Thank you. I first want to thank Dr. Shi-raishi, Dr. Hoshika, and the staff of the Center for Barrier Free Education. And I also want to thank all of you for coming here today.

Dr. Ishikawa gave us a very inspirational keynote speech, and I am not sure if I can quite follow in his footsteps, but I want to talk about something which has been a central part of my research and my research interests for a while, and that is the intersectionality of disability and sexuality.

As Dr. Shiraishi said, anthropology is the study of human variation, and as such, disability and sexuality are part of the natural human variation that all human beings have. And so studying disability and studying sexuality has to be fundamental to a good understanding of what anthropology does and what the human species is.

Today I want to talk about disability and sexuality in a very sort of broad landscape, and my talk today will have two components historically. One is what I call the first wave of disability and sexuality studies. And this is where people were first starting to think of what happens when we add the consideration of sexuality into disability. Then the second wave becomes, what happens when we think of disability and sexuality as intersectional identities? How do they combine? What are some of the more complex ways that identities emerge when disabilities combine with sexualities?

So let me move to my first part where I am talking about the process of reclamation—the recovering of sexuality within disability. Now in 2006, I think many of you saw the film “Babel”—within the film there was deaf teenager played by Kikuchi Rinko who had a very sexualized identity. There is a very pivotal scene where the police detective investigating a crime comes across Kikuchi Rinko's character, and she's naked. And it's surprising I think for many non-disabled viewers because this idea of, “Oh my gosh, a deaf teenager might have her own sexuality, might have her own sexual needs.” And yet, why is this surprising? Why should it be surprising? There are many teenagers in the audience, right, and I think they will all tell you that they have sexual needs and desires. And so deaf teenagers as well would have that; it's obvious I would think. And yet it isn't. The filmmaker relies on that, relies on that feeling of surprise among the viewers.

And so I would like to make the obvious argument that, as a human species, we have many needs and desires and including sexual ones. And within that sphere, that people with disabilities (PWDs) are also human beings, and as human beings, have also a broad range of sexual needs and desires.
Again this should not be surprising, but it still is. Right? So I’m using a bit of set theory, and it’s in your handouts, that within the broader scope of human beings, people with disabilities are human beings, and what applies with the larger set also applies with the smaller.

And yet when you look historically, people with disabilities have consistently had sexuality denied to them. You can go back to the eugenics movement of the late 1800s to 1900s and see this in full force: the full diminution of people with disabilities through various strategies used to treat people who are considered unfit or undesirable.

These strategies include: selective abortion, make sure that people with disabilities are not born, make sure that people who are undesired are not born. Sterilization, make sure that even if people who are born with a disability exist, that they do not propagate. Lobotomization, so that if people with disabilities, unfits, undesirables are born, that they do not have the ability to self-determination. Institutionalization, that even if people who are considered unfit are born, that they are not allowed out in public. And to this I would add the fifth one which was in full force in Nazi Germany, which was execution, so that people with disabilities or other unfit and undesirables, if they are born: let’s get rid of them, let’s kill them.

This photograph here that I have on the right is Rose Marie Kennedy. She was the youngest sister of Ted Kennedy, John F. Kennedy and Eunice Shriver. She is quite famous. She was born with, we’re not quite sure, the Kennedy family is very secretive, but she was born with either a slight intellectual disability or maybe psychosocial and emotional disability. But it is clear she acted out a lot, and part of the acting out she did was also sexual acting out.

And as a result, the Kennedy family first tried to institutionalize her, she was in a nunnery with Catholic nuns, and that didn’t quite temper her down. So when she was 24, they lobotomized her? They sliced open her frontal lobes, and that quieted her down. And it’s quite sad to think that she lived for another 75 years in that sort of zombie state.

