

BARNARD CENTER FOR RESEARCH ON WOMEN

THE SCHOLAR & FEMINIST CONFERENCE XXXVI

MOVEMENTS: POLITICS, PERFORMANCE AND DISABILITY

SATURDAY, FEBRUARY 26, 2011

Janet Jakobsen: I'm Janet Jakobsen. I'm the Director of the Barnard Center for Research On Women. And I'm here to welcome you to this, the 36th Annual Scholar & Feminist Conference.

The Scholar & Feminist Conference, our annual conference, began in 1974 as a means of bringing together the best of academic feminist work and contemporary activism.

And we believe that this issue not only intersects with feminism, but displays precisely those important connections between academic scholarship and activism that are so crucial to what has made the Barnard Center for Research on Women, so important for nearly 40 years now.

So we're very happy to be able to do a full conference on Feminism and Disability. It is true, however, that sometimes these issues of activism are close to home, as well as in the broader world. And in this case, the question of the

relationship between feminism and disability is one that has been raised with some urgency in recent years here at Barnard.

As a women's college, Barnard has a long history of feminism, and we also have a relatively long history of commitment to accessibility for disabled students, faculty and staff. This is due in large part to the efforts of Julie Marsteller, who here at Barnard, became the first full-time Dean for Disabled Students in the United States.

And the campus was, for some time, a true leader for making college available and accessible to students with disabilities. In recent years, however, we seem to have lost our focus on disability access, openness and integration. Decisions have been made about both buildings and events that have not taken these questions fully into account.

And the members of the BCRW Advisory Board, along with the members of our Conference Planning Committee and many, many members of the Barnard community -- feel that it has come time to revive both our history and our focus.

In other words, we need to find a way to make this history not a record of past accomplishment which allows for current neglect. But rather, a living history that will provide a source of inspiration and motivation for those attending to these issues now and into the future.

And in order to do this, we joined forces with our good friends at the Columbia Oral History Research Office, and with long-time feminist and disability activist, who I'm sure many of you know -- Ynestra King.

And we produced a few oral histories of women who have attended Barnard and Columbia. There is no better way to make history live, so to speak, than to do it live. One of our lunchtime workshops will focus on the oral histories with both Ynestra and Mary Marshall Clark, who is Director of the Center.

And that will be in this room, if you want to learn more. But I want to show you clips from three of the oral histories. One is a video-audio clip. And two are slide shows with audio.

First, however, I do want to say a few words about Julie Marsteller because without her, we probably would not be here at Barnard today. She spent a good deal of time thinking, although not just thinking about women with disabilities.

She saw that women with disabilities faced gender-specific issues, and these are now her words from the 1970s: "I think women with disabilities are doubly disadvantaged. Women's salaries tend to be lower. Disabled women's salaries are particularly low. But also, expectations of disabled women can be lower than expectations of disabled men. I think that had I been a male child and not a female child, we wouldn't have waited until halfway through my senior year in high school to

decide what to do about college. There just would be an expectation that a man is going to do something."

And "do something" is precisely what Julie Marsteller did. She graduated from Barnard in 1969. Served as Assistant to the President of Barnard. And she applied for the first grants for wheelchair accessibility. She also served as the College Archivist. And in 1979, became Dean for Disabled Students.

She was the first Chair of Barnard's ADA Access Committee, and founder of the Office of Disability Services. As you will hear in the oral histories, during the time that Julie Marsteller worked at Barnard, and directly afterwards, our campus had a standard for access.

And students with disabilities, including Julie herself, often transferred to Barnard because we could better provide access to education -- than many of our peers.

Over the course of the decades between 1979 and now, Barnard -- and I think probably Barnard is not alone in this problem -- has had a mixed record on the needs to create better and a more just world for all people, including those with disabilities.

Our institution has acted in ways that are both encouraging and sometimes frustrating. We have acted sometime with a clarity of purpose; and sometimes in a manner that is neither sharp and focused, nor clearly well thought-out.

So in the videos we hear some histories of what it was like to be a student at Barnard and Columbia, about some of these frustrations, and about the up-and-down path that leads to social justice. We begin with Simi Linton, who as you know, helped us plan this Conference, and who will introduce the dance in the afternoon. So you will all get to meet her in person.

[Transcript of film clips]

### **Simi Linton, author and filmmaker**

Simi introduces herself:

I'm Simi Linton. I am, depending on the day of the week, a writer, and consultant, and filmmaker. I'm working on a documentary film right now called *Invitation to Dance*. The narrative arc of the documentary is based on my life experiences as a disabled woman over the last 40 years. It traces both my own development and growth into disability as an identity as part of who I am, as at the same time, the disability rights movement, and the disability arts and culture movement, and disability studies were evolving. We're looking, in the film, at the intersection of my life and experience and those movements, how they have influenced me, and how I have had an impact and engagement with them. The focus of this inquiry, this path, is on dance as a coming out narrative, as an expression-- creative expression-- and as the sort of anti-stereotype way of thinking about disabled people, as joyful, as creative, as using our bodies in unexpected ways.

Simi takes defining class at Barnard with Mary Brown Parlee:

So I didn't understand how to think about disability and disabled people as a constituent group. I didn't have a basis and a way of thinking about it. But in my last year here, there were two things that helped. One was that I took a class over at Barnard in psychology of women with Mary Brown Parlee. I told her that I was interested in disabled women and

our experience. She was very enthusiastic, and I did-- you'll be happy to know-- three oral histories focused on disabled women and sexuality in that class in 1977, I guess. I have that paper somewhere. I started to talk with other disabled women about their experience. That was very meaningful.

Simi on feminism, disability, and the opposition to pleasure and aggression against people with disabilities and women:

If we think in terms of feminism, when we talk about women on pedestals and what is horrific about that, is this idea that men weren't hurting women. They were taking care of women. Until we unearthed what was aggressive about that, the domination of men and the aggressive impulses of men to contain is to protect men from women, from real women, but the real feelings and emotions. I think when we think about institutionalization or care and cure kinds of agendas, some of it is to help disabled people be more comfortable physically, and to have opportunities, and so forth, but a lot of it is to do it in a very contained way that is primarily about protecting the non-disabled majority from the real us, our real force and will.

Otherwise, I don't think you would see a brand new building where the wheelchair ramp and entrance is off to the side in a less elegant, a less felicitous, a less bright, a less integrated way. I think that's a mark of aggression. I think we have to start labeling it as aggression. That's where I've landed in my thinking. That's why dance seems to me the ultimate frontier and the ultimate barrier against that kind of oppression and aggression.

**Dr. Sui Zee, Chief of Pathology, Stonybrook University**

I was born in '63, and I had polio when I was one. This was all in Hong Kong where I was born. So I grew up in Hong Kong until I was about ten. Then my parents immigrated to the United States. So the polio basically left me without any use of my legs. So I'm a palaplegic. When I first came here-- it's kind of a funny story-- at that time in 1975, I had three siblings. There were four of us. My father got a call from school that said, we saw that you have four kids. How come there are only three is school? So it was funny because they didn't realized that I had to go to school. Because when I was in Hong Kong, I was home tutored, and I didn't go to school basically.

So then he said, oh I didn't realize she can go to school. Of course she can go to school. I think that was the year they'd passed some kind of law saying that everybody, regardless of disability, has to go to school and was also enabling people with disability mainstream into the classroom. I think that was the basis of the law. Because at that time, my husband was in a special school. He was in a special school for people with disabilities.

So when I get to Barnard, the Office of Disabled Services was great. They were very helpful and supportive. Also there were other people in chairs that I can relate to. One of people was Julie-- I forgot her last name-- but she used to work for the Office of Disabled Services before she passed away. So that was very helpful for me. Susan Quinby of course, she was a real supporter. Again, I was happy to be able to concentrate on my studies without having to worry about how I am going to get there.

Dr. Zee was the first paraplegic admitted to Einstein Medical School. Here she talks about how it was to enter training, without a history of role models:

So when I went into Einstein, they were very direct. They never had anyone in a chair before. So they said, well how you going to do this? How are you going to do that? I said well, there's always more than one way of doing something. I don't remember exactly what kind of things they were asking me, but I think I gave them up a positive outlook in the way that I would do things, and that I am able to do it. At that time, I felt I was able to.

They were reluctant, because I think they never had anyone in a chair before going through medical school. So I was waitlisted, and that means that they would say, well if there's a position that opens up, you're in line. A couple of weeks later, they accepted me. So that was a high point of my life.

