

**GLOBAL FEMINISMS
COMPARATIVE CASE STUDIES OF
WOMEN'S ACTIVISM AND SCHOLARSHIP**

SITE: U.S.A.

**Transcript of Adrienne Asch
Interviewer: Anna Kirkland**

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Adrienne Asch, born in 1948, is the Edward and Robin Millstein Professor of Bioethics at the Wurzweiler School of Social Work, and Professor of Epidemiology and Population Health at the Albert Einstein College of Medicine, both at Yeshiva University in New York. Asch received a BA in Philosophy from Swarthmore College, an MS in Social Work and a Ph.D. in Social Psychology from Columbia University. Much of her scholarship examines issues of bio-ethics, reproduction, and disability. A long-time member of the Society for Disability Studies, she served as its president from 1996 to 1998. In 1997, she was named Blind Educator of the Year by the National Federation of the Blind, and in 2001, she was awarded an honorary degree from Swarthmore College. Asch has been a member of the board of directors of the American Society for Bioethics in Humanities and served on the Clinton Task Force on Healthcare Reform and the Ethical, Legal, and Social Implications Policy Planning Group of the National Human Genome Research Institute. She has also served on the board of the Boston Women's Health Book Collective. She has authored numerous articles and book chapters and is editor with Eric Parens of *Prenatal Testing and Disability Rights*, and a co-editor of *The Double-Edge Helix: Social Implications of Genetics in a Diverse Society*. She is currently working on a book on assisted reproduction.

Anna Kirkland is Assistant Professor of Women's Studies and Political Science. She earned her J.D. (2001) and Ph.D. (Jurisprudence and Social Policy, 2003) from the University of California, Berkeley. Her research focuses on the construction of the legal categories that receive civil rights protections in various jurisdictions of the United States, particularly gender, race, sexual orientation, and disability. She is interested in the politics of gaining legal protections as well as the ways in which ordinary people understand and negotiate their identities through the law. She is completing a book manuscript entitled *Discriminating Differences: Identity and Personhood in American Antidiscrimination Law*. Other ongoing projects include a qualitative interview study of fat rights activists and their perceptions of law and a mixed methodology study of undergraduates' ideas about what diversity means. Her published articles analyze transgendered plaintiffs who win their cases, transgender discrimination as sex discrimination, and the efforts of fat rights organizations to combat weight-based discrimination. Her work has also been featured in the recently published collection of *The Fire This Time: Young Feminists and the New Activism* (Anchor Books 2004). Professor Kirkland teaches courses on gender, sexuality, politics and law in Women's Studies and Political Science, and was recently a Visiting Assistant Professor of Law at the Michigan Law School.

Transcript of Adrienne Asch

[Song] *We who believe in freedom cannot rest
We who believe in freedom cannot rest until it comes
We who believe in freedom cannot rest*

*We who believe in freedom cannot rest until it comes*¹

Anna Kirkland: Hello, and welcome to the Global Feminisms Project. I am Anna Kirkland, Assistant Professor of Women Studies and Political Science here at the University of Michigan. I am here with Adrienne Asch. And first I'd like to thank you so much for coming.

Adrienne Asch: Thank you for inviting me and considering me to be one of the people that you wanted to interview.

Anna: Wonderful. So first we're going to talk about your background, both in activism and scholarship. And then we're going to discuss some particular areas of your expertise--disability rights, particularly women with disabilities, bioethics, and reproductive rights. And we'd also hoped to hear some closing thoughts from you about some of the important challenges you see ahead in these areas.

Adrienne: Thank you.

Anna: So could you start us off by talking a bit about your background and life story that have made you the scholar and activist you are today?

Adrienne: I think the most important influences on who I am today have to do with growing up in a small town with very nonconformist parents, but not nonconformist parents who waved a flag about how nonconformist they were. They just were nonconformists. They were Jews in a non-Jewish town. They were Democrats and leftwing Democrats in a very conservative Republican town. They believe in things like federal aid to education when that was considered a really radical act. They read *The New York Times* when people didn't even...and they went to New York to museums when people didn't go to New York, even though we were half an hour away.