Now this also goes on in Japan, and one of the pivotal people who has been doing research around this is Asaka Yuho, I think a familiar name to many in this audience. So Asaka-san was born in 1956. She went to the United States, to Berkeley, to study at the Independent Living Center. She came back, was one of the founders of the Independent Living Movement here. And one of the projects she engaged in, in the 1990s, was the study of eugenics movement in Japan, the Yusei Hogo Ho. And in her sampling of people with disabilities in 1993, she found that there were 22 men, 4,948 women sterilized. Her most recent book has data which is much more encompassing and includes historical data, and she notes that as of 2010, that there were a total of 16,000 people with disabilities who were sterilized under the Yusei Hogo Ho.

And even in my own work in the deaf community, I came across many women who were sterilized, who had their ovaries removed or the uteruses removed by the doctors on order of their parents. It
was a very common phenomenon. If they did not have hysterectomies, their families prevented them from getting married or having children? So this was a very real phenomenon. And this was not something that happened in the deep, dark past of the Showa. These are things that are continuing to happen. One of the really moving elements of Asaka's most recent book is she talks about her friends, her colleagues who are being told that they need to have hysterectomies in order to go into institutional care.

And it's also the case in the U.S. I want to bring up the case that hit the news in the U.S. in 2007. I don't think it is familiar to many Japanese. This young woman's name is Ashley. She was born in 1997 in Seattle, Washington. And when she was born, she was found to have profound intellectual disabilities. There was no official diagnosis released at the time, and there's still no diagnosis. Her parents and her doctors say she has the intellectual ability of a 3-month-old, but there's no explanation why that is.

Now when she was 9, her parents, in consultation with the doctors and with the permission of the medical ethics board of the hospital that she was going to decided to undergo what they called the “Ashley Treatment,” the name given to it by the doctors and the parents. This Ashley Treatment had two elements. The first element was the surgical removal of a uterus and also her breast buds. The second element was high-dose estrogen therapy, which was designed to stop the growth of her bone structure, right, to prevent her from growing any larger. The overall goal was to keep Ashley in a 9-year-old's body in every way, in terms of her physical size, so she would not grow any larger than what a 9-year-old might have in terms of body size, that her breasts would not grow any larger than what a 9-year-old girl might, and that she always remain pre-menstrual.

Now her parents put out a statement, and they have a website where you can read about their explanation of the Ashley Treatment. The parents say that it was not for their own convenience that they did this. It was really because they wanted to improve Ashley’s quality of life. And I'm not sure if the simultaneous translator can relay this but my voice is dripping with irony. I am not a big fan of these parents.

Now this is another diagram that they pushed. They call her their “pillow angel,” which makes me think of a toy company coming out with a series of pillow angels. It sounds like a product rather than a human being. But they went for the pillow angel treatment. The parents respond to each element of a counterargument. Why did they remove her breast bud? Well, they did not want to have her to have large breasts, because large breasts are really uncomfortable. Her mother, her grandmother had large breasts, and who would want large breasts? So let's remove it. That was the primary goal: comfort. A secondary goal was they didn't want her to be sexualized by her caregivers and maybe have sexual harassment.

The hysterectomy was also because, well, what women here wouldn't want to be done with the trouble of having a period? And since Ashley's never going to have children anyway, why deal with a
period? Why don’t we get rid of that for her? And then the sizing, to keep her as a 9-year-old body, well, it makes her more mobile. If she is lighter, she can go more places.

So you can see the types of explanations that the parents are using. If any day you want something to get angry at, just go to the parents’ website and keep reading. It is a sure way to get really pissed off with the world.

Now what’s surprising to me being on a university ethics board is that the ethics board allowed this. This is the ethics board explanation [see sceren]. At some level, I can understand the parents. The parents are in a very difficult situation, America has really horrendous national healthcare. But the ethics board allowing it? This is unbelievable to me.

This is what the ethics board director said: “Many profoundly disabled children are traumatized by menstruation. They don’t understand why there is blood coming from that part of their body. Ashley is a little girl who has always had experience of being terrified of blood.”