### **Chai Feldblum, Commissioner of the Equal Employment Opportunity Commission**

Chai on identity politics, equality, and justice:

This is the whole point about identity politics versus post-identity politics. I personally am a believer in identity politics, in the sense that we need to have a sense of a group that we belong to, in order to create some sense of stability, "us-ness," who we are, what matters to us, what our values are. But in terms of true justice in the world, we have to break down the us and them divisions. But breaking down us and them divisions doesn't mean having no sense of identity. It means having a sense of confidence and pride in your identity, and then recognizing that someone else with a different identity, a different set of make ups, is of equal value.

That's why my whole "Rectifying the Tilt" article is about recognizing that equality is not just treating everyone the same. Because we're not all the same to begin with. Instead we have a dominant culture that sets some normative assumptions, and if you're different from that, and you're treated the same as everyone else, you're not going to be treated equally. You're not going to be treated as I call it, as an equal. Treated with equal dignity. So everyone can come into the building. Everyone is treated the same. The building has steps. Everyone is treated the same. By definition, if you were building that building with steps, you are not seeing everyone who's in society. Because if you did, and you were committed to treating everyone as equals, with equal dignity and respect, you would never build it with steps. Because that means someone using a chair can't come in.

Chai refers to her anxiety disorder:

So now I'm at Harvard. So what was I coming to Harvard as? I was coming as someone who had at least some awareness of sex and sexuality. But not a deep sense of it. A sense of identity that was still very much around performing, producing, and performing and producing around justice and making change. It was someone who had no self-awareness of herself, as a person with a disability yet. That is, as a person with anxiety disorder. No clue. My anxiety disorder simply manifested as productiveness, as energy. So I was a very energetic, very lively, and I had never failed yet. So for someone with anxiety disorder it can kick it when you fail, if again your sense of self is around producing. So none of that had happened into law school.

Chai on love, sexuality, and integrity:



So I performed well, did well. There I am on law review. So my third year in law school. I'm on law review. I'm dating a guy, also on law review. And then someone else from law review, whose name I won't use just because hopefully these things will be seen by some people. And I'm totally attracted to her. She's completely butch. And so I say, oh let's go to dinner. She's also dating this totally cute guy on law review. So we go to dinner, and we're talking, and then I say, so have you ever thought about women? Dating women? I felt let me ask that in a more general way first. And if it's yes, then we can start talking about a specific woman that maybe she might be interested in. So what do you think about women? She goes, well, yeah I thought about that. I could see that, but you know what, I could be with guys, and I can be with women. And being with guys will be better for my career.

I remember, it's like literally my jaw dropped.

Simi on dance as coming out:

What I realized, is that in the early days of disability in terms of my professional focus, is that I was very interested in sexuality, in the personal expression of pleasure and freedom. What I came to was that the personal expression of pleasure and freedom, and the private expression of pleasure and freedom, was made manifest there on the dance floor, that it is a coming out. I could still pursue the social justice and lustiness drive, but I could pursue it in a way that also had a lot of creative excitement for me.

Janet Jakobsen: So that is what we intend to do today.

Pursue the social justice and lustiness drive, and we hope to have a good time along the way. Thus it is my distinct pleasure now to introduce the moderator of this morning's panel.

Rosemarie Garland-Thomson, who we had the pleasure of hearing from yesterday at Columbia University, and who will both moderate and respond to this panel.

And I also want to invite the panelists up at this time. Rosemarie Garland-Thomson is a Professor of Women's Studies at Emory University. Her scholarly and professional activities are devoted to developing the field of disability studies in the humanities, and in women's studies.

She's the author of many, many books, which for the sake of time, I will not name. But most recently, *Staring: How We Look*, from Oxford University Press, 2009. And she's working on a book that is called *Cure or Kill: The Cultural Logic of Euthanasia*, which traces eugenic thought through American literature.

Rosemarie Garland-Thomson.

(applause)

Rosemarie Garland-Thomson: Good morning. Thank you Janet, for organizing this conference, for that really marvelous set of introductory remarks; and certainly, for the ethnography of disabled women that you presented to us.

It's an honor to be here. It's an honor to moderate this fabulous plenary panel entitled "Aesthetics and Politics in Action." I would like to introduce the panelists all together here, so that you'll have a strong sense of the accomplishment and distinctiveness of these panelists, as you hear from each of them.

So, I'll introduce them in order of their presentation. First of all is Carrie Sandahl. Carrie Sandahl is an Associate

Professor in the Department of Disability and Human Development at the University of Illinois at Chicago, where she is the Director of the Ph.D. Program in Disability Studies.

She is also the Director of the new program in Disability Arts, Culture and Humanities that explores the disability experience through research on the arts and the arts as a research methodology.

Her program is the new administrative home of Bodies of Work -- a network of disability arts and culture, which is a consortium of 50 Chicago-based arts organizations, individuals and non-profits whose mission is to serve as a catalyst for disability and art that illuminates the disability experience in new and unexpected ways.

Bodies of Art is busily planning a citywide festival to take place in 2013. We will all be there. Carrie's scholarly and creative activity explores how arts contribute to the creation of disability identities and cultures, as they intersect with gender, sexuality, race and class.

She is currently working on a documentary film entitled -- this is great -- "Code of the Freaks," that explores Hollywood's fetishization of disability. Her talk today is called "The Limits of Accommodation: Ruminations on Being an Undue Burden."

You know, I think I will actually introduce each of you just before you give your presentations, which makes more sense; and I'll just use Alice's microphone.

Carrie Sandahl: All right, so my talk today is called -- "The Limitations of Accommodation: Ruminations on Being an Undue Burden."

My PowerPoint includes a lot of the text that I will be sharing with you, and I do know that it's a bit of a faux pas to read some things from PowerPoint, but I'm doing it as a reasonable accommodation for people who like visual reinforcement.

All right, so here I go. On July 26, 2010 our country celebrated the 20th anniversary of the Americans With Disabilities Act -- also known as the ADA. This civil rights legislation has improved the lives of millions of people with disabilities and their families, by increasing access to education, employment, public places, communications and voting.

But amid the celebrations and self-congratulations that were going on around me, I have many personal and professional experiences that exposed the limitations of this legislation. Primarily around the concept and the practice of -- reasonable accommodation.

Now, I am not a lawyer, nor do I play one on TV, so if you ask me specific questions on the various titles, I'm going to

have to defer to probably those of you who know a lot more about the law than I do. I'm using it in a more general sense, and as a metaphor grounded in material experience.

So what is a reasonable accommodation? In the ADA, if you look at the text, sometimes it's also called reasonable modification. So I just want to read to you from Title III. And this is from [ada.gov](http://ada.gov).

"A public accommodation must reasonably modify its policies, practices or procedures to avoid discrimination."

The next sentence is the key part. "If the public accommodation can demonstrate, however, that a modification would fundamentally alter the nature of the goods, services, facilities, privileges, advantages or accommodations it provides -- it is not required to make the accommodations."

Now, I'm going to give a couple of personal anecdotes. I have an eight-year-old son who carries multiple mental health diagnoses. He has just been kicked out of his fifth school, and it's because he's not able to be reasonably accommodated in any of the schools he's been in.

And I realize through these experiences of finding a school, him getting kicked out; finding a school, him getting kicked out -- is that the entire educational system would have to change to reasonably accommodate him. So we're in this kind of limbo with him.

The other thing, the concept of undue burden. So if modifications would cause an undue burden, and you can prove it; and again, the ADA doesn't require you to make the modification or the accommodation. And it's defined as a significant difficulty or expense.

So the limitations . . . what I found with accommodation and invoking accommodation -- is that fundamental aspects of structures of all kinds do not need to change, including attitudinal and architectural accommodations. And essentially I found that this concept separates the disability community into two parts.

We have the able disabled, which is a term we use among ourselves for those whose presence causes minimal, if any, disruption. And then we have -- this is, I'm just making this up -- the undue burdens. And I am slipping more and more into that category, and am experiencing more and more the limitations as my body changes as I age.

Robert McRuer in his book *Crip Theory*, also -- I think his concept of the severely disabled is similar to what I'm calling undue burdens. But the ramifications of this unspoken categorization in terms of professional opportunities and outcomes for artists -- is what I'm going to talk about today.

So in my research on the arts, I've found these limitations in terms of arts education and training, professional

development, art-making practices. But also, in surprising ways in how it generates aesthetic alternatives.

