differently if I had a chance.

I think the other thing that I would probably like to do is to continue to find ways to make the work more accessible. I think that it's always very difficult and challenging, and I think that it's particularly difficult and challenging for a woman philosopher. Why do I say that? First of all, because I think anybody listening to this well understands that philosophy is not always a welcoming place for women, especially women who work in what are sometimes referred to as “soft” philosophy, like ethics. And that the same that I was trying to write a book that would be accessible for the general public, I was struggling thinking I want my peers to still respect me and to still see me as a philosopher. So, you can imagine the constant tension between wanting to meet that standard, of “Yes, trust me, I am a rigorous philosopher, I can write all about the slippery slope, and I can do all these other fancy things,” and then having to question, “Does the general public really need this content? What am I doing here? How much do I put in? How much do I leave out?”

And I think for me, what's been really interesting since the book has come out is reflecting on some of the choices I made along the way: some of the stuff that I wrote and threw out, some of the stuff that at last minute, I felt the need to expand. But I would say, for me as the author, that was a constant tension: how do I meet the standards of my discipline and how do I do what I think is actually really important, given my own views and commitments about what philosophy should be in the world?

Russell: I think many non-male, non-white philosophers can probably relate to that tension.

Lundquist: Throughout the book you make a case for public engagement with issues surrounding gene editing. You write, for example, “In my view everyone should have a say in whether modifying our genes and the genes of our descendants is something we should do” (AI 4). And near the end of the book, you characterize this work as a call to action. You write, this is “a call for us to take collective responsibility for our biological and social future” (AI 220).

You acknowledge that there are numerous obstacles to the kinds of engagement and consensus-building that you want to see and hope to see, and partly in response to those obstacles you explain several of the roles that scientists, ethicists and laypeople can play in that process. What for you are some of the most daunting obstacles to a just, productive, and collaborative engagement with the ethics and politics of gene editing, and what, for you, are the best approaches we can take in our efforts to overcome them?

Baylis: I think that one of the really big obstacles from my point of view, is trying to shift the discourse from one of rights to one of responsibilities. And I think that that for me anyhow is so important, both in the context of discussion and debate about reproduction and also in the context of discussion and debate about genetic technologies and in the context of what is it that we need in order to have a trusting and respectful discussion generally about any kind of topic.

One of the things that I find very difficult and I will admit frustrating, but I say it everywhere I go, and I say it recognizing that not everybody agrees with me, but I think it’s really important for me to articulate this view: when we look at reproductive technologies and when we look at a lot that has been written, whether that’s written in academic context or in the media, it’s all about rights and people asserting their rights to access technologies, their rights to build a family, their right to have children. And I want people to see at least my perspective, even if they don’t agree with it, and my perspective is having children is not about rights it’s about responsibilities. And hopefully these are responsibilities that are taken on willingly, but we know, in fact, that is not always true, and we need to think about that in terms of women’s rights to control their body—and I am using “right” there differently from this claim about the right to reproduce. And in that context, I think what I want is for people to understand that family making is about is about caring and loving and taking responsibility for the shaping of another human being who will become a member of our society.

And I think for me that fits with a lot of feminist work around the fact that we’re all second persons and that’s how we become persons—it’s through those relationships. And so, because of a lot of views I have around that, I think too many conversations get almost misdirected from the beginning, because people are asserting their rights and they’re not willing to at least entertain a different frame of reference for the conversation. So, that’s the first thing to say, and in certain contexts I’m at pains, to be able to say to a broader public, that does not mean that I do not understand or empathize with the suffering that people experience when they are infertile or for other reasons are unable to have children. And I do think that as a society we should try to respond to that. I just don’t want the conversation to start with a rights claim. I’d rather it start with a suffering claim, I’d rather it start with many other kinds of claims that I want to be able to respond to. I just don’t want to do this assertion of, “I have a right and therefore you must respond in a particular way to this right claim.”

I think it’s also important to try to think about diversity in a different kind of way with respect to who gets to speak to which kinds of questions. And I think again for me that fits very much with feminist philosophy and attention to who sets the research agenda. There’s that idea that whoever gets to control the question ultimately controls the answer, and I think that’s what we’ve seen

recently and maybe for millennia—I don't know, I'm not a very good historian. But the sense that certain people get to decide what the right questions are, and certain people get to constrain therefore what conversations can or can't happen. And so, when I talk about broadening the conversation, it's not about broadening it so that we can all answer the question that somebody else has already determined is the right question but so that we can come together and look at a technology and decide what are the important questions around that technology. And I'm going to put forward questions such as, "Is this technology going to be helpful? Will it help build a better world?" Somebody else might be asking the question, "Can this technology be patented? Can I make a lot of money off it?" I think we do have different frames of reference, different lenses through which we might look at the same technology.