Absolutely astounding. But again this is the same argument that I see when I am reading Asaka Yuho’s work when she’s talking about her friends with cerebral palsy going into institutions. They are also being told, “we can’t give care to someone who is menstruating. So let’s just get rid of your uterus. You won’t use it anyway, right?” Absolutely incredible.

Now, unfortunately, or I should say fortunately, in the wake of this incident, the doctors at this hospital (perhaps feeling very good about themselves) had the sheer audacity to publish their results in a medical journal. And there was an outpouring of media as well as disability activists against them. As a result, Washington State did an investigation and found that it was a violation of state law, you cannot remove the reproductive equipment of a person in disability without a court order. But no criminal complaints were ever filed, which I think is a travesty. Perhaps the only justice, and it is only justice if you believe in a God who is in heaven, is that the doctor who did this surgery committed suicide just as all of this was coming into the media’s attention.

Okay. So let’s go back. So this notion that people with disabilities might have sexuality still seems somewhat foreign to nondisabled people. Now, very fortunately, the United Nations Convention on the Rights of People with Disabilities fully recognizes the rights of people with disability to marry and have children and to maintain their fertility. And I’m really glad that they managed to include that, although they don’t include words about the right to have a sexuality, right? It’s still very mechanistic and conservative here.

And that’s why I want to get into this second aspect of when we’re still talking about reclaiming sexuality. Many of you know of this book that came out in 2004, “Sex Volunteers,” about sex workers and volunteers for people with disabilities. I was looking at independent living movements in Japan at the time and remember everyone being very shocked about sex volunteers. It was sort of a dirty
secret that some of the men with disabilities would use their personal assistance to go to soap lands.
Now, in the wake of that, we now have things like barrier free sexual delivery health (which I am not sure is quite within the scope of the Center for Barrier Free Education). And following that first book, other titles such as [Japanese] “I’m a Health Delivery Girl for People with Disabilities,” have come out.

So we move from a notion of sexuality in the terms of basic reproductive freedom, reproductive justice, to a more advanced understanding of sexuality in terms of sexual desire and sexual pleasure.

There’s a 2005 film in the U.S. called “Murderball.” It’s about the American wheelchair rugby team. And these guys are real athletes and real jocks. Most of them got into accidents such as they were driving in their truck while drunk and hit a tree, and that’s how they ended up in a wheelchair. But they retained a real sense of being a jock, being an athlete. And I had real trouble translating this into Japanese, but most of them are “assholes.” I don’t know how quite you say it in Japanese, but most of them are real bigots and jerks. They get very misogynistic, and they talk about wanting to get laid, have sex and so forth, right? They retain all of that masculine sexual desire, which again shouldn’t be surprising. There’s nothing about being in a wheelchair that suddenly means that you’ve lost your masculinity (or become a better person). But again it still seemed surprising to some people. I mean, that was the point of this film, was to go over that barrier, saying, “men in wheelchairs still remain men.”

But wonder why I want to ask, is this the best that we can do, right? Is approximating, approaching normal society the best we can do? Is getting misogynistic disabled men? Is getting delivery health services for people with disabilities? Or is this getting these passive women who are just waiting for their sex volunteers to come each week? Is that the best we can do? Or can we dream more?

Intersectionality Theory

And that’s where I want to approach the second part of this talk, by looking at a combination of disability and sexuality in more complex ways. And it’s here that I want to bring in what’s called intersectionality theory. Intersectionality theory came out of critiques of second wave feminism in the United States.

Second wave feminism was the movement that came really out of the White middleclass women’s experience. But as it started to gain force, other women started to ask about some of its principles, namely, African-American women and third-world women starting to ask: does the experience of White women really stand in for everyone else? Aren’t there more complexities that come out when someone is an African-American woman that are different from being a White woman?
And so the creators of intersectionality theory—Kimberle Crenshaw and Patricia Collins—said, no, actually things are much more complex. A Black woman isn’t simply all the problems of a Black person plus all of the problems of a woman. The two, combination of the two will interact. And you need to understand that these identities and categories interact in complex ways.

