Disability Deep Dive Episode 76: The Ethics of Innovation: Disability, Technology, and Reproductive Justice – with Katie Hasson

Jodi Beckstine (00:01):

Want to talk and explore how disability science and ethics collide in today's tech-driven world? We're diving headfirst into the ethics of innovation on this episode of Disability Deep Dive.

Keith Casebonne (00:38):

Hello, listeners. We are really glad you're here. I'm Keith.

Jodi Beckstine (00:41):

And I'm Jody. Welcome back to Disability Deep Dive.

Keith Casebonne (00:45):

Today's episode is called the Ethics of Innovation: disability Technology, and Reproductive Justice, and we're joined by Katie Hasson, associate director at the Center for Genetics and Society.

Jodi Beckstine (00:57):

Can I be honest, when I first heard this topic, I thought, Ooh, this is going to be tough to wrap my head around. But Katie made it so accessible and I walked away with a whole new perspective.

Keith Casebonne (01:08):

Yeah. Yeah. Same here. She's absolutely brilliant at breaking down these big complex issues in a way that really made sense. I felt the same way, but in the end, the conversation really stuck with me.

Jodi Beckstine (01:18):

Yeah. It's going to be one of those episodes that make you rethink how disability fits into the bigger picture, especially when we're talking about science ethics in the future.

Keith Casebonne (01:26):

Yeah. It's a fascinating conversation. And be sure to stick around after the interview for something extra in our deep cut segment. You won't want to miss it.

Jodi Beckstine (01:33):

That's right. This week's deep cut connects beautifully to our conversation with Katie. It's the powerful documentary, Fixed: The Science/Fiction of Human Enhancement. Fixed explores the ethics of genetic technologies and those who often get left out of the conversation.

Keith Casebonne (01:48):

Yeah. It's really great. So what are we waiting for? Let's dive in.

(01:56):

Hi Katie. Thanks so much for joining us. Can you start things off by introducing yourself and sharing a little bit about the Center for Genetics and Society, the kind of work you do there, and maybe what drew you into that space?

Katie Hasson (02:09):

Hi, thanks so much for having me. I'm Katie Hasson. I'm the Associate Director at the Center for Genetics and Society. And Center for Genetics and Society is an independent nonprofit. We work to ensure that social justice, equity, human rights, and democratic governance are really front and center in public and policy debates about human genetics and assisted reproduction. And our goal is to confront the ways in which misuses of these technologies could revive pernicious eugenic ideas and practices, as well as exacerbate the already dire levels of inequality that we have in the US and in the world. And CGS is really the only United States-based nonprofit whose primary focus is these urgent set of challenges raised by human genetic and reproductive technologies.

(03:03):

And the kind of work that we do, the way that we approach this, we're really seeking to build a cross-sector movement to ensure justice and equity in human biotechnologies. And we do that in three key ways. One is our work in communications to reshape narratives about the social meanings of human biotechnologies. Another way is coalition and capacity building. We facilitate collaborations that bring voices and perspectives that have really been missing in these conversations. Especially those grounded in disability, reproductive, gender, racial, LGBTQ, and environmental justice. And then we do policy education and advocacy that really centers social justice and human rights. And CGS has been doing this work for 25 years now. Really working to amplify underrepresented perspectives on these technologies, building a broad network. And so as associate director, I'm really involved in all aspects of this work to one extent or another, as well as the behind-the-scenes stuff like the fundraising that keeps all the rest going.

Keith Casebonne (04:17):

That's wonderful.

Jodi Beckstine (04:19):

I have dwarfism and over the past couple of years, I've heard a lot about genetic testing and embryo screening with dwarfism. So when we talk about these new biotechnologies, what are some of the ethical concerns you see coming up, particularly when it comes to how disability is talked about or understood?

Katie Hasson (04:39):

Yeah. I would say one of the biggest issues is just the way that these technologies are really built around a medical model of disability. Really frames disability as a biological problem that must be cured, and that can be predicted through genetics rather than a social model that focuses on access or an identity model. So really we see a lot of conflation of disability with disease, those two things being equated in a way that just assumes that disability equals suffering. That's the basic understanding behind these technologies. And that means that they don't really reflect the needs or the wants of disabled people or communities. And you even hear a lot of the arguments for these technologies are made on the grounds of eradicating disease in ways that are really harmful I think.