So what my argument is going to be today is that where reasonable accommodation ends, deep structural change begins. And that we need to crip -- which, I'll discuss later what I mean by that -- the languages and practices of inclusion to show how it intentionally excludes.

It doesn't unintentionally exclude. It intentionally excludes people with disabilities who are undue burdens. And for those of us who are involved in social justice for all disabled people, and not just the able disabled -- we need to demand unreasonable accommodations.

We need to invoke our identities as undue burdens because being a burden is what breaks the structure. I was thinking about the straw that breaks the camel's back. That would be me. So my focus today is going to be, from that list that I gave you, of different areas in the arts that I see are impacted by this limitation.

Unreasonable accommodations to artistic processes, but how those can result in aesthetic innovation? So I'm going to provide examples from three performance projects. And before that I'm going to give you a little note about language.

I'm going to be using the term "crip." For those of you who are unfamiliar with this insider term, it's a radical,

positive, resignification of a previously injurious term. And it's been taken up by people with all sorts of impairments, so it's not just describing people with physical or mobility impairments.

And it's a term we like to use with affection, with anger and with a wink. And then I'm going to be using "crip" as a verb, and you can also call it crippling. And I've written about this earlier, as has Robert McRuer. But basically, when you crip something it's kind of akin to queering something. But basically when you crip something, it spins mainstream representations or practices to reveal their able-bodied assumptions and exclusionary effects.

And it reveals the arbitrary delineation between what is considered normal, and what is defective, and the negative social ramifications of attempts to homogenize humanity. And it's irreverent.

So one thing I like about it is its political correctness. Because political correctness can mask the jagged edges, the underlying beliefs and the potentially productive fissures in any given structure.

So what I want to talk about first is -- crip time, which we've experienced already today.

(laughter)



Which is the extra time that it takes people with disabilities to perform certain tasks or do certain things because of the way our bodies, our senses are configured. And I want to talk about crip communication, which you see happening all around us here with interpreters and the captioning.

But basically, when we were creating this script for a video called the "Scary Lewis Yell-a-thon," which is a wicked parody of the Jerry Lewis Telethon, with this group called the Mickee Faust Theater in Tallahassee that I was part of. The writing team was trying to come up with a script collaboratively.

But what was happening, because of crip communication, non-disabled people who were part of the company were just getting too frustrated with us; because we weren't working fast enough.

So basically, Terry Galloway who is deaf and a lip reader, and she is up there looking like Jerry Lewis. And Lori Violette, who is playing Little Lori Little, in the chair, and I -- we got together and we had our own script development meeting.

Because the issue was, Lori has cerebral palsy, which Josh Blue would say is the sexiest of the palsies. And she has a CP accent, so Terry could not read Lori's lips. And so, what would happen is . . . and a big part of it was Lori's contribution. So Lori would say what her contribution was.

I would have to try to figure out what Lori was saying. And then, I would have to repeat what Lori was saying to Terry, so she could read my lips. And this process created so many misunderstandings, miscommunications and . . . I mean, it was hilarious.

We generated so much material about, just because we didn't understand each other, that we ended up working that material into the script. So I think a lot of times, what's considered an undue burden can actually -- it was just really funny and it was absurd.

And that tone and some of those elements we came up with, ended up being important to the script itself.

Next is what I'm calling crip comportment. And this is, to me, one of the most intractable ones that I've had at disability arts events. And this, when you have significant numbers of undue burden-type people, who are in audiences. And maybe their impairment-related behavior is considered disruptive.

So I want to talk about when I was on the board of the Center for Independent Living in North Florida, called Ability First. And we started a series of performance fundraisers. And I brought in Lynn Manning, who has a solo performance called "Weights." And he is blind. And it's significant to this story, as you'll find out.

So anyway, after his performance the board met. And we had gotten many complaints from non-disabled audience members and disabled audience members about how disruptive the audience was. We had people who came in a bus, to attend the performance who had never been to the theater before.

And they wanted to know whether this group could attend this performance because it was billed as a disability performance. We're like -- sure, come on in. And they spoke back to the stage. They were loud. They said inappropriate things during dramatic moments.

And so anyway, some of the people who we were trying to raise money from were very upset by this inappropriate behavior. And then I was mostly disturbed that some of my disabled friends on the board were saying -- well, maybe we should have two events. One where we can invite the people who are disruptive, and so . . . and so we had to show the proper face to the non-disabled community who we were trying to get money from.

And to me, the event was a beautiful demonstration of a disability community at work. And Lynn handled it beautifully because Lynn sometimes says at the beginning of a show, that -- I want to hear from the audience because I can't see you. I want to hear your feedback.

So Lynn loved it and also, he comes from a performance tradition that's call and response. So for him it was like, call and response, with disabled audience members.

So Lynn wasn't upset about this performance. I thought it was great. But to me, that was another moment where, if we're really going to create community, we need to allow some change.

So I've gotten a note that I'm out of time, so I'm going to skip my third example, but I can talk about it later. And this was about crip bodies being unreasonable with pain, stamina issues, interruptions for medical procedures and travel difficulty. But I will skip that for now.

So I want to end with a final provocation, which is -- as feminists we know the history of women's oppression based on our supposed lack of ability to reason. To be reasonable. To fit in. To not be burdens. And instead of meeting that accusation with denial, I urge you to consider the radical potential of being unreasonable. And being an undue burden so that we can make new ways of being together possible. Thank you.

(applause)

Rosemarie Garland-Thomson: Thank you Carrie. I hope we can return to some of your comments in the Q&A that we will have. Our next speaker is Alice Sheppard, who earned her Ph.D in Medieval Studies from Cornell, and was Associate Professor of English and Comparative Literature at Penn State University.

In 2005, she resigned her position to learn to dance. She studied with Kitty Lunn to make her debut in 2006 with Infinity Dance Theater at the Joyce Soho. She then joined AXIS Dance company in Oakland. She attended their 2008 Summer Institute with the Urban Bush Women Women, and the 2010 Summer Institute with Liz Lerman Dance Exchange.

She is particularly intrigued by movement that challenges conventional understanding of disabled and dancing bodies. Alongside AXIS's dance and performance schedule, Alice is at work on her second book, a scholarly work about disability and dance, tentatively titled -- and this is a wonderful title -- *Back Matter*.

Her talk today is called "Unruly Bodies in Dance."

Alice Sheppard: Most of the professional dance world claims that the architecture or forms of dancing bodies enables the gate keepers to control the dancer's type, muscle tone and weight. My paper today is about what happens when a disabled dancer encounters this discourse of bodies, movement and control. My thesis is simple -- movement is the movement.

The movement of disabled bodies undermines the gatekeeping and opens the door to a new aesthetic of moving bodies. In the dance world, diversions from the set of physical norms is not seen as difference, but as losing conformity.

In December 2010, Alastair Macaulay, *The New York Times* dance critic, remarked that one of the New York City Ballet dancers had eaten a sugar plum too many.

That performer was Jenifer Ringer. Miss Ringer is 37, a mother and a dancer who has spoken publicly about this. There was a large outcry in the disability and feminist blogospheres, and on the Huffington Post.

Back to Mr. Macaulay. Ringer appeared on NBC's Today show. Her crime, well beyond fat. Forced to defend himself, Macaulay responds by transforming Ringer's "fat" into deformity, into disability.

"My own history makes me intimately aware of what it is like to have a physique considerably less ideal than those I have mentioned." And this is Macaulay talking about dancers whom he considers deformed, fat, spinal curvature. "Acute asthma in my childhood gave me a chest deformity that often made me miserable throughout my adolescence. It was ameliorated by major thoracic surgery at age 20."

He continues: There's no link here? "On my doctor's orders I lost 20 pounds last year."

For dancers of African descent, body gatekeeping is even more personal, as Jawole Zollar notes. Chapter by chapter, she explores the restrictions on hair, feet, thigh and yes, on the

buttocks. Dance technique and the ballet technique, in particular, requires the butt to disappear.

In response, a non-disabled black dancer working in the mainstream ends up making one of the two choices. Tuck and suck. Or proudly shake it out. In response to her own standard ballet instruction to tuck, and desiring to speak back to this tradition, Jawole Zollar created "Batty Moves." And batty is the word in Jamaican English for "booty." So we're talking about butts.

Now performed by Zollar's Urban Bush Women, "Batty Moves" talks about the dancer's history, where their bat is. One by one, her dancers come forward and rap their stories about their booties.