Using that set diagram I showed before, that the intersection of C between these two categories A and B isn’t simply A plus B, right? It’s much more complex than that, that the C is somehow fundamentally changed by benefit of being at that intersection. It’s not simple addition. So this diagram, it’s not being a Black plus being a woman plus having a disability. It’s a combination. Somehow it’s a combination of Black women and disability who interact; all three will be fundamentally changed.

And this is where it fits into nations of queer theory, that also seek to ask the question about categories. So within academic queer theory, we have a fundamental critique, an analysis and critique, of normativity, of categories, of notions of compulsive heterosexuality, or what you might consider, what’s the normal and ideal way that human beings are supposed to interact sexually.

Queer theory asks, critiques, and challenges the artificiality of categories, saying that we need to understand that very categories A and B themselves are artificial. They’re created. There’s nothing essential or natural about them. So whether those categories are male, female, whether those categories are heterosexual, homosexuality, those are artificial categories. We can understand them historically. And this understanding needs to come through to understanding the processes that are going on externally, historical processes, institutional processes, social processes, as well as internal processes. How is it that people are coming up with these notions of identity?

And within queer theory, the academic links very strongly with the activist side. So that we take these notions of artificiality of identity and then try to move those deeper concepts into actual work in the world. So, how can we creatively destabilize norms? Or to use the somewhat dirty language of queer theory, how can we engage in gender fuck, in gender queer and other notions at play.

Importance of PLAY

And it’s this notion of play here that I think is very important. Play, “asobi,” right? That I think really lies at the fundamentals of what queer theory allows us to rethink what we can do. Let me think out loud about play, and especially play in terms of sexuality.

All of you think back when you’re 18, or if you’re not 18, think four, two years ahead till when you will be 18. Think when you first had your first boyfriend or girlfriend, and you spent one of those really long afternoons just really playing with each other, sexually playing, right? The exploration of
each other’s bodies and thinking of all the potentials that you could do, right? Do you remember back to those days when sexual plays seem to contain infinite possibilities, right? You had never thought of your little finger being a sexual organ or ear being a sexual organ. But it was through play that you suddenly had all of those possibilities opened up, right? Nothing like love to really give you a new outlook on life. And it’s that notion of play that expanded your notion of what your body could do. I want to get into that.

Now when you look at inter-sexualities of what, I am changing the language here, crip or gimp politics and queer identities can result in.

The first woman I want to introduce is Aimee Mullins. And she wants us to rethink disability, moving from disability to augmentation. In doing that, she wants us to rethink beauty and destabilize notions of normativity. And this is a small film here from the TED conference I want to show you.

[Start of Video Presentation PartI]

Aimee Mullins: I was speaking to a group of about 300 kids ages 6 to 8 at a children’s museum, and I brought with me a bag full of legs similar to the kinds of things you see up here, and had them laid out on a table for the kids. And from my experience, kids are naturally curious about what they don’t know or don’t understand or is foreign to them. They only learn to be frightened of those differences when an adult influences them to behave that way and maybe censors that natural curiosity or reins in the question-asking in the hopes of them being polite little kids. So, I just pictured a first grade teacher out in the lobby with these unruly kids, saying, “Now, whatever you do, don’t stare at her legs.”

But, of course, that’s the point. That’s why I was there, I wanted to invite them to look and explore. So I made a deal with the adults that the kids could come in, without any adults, for two minutes, on their own. The doors open, the kids descend on this table of legs, and they are poking and prodding, and they’re wiggling toes, and they’re trying to put their full weight on the sprinting leg to see what happens with that. And I said, “Kids, really quickly – I woke up this morning, I decided I wanted to be able to jump over a house – nothing too big, two or three stories – but, if you could think of any animal, any superhero, any cartoon character, anything you can dream up right now, what kind of legs would you build me?”