(05:41):

So some of the questions that we ask around this or the concerns that we have is what does it say to people currently living with disabilities about how their lives are valued to be putting so much effort and resources and marketing behind technologies to prevent people with those same disabilities from being born? And then especially if we're talking about something like gene editing. To back up just a second, I want to be specific about two different kinds of gene editing that we can talk about. There are two different ways that gene editing can be done. One is called somatic gene editing or gene therapy, and this is when gene editing technologies are used as a treatment for a person with an existing disease who's seeking a cure for that. So examples of this that you'll see in the news recently are the gene therapy that's been developed for sickle cell disease. To treat adults and children with sickle cell disease.

(06:48):

On the other hand, we have what is called germline gene editing or heritable gene editing. And this is when gene editing tools are used to change the DNA in an embryo or an eggs or sperm, and the idea is to change the DNA in every cell of the person who is born that embryo, and then even to pass those changes onto future generations. And this germline or heritable genome editing is the one that we have really strong concerns about. It's this unprecedented ability to attempt to alter the traits of future generations to really create children who specifically have or do not have certain genetic variations or traits. So when we're talking about something like germline or heritable genome editing, in addition to the stigmatizing way that will often argue for using these to prevent disability, it also has tremendous safety risks. We don't really know what kinds of unintended side effects could happen from these form of gene editing. And so that I think is another set of concerns.

(08:08):

So there really are a lot of concerns around both the ethical questions on heritable genome editing, particularly as it relates to disability. What message does it send to people currently living with disabilities about how their lives are valued? What does it say that we would risk using these technologies with tremendous safety risks in that same goal? And how would the use of these technologies in reproduction work to both increase stigma of disability as well as to reduce support and material resources for disabled people and communities? And then I think really the biggest red flag is just the long-standing history and legacies of eugenics in the United States that we just have not dealt with. And the eugenic logics that underpinned these technologies that too often go unquestioned. Especially as we see intense resurgences of blatant eugenics in our current political environment. So what happens when we introduce these kinds of powerful biotechnologies that potentially have the power to change the human species? What happens when we introduce those technologies into this mix?

Keith Casebonne (09:32):

There's a lot to unpack there for sure. So many different threats and risks involved with this. I can see how some people on the surface see this as, oh, this will make this one change and it could be for the better, but there's so many possible ... Like you said, the risk of the procedure themselves and up to the idea of mass eugenics and really horrible things that could come from this. It's a lot. I feel like in the past, just doing other interviews, medical model comes up a lot when it comes to maybe a lot of these problems are rooted. They're looking at, like you said, they see things as disorders or diseases and not really looking at how as human beings in society, there's a very different way of looking at these things and they often miss that. Well, and that being said, of course, there's also often a lot of excitement around certain medical and technological advances. So how do you approach conversations where innovation might be seen as being at odds with recognizing disability as a valued part of human diversity? Building on what you were just talking about there.

Katie Hasson (10:40):

Yeah. Yeah. Definitely. I think one place to do this is to, again, make that distinction between gene therapies for people who are seeking cure for disease and do want that. How can we support the development of gene therapies that are safe and are effective and are accessible to the people who want to use them? Where we are right now as the few gene therapies that are available have multi-million dollar price tags, which makes it inaccessible for most people. So on the one hand, how can we promote medical innovation for those kinds of therapies where they are desired in ways that are ethical and just and stay away from technologies like heritable genome editing that are not safe and that carry such grave ethical and societal risks. So I think one step is making that distinction. Another, I think is doing more in our conversations around disability, especially in medical communities, to distinguish between disability and disease or disability and health. Disability does not automatically mean unhealthy, and I think there's a lot of room in medicine in biotechnology to really question some of those assumptions that people with disabilities automatically want or need to be cured versus seeing the way that disability can be a valuable experience, a valuable contribution to society, a way to make the world a richer place.

(12:20):

And also, I think there's an interesting conversation to be had about areas where people with disabilities and disabled communities need and want certain kinds of medical innovation that don't have anything to do with cures, but would improve their lives in a variety of ways. But somehow that's not where the efforts toward innovation tend to go. CGS had a webinar a couple of years ago on changing disability narratives around gene editing and genetic technologies. And one of the really interesting conversations that came up among the disability study scholars and the advocates in this webinar was just, why isn't medical innovation being applied to say, curing bed sores versus these other high-tech interventions that aren't necessarily wanted, but yet all of this money and just media attention.