But I'm trying to preempt the questions being pre-determined by an elite, whether that's a scientific elite, or a political elite, or an industry perspective, etc. And the only way I can see to do that is to defend the kinds of claims I make, which is to say the human genome belongs to all of us. And when I say that, it's not a rights claim, it's a responsibilities claim. We have responsibilities and so I'm actually saying it's a call to action. I'm asking you to assume your responsibilities to participate in the conversation. And I recognize that having said that, then one of the things I can do is try to help people who are interested in meeting that responsibility by providing them with tools. I think the book tries to do that, at least for a segment of society that's outside of academia, and I try to do that at several levels. Partly, I would say by trying to simplify the relevant science and make it accessible. And then also trying to lay out what's at stake and trying to make clear that certain peoples are really enthusiastic about certain kinds of opportunities and what does it mean to look at those opportunities from multiple perspectives.

So, I think that's what I'm trying to do and I'm sure that if you read it closely, you can tell what my own views are. And I'm not trying to hide them, but I am trying to not have them dominate. This was not a book to argue, "This is the right answer to this question." It is a book that's about: "Here's some really complicated science, we are at a fork in the road, you too can think about this and have an opinion and moreover, you should stand up and let us know what you think is important because we're creating the world that we're going to live in, and you and your descendants will live in that world. And it can be different, depending on who gets to have to say, right?"

Lundquist: I was looking through the book trying to find some particular passages that struck me that have to do with what you're arguing here, but I almost wonder then, if the problem runs deeper because near the end of the book, you're quite critical of a sort of liberal individualist notion of the self and calling for a notion of the self that is vulnerable and interdependent, very much a social self. But this almost makes me wonder if there's a lot of work that has to be done, for example on the American people, on our consciousness of what it means to be responsible to each other rather than just asserting our rights. If there's a lot of work that has to happen before we can have the kinds of conversations that you want us to be able to have that can be inclusive, and just, and productive, and fair-minded.

Baylis: I think what you're saying is absolutely right, and I think that the evidence of that is the pandemic we are living through. We're not doing so well in terms of understanding our moral obligations and responding to them. We are not doing so well in terms of understanding our interdependence in terms of looking to respond to the needs of the vulnerable, understanding we're all in this together. And when I say that we're all in this together, I want to be really clear about

that because we've seen a version of that statement bandied about quite a bit. And I certainly am amongst those who, on the one hand, would say, "Well, no, that's actually not true. And you're in fact erasing a lot of injustice and discrimination, and this illness is experienced very differently by people who are situated differently." But when I say, "We are all in this together," it's with respect to, "We *could* be all in this together in terms of care and compassion," but I will admit right now we're failing.

The thing for me that's interesting is when I wrote that book, I had no idea this pandemic was coming along. Maybe other people did. I don't work so much in the area of vaccine. But I have done work in public health ethics and I have been arguing there the very same kind of thing, that we need to be thinking about us as interdependent beings with a common interest in survival and safety, and I have come to think that the book I wrote about heritable human genome editing, I could have written about COVID and it wouldn't actually be all that different in terms of some of the big broad strokes that I'm arguing for. It just would have been a different case study. I think for me that was really telling when I had that kind of realization that were I to be thinking about writing a book now, it would actually be the same book. So, it wouldn't be very interesting, would it? It would just be COVID instead of genome editing, but I'd be trying to say the same things.

Russell: That's really interesting. I think it leads to another question I was thinking about. So, in the book, you also advocate for slow science. You write that slow science, "invites scientists and the scientific community to think deeply about how their time and talent might help achieve societal rather than commercial goals—and to assess critically the expectation that science develop, produce, advertise, and embrace science and technology as the means to personal and commercial success" (AI 126). That's the end of your quote. You've already spoken a little bit to some of our ethical failures in terms of bringing people to the table to think about our common good during this virus. But I'm curious when we think about the vaccine development and how quickly that's occurred—you know, and I don't want to let the audience to think that fast science is all about speed—but I'm wondering if you think that the fast science framework, the more commercial less democratic version, occurred during vaccine development or whether we might have seen some examples of some more slow science, in the sense of thinking about the common good, among scientists, at least, even if we haven't quite gotten it as a general society. Do you think that scientists were more cooperative in this venture in any significant ways?