And immediately a voice shouted, “Kangaroo!” “No, no, no! Should be a frog!” “No. It should be Go Go Gadget!” “No, no, no! It should be The Incredibles.” And other things that I don’t aren’t familiar with. And then, one eight-year-old said, “Hey, why wouldn’t you want to fly too?” And the whole room, including me, was like, “Yeah.” (Laughter) And just like that, I went from being a woman that these kids would have been trained to see as “disabled” to somebody that had potential that their bodies didn’t have yet. Somebody that might even be super-abled. Interesting.
Today, I have over a dozen pair of prosthetic legs that various people have made for me, and with them I have different negotiations of the terrain under my feet. And I can change my height; I have a variable of five different heights. (Laughter) I have an entirely new relationship to door jams that I never expected I would ever have. And I was having fun with it. And she looked at me, and she said, “But, Aimee, that’s not fair.” (Laughter) (Applause) And the incredible thing was she really meant it. It’s not fair that you can change your height, as you want it.

And that’s when I knew—that’s when I knew that the conversation with society has changed profoundly in this last decade. It is no longer a conversation about overcoming deficiency. It’s a conversation about augmentation. It’s a conversation about potential. A prosthetic limb doesn’t represent the need to replace loss anymore. It can stand as a symbol that the wearer has the power to create whatever it is that they want to create in that space. So people that society once considered to be disabled can now become the architects of their own identities and indeed continue to change those identities by designing their bodies from a place of empowerment. And what is exciting to me so much right now is that by combining cutting-edge technology—robotics, bionics—with the age-old poetry, we are moving closer to understanding our collective humanity. I think that if we want to discover the full potential in our humanity, we need to celebrate those heartbreaking strengths and those glorious disabilities that we all have. I think of Shakespeare’s Shylock: “If you prick us, do we not bleed, and if you tickle us, do we not laugh?” It is our humanity, and all the potential within it, that makes us beautiful.

[End of Video Presentation]

As you can tell, Aimee is very striking. And what’s interesting to me is, do you guys remember the Beijing Olympics? There are two really interesting things that happened in that Olympics. One of them was this question of a trans or maybe inter-sex person who people were debating, should she be allowed to perform as a woman?

And the second was Oscar Pistorius. He is wearing the same cheetah legs that Aimee does, and he was surprising because as a member of the South African running team, he was reaching speeds on his cheetah legs that almost made him Olympic qualifier. And the Olympic Committee, the IOC was terrified, what would happen if a person with disabilities was running just as fast or even faster than non-disabled people? What if he wouldn’t stay in the Paralympics as he was supposed to as a nice little boy, what happens if he wants to run in the Olympics? And they were terrified. Fortunately for the IOC, Oscar did not make the qualifiers, and then they tried to do some sort of ruling to say that the cheetah legs were an invention which were not allowed under their rules, because they had springs in them. But I still find very interesting that once a disabled person starts to approach or even go faster than non-disabled people, that people start to get very, very worried.

Now there are people in Japan who are also thinking about the intersectionality of disability and sexuality. As I mentioned before, Asaka Yuho is definitely one of them. If you get a chance, read her
I would like to introduce another one girl from the United States, or actually she’s from Canada, Jes Sachse. Jes is trying to, in collaboration with a photographer, Holly Norris, really get us to think about the visual representation of bodies, especially in advertising media and what they say about normality.

Now, together with Holly Norris, Jes put together a fake advertising campaign. There’s a brand in America called American Apparel. It is sort of like Gap, same sort of trendy clothes. And Jes and Holly put together their own fake advertising for American Able where they took the American Apparel clothes and put them on Jes’s body. And the campaign is just great.

Now I want to give American Apparel a lot of credit, because I think many companies, if they were faced with this type of spoof campaign, would send out their lawyers to try to close it down. But instead, American Apparel thought this was fantastic, thought it was great, thought it was a lot of fun, and actually helped co-sponsor this exhibition. So I think it’s great for them.

I want to show a short video where Jes talks about why she’s doing the type of work she’s doing, especially in terms of posing naked.