(film clip)

Okay, it's a ground-breaking moment in dance. Scholarly analysis of "Batty Moves" takes place usually in dance or performance studies. Critics apply critical race theory or feminist frames to engage the history of women's sexuality, bodies, objectification.

Such approaches is almost universally refereed to the history of Miss Baartman, the so-called Venus Hottentot, and they point out the liberational and celebratory aspects of the work; they highlight the political message. I found only one essay that claims the black feminist disability approach.

With that regard, on Thomson's work on freaks -- a carnivalesque body is a disabled body, and it must be accepted as such without healing or curing medical intervention. None of that current criticism understands disabilities of material reality of the body. None of the work posits the possibility of a disabled dancer with African descent.

These celebratory (inaudible) are to me, as much gatekeepers as Macaulay is to Ringer. To begin with the body -- and you've all seen plenty of my ass at this point . . . and to begin with my ass.

In public, and in particular, in dance places I frequently name as my ass -- the carbon composite platform on which I sit, and or, my two (inaudible) rear wheels. It's a deceptive shorthand. The addition of a carbon, titanium, silicon butt does not mean I lose my rather fleshy ass.

I gain an additional rear. And in so doing, I create for myself the complex embodiment of two or three asses -- and depending upon how you count them; and anywhere between two and six legs. Read negatively, this fleshy metallic mix is excessive.

It is on the continuum with the kind of excess that leads disabled bodies to be seen as freaky. But it is my body, and it is the body with and in which I dance.



The architecture of me is in tension with the architecture of the places that stage and teach dance. As a studio, "Steps" in New York has justly earned a place in the history of dance. It is a place where dancers at all levels take class. The architecture of this historic place is beautiful; it's on 71, 72 and Broadway, over the Fairway.

But the design of the building makes it possible only for a certain kind of dancer to get there. The one who can climb the stairs and fit in the non-ADA-compliant elevator.

To get to dance there I have to -- unbelt myself, stand up, dismantle my chair. Do something with my dance bag. Hold the elevator door; take the wheel off, get in, put the wheel back on, while holding the elevator door. Sit down, find my dance bag, close the elevator door. And go up.

Usually I do it in public, before a bunch of non-disabled dancers who are like . . .

(laughter)

The inaccessibility of the environment forces me to move in ways that uncomfortably extend the form of my real body. But I find it a complex dance and disability studies moment. With conventional disability rights analysis, the lack of access and the injustice it creates are clear.

But in that analysis I suspect that the movement I performed to get inside the building, registers primarily only

as functional adaptation to a hostile environment. I see it as dance. My body's capabilities vary. On the days I have that movement available to me, I want a framework that does not force me to choose between dance and adaptation.

Cultural disability analysis, focusing on disability aesthetics -- tends to the movements itself and the forms it creates, and that forms that created it. Tobin Siebers presumes that disability aesthetics "embrace beauty that seems, by traditional standards, to be broken. It's not less beautiful, but more so as a result."

Note -- it's not a matter of representing the exclusion of disability and that's an important point -- but of making the influence of disability obvious. This goal may take two forms. To establish disability as a critical framework that questions the presuppositions of the underlying definitions of aesthetic production appreciation.

Two -- to elaborate disability as an aesthetic value, and in itself worthy of future development.

To you guys, I'm going to be right on top of you.

(performing)

(applause)

Thank you. That phrase was created last week in rehearsal. It's a practice phrase. It was created by one of our dancers, under the task of -- create a dance phrase that is the essence

of Alice's body, and then teach it to Alice. The phrase recognizes the power and the pleasingly aesthetic form of the traditional symbols of my brokenness.

It acknowledges all of my asses, as the initiation point of my movement, the center of my technique. For me to say, as I did say to you -- movement is the movement. It is to recognize how my disabled form, disabled architecture of my body puts me in motion.

It's to recognize how that motion challenges and influences others in the dance world. What do the gatekeepers think? Adam Alrich, *San Francisco Chronicle*, November 2009: "Who, twenty years ago, could have believed that a dance troupe of integrated conventional dancers, and dancers with disabilities could flourish on the basis of artistic merit alone?"

(laughter)

*The New York Times* is even better. Bruce Weber, *The New York Times*, November 2010. "AXIS Dance Company currently has seven dancers, four of whom are physically disabled and perform in wheelchairs. The initial impact of this on the audience is vexing. It's a visual mixed metaphor. And you can't help feeling, well, sympathy for the dancers without legs."

Like much surprising in art however, AXIS's work instructs the viewer in how to appreciate it. The lesson is delivered with cogent force. Sympathy is irrelevant. To get what isn't

here, pay attention to what is. Recognize the chairs for what they are, and not the substitutes for what they are not.

Thank you.

(applause)

Rosemarie Garland-Thomson: Our next speaker is Susan Schweik, who is Associate Dean of Arts and Humanities and Professor of English at the University of California, Berkeley. She's also the recipient of the Chancellor's Award for Advancing Institutional Excellence.

A former presidential chair in Undergraduate Education for Disability Studies at UC Berkeley, she has been involved with the development of disability studies at Berkeley for nine years. And this is the important point -- during that time she has also been co-coordinator of the Ed Roberts Fellowship in Disability Studies Post-Doctoral Program at Berkeley.

She has taught and co-taught undergraduate courses ranging from disability in literature, disability in integral storytelling -- to race, ethnicity and disability. Her other teaching and research interests include 20th century poetry, which we will see some today in her talk. Late 19th century American literature. Women's studies and gender theory. Urban studies, war literature and children's literature.

She is the recipient of Berkeley's Distinguished Teaching Award, so she's built lots of institutional structures. She is,

and this is very important, the author of *The Ugly Laws: Disability in Public*, which was published in 2009 from New York University Press, and is recently released in paperback, so you can all adopt it for our courses.

Susan Schweik: Thank you. I love that last line. That's the kind of introduction you want. Thank you so much; I'm so excited about this event. What a panel.

There's a little preface to my talk first, and it involves the image I'm showing up on the screen. It's a painting from sometime in the late 1500s; it was part of a cabinet of curiosities in Innsbruck, Austria. And here's how it was described by Volker Schonweise and Petra Flieger, who did this really amazing participatory action research project, disability arts project organized around this painting in 2005.

So this is their description of the painting:

"The painting shows a naked man with a disability, lying on his stomach on a dark-green cloth which rests on a table or a pedestal. The limp and deformed body is painted in an entirely realistic style. The curator has been able to verify that the body of the man was originally covered by a sheet of red paper, if a patron wished to see more, he or she could lift it and take a direct look at the naked body."

Okay, that's the preface. Now here's my talk which is called "Advance Directive or -- Can You Hear Me Now?"

Last year a well-known medical ethicist, Joseph Fins, was interviewed by *The New York Times*. I suspect many of you, maybe read this article. And what he was interviewed about was a new scientific discovery that, the brains of people who were diagnosed as being in severe vegetative states or minimally conscious, were actually revealing conscious brain activity when their brains were being scanned.

Language centers were lighting up. And not only did that suggest that people who were thought to be utterly beyond consciousness, some people actually might be conscious and locked in; but what this particular study did was they began working with a man who seemed, in every way, unresponsive. And they began neuro-imaging his brain.

And they figured out that, for all of us in this room, our brains will light up in the same place when we say "yes" or "no." And so, they tested with this man and they began to ask him factual questions, to make sure that the yeses or the no's were accurate.

And after they did that for a long time, they realized they had a new form of assisted communication through brain imaging. And they could talk to this man.

And so what Joseph Fins said was -- we've opened up a communication channel with this technique, but in some ways it's

like a very bad cell phone connection." And that was the quote of the day in *The Times*.

So Fins is particularly concerned about the ethical implications of this new form of prosthetic communication. And what he is especially interested in is how answers to yes or no questions that are asked through this means might invalidate or contradict previous advance directives that people need.

And what do you do if somebody is giving a different answer to questions that they signed about what their wishes were. And he says -- if you ask a patient whether he or she wants to live or die and the answer is "die," would you be convinced that that answer was sufficient? We don't know that; we know they are responding, but they may not understand the question. Their answer might be "yes, but . . ." And we don't know how to get to the "but."

Now, I can personally think of a lot of interesting questions that they maybe are actually asking. I mean, it goes on and on. Like, well, I'll just say two because I don't have a lot of time. Like -- do you want me to be asking you these questions? Or -- are you experiencing this as an invasion of privacy?