Baylis: I do think that the scientific community has been much more cooperative than in the past in terms of sharing information and in terms of understanding that there was an imminent threat, and that this was not just going to be about publishing articles and getting patents and meeting the metrics that many scientists have to meet in the academic setting. They just have different metrics in the commercial setting. But I think people were less concerned about those sorts of metrics and much more concerned about human health. So, one of the things I really hope will happen is that there will be some carryover of that and that it will not have turned out to have been a kind of little blip.

But I do think that there are other ways in which we need to think about science, where we have failed to do things differently, and I think that's in the issue of access to the benefits of science. And I think that we're seeing that with sort of this new phrase we now use of vaccine nationalism and the ways in which science has solved one problem and that it's given us a vaccine—it's actually given us more than one vaccine—but we haven't seemed to understand that a pandemic is in fact a global challenge and you can't actually solve it within geographical borders and that's

because smart as viruses are, they don't recognize borders and so they're doing what they need to do. I say that somewhat facetiously, but it is kind of almost like one of these things, that when I said: "We know about gene and environment interaction, but we're just going to talk about genes." And, "We know how viruses work and we're just going to pretend that our only obligations are to people within a particular geographic space."

I have to say, I am actually quite surprised that neither moral suasion nor self-interest has actually been able to function yet to get people to do the right thing. Now, hopefully, that will change, but I guess what I'm trying to say there is that when we think about the pandemic and we think about science, one of the things around science is who is going to benefit from the fruits of that science? Who will have invested in that science? Much of that science is taxpayers' dollars. Many of the people who are going to benefit first in line are not necessarily going to be the most vulnerable. There are issues of distribution, there are issues of global access, and for me, that's all part of what I'm talking about when I'm talking about science. It's who asked the question, who solves the question, who benefits from whatever solutions were offered to the question. I'm thinking about that as a broad continuum of activity.

Russell: I'm curious too about when we think about these national divisions and the ways that they continue to operate and also about the inequality in the world. I think this is an important notion for your book and an important one generally, but how do you maintain your faith in the notion of a common good? When we see people so divided in terms of what they have or are able to access, in terms of what they think is the best way forward politically—how do we get a common good in there?

Baylis: Well, I have some very sad days. I think that I want to believe that there are enough people who genuinely want to make this world a better place. Many of us have different ideas about what that might look like. Some of us have sufficient humility that we're prepared to engage in conversation and acknowledge that maybe the vision of the world that we have is not the only one that's possible. But I think that as we continue, and I think this is a very sad way of thinking it might happen, but it might happen that as we continue to experience some of the challenges that threaten our survival on this planet, whether we think about that in terms of the climate crisis, in terms of food insecurity, in terms of overpopulation, at some point, I'm hoping that there's going to be enough like-minded people who will want to say let's come up with a solution. The problem, and I don't have answers, is that we're nearly eight billion people on this planet. The problem is that the disparities are such that some of these conversations are pretty highfalutin when all you want to do is put food on the table.

I'm not ignorant of that kind of limitation. I think that it's really important when looking at some of the claims that I'm making to think of them metaphorically. Do I imagine eight billion participating in a conversation to arrive at consensus? No, that's not what that claim is about. But the claim is trying to make space for ideas that are not part of the dominant worldview, and to say that we might actually learn something, and it might be really critical to our survival, if we can at least get to a view that we have something in common, like the desire to survive.

And I certainly know in my work over the years, even in the area of genetics specifically, but also here with respect to CRISPR, I'm constantly amazed at how much I learn from our First Nations, our indigenous peoples. Partly because I have access to be able to speak with people, and I'm just saying that's an illustration, I'm sure there are other communities that I could learn from as well. But one of the things I'm always struck by is that their starting assumptions about their

place in the world are so different that they get to different places. They talk very clearly and differently than the dominant worldview about responsibilities to Mother Earth, about responsibilities to non-human animals, about responsibilities to each other. And it gets framed in terms “I have a responsibility to walk the land” —well, what does that mean? Well, it stops other humans raping the land in effect.