Anna: Hm.

Adrienne: So, um, and we had guests from lots of foreign countries that were friends of my parents when people didn't...were very parochial. That was one big influence. My parents taught me to think for myself and to be comfortable with who I was, even if people around me weren't entirely comfortable with who I was either as a leftwing type or somebody who loved classical music, or someone who was Jewish, or someone who was blind. So they just taught me to be myself. And that was a big thing. And the other big thing was going to Swarthmore College, which was a place full of intellectual engaged people who loved scholarship and also loved activism, and I was part of Swarthmore College work in the anti-Vietnam War movement² and in the civil rights

¹ These lyrics from "Ella's Song" by Sweet Honey in the Rock precede a biographical montage of each US site interviewee.

² Along with the Civil Rights campaigns of the 1960s, *the anti-Vietnam war movement* was one of the most divisive forces in twentieth-century U.S. history. The antiwar movement actually consisted of a number of independent interests, often only vaguely allied and contesting each other on many issues, united only in

movement³, and found a great emotional home with like-minded people in the '60s. I'm very much a person of the '60s who, not that drugs and rock and roll part of the '60s, but the politics and cultural rethinking part of the '60s. That's very much who I am.

Anna: And in your writings you say that your disability isn't something you find inherently interesting. I mean, you speak of your blindness as something that other people label you with rather than something your...you take on for yourself. So can you tell us what it's been like to forge your identity both with a disability as well as apart from it?

Adrienne: It has been very difficult to force my identity apart from disability, because people, really, my whole life, have been trying to tell me that that's the most important thing about me. And so when I say that it actually isn't, and that the most important things about me as far as I'm concerned are that I do bioethics or that I'm a leftist or that I went to Swarthmore, or that I love Renaissance music, people really often don't like that. They want me to tell them that I'm blind. That's really important. So the biggest challenge of having...of being a person with a disability, I think, not just for me but for most people in today's society is saying, yeah, that's true. I have a disability, I don't read print without a scanner and I read Braille and whatever. But I'm really interested in what I read, not how I read. I'm not...I really...it's not really amazing to me that I travel with a cane and go around the country or the world or whatever it is I'm doing. It's what I'm doing when I got there. And people are much too interested in technology or how much help I need or things like that. I mean, and I think they're focusing on the wrong things, because they're...oh, I think disability makes people quite uncomfortable and it doesn't have the political cachet that race or sex or sexual orientation now have. It's still considered a tragedy and a misfortune and something...It's actually something...people with disabilities are either supposed to be very unhappy about or very proud of, and I'm neither unhappy nor proud. I just am.

Anna: Um-hum. And so I understand you were active in the civil rights movement. How did those experiences affect you?

Adrienne: Well, they were really outgrowths of just being the person that I was, and believing that...and in a way this is very quaint, the content of one's character and not the color of one's skin was what was important and that was true about the content of one's heart and not the sex that one was born with should be important either. So it was very

opposition to the Vietnam War. Attracting members from college campuses, middle-class suburbs, labor unions, and government institutions, the movement gained national prominence in 1965, peaked in 1968, and remained powerful throughout the duration of the conflict. Encompassing political, racial, and cultural spheres, the antiwar movement exposed a deep schism within 1960s American society.

³ The African-American *Civil Rights Movement* refers to a set of noted events and reform movements in the United States aimed at abolishing public and private acts of racial discrimination against African Americans between 1954 to 1968, particularly in the southern United States. By 1966, the emergence of the Black Power Movement, which lasted from 1966 to 1975, enlarged and gradually eclipsed the aims of the Civil Rights Movement to include racial dignity, economic and political self-sufficiency, and freedom from white authority.

natural to me to be involved in working on civil rights for people of color. And, I mean, it was also part of just general leftwing politics in the '60s, wanting to change societal distribution of income and wanting to make sure that...I mean, it was just preposterous to me that there was any kind of segregation or any kind of unfairness, or that race or sex was a...a thing that people would use against someone. Swarthmore was a wonderful co-ed college⁴ that I think did not differentiate between what women did as undergraduates and what men did as undergraduates. And I like that. I had no particular interest in going to a single sex college. Um, ah...and disability didn't come into my calculations at the time. I mean, I thought of myself as a woman or as a middle class White wanting to change the world for people who weren't White, but I didn't think about disability because I didn't think it was a political issue at all. And then I took that kind of political mentality about how the world had to change into the kinds of discrimination that I and other people with disabilities faced, when I realized that we faced it.