Jodi Beckstine (13:24):

To piggyback on that with the common assumptions and narratives, how do you see how that they shape how these technologies are promoted or presented to people?

Katie Hasson (13:37):

Yeah. I think one of the most problematic ways is the idea that something like CRISPR gene editing will eradicate disease, eradicate disability. That this is supposed to be a common goal without the recognition that you're talking about people. You don't eradicate a disease, you are preventing people from being born because they might have that disability or disease or a particular just genetic variation that's associated with that. And then if we turn back to the range of genetic testing and genetic selection that's been increasing in reproductive technologies, something that we've seen is the way that most people are familiar with prenatal genetic testing, but with the use of reproductive technologies like IVF, they're pushing this testing back even earlier. So there are these ways of doing genetic testing and screening on IVF embryos. And this has been done for a while for more than 20 years to focus on say, one particular genetic condition that the parents know that they're at risk of passing on. And if they make the decision to screen for that, they can look for that particular thing in the IVF embryos that they have.

(15:08):

But what's happening now is that there are these companies bringing to market what's called polygenic embryo screening. And the idea here is that you will look across the genome of each of those IVF embryos and calculate their risk for all kinds of ... From common medical conditions to more rare to even traits that they can look at all of these things where the genetic link to that or the genetic cause is made up of tiny genetic changes all across the genome. So they're looking across all kinds of genes, adding up all of these tiny risks and trying to predict each embryo's chance of having, for example, heart disease or diabetes or moving into mental health conditions like bipolar or schizophrenia, autism, and all the way up to companies are now openly promoting that they'll predict the hair or eye color or even what they're saying will be the IQ of that embryo. There are companies that are marketing these kinds of tests to prospective parents and two fertility clinics right now.

(16:26):

And the way that these tests are promoted is all around health usually. That you want to give your child the best start in life. You want to make sure that your child is healthy, and therefore we are going to do this genetic testing, use our proprietary algorithms to add up all of these potential small risks and give you a score of which embryo will be the healthiest or the best. And then this is something that you as a prospective parent should want to know as much information as possible and should want to do everything that you can to prevent a child being born that has any kind of genetic risk or any kind of disability. And then pushing into, you may as well get all of the desired traits that you want.

(17:16):

There's both this automatic assumption that every parent does or should want to avoid birth of a child with disabilities. There's this common sense ableism, I've heard it called that it's just assumed that this is true. And it feeds off parents very normal desires to give their children the best start in life, but it interprets that as giving them the best genome and then it starts to filter over you need to have the best possible child to start in life. So there are ways that it really intensifies, especially non-disabled parents fears of disability, and especially because as disability scholars have pointed out at the point when you're doing embryo screening, any information that you're given is basically all of the information that you have about this potential person who will come into being in the future. And so anything that shows up as a "negative finding" is going to have outsized influence versus once a child is in the world, there are so many facets to their personality and who they are that whatever has turned up in a genetic screen may be just a small part of the person that they are.

Keith Casebonne (18:40):

Fascinating. One thing you said earlier about some of the research and development that's out there related to disability reminded me of the book, Against Technoableism where one of the points made was talking about that exoskeleton that, oh, if you can't walk, this will help you walk. And it looks great and trade shows and conference floors and things like that, but did anybody with a disability ask for this? Is this really what you want? And when you talk to the community, what they really want is just give me a ramp so I can use my chair, or maybe improvements to the chair itself or things like that. And all this money and time goes into developing these things that really no one's ever going to be able to afford. It look glitzy and awesome, but when you really think about it's not all that helpful. So leading from that, what kind of roles do you think disabled people in communities could or should be playing in helping to shape bioethics research priorities and public policy around this?

Katie Hasson (19:43):

Yeah. I think just from the start, there needs to be much greater inclusion of people with disabilities in these public discussions and the policy discussions. That just needs to be the floor though. That there's more involvement, but not just that. It needs to come with a greater understanding of disability and disability rights. Center for Genetics and Society has been involved in these high-level conferences and policy conversations for over 20 years now. We do bring the perspectives of our partners from disability rights organizations into these spaces whenever we can. But we just see over and over that there are not disability rights advocates included on the program for these kinds of discussions about the future of gene editing technologies and reports about the ethical questions on these technologies, how they should be used, how they should be governed, make even just very little mention of disability. And when they do, it's always this conflated term of disability and disease joined together.