But anyway, we all get why the life and death question is of interest to Fins.

As Alan Roper wrote in his comment on the new study -- physicians in society are not yet ready for "I have brain activation, therefore I am." That would seriously put Descartes before the horse.

(laughter)

Now, I don't know exactly why *The Times* didn't pick that quotation, but I'm more interested in the one they did pick. Fins' line about the bad cell phone line. My talk today is about how disability arts and activist culture has taught me not to fear the bad cell phone connection.

And in fact, not just to relax about its ordinariness, but to celebrate it; and in the context of art, to court it. I heard Fins speak recently, and as I thought about the problem of communication and advanced directives, it occurred to me that as a person who is in the process of getting divorced, I'm keenly aware that what I know I want and I'm willing to sign on the dotted line to seal it -- may change over time.

Wedding ceremonies are a form of advance directive and we know enough, as a culture, to build in ways out of that advance directive down the road, when experience brings us new information and decisions.

So I'm pretty wary of much direction in advance. And at the same time, if you're ever going to be trying to decipher whether I want to live or die. Or if I'm ever going to be



trying to decide for it for you, a few conversational rules of thumb in advance would be helpful

So what follows -- can you hear me now? -- is my advance directive. My advance directive would say nothing about what I want or might want in the future, because I don't know. It would consist entirely of suggestions about a few things that the person or people trying to figure this out on the spot, should do to be prepared for the occasion.

All these things involve exposure to disability arts culture, although somebody suggested to me yesterday that I might suggest that people watch "Showgirls." So, do that too.

The phrase, universal design, suggests a dream of unimpeded access. Disability justice is often figured as the removal of barriers. But in disability culture as both the speakers before me made clear -- it becomes clear that in a very real sense, access is an impediment, as much as it is in contradiction to it.

Things take longer, are clunkier and clumsier. These layered extending static communication channels get accentuated in some of the most interesting work and disability arts culture. They get toyed with, and several things happen in the process. Access gets built in from the ground up, rather than added on; and the ethics of the communication channel are self-consciously explored.

And Carrie already talked about this. My advance directive asks this -- before you decide what I'm saying or what I'm trying to say or want to say . . . or before you decide what you want to say about me, or how to describe what you're seeing in me, let your brain be activated by some of the work in disability arts culture that engages in what I'm going to call "twice-described description."

And then, what I want you to do is -- twice behave yourself. I'm following here on the heels of Richard Schechner's famous definition of theater as "twice-behaved behavior performed for pleasure." The theater is appropriational, wrote Schechner. Theater can take something and play with it, either monetically or through repetition. The very act of twice-behaving distinguishes theater.

Now, disability culture conventionally involves sign language or audio description or captioning -- an extra grid of one's describing. But I'm talking about something more than that, and here are a few examples of what I mean when I'm talking about disability art that engages in twice-described description.

It might be description commenting on itself, engaging in bad twice behavior, in order to foreground the power dynamics. The unconscious desires and the conflicts and the ethical binds

that attend the blandest act of describing in a culture of ableism.

Pay especially close attention to these when you interpret my brain activity, please. For instance, don't miss the production of Kaite O'Reilly's classic disability arts work, her play "Peeling," which is put on by Graeae -- a disabled-led theater company in the U.K.

And I'm going to read you just a little bit from O'Reilly's introduction to the play. She describes the play as: an attempt at total communication. We have taken certain devices such as sign interpretation and audio description and woven them into the fabric of the text. It's an attempt to subvert, but also explore the theatrical possibilities of these devices, while making them central.

So in this play, three women with these huge costumes are tied to chairs. And they are part of a set design for a production of "The Trojan Women" which is going on somewhere else, and so that's a play about epic warfare and women in relation to it.

And the three women use the devices of theater, including narration and audio description and sign language interpretation -- even when there isn't any apparent audience at all.

This is Kaite O'Reilly: "They bicker, play, interrupt and share the devices, sending them up; ruining each other's

moments, passing easily between the formal rules at play -- like actor or being an interpreter or a describer -- and being themselves."

Like suddenly they heckle or they do that kind of thing. And they obviously lie at times. For instance, there's a moment in the first scene when two of the women are pretending not to understand what sign language is; and as they're saying "I don't understand what sign language is," they are signing. That's a typical example.

The cultural artifacts I'm directing you to advance also involved description aware of who gets the power described. Who in the word gets let in. Who gets let into the room to do the describing. They might make art that aims, not just for thick description, but disability experiences -- but for thickened description. Art that invites in the so-called thick tongue; or the putatively thick in the head, the rerouted connection.

I don't have time to go into the examples of the kind of work I'm thinking of that I'd like you to be exposed to before you decide anything about my life or my death, or my yesses or my nos.

But I'll just say that my advance directive would invite you to check out the BBC Radio adaptation of Victor Hugo's "Hunchback of Notre Dame," which was done in 2008. We all know about the hunchback's hunchback-ness. But the hunchback is also

deaf in the novel, and in the BBC Radio version, a deaf actor played Quasimodo. It's quite amazing.

And the script and the performance process and the surrounding apparatus -- they tried to find a structure in which first of all, English mimicked deaf syntax. And then there's all kinds of twice-described describing, as a deaf actor performs in the radio studio. And then, as the radio company tries to think about what deaf access to radio is.

Another example I want to point you to. Shira Avni's short animated film, "John and Michael." And I'm not even going to talk about it; I don't have time. Just, Shira Avni -- you can find this on the web . . . "John and Michael."

Finally, consider exploring the communication channels opened up by Quiet Bob 97, in his videos on YouTube. Quiet Bob 97 identifies as hard-of-speaking. He describes himself as voiceless, not speechless. He has no larynx, so he uses an artificial larynx and produces audible speech that's audible in different ways than we ever hear speech as.

So go to Quiet Bob 97's site over and over, as you think about what to make of a bad cell phone connection. Know what lexicon we're speaking in through our communication channels, you and I -- especially you. Before you decide what I'm deciding, take a look at the marvelous dictionary organized by

activists, in conjunction with the display in Innsbruck in 2008 of the painting I showed you in the beginning and described.

Disabled people in the community gathered together to produce a little word book to accompany the viewing of the painting. This is such a portable idea, what they did. What they did is -- they produced a series of words which different people came up with, disabled people in Innsbruck, of words that would be important to define and to meditate on before you lifted or shredded that imaginary red sheet of paper that still hides this image, and guards this image, and turns every encounter into a kind of prurient interest.

You might start by paying close attention, for instance, to their entries on "leben" and "angst." And their entries on "embarrassment" and "loneliness" and "ambivalence." Because the entries are in German, you'll have ample time to enter the space of translation that you and I are occupying.

One last thing. This is how I direct you in advance. Understand -- you are not dealing in silence. Think of what you are up to, as a version of what literary critics call ekphrasis. You are producing a verbal description of a visual image of my brain firing. Make a thick, a twice-described description.

Think of yourself as producing a work of art that describes a work of art. Approach me the way Richard Lovelace approaches the painting that he described in his poem titled "Upon the

Curtain of Lucasta's Picture, It was Thus Wrought." Lovelace requires a long pause before access to Lucasta. And the last line I'm about to read you insists on an understanding that you won't only be drawing, that is, pulling aside a veil. You'll also be drawing that curtain, creating its outline, its thick cover for yourself.

So here's Lovelace:

"Oh, stay that covetous hand. First turn all eye, all depth and mind, then mystically spy her soul's fair picture, her fair souls in all so copied from the original, that you will swear her body by this law is but its shadow, as this, its now draw."

(applause)

Rosemarie Garland-Thomson: Our final speaker is Nirmala Erevelles. She is Associate Professor of Social Foundations of Education and Instructional Leadership at the University of Alabama. Her research and publications are in the areas of disability studies, multicultural education, feminism and sociology of education.

She has published articles in several journals such as *Educational Theory*, *Studies in Education of Philosophy*, *The Journal of Curriculum Studies*, *Disability and Society* and the *Journal of Literary and Cultural Disability Studies* -- among others.

Her book, Disability and Difference in Global Contexts: Toward a Transformative Body Politic, will be published -- yay -- by Palgrave MacMillan in 2012. The title of her talk today is "Enabling a Materialist Aesthetic of Disability."

Nirmala Erevelles: Thank you so much for inviting me here today, and it's kind of hard to finish up a panel that was so brilliant, so I'm going to do my very best. I'm going to be starting my paper, actually I'm going to be interweaving in my paper the poetry of Palestinian-American poet Suheir Hammad, throughout the presentation.