And so, I think that if you’re open to other ways of understanding your place in the world, you can then see perhaps other ways of coming up with solutions to really pressing problems. I think the kinds of claims that I’m making are grandiose in some sense, it’s very easy to sort of set them aside and say, “Impossible.” And I have enough humility to say you might be right, it maybe is impossible. But the thing I keep returning to is we’ll be better off just for having tried. So, it actually at some level doesn’t matter that you know what I’m holding out as an ideal can’t or won’t happen. The effort of trying will make for a better, different world than the one we’re in now.

Lundquist: That’s very beautifully said. I very much appreciate your response to that question. Our next question also has to do with ideals. But it’s kind of about questioning an ideal that maybe we’ve set up for ourselves surrounding gene editing. At one point in your book, you mention a dinner party at which the host asks “Why wouldn’t I want to be Usain Bolt?” You go on to explore the possibility of genetic enhancement, including genetic modification aimed at increasing, for example, athletic potential. I loved the example of Usain Bolt because it involves an irony, and points to a potential short-sightedness in the way we might think about genetic enhancements. Most people know that Bolt is the fastest man alive, but I’m not sure how many know that he has scoliosis. Exercise physiologists have asked whether his scoliosis— which impact his gait— rather than being a detriment to his performance, may actually have enhanced it, and Bolt has linked his unusual training techniques to the need to compensate for the unusual curvature of his spine. My understanding is that we are just beginning to understand the relationship between genes and scoliosis, but whatever it’s genetic component may be, we would not think of it as an “enhancement.” There are many other stories of athletes (and scholars, and artists, and so on) who attribute their success—their excellence-- precisely *to* the perspective and lived experiences flowing from aspects of their so-called impairments (musicians who are hearing impaired; writers who are dyslexic, actors with ADHD and so on). You argue that “all treatments” are enhancements. Do examples like Bolt’s call us to rethink or to be skeptical of that idea—that treatments are enhancements, or even of the idea of genetic enhancement as an enhancement— in any way?

Baylis: I think the thing to me that’s interesting about that question is, I did not know that he had scoliosis, so thank you for letting me know that. But I think that one of the things that’s important is that to me it just illustrates so well the issue of gene-environment interaction, so it’s not necessarily about his genetics. And if you thought it was, then you’d be trying to have all runners have scoliosis and that would not be the goal or objective to find all runners and ensure that they had that in their next generation, or alternatively, find all people with scoliosis and say you will be the best runners. The thing for me that’s important about that is, it speaks to other things, like training, like commitment, like having a family that was supportive of this huge commitment that would have to be made by an individual person. So, first of all, I think that’s a great example of the importance of recognizing it’s not just genes that are going to make you be the fastest person in the world.

I think though that’s kind of a separate question from the idea of whether or not treatment ultimately collapses into enhancement. I make that claim in the book, largely because there’s a

vast literature around the difference between the two, and this kind of easy baby bioethics that “says treatments are good and enhancements are bad, so we know we have this moral demarcation line, and we should stick with that.” And so, some people then say, “That would be unethical to do as an enhancement, but it’d be quite fine to offer a treatment.” I also in my work then explore what if we were to take a case study, where the exact same intervention would be called an enhancement, for one, a treatment for the other, only because of background conditions, and you wouldn’t want to say that demarcation line was that robust.

At the end of the day, what I’m trying to do is actually just get rid of that demarcation line and not allow *it* to do the work that *we* need to do in terms of understanding what are the goals and the objectives of the intervention. Because the goals and objectives of the intervention are what should tell us rather than label that we choose to attach to it. So, part of what I’m saying when I think all treatments are ultimately enhancements, is that when you’re offering a treatment or even a prophylaxis like a vaccine, what you’re trying to do is make an improvement of some kind. And typically, we thought of treatments as making that improvement, such that the person gets to baseline—baseline being species typical functioning—and that when you go beyond that you’re now looking at an enhancement. I would say that you could tell me my glasses—I’m not wearing them right now—but my glasses are an enhancement. Right there, they’re improving and getting me back to 20/20 vision, which I don’t have. You could say that a prosthetic shoe is an enhancement since it’s allowing me to have the proper gait.