(21:04):

So then there's also this conflation of disability rights advocates and patient advocates that I think is very complicated. There are patient advocates and disease advocacy groups that have much easier access to these kinds of conversations because they are more aligned with the scientists and the medical practitioners who are organizing these conversations. They're more intelligible and their interest in increasing money for research and searching for cures is more aligned. And there's a real lack of understanding of the difference between patient or disease advocacy and disability rights. Their political advocacy is not around cures. It's around access and rights. And it may have nothing to do with trying to increase funding for certain kinds of biomedical research, and they may have objections to something like heritable genome editing as a whole because of the threats that it can pose to their community. So I think there does need to be a much greater role and a much better understanding of disability rights shaping bioethics and policy.

Jodi Beckstine (22:27):

Well, with that in mind, are there any examples of a policy or a coalition, a particular framework that you think is moving the conversation in a positive direction?

Katie Hasson (22:39):

Yeah. Well, if I could talk about CGS for a minute, I would love to.

Keith Casebonne (22:47):

Please.

Katie Hasson (22:48):

I would love to say a little bit about one of our initiatives. We started this initiative a few years ago, and we call it The Missing Voices Initiative to highlight the missing voices and perspectives coming from disability rights and justice, but also a range of social justice and human rights advocates that really should be in these conversations and have not been. In reality, they are not really missing voices, but excluded voices because these conversations are going on, but they're not being brought into the rooms where these bigger policy conversations are happening.

(23:26):

And as part of our Missing Voices Initiative, we have a gender justice and disability rights coalition on heritable genome editing, so specifically focused on germline heritable genome editing. And this is a group of 16 advocates and scholars from 10 countries, and they come from a range of civil society organizations and academic institutions. And some of our disability rights partners in Missing Voices and on this coalition include the Disability Rights Education and Defense Fund, Autistic Self-Advocacy Network, and the Longmore Institute on Disability. And so this group together published something we call the Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing. It's a bit of a mouthful, but it's a framework of 11 principles that come from a feminist anti-eugenic lens, and that really center the health, rights and freedom from exploitation of women and people who could get pregnant and affirm the worth and full inclusion of all people of disabilities. And we really ask, what does it look like to talk about heritable genome editing from that perspective? What principles are missing from these conversations that come through so clearly when you start the conversation from a very different place.

(24:54):

So I would share that initiative. But a few others that I wanted to mention, I mentioned Autistic Self-Advocacy Network, who was one of the members of our Gender, Justice and Disability rights Coalition. They have a really great statement on genetic research and autism that has a lot of background and recommendations for how this research should or shouldn't go forward. It's written in plain language, and it is a really great resource for learning more about the issues and seeing what kinds of recommendations are coming from that self-advocacy community. And then the last thing I would mention is the National Council on Disability in the US has over the past several years done a series of reports on bioethics and biotechnologies. And they have one from 2019 called Genetic Testing and the Rush to Perfection, which really looks at the range of prenatal and pre-implantation genetic testing.

(26:04):

And then they have one that just came out in 2024 called From Fetal Surgery to Gene Editing: The current and potential impact on Prenatal Interventions on people with Disabilities. And this was a really interesting one. Both of these reports, they get input from a whole range of disability advocates and organizations. And it was very interesting to be on the listening session where some of the groups were giving their recommendations and experiences around gene editing for this 2024 report. And it was interesting to hear from groups that we're saying, "Well, we haven't actually had a chance to make a position on this yet. Our organization is just starting to deal with these issues." But there were really interesting points that came up in those reports as well that you don't see in other reports on these topics. So I think those are three that I would mention.

Keith Casebonne (27:11):

I think all three of those sound incredible. Yeah. I love those directions. I think that's wonderful. So before we wrap it up, we like to take things on a creative note. Is there a book, a movie, a TV show, or a piece of music, anything in that realm that you think really captures some of what we've been talking about or that you've been thinking about lately in terms of genetics in society and that this work you do?