So if there is a shift between my pedantic prose and lyrical poetry, it's her -- not me.

(laughter)

And I start with Hammad. "We spent the fourth of July in bed. Even now, walking girls are exploding legs, stepping on shells of American hatred left dark in Iraqi soil. Even now, Malaysian girls' shoes, between sex trade and hunger. Filipinas go blind, constructing the computer discs, poems like this are saved on. Even now, lover as we lay in amazement, and if baby as you say, my skin is the color of sun-warmed sand and you're my moonless night, and we the beach -- wet, tidal. All that good, shhhhh . . . wet."

In her brilliantly-evocative essay "Mama's Baby, Papa's Maybe: An American Grammar Book," African American literary



critique Hortense Spillers writes, and I quote: "Before the body, there is the flesh. That zero-degree of social conceptualization that does not escape concealment under the brush of discourse, or reflexes of iconography."

In this essay, Spillers startles her readers into recognition of the stark materiality of the body, as constituted within the violent history of slavery. Spillers' conceptualization of the flesh, as primally narrative of embodiment, proposes a visceral theorization that could arguably exceed equivalent contemporary theories of racialized, gendered, queer and/or disabled bodies.

Referring specifically to the middle passage, where black bodies jammed like animals in the hulls of merchant ships, were transported as human cargo to be sold as slaves in the New World, Spillers describes this terrible journey through the primary narrative of the flesh, with "its seared, divided, ripped apartness, riveted to the ship's hull, fallen or escaped overboard."

It is this primary narrative of wounded flesh that I turn to in order to conceptualize the historical materialist theory of disability. But I do this with much trepidation, fully aware that I am invoking quite problematically a vision of tattered flesh, of bludgeon's body, of victimized subjectivity.

Images that fit uncomfortably with any radical aesthetic of disability. But I mean to be provocative, to travel any easy conceptualization of disability, especially at the intersections of race, class, gender and sexuality.

Spillers' essay painfully unearths the violent history of slavery that gave rise to an American grammar that continues to this day, to propagate, dehumanizing depictions of black bodies -- both male and female. In Spillers' analysis, grounded in the originating metaphors of captivity and mutilation -- what becomes exceedingly clear is that it is the materiality of racialized violence that becomes the originally space of difference.

By materiality I mean -- the actual social and economic conditions that in fact disable people's lives, and that are concurrently mediated by the politics of race, ethnicity, gender, sexuality and nation.

I propose here that Spillers' essay is as much about the materiality of racialized violence, as it is about disability. And more specifically, about the materiality of disability identity. While there's merit to the argument that disability is the most universal of human conditions, there's an implicit assumption here that the acquisition of a disabled identity always occurs outside historical context.

Spillers' argument reminds us otherwise. In the specific historical context of slavery, the attribution of disability to the female captive body, for instance, enabled this body to become a site where the flesh became the prime commodity of exchange in the violent conflation of profit and pleasure.

In this case, I situate disability not as a condition of being, but of becoming. And this "becoming" is an historical event. And further, its material context that is critical in the theorizing of disabled bodies and subjectivities.

Conscious of the danger of invoking an able-ist aesthetic, my project here is to echo Robert McRuer's provocative question. What might it mean, and I quote, "what might it mean to welcome the disability to come, to desire it?"

In response to this question, contemporary scholarship in disability studies have turned to philosophers Deleuze and Guattari, to theorize the disabled subject as the irregular contingent effect of shifting signifiers producing disorganized collections of hybrid associations or assemblages that morph into an unstable and transgressive body without organs.

No longer marked as abject, these transgressive theories of embodiment fiercely embrace a form of contra-aestheticism (I'm using Tobin Siebers' term), that marks the normal. Rejecting disability's limited role as prosthetic in identity politics,

and engaging in a more transgressive political act of coming out  
crip or crippling. And here, I'm using McRuer's term.

Exciting and critically-necessary as these theoretical  
interventions are for an outlaw anthology of disability, my  
project angles the analytical frame or purposefully to  
foreground the transnational, historical context that enables  
becoming disabled.

And I'm using Hammad again: "And though my head is filled  
with your sweetness now, this same head knows, Nagasaki girls  
pick maggots out of stomach stools with chopsticks. Hiroshima  
mothers rock headless babies. This head knows Palestinian youth  
dead, absorbing rubber bullets. Homes demolished. Trees  
uprooted. Roots dispersed. The same head, with all those love  
songs and husky whispers knows, as we lay and love, our touch is  
not free. It comes with responsibility."

On one level, my project does not appear very different  
from feminist scholar Margaret Shildrick, who also  
conceptualizes disability as -- becoming in the world, as a  
material engagement often through the direct contact of flesh  
and blood encounters, that do not simply affect us on the  
surface level, but effect the very constitution of embodied  
being.

My difference with Shildrick begins with the critical  
significance I place on the transnational historical context, in

which the social encounters between ourselves and others occur. While Shildrick acknowledges that the historical context of globalization might disturb and distort the intercorporeal possibilities between diverse bodies, her embrace often effects an encounter results in an affective response to difference, rather than a transformative one.

In fact, a transformative politics is shunned, because Deleuze's horizontal rhizomatic proliferation of linkages that Shildrick embraces rejects the recognition any vertical, and therefore hierarchical relationship between self and others.

The problem with horizontal rhizomatic proliferation is that it is rendered inadequate in the historical context of transnational capitalism, where bodies encounter each other, often in violent collision where captivity and mutilation are no metaphors, but instead, inform -- a brutal materiality that foregrounds the hierarchical binary of master/slave.

Here Deleuze and Guattari's desiring machines cannot support the seamless horizontal current of flow between intercorporeal entities, now interrupted by the hierarchical social relations where productive desire that is constitutive of some bodies, is enabled through the consumption of the seared, divided, ripped-apart, mutilated flesh of other bodies.

It is this violent moment of intercorporeal assemblages that produces disability and its becoming in the world

foregrounds a dialectical tension between the historical and the contemporary; between production and consumption; between desire and need; between continuities and discontinuities; and between conditions of possibility and the violence of its limits.

By conceptualizing disability as becoming in the world, while rejecting, at the same time, its ahistorical association with lack, I reframe McRuer's question to ask: Within what social conditions might we welcome disability to come, to desire it?

In raising this question, I situate desiring disability as a historical condition of possibility that does not reproduce social and economic exploitation. And I'm ending now with Hammad again:

"I've got to tell you now, there ain't enough good feeling to push the pain and awareness out. Not enough nothing to make me forget. And I ain't no woman of steel. It feels needed, this kiss, that touch. There, that rhythm needed and wanted. Now, hold me a little while longer, just a bit because we gotta get up soon. There's a war on outside. Come on, baby, we got work to do."

Thank you.

(applause)

Rosemarie Garland-Thomson: I'd like to offer a very few remarks that may help us bring together these four really

amazing papers by my beloved colleagues who are also, and this is in deference to Alice's vocabulary -- kickass activists, artists and academics.

I want to call attention to one of the, I think, most important contributions that disability studies makes to the generation of knowledge in the world. And that is, to offer new vocabulary, new ways of talking about things.

New ways that clarify, new ways that open our paths to the project of social justice. So I'd like to call attention to the cultural work of language and begin by the premise that the language that we have available to us, in the dominant culture into which we are all acculturated, is inadequate language. It's discriminatory language.

It's language that obfuscates rather than clarifies our project of disability studies. So part of what disability studies does -- and this panel was exemplary in this respect -- is to offer up fresh, vivid, precise and nondiscriminatory language that helps us reframe disability.

Because the language that's available is particularly virulent and inadequate. So I'm going to call together, or suggest three possible realms that we might want to consider in terms of the cultural work of language.

One is -- the politics of self-naming, much of which was brought forward here today. For example, Carrie Sandahl offered

us the idea of crips, as part of a way of naming the identity group that is disabled. That is a productive way to think about and to talk about and to frame this group of subjects that comes precisely from within the identity group, rather than a definition or a name that is imposed from the outside. One example.

Another -- politics of self-naming, which I think is very important that I'll use as an example. Politics of naming, perhaps, might be more accurate -- that doesn't come from our panel, but I use these examples quite often.

Is -- the language offered up by our colleague Georgina Kleege, who is at the University of California, Berkeley, in a book she wrote, called *Sight Unseen*. If you haven't read it, you should.