So, all I was really trying to do in that context is to say, we should not *rely* on these broad categories as if they are good proxies for what is good and what is wrong. We actually need to do the moral work and we need to understand why we are making this intervention. Are we responding to suffering? Are we responding to fashion? Are we hurting somebody in the context of what their life goals or objectives might be? What assumptions are being made? An example that’s not in the book, but I struggled with whether or not to include it is this woman who has been doing all kinds of cosmetic surgery to look like a cat. And then there’s another woman who’s doing all kinds of cosmetic surgery to look like a Barbie. What’s the difference? Some people think this is moving towards some standard of beauty that is understood, embraced, accepted, so somehow, even if that’s an enhancement, it goes in the positive category. But this person who’s trying to make herself look like a cat, well then, we’re sort of dismissive of that, and we may not be even thinking about it as an enhancement. So, this person narrowly thinks of it in those terms, but socially you might be saying well how do you get to walk about society and get the adulation that the person who likes like Barbie might be getting?

All I was really trying to do is break down a certain set of assumptions around these categories and to say we can’t let the category do the work, and I think those categories have really come to the fore in the context of the CRISPR debate. And the reason I say that is, with the debate around CRISPR, there have really been two axes of concern. One is making manipulations to patients who are suffering, offering them treatments; the other is making changes to embryos and enhancement. So, those are the two extremes. Some people have pulled them apart and said, “let’s talk about making changes to patients and making changes to the next generation, both of which will be considered treatments, or let’s have those same conversations but with respect to enhancement.” So, it’s largely because it’s doing work in that debate that I thought it was important to engage with it. But I admit, it has intuitive appeal. People kind of understand the difference in theory between this is a treatment and somebody is suffering vs. this is an enhancement and somebody is looking to make themselves better than well.

Lundquist: I think you do address the downside of even what we might consider a treatment or a mere treatment, something that would *only* improve someone's quality of life. In the book you talk about the social cost of that. I wonder, though, if it would be possible to elaborate in the future on the downside of fixing the things we see as being harmful conditions where very often they lead to unique kinds of human excellence, not just a good life or certain kind of community that surrounds individuals who have this condition, but also really just wonderful forms of human excellence that might not otherwise be possible.

Baylis: I think you're raising two points that I'm interested in. One of them is the seeming inability amongst many of us to actually genuinely embrace difference and diversity and just enjoy it for whatever it is. We tend to have this very quick move to better or worse, or bigger or smaller, whatever it is, we just also seem to have to bring this evaluative component that is about enhancing or valorizing one over the other. I think that's one of the things that's really complicated in this area—we don't seem to be able to just say well that's a different way of being in the world. I think that there are certainly a number of communities that are trying to say that very clearly. That we actually need to not be thinking about homogenization as a goal or objective but that there are different ways of being excellent, there are different ways of just flourishing. I think that that's actually really an important point that we need to underline. I had a second point, but I can't remember what it was.

Russell: I'm going to shift us a little bit. We have these scientists who really are promoting this notion of "better than well" (i.e., people should be able to carry out whatever traits they want and modify themselves to pursue their own goals.) But we also have those scientists who are interested in genetic enhancements for the good of society. People who would have us use our powers (when available) to promote sociality, altruism or empathy through altering the human genome. You note in the conclusion that at least such ideas shift the conversation away from individual parental desires toward the idea of addressing shared human problems. Nevertheless, I am struck by the biologizing or geneticizing of these characteristics (sociality, altruism, empathy).

Why assume that our genetic failings are blocking our empathy rather than the problematic social imaginaries and extensive social propaganda that constantly work to convince us that many people around us are not quite fully human or not really deserving of empathy (only possibly pity)? We have all these messages about who we're supposed to care about or not, which seem like huge blocks. I think of some relatives of mine who have political views that I don't agree with, who I know to be very empathetic people in their personal lives, who still are led to support political positions that I think are the opposite of this empathetic approach. Why do the scientists think that genes are the answer here, instead of worrying about all the ways that we shaped people to believe these different things, and to point their empathy or altruism in a really narrow way toward their own community?

Baylis: I want to say first and foremost, I don't believe in moral enhancement. But I also want to say that it's not just scientists who are thinking of that. We actually have some philosophers who defend that view. One of them is a colleague, Julian Savulescu. I disagree with him about that and many other things to do with CRISPR. But I think that for me, one of the things that's really important is it's an opportunity generally just for me to say that I do think that there may be an interesting conversation to be had about gene-environment interaction with respect to that, so I

don't know the answer. At the outset, I'm not particularly sympathetic. I'd invest a whole lot more in moral education than I would in CRISPR technology to find a gene for good moral behavior.