Katie Hasson (27:41):

Yeah. Well, it's hard to talk about these issues without the film Gattaca coming up. I'm sure you might be familiar with it. It's Over 25 years old now. It's a very evocative and provocative picture of what a world based in these kinds of technologies of genetic optimization and even enhancement would look like. The rigid social structure and the divisions between people who are enhanced and people who aren't, and how harmful that is to everyone in society. It is a complicated film from a disability perspective. It both shows the damage that this search for perfection can do to everyone, but it also relies on some damaging disability tropes around suicide that make it a very complicated film. Several years ago when Gattaca was 20 years old, CGS had an event where we did screenings and had some discussion panels after, and one of them was in partnership with the Longmore Institute and Superfest Disability Film Festival. So that was a really interesting conversation about ... I believe the question was framed as, what the heck kind of a disability film is this? So there's lots to say there, and I felt like I have to mention Gattaca. But another one that I might ... If I can just-

Keith Casebonne (29:10):

Please.

Katie Hasson (29:11):

Say two.

Jodi Beckstine (29:12):

Yeah.

Keith Casebonne (29:12):

As many as you want.

Katie Hasson (29:13):

Yeah. There's a really great documentary called Fixed? The Science/Fiction of Human Enhancement by Regan Brashear. And I think that's an excellent one. Really looks at these questions from a range of perspectives from people with disabilities and disability communities. What does it mean to be normal, to be enhanced to repair? And I love that that film also brings in dance and other cultural forms as ways of reflecting on these questions as well. So those would be the two that I would mention.

Jodi Beckstine (29:50):

Great choices.

Keith Casebonne (29:51):

Yeah. Excellent. Katie, thank you so much. This has really been interesting and informative, and it opened my eyes to a number of things that I don't think I had previously really been aware of in this space. It's definitely a higher-end technical area that maybe the average individual doesn't think about every day, but I think people should think about it a little more. And so I'm really glad that you joined us and had this conversation with us.

Jodi Beckstine (30:18):

Absolutely.

Katie Hasson (30:20):

Thank you so much for having me.

Jodi Beckstine (30:34):

A quick note before we dive into this week's Deep Cut. Documentary Fixed: The Science fiction of Human enhancement isn't rated like a traditional film, but it's often used in high school and college classrooms. It explores mature themes like ableism, bioethics, and the human enhancement. So best suited for older teens and adults ready for a thoughtful, nuanced conversation.

Keith Casebonne (30:57):

This week's Deep Cut takes us to Fixed: The Science/Fiction of Human Enhancement. A powerful documentary that explores the evolving relationship between disability, biotechnology and what it means to be normal. Released in 2013, it's still a vital conversation today.

Jodi Beckstine (31:15):

What's so compelling about Fixed is that it doesn't take sides. It brings together voices from across the spectrum, disabled, activists, scientists, transhumanists, and it lets them speak to the promise and pitfalls of technological advancement.

Keith Casebonne (31:30):

Yeah. It does. So well, let's start with the big question. When we talk about fixing people through technology, what are we really saying?

Jodi Beckstine (31:41):

Yeah. That question, it really hit me because at its core, it forces us to confront the assumption that something's wrong in the first place. And what you hear in the documentary from disabled people, they're saying, "Wait a minute. Wait a second. I'm not broken. The world just wasn't built for me." And it's a shift in perspective that we don't always see. It was very powerful to me.

Keith Casebonne (32:09):

Yeah. Speaking of perspectives, what were some of the perspectives in the film that stood out to you the most and why?

Jodi Beckstine (32:15):

Well, I had a lot of feelings watching this.

Keith Casebonne (32:19):

Yeah. Me too.

Jodi Beckstine (32:20):

One of the voices that stood out to me was an activist who said that these technologies aren't neutral. They reflect what the values of the people that are actually creating the technologies. And that stuck with me because if the goal is to normalize or erase disability, then whose bodies are being centered in this discussion? Whose lives are being deemed worth enhancing?

Keith Casebonne (32:47):

Yeah. Yeah. That's a huge question. A lot of different viewpoints throughout. Not one answer, thankfully. I like that it kept it open.

Jodi Beckstine (32:58):

Absolutely.

Keith Casebonne (32:59):

Yeah. Well, and so how does Fixed help us challenge the assumption that disability equals suffering?