She makes a distinction between the subject positions of blind people, or a blind person, which is -- a subject position that is very well known in the dominant culture.

And she brings forward another subject position that is less available to us in understanding the dynamics and the politics of disability. And she talks about sighted people. She talks about the subject position of sighted people. And when I was teaching this book, one of the students said to me -- a woman who identifies as a lesbian. A woman who identifies as



bi-racial; a woman who is very in touch with terms of identification, both achieved and ascribed.

And she said in a moment of wonder -- I never thought of myself as sighted. And I thought -- this is a really important piece of work; this is a cultural realization. The kind of cultural realizations that are brought forward today.

Another example of that comes from one of our colleagues whose name is Alice Dreger who wrote another kickass book on conjoinment that's called *One of Us*.

And she, much like Kleege in *Sight Unseen*, names what I call the veiled, non-dominant subject position; and that is . . . pardon me, the veiled dominant subject position that is not brought forward in culture very much -- by telling us that, and I presume everyone in this room could identify or identifies with this subject position.

And that is the subject position of a singleton. We are singletons in the sense that we are not conjoined. And this kind of, I think, fresh and interesting naming is very important. Much of this occurred today. Some of the ideas that were brought forward have to do with subjugated knowledge.

That is to say -- ways of being in the world that are non-dominant. Ways of being in the world that go unrecognized. Ways of being in the world that are discriminated against and imagined as unlivable ways of being in the world.

Many examples came forward today. I particularly liked the idea of the new definition of butts that Alice offered up. Multiple asses, if you will. That is to say, the understanding of an ass as being the fusion of flesh and metal.

I think that Carrie Sandahl, as well, offered us some interesting new terminology that is non-discriminatory. She speaks about the way our bodies are configured, rather than using the dominant conception. Which is to say -- what's wrong with us? Or what's wrong with you?

She offered up the very interesting idea of a CP -- Cerebral Palsy accent, rather than talking about this distinctive way of speaking as a speech impediment, which is the dominant way of understanding such ideas.

Alice offered us, as well, the idea of movement as the movement. Which I think, introduces the third category of language that does important cultural work that I wanted to offer. And that is -- the new language of disability as theoretical language. So, movement is the movement -- is a particularly important example of that.

Susan Schweik offered us, as well, twice-described description, which I think is a really wonderful way to talk about what Carrie Sandahl meant, called crip time. The alternative way of being and thinking and understanding the world, that is part of disability experience.

I also just wanted to say that twice-described description, for me, invokes a yummy comfort food that's twice-baked -- potatoes.

(laughter)

And somehow I want you to get that one in there.

Nirmala Erevelles offered us a very important critical vocabulary that comes from disability experience. The idea of becoming in the world, as a way of describing disability experience. Rather than describing it in the dominant way of a problem to be solved. She reminded us, as well, I think of Tobin Siebers' very important concept, and that is -- contra-aestheticism.

So I don't want to spend too much time because I want us to have fifteen minutes for questions and comments, and an interchange between the panel and the panelists, which will be choreographed by people with microphones somewhere.

Thank you. So if you can indicate that you have a question in some way, the people with microphones will come around, being attentive to the principle of cues, and direct their questions to our panelists.

Audience Member: I'm Elaine Cole and it's just a thrill to be here. Thirty years ago, at this point, I was in Australia on a Fulbright scholarship as part of the International Year of

Disabled Persons. And I had already written a song called "A Crip Can Be Hip."

So, it's really . . . which I would sing, but we don't have time for that right now. So I'm really, really happy to hear the extension and development of cripdom, because us crips are cool. And the only negative or odd thing -- I won't say negative, but odd thing -- is that on the Internet, I have sometimes been contacted by people who were like, Crips, as in Bloods. And they were annoyed at our cripness.

But I'm annoyed at theirs, so . . .

(laughter)

Audience Member: Hi, my name is Corinne Kirchner. I teach a disability policy course and so, while being inspired, I was trying to translate some of this into policy implications. And Carrie, I'm going to focus on your notions. You took that . . . the notions of undue burden in the law, and reasonable accommodation, were very, very politically chosen.

They do political work. And now we're at a point where we want to consider getting rid of them. And you have turned them into lemonade really emphatically. But what I'm wondering, and I'm just beginning to think about it and I don't know if you did -- is whether we can really get rid of the undue burden provision, because that is what's stopping real change. It's an escape clause.

And so, the only think that I'll suggest, as I was trying to begin to think about it, is -- the notion of what "reasonable" means. And I remember, years back, on jury duty they gave us the definition of -- beyond a reasonable doubt, as a doubt for which you can state a reason.

Which I always thought was really nice. And I'm just wondering if we can do that with reasonable accommodation because as it's used -- and I think language is extremely important -- it's used to allow that escape clause. The undue burden is the unreasonable. So, I toss it out.

Carrie Sandahl: All right. Like I said, I'm not a lawyer. But the way that I've experienced it lately, just because of different medical issues that I've been facing, is a series of people telling me no -- and I'm not very used to people telling me no.

I mean, it really marked, like I said, my transition from being an able disabled, to an undue burden. Because I think I was easy to include before. I could be the disabled person because I didn't really cause too much commotion.

So I don't think that any of us can individually change these systems. Like I said with the situation with my son, I came to the realization that there is no way that the current educational system, and any of the choices that were available to us, could accommodate him.

So it just has to be a complete systematic change, and it's not going to happen as long as there's this -- like I said, this opt out. I mean, down to petty things. For instance, I recently had back surgery and in order to be able to return to work, I wasn't able to lift five pounds. I couldn't get my wheelchair in and out of my car.

So I asked the University whether, when I came into work, I could have a student assistant or somebody to carry my bag for me and take the chair . . . that was considered an unreasonable request because that's personal assistance. And it wasn't necessary to the function in my job.

So I got turned down, although they would buy me a couch, but I couldn't get this assistance. So what my students ended up doing, they wanted me to come to class. That was the only thing keeping me from coming to class. They just organized it themselves, and assisted me.

I don't know what would have happened if anyone had gotten a back injury from lifting my chair -- I don't know. But anyway, like I said -- I hadn't been used to being told no. And I'm experiencing it more and more for myself, and also for my children.

And I think that this is, nothing that we can do individually. I don't know if we can get rid of it; I really need these policy types to help figure this out. I just think

that it's something we need to think about. These constant escape clauses allow people to make such minimal changes, that it's leaving out a lot of our brothers and sisters with disabilities.

Audience Member: Hi there. My name is Jean and I'm a member of the class of Barnard '62.

(applause)

And I seem to have inherited various abilities or not from my grandparents, one of whom was severely arthritic, and it seems to be coming on real fast these past couple of months since the snowstorm.

Thank you very much. This is an amazing thing already, and I'm sure it's going to get better. I need to make a critical remark, but I don't mean it in any negative way. I have been hearing the world differently-abled, and I kind of laughed at it. It was hard for me to get into feminist terminology.

On the other hand, I didn't hear it once today. And I have to say that I really appreciated the, when you said they were saying no to you and no to your son and stuff like that -- that hasn't happened to me, but I appreciate it. I appreciate that it could happen in the future.

And I did have problems with my son. But I just want to ask very quickly -- what about calling this whole thing Ability

Studies? Just -- Ability Studies! I'm just tired of hearing the "dis"; I feel dissed.

Thank you. Also, the "sighted" thing and the singleton thing. I thought that was incredible. I wonder what's going to happen to Abby and Brittany as they grow up. I wrote a poem about it. It's freaky. But they're not freaks. They're out in the world; they've been on television, you know. So anyway, thank you very much. Ability Studies -- please!

Audience Member: I'm Elena and I danced with Dis Ability and I'm also a psychologist who is interested in helping people from different categories communicate with each other. So I was so excited by Alice's presentation and there was a moment when I cringed twice.

You talked about a reviewer who admitted to feeling sympathy. And I heard the reaction in the room. And I wondered, was there space to allow people from the dominant culture to have their own honest reactions? Is there room for us to accommodate? And I especially appreciated the framing of sighted or singleton, as a way of understanding that in some ways, we are all actually part of that dominant culture, as well.

So, how do we work with that? It's a question for Alice or anyone on the panel.



Alice Sheppard: The first thing I want to say is -- this afternoon's dance performance will take on your reactions, and be a mainstream dominant audience, non-disabled audience's reaction. And deal with that, talk about it, open it up; and so it's specifically to your question -- is there space? This afternoon there will be space to challenge, explore and feel and discuss that moment.