[Start of Video Presentation Part II] You do not have to be good. You do not have to walk on your knees for 100 miles through the desert repenting. You only have to let the soft animal of your body love what it loves. Mary Oliver. Body language. By Jes Sachse.

“Since the day my spine was fused as a child, it has been resisting beneath my flesh. I decided to pose naked on this crane. I was and I am just like you. I feel, I laugh, I love, I grow. When you tell me that I’m brave, don’t believe I’m not scared. I was scared that day, the day I tore my clothes off and started taking pictures.

To understand, you need to know that I never did this: let you see me naked. I never let me see me naked, but I needed to find what everyone was staring at. So that day I looked, hard, long, frame after frame. Alone, scarred, beautiful. Are you scared? I’m scared each day I try to love myself completely.

To understand, you need to know that this is everything. I want you to be scared. I want you to look at these photos and see you, and I want you to imagine loving it all, every mole, every scar.”

The final photograph closes in on an image of a tattoo on her chest: an outline of a heart and a ribbon with the word crooked.
For Peterborough. Envisioning New Meanings of Disability and Difference. A Partnership Project...
[End of Video Presentation]

Now there are some other interesting people that I wish I had time to talk about. One of them is Eli Clare who is an FTM, female-to-male, trans activist as well as a person with disability. Does very interesting work. But I don’t have time. But Eli would say, we need to get into a conversation about normal and ideal bodies, and how, whether it’s a queer body or it’s a disabled body, these are disruptive.

One example I want to use is: I notice that even here that there are three bathrooms, a female bathroom, a male bathroom and a disabled bathroom in the middle. What does that mean? Does that mean that people with disabilities are neither male nor female, that there is some sort of third gender?

One of my friends, Kojima Naoko who is in this audience has really in a wonderful book, a very provocative title, “Please Allow Me to Shit from My Mouth.” Because she talks about that being in a wheelchair, she has to plan her day (and I think many people in a wheelchair feel the same way) around accessible bathrooms. Bathrooms – the conventions of the bathroom and what it represents, how they are made – represent normalized and ideal bodies. What is interesting to me is to talk to my friends who are transsexual or to talk to people who are inter-sex, who don’t look normatively male or female, and to find that they have the same problems surrounding bathrooms.

There are some other interesting people, and I’ve given short descriptions on the sheets that you have: Mia Mingus, Bethany Stevens, Margaret Pfizer [ph], also doing very interesting work. But perhaps I’ll talk about them another time and about the projects that they are also engaging in to make us think about how disability and sexuality together give us a much more productive feel.

Now, I want to close my talk with a call to arms, and if you don’t have arms, other body parts. Okay. So I want to argue that the crip and the queer movements are inherently intertwined, that our movements are fundamentally about non-normal, nonideal bodies, and non-normal and non-ideal desires. And that’s great, and I think that is something that we should celebrate. And our solutions are not going to be mirroring normativity. Trying to approach normal is a dead-end solution. We need to figure out how we can destabilize the normal. We need to figure out how we can go right past normal and go in our own directions.

And how can we do this? And this is why I want to get back to that original notion of play. Let’s play. Let’s have fun. Let’s really figure out what our bodies can do, what potentials lie within our minds. And use that as a new expansive direction. I think part of the problem with the disability movement is that we’ve been much too serious up to now, and it’s time for us to not be serious and to really guffaw.
So my call out to all of you is please go home and play. Play with yourself, play with your partner. Play with other things.

And this ends my talk in thinking back to a last interesting person that I want to introduce to you, is you. That really this talk and I think the whole notion of the Center for Barrier Free Education can’t be about the educators, it’s partially about the students, but it’s really about you. Right? Everyone in the audience, all of the sort of potential audiences that this material might have. That if we’re going to change society, we need to be able to change your perspectives, right? You can’t be passive audience members. And I want you to ask, is there any way that you could take all of the areas that are considered abnormal and really try to move beyond them, to try to move to something that is more than normal? Thank you.