Jodi Beckstine (33:07):

Well, first, they interspaced a lot of the ... Part of the documentary with people dancing and showing all of them together that disability can be beautiful and be included in everything. It shows people living these rich complex lives as advocates or creating art and saying, "My life isn't something that needs to be fixed." There was an advocate. I wrote her name down. Patty Berne. She works at the Center for Genetics and Society and is a wheelchair user. And she said, "People see disability as a personal tragedy." And I'm paraphrasing here, but she said, "From a disability rights perspective, is the problem that I can't walk up the stairs or is the problem that the building was designed to not include people in wheelchairs?" And that's really powerful. What actually needs fixing? It's not the people with the disabilities, it's the society around them.

Keith Casebonne (34:07):

Yeah. She made really good points. I think she was the same person on there that when talking about there's all these bio enhancements out there, but really she just needs a reliable way to get her chair fixed.

Jodi Beckstine (34:19):

Yeah. That's such a big deal. We're talking about these big expensive biotechnologies, but there's so many people that don't even have the basic needs just to get around for whatever reason. That really was a strong point that she had made.

Keith Casebonne (34:39):

Yeah. For sure. So what's the danger in viewing human enhancement as purely progress?

Jodi Beckstine (34:46):

For me, I think we start to lose sight of diversity. We start narrowing down the definition of what it means to be human, not just for disabled people, but for everyone. Because the more we start to engineer perfection, the less space there is for anyone to be different. And even as it is now, to be different is such a othering type of thing. And I think difference is where our strength as humans lie. This documentary was the first time I had heard the word transhumanism.

Keith Casebonne (35:26):

Me too. Yeah.

Jodi Beckstine (35:27):

I had never heard it. Basically, it's the idea of going beyond and using technology to go beyond human limits, but it raised a flag for me because when we're so focused on transcending what it means to be a human, where does that leave people being told that their bodies are already not good enough? And as someone who is disabled, that framing made me feel really uncomfortable, and it was just simply, in my opinion, was just ableism.

Keith Casebonne (36:00):

Yeah. No. That makes a lot of sense. I don't remember who said it, but someone said that our limitations are inherent to being human. It's another way of looking at it very much against the transhuman approach.

Jodi Beckstine (36:18):

Yes. Absolutely. One of the strengths of this documentary is how it centered disabled voices, even when the science seemed to move on without them. Why do you think it's essential to include disabled people in conversations about innovation?

Keith Casebonne (36:33):

Yeah. Well, first of all, you can't make decisions for people without understanding what their needs are, what they actually seek. And it goes back to the same idea of, I need to reliably get my chair fixed, or I need to know that I have basic healthcare needs before I need to worry about a bionic leg or an exoskeleton or something like that. So it's really important to make sure that you're including people in these discussions that have disabilities. That inclusive decision making is crucial, and it's the central tenet of nothing for us without us. You need to be a part of that. You need to have a voice in that. And sure, there's perhaps well-meaning scientists out there who are interested in creating this and that with the idea that, well, these people must want to be "fixed". Well, have you spoken to "those people"? Do you know what they really want or is this because you want it?

Jodi Beckstine (37:40):

Yeah. So what role does this lived experience play, do you think, in shaping the ethical framework?

Keith Casebonne (37:49):

Yeah. The lived experience is crucial. I don't think anybody can truly claim to know what anyone else is thinking. And that goes beyond disability, honestly. So many times people are like, "Yes, I know exactly what you're thinking there." You don't. I don't think anyone really does. And in this case, it's just even more crucial and important when it comes to essentially making decisions for others on the idea that you know what other people want. Now I will say what was interesting is a couple of the people who were pro technology and pro enhancement were people with disabilities. And one individual, I think he was an engineer, and unfortunately I don't remember his name. I didn't do as good job as you writing down the names of these people, sadly. But he was all about creating these advanced artificial legs that he could use to mountain climb and play sports and do all sorts of different things. I think he was a below-the-knee amputee, and that's what he wanted. Well, okay. This is the other thing that makes this tricky is not everyone ... The community of people with disabilities is a huge, vast community. It's one of the things that makes the disability community so unique is that they're made up of different races and backgrounds and genders and ethnicities and religions and etc. And so they're still going to be a variety of wants and desires and needs in that group.