With regard to my experience, you know, if you throw a ball and people catch it, or not -- and I have no control over what happens. In the talk-backs we do get a lot of the -- aaaah, you are soooooo inspiring!!!

(laughter)

I just couldn't believe it! And we have to honor that. And then, take it further through that critical frame, to talk about what are the assumptions that led you to be in such a space that you are moved, inspired? What did we do that was beautiful, powerful, challenging in its own right, regardless of your slightly-discriminatory or prejudicial assumptions?

Look at those ways. Yes, we honor that feeling, that reaction and we talk about it and place critical frameworks for it to be analyzed and for it to change, if necessary; or to let it sit.

Can I take the word "ability" for a second? Because it seems really important to address that. I want to just make two

points. One is -- we could do that. But as currently used, the ability studies language or the "I'm really able, I'm handy, capable" -- that ableness has been not hijacked, but is taken, occupied and used right now in the realm of people who are reacting strongly to a medical diagnosis, or a medicalization of their bodies in some ways.

The disability part of it, it's a political statement. It's a political, cultural, social statement that arises with pride and with power; and is owned by the disability community. It's a reclamation. And it's a word that comes from us in a way, the disability rights movement.

It stands very strongly -- I mean, I personally say "disabled people," for the most part. I almost never say -- people with disabilities. I don't use "person first" language. I used "disabled first" language. And that is a political commitment on my part.

So I see the field as coming out of those ideas, in being part of those ideas. I see it being disability or disabilities-centered.

Carrie Sandahl: Can I also comment on that? I just would like to invoke Simi Linton's title of her book -- *Claiming Disability*. Because to me, I'm not so interested in ability. Thinking about disability in non-negative terms, but as Rosemarie pointed out, different ways that we are configured.

To me, it gives us an opportunity to talk about the materiality of our experience, the exact stuff that Nirmala was talking about. Especially, it gives us a way, more recently we have been talking a lot more about impairment. And impairment is more like the physical, the flesh, I guess you could say; our body's configurations.

And we need some space to talk about those things. But we need to be able to talk about pain. We need to be able to talk about stamina. We need to talk about our experiences with medicine.

And we can talk about ideologies of ability; I think that's great. But we have not spent enough time talking about, and we're just now starting to figure out what disability is. And so, I'm happy to spend some crip time there, trying to understand its generative potential, rather than deflecting the ability again.

Some other people can do that. That would be cool.

Audience Member: Hi, I'm Adrienne Ashe. It's quite amazing to be at this conference. I remember Susan Quimby. I don't know if you're here, Susan, but Julie Marsteller, of course. I taught a course on Disability and Society at Barnard College in 1982. And there were seven people in the class. Things have changed.

(applause)

Many comments I could make, but my question, for Sue Schweik. I think that your discussion of the bad cell phone connection and some of what Joe Fins was talking about, reported in *The Times*, and that he talked about two weeks ago at a conference I think we were both at -- in terms of persons with minimal consciousness and their advance, and whether you could understand what they were saying now, and their advance directives.

I guess my question is -- we have to figure out a way to validate what people say contemporaneously in whatever state we are in . . . I'm sorry, I'm concerned that the comments about minimal consciousness there abroad, would undermine the recognition that people with minimal consciousness are part of our community, as people with disabilities.

And that we need to spend time, resources on rehabilitation. I don't know whether that was an implication of what Fins was saying. It seems to me that it was. I think we all need to think about how to frame our advance directives for health care, so that we think about, as you were saying, capacities and what we want and what we might want at the time; and try not to project too much into the future. I just wondered if you'd comment on that, Sue.

Susan Schweik: Yeah, thank you so much, Adrienne. Yeah, what I said really was provoked by Fins' talk two weeks ago at

New School where we both were. And I don't know enough about his work to know. But I was struck -- during the talk, I was struck by the way, what he said during the talk was different from what he said, for instance, in *The New York Times* article.

So, during the talk he said -- well, what do we do about, if someone is telling us they want to live now and they said they wanted to die in their advance directive? In *The New York Times* article, he says -- what do we do about, if someone said they want to . . . I'm getting it wrong.

Basically, what he was concerned about when he was speaking extemporaneously, was the possibility that someone might have said -- don't use any extraordinary measures.

And now they are using this new neuro-imaging, and what is happening seems to contradict that. In print, he reversed it, and his example was someone saying -- now I do want to die. Or the brain scan reading -- yes, I do want to die . . . when the advance directive said "please use extraordinary measures."

I thought that was potentially very interesting because it strikes me -- and I am not judging Joseph Fins at all. I'm judging from my own, I'm proving it on my own pulse. It strikes me that the more powerful impulse is the exhaustion and fear that comes from wanting someone to die, however much one has the desire that someone live.

And so, I thought it was very interesting that he did it two different ways. Both ways are of concern, in trying to figure out what to do with this new technology which is -- talk about a new meaning to assisted communication device.

This is so radical in its implications. And so, like you, I'm very interested in what the other uses and questions of this would be. It interests me very much in the cultural discussion, went straight down to death, or life . . . and bad cell phone connection. That worries me.

And I think that many, many practices -- for instance, Nirmala's work on assisted, facilitated communication with autistic people . . . there are many, many ways in disability arts culture now, that these things are being explored.

I think it's easier to talk about it in the context of art than in the context of policy, as we saw with Carrie's talk too. That's part of the use of art, is to create the framework to explore these things. So that the attitude that one brings to these ethical questions, the attitude that the culture brings to these ethical questions is freer and looser and deeper and smarter, about the range of things that might occur.

Rosemarie Garland-Thomson: Our organizers have asked that we have one final question. Good luck to you folks with the mikes.

Audience Member: Yes, I have a cerebral palsy.

Rosemarie Garland-Thomson: Can you say your name?

Audience Member: My first name is Laurens, it's an uncommon spelling. It's L-A-U-R-E-N-S. What I would like to see more of is, integration; I mean, there are a lot of disability rights groups, there are a lot of feminist groups. And because I'm personally a member of NOWZA[?], New York City Chapter. I mean, there are so many women's groups, media centers; and of course, Dis-Abilities, there's ADAPT.

There's different (inaudible) like UCP and Multiple Sclerosis and so on. The thing is, I think that we need to do more functions together, between the two communities. It's obviously made a lot harder with the elections this past fall, and all the anti-union outcry.

And because it's not about promoting party label, it's about promoting policy.

Rosemarie Garland-Thomson: Do you have a question you can get to?

Audience Member: I obviously have been hearing comments. My question is -- is anybody really working on the integration, the cultivation between the two communities in terms of the individual chapters and the groups -- to get them side by side, in the same room, talking to each other?

Is anybody really working on that? So it's more of, I guess it's more culminated.

Rosemarie Garland-Thomson: Will someone on the panel address that? The two groups -- you mean disabled and the non-disabled? Or do you mean intra-disability groups? Intra-disability groups.

Audience Member: Okay, you're asking me what I'm clarifying. I mean, it's, I guess another way of looking at it is -- plenty of different people have disabilities. Of course, race, gender, transgender, LGBTQ, color.

Rosemarie Garland-Thomson: So are you asking about alliances and . . .

Audience Member:: Absolutely.

Rosemarie Garland-Thomson: . . . and shared advocacy across different groups? I think a lot of people would have things to say on the panel about that.

Audience Member: Yeah, definitely.

Nirmala Erevelles: Actually, I think my presentation addressed that, in a way that there are possibilities of intersections between different social groups because we also assume that each of these social groups -- race, class, gender -- as if they are not already having, as if people already have just one single identity, but not multiple identities in there.

And so, the argument I think I was trying to make, and I know there are quite a few people in disability studies who are making, is that we need to in some ways, conceptualize how -- we



don't see bodies as if they are marked by one particular category. But to see how they are, in fact, in relation to each other. And history and politics and economics and the social.

And I think actually, all our talks in many ways kind of attended to it in different angles. Yes, I mean, there are possibilities in the conversations. I think some of these conversations are happening. It's just that we need, we keep having to struggle with a clearer framework to have clearer frameworks, in a way, to talk about them.

Rosemarie Garland-Thomson: I'm sorry to say we have to end now, because I think it's lunch time. But thank you all for coming. Thank you for this wonderful session.

(applause)

Janet Jakobsen:

Thank you very much, and thanks to our panelists. This was everything we could hope for.

(applause)

[END OF TRANSCRIPT]