But if I take it back to the book and I'd say I'd be more interested in having that conversation I have to admit it's because I am so frustrated and so uninterested in the dominant conversation. It would be more fun to talk about this, I would find myself on one side of that debate, but at least it would be a debate that I think would be worth having. Why? Because at least in theory, the people with whom I would be debating that, would have a common goal or objective. We think that the world should be more moral than it currently is, whatever that might mean. So at least we have some sort of common objective that I can sort of agree with or have some sympathy with. We then might have very different views about how one goes about trying to secure that objective.

But I want to say very clearly the reason I'm interested in that is because I'm open to being wrong. Okay, so I said at the beginning, I don't think there's such a thing as moral enhancement. I'm willing to be told that I'm wrong. I would find that conversation interesting. I do not find the current conversation, which is the prime mover behind the argument that we absolutely need to develop this technology, which is for people (couples) to have healthy genetically related children in any way, shape, or form, as convincing. So, I am surprised, and I continue to be surprised by how forcefully that view is defended, and I find it difficult to be sympathetic to the view for two reasons. I think it very much contributes to reification of the gene. It very much contributes to undermining the richness of family and what it means to be a family, that somehow the only true families or legitimate families or welcoming families or warm families have to have this genetic tie. I think we've made so much progress over the last 10, 20, 30 years in breaking down some of the assumptions that we're tied to that and valorizing new and different ways of making families, that this is backwards and that you would in fact be legitimizing the calling into question of all these other ways of making families by saying this is so important that we have to invest time, talent, and treasure to respond to the needs of very, very few.

Very recently, the International Commission of Science Academies issued a report on heritable genome editing. In that report they actually do some of the numbers around different kinds of illnesses and one of the ones that struck me was cystic fibrosis. So that they look at the incidences in North America of that particular illness, they estimate the probability that two people with the illness would marry and therefore all of their children would also have this illness. And they come up with one couple every 15 years, and I'm saying: "We're having an argument about this? That's what's going to motivate the use of this technology? That's what's going to motivate what's going on?"

And so, I do think that in some ways, the idea that that's a good reason to go down a particular path at this fork in the road isn't good enough for me. I know it's good enough for other people, the people that defend that view. I'm willing to say that maybe that is the path we should go down, but please give me a better argument for it. I do mean that sincerely, unlike other people who hold a different view. There are people, including people with whom I have authored papers, who strongly believe that there are no conditions under which it would be possible to pursue this technology. I remain open minded about that. I'm not prepared to say there are no conditions under which it could be pursued. I don't know what those are yet, and I need somebody to help me imagine those. But I just know that the one and only argument we have right now, for me, doesn't cut it.

Lundquist: It has often been said that our technology is outpacing our ethics, or that "ethics is lagging behind science." For you, this view is false and disingenuous, and tends to be code for

“ethics is slowing science down” (79). But perhaps you would agree that it’s often the case that before we—scientists and ethicists and laypeople—have time to deliberate on the consequences of the latest scientific discovery or technological innovation, we find it is already reshaping our lives in ethically-significant ways. Perhaps you would also agree that we—scientists and ethicists and laypeople—tend to focus our ethical analysis on the past and the present—on assessing what has been done or trying to make sense of the problems that already confront us.

One of the things I appreciate about science fiction is that from its inception it has not only anticipated the technologies that will emerge and reshape our world, but has also called on audience to think about the ethical consequences of that reshaping. When we read a work like *Brave New World*, for example, we’re invited to reflect on a possible or probable world, a world that may resemble the world we or our progeny inhabit— in the future. In that sense, it buys us time for ethical reflection.

You write that “innovative bioethics prizes the moral imagination,” and you seem to value the moral imagination more generally. How important is speculative fiction and science fiction for the development of our personal and collective moral imagination, and how important is the moral imagination for our personal and collective reflection on the ethics of gene editing? Is it so important that we might have an ethical obligation to expose ourselves to speculative and science fiction in order to foster a better moral imagination?

Baylis: I certainly think that science fiction, literature, film, etc. is very important, and in the book I actually have this table where I talk about science and society, or I create this grid and it’s peppered with that, along with the major scientific discoveries. And that was really purposeful to say that while science is doing this, here’s the conversation that’s happening in a different realm in society. So, I do think it’s extremely important. I’m mindful that in certain conversations, if you bring up science fiction it is very easy for the people who are part of the scientific community to want to set that aside. And for me, the whole thing is it doesn’t matter whether they’re going to be accurate with respect to their predictions; that’s not what it’s about. It’s actually the fact that they’ve created a whole world, within which you can try to insert yourself and imagine what would it be like to live in this world.