(39:39):

Now, I will say too, that engineer, maybe he's ... I don't know, they don't say this in the documentary. But maybe he makes a lot of money and has incredible insurance and all that stuff's covered for him so now he can focus on these bionic legs and constantly improving them. Hee talked about getting software updates once a month. And I was just like, that annoys me on my computer. I can't imagine if my legs needed software updates. So maybe he's had these other needs met, but there are plenty of people who don't have good insurance, don't have good healthcare. Not long before we started recording this, we have some impending changes to Medicaid coming that are going to infect a ton of people. And that's the stuff that I think that majority of people with disabilities are worried about because unfortunately, they also mentioned this in the documentary, disability has a link with poverty, unfortunately.

Jodi Beckstine (40:33):

Absolutely.

Keith Casebonne (40:33):

And it just makes enhancement very unlikely. So I'm getting off the topic of the question in a sense, but the idea that lived experience, it does shape what people really, truly want. But it's interesting to see in this documentary how it does still vary. There is still a variation throughout the range of people with disabilities. It's just I think those basic needs need to be met first.

Jodi Beckstine (41:03):

Yeah. It's where they fall on the spectrum. One thing that I noticed is they were doing these cutaway interviews with people that I am absolutely assuming are able-bodied talking about what enhancements they would get. I want to fly. I want transport. I want to do all these things.

Keith Casebonne (41:22):

I want a camera in my eye so I can take pictures. I'm just like, okay. Yeah.

Jodi Beckstine (41:26):

And then if you were to ask those same people ... And it goes back to what you were saying, "I just want my wheelchair fixed." There's such a spectrum of wants and needs, and I think the documentary did a good job at showing that even if you are somewhere in a different part of the spectrum in your views, they did really well at showing that. How do you think the film modeled good inclusion?

Keith Casebonne (41:56):

Oh, I think it did a great job modeling inclusion. Again, there was such a wide variety of voices, journalists, scientists, engineers, but also advocates, attorneys. And it was just a broad range of voices that would have real compelling interests in this subject and how it should move forward, or who is this really for and so on. So yeah. The representation and inclusion I thought was really incredible. And they even did a really great job. Like I mentioned, the individual with a disability who was an engineer and loved the idea, there was another individual with a disability who was also a scientist. I think he was a biochemist. And he was completely against it. He just was like, "That's just ... No, I don't need that. I get around just fine." So again, I think they really did a wonderful job finding that really broad array of voices, and it shows that there is no answer. Really there's no easy answer. We can't just say, "Well, we've decided this is good for people with disabilities, or this is absolutely not good people disabilities." I think if anything, if you the listener, watch this and we really hope you do, it'll just create more conversation and more thought and keep the conversation going on this topic, which I think is really important.

Jodi Beckstine (43:29):

Yes. Definitely.

Keith Casebonne (43:32):

As we just alluded, Fixed doesn't tie everything up with a bow, and that is part of what makes it so powerful. It really leaves us asking what kind of future are we building and who gets to decide?

Jodi Beckstine (43:44):

You can watch Fixed: The Science/Fiction of Human Enhancement through educational streaming platforms and some libraries. It's also available for purchase via the filmmakers website at fixedthemovie.com.

Keith Casebonne (43:55):

Whether you're a technophile, a skeptic, or somewhere in between, Fixed is a thoughtful, accessible way to start some big conversations about ability, identity, and ethics. Well, that's it for this episode of Disability Deep Dive. A huge thank you to Katie Hasson for joining us and helping us unpack some of the biggest ethical questions at the intersection of disability, biotechnology, and reproductive justice.

Jodi Beckstine (44:23):

Katie brought so much clarity and depth to a topic that's often complex and overlooked, and she really reminded us how important it is to center disabled voices in those conversations about the future.

Keith Casebonne (44:34):

Yeah. She did. If you enjoyed this episode, make sure to subscribe. Leave us a review and share it with someone who'd benefit from hearing it.

Jodi Beckstine (44:41):

You can also learn about the Center for Genetics and Society at geneticsandsociety.org. Thanks for listening, and we'll see you next time on Disability Deep Dive.

Announcer (44:51):

Disability Deep Dive is produced by Jodi Beckstine, Keith Casebonne and Disability Rights Florida. Florida's Protection and Advocacy Agency. You can learn more about the services we provide, explore a vast array of resources on a variety of disability-related topics, and complete an online intake at disabilityrightsflorida.org. Any comments about the podcast can be sent to podcast@disabilityrightsflorida.org. Thank you for listening to Disability Deep Dive.