Now, given that my project is to ask people to answer the question, “What world do you want to live in?” this is really important material for you to actually have an opportunity to say well that’s not the world I would want to live in. But then also to have the ability to reflect on the world you’re currently living in: Is that the world you want to live in? Or can you in fact exercise your own moral imagination and actually think of a world that’s different from the one you’re in? Maybe different from the one you’re reading about, but that you can see things that you think are worth imagining. In order to make something happen, I think you have to first imagine it. What would it be like?

And I’m reminded of the phrase, and I’m sure I’m going to get it wrong now, but it’s to the effect that we can imagine the end of the world more easily than we can imagine the end of capitalism. I think that that’s for me, a really important thought, and I say that because I do think, at the end of the day, if you sort of unravel the kinds of things that I identify as problems, many of them are tied to capitalism and the injustice that is only getting greater by the day, by the minute, by the hour; however, whatever time frame you want to use. And it has been exactly exacerbated in the context of this pandemic. And so, I think it really matters, whether or not we can imagine something in order to be able to try to move toward or away from it. I think exercising the moral imagination is really important. And when I say that it’s not just in terms of the imaginings of the

trappings of the world, but the obligations and the responsibilities that come with then trying to move us towards that world.

Russell: It also brings to mind for me, the lack of gender and ethnic diversity in science fiction writing, especially here in the US. And it makes you wonder whose moral imaginations are sparking our moral imaginations?

Baylis: Have you read Octavia Butler?

Russell: I have, yes.

Baylis: So, there are a few.

Russell: No, there are some very excellent examples, but I do wonder if that's its own kind of problem that we have. When I have read feminist science fiction, it really has helped my moral imagination quite a bit.

Baylis: I take that to heart, and I think that I started this conversation with alluding to who sets the research agenda, who controls the question, etc. I think we see the same thing happening within the arts. What counts as art is actually quite constrained. What counts as storytelling is actually quite constrained. What constitutes knowledge production is actually quite constrained. One of the things that's really important, and this alludes to work that I did with Sue Sherwin many years ago, when we wrote a paper about the responsibilities of the ethics consultant in the role of both architect and advocate. Part of that work was very much to say that we have a responsibility to make spaces in which other voices can be heard. And we have a responsibility to help people to understand that that means more than opening the door. You cannot just say "the doors open, it's not my fault, nobody comes through." It's like, "No, it's not a very fun place to be on the other side of the door," and you don't necessarily feel welcome just by having the door open.

And then beyond that, we really struggled with the idea that, if you have voices that are unable or unwilling to speak for any number of reasons, how can you help speak with and for? And then we actually asked those questions: should you ever be speaking for? How do you understand speaking for vs. speaking with? So, I still struggle with understanding the right place in certain contexts, and my most recent work and those ideas are in this book, but I continue to work on them, is to try to speak about the difference between public education engagement and empowerment and what I say, in that context, is we've been doing what we think is public education for a very long time. It's very limited, it's flawed, etc. And the biggest was that it starts with a knowledge deficit model. I then argue that we absolutely have to do public engagement. In some places we do that well. It's a two-way street in terms of who gets to speak and who gets to answer and who has ideas and who's credible, but we still haven't got to the sharing of power. And that's what ultimately matters and that's why we have to get to public empowerment. We're not there yet and it's something that I'm prepared to imagine, that we could get there.

Russell: Thank you so much. I think we could probably keep going for hours, but you might – since you're forced to speak the most – get exhausted.

Baylis: Are you kidding? It's a treat to be able to have an opportunity to talk about my work, so I really appreciate that.

Russell: We really appreciate you and the time you've taken to engage these questions, and we really appreciate your wonderful text. And the way that it's helped us to think about how this model could not just help us with CRISPR, but everything. What if we were all engaging with different people around all kinds of technologies in science and the question of what kind of world we want to live in? So, it's really very inspiring work, it's very generative, and we just really appreciated having a chance to read your book and to talk to you about it.

Baylis: Thank you again so much. Aside from obviously enjoying speaking about my work it's always nice to actually get really good questions that help surface some of the ideas that you might have not elaborated as fully or that you would say in slightly less academic terms, that you get to do in this kind of an interview. So, thank you, I appreciate it very much.