Anna: Um-hum. I know from my teaching that a lot of students haven't encountered disability rights scholarship. And it's the ways of thinking that you just described are fairly common – thinking of a disability as something to react to with sympathy or offers of assistance or things like that. But can you...can you help explain your conception of disability and how it challenges that view?

Adrienne: Well, I think in a way I already did a little bit. You know, do people with disabilities need help in particular situations? Sure. But then everybody needs help. So I don't like having doors opened for me any more or less than women in the '60s liked having men hold doors open for them. Or for us. I mean, now a lot of us fortunately don't much care. But...but that's because we've proven our point, at least to some extent, that we can do pretty much any job and do it as well as anybody else. That's women. Well, the same thing is true for people with disabilities. That's the point we want to prove and yet I'm...I'm often pushed to the head of lines in a bank. Or given seats that I don't need, because as far as I know, there's nothing about blindness that affects my mobility or my ability to stand. Or people ask a companion who's with me, if they're non-disabled, what I want, rather than speaking to me. Well, all of that is just denigrating and stupid. And I'm indignant about it. And unfortunately, never let those things go, because I think that they're assaults on just one's own personal dignity and self respect, and I cannot tolerate them. And most people with disabilities who are comfortable with themselves as people who have disabilities, just take the disability as a fact of life and then want to get on with their lives. So if they...if somebody uses a wheelchair, they want to just use the wheelchair and get where they're going, and have curb cuts so they can get there, and not have people marvel at them for going somewhere in a wheelchair. Well, the same is true about any disability. If we had more interpreters, if more people knew sign language, it would be easier for people who are deaf to just go about ordinary life and communicate. Same with the non-apparent disabilities that lots of people have. People with epilepsy or diabetes often try to hide those things because there's so much stigma around disability, and so much fear in the public that the fear is if you reveal a disability, people will shun you or pity you or be sad and tell you that you can't play with their friends or go out with

⁴ *Coed*: Of or relating to an education system in which both men and women attend the same institution or classes.

their daughters, or whatever. When disability just isn't necessarily interesting to people. It's just a part of them, like being five-foot-two, or five-foot-seven, or having blue eyes or something.

Anna: Um-hum.

Adrienne: But that's not how the world sees it.

Anna: So in one of your articles on critical race theory⁵, feminism and disability, you point out that a minority group model⁶ in which legal rights are considered the central thing to aim for hasn't really done that much for the disability rights movement. And you advocate instead universalizing concept of disability, and that made me think of all the ways that so many people who are not considered disabled nonetheless have trouble functioning according to rules that they had no part in shaping. And the example I thought of was problems that pregnant women encounter in the workplace, for example, a workplace that is not organized around that event. So can you talk some more about what a universalizing concept of disability is, and how it might be more effective in bringing about social change?

Adrienne: Yeah, but I...first I have to say that the minority group model hasn't done everything that we want it to do. But it has done something really important. It's put people with disabilities into civil rights laws. It has helped Congress⁷ and states to understand that this is a group of people who, because of society's attitudes, are discriminated against and need protection. I would like to get rid of the need for civil rights laws. But until there's an end of discrimination, we can't. So I...I think I have to say we need civil rights laws for women and for people with disabilities, and so...But in terms of universalizing, I think your pregnant woman example is a good example. Or let's think of another example. In a Supreme Court⁸ case from many years ago, a job requirement of having to...ah...I'm sorry. Lots of job requirements, not just pregnancy, turn out not to be related to the job. I mean people used to think, well, you had to have a college degree to do some job or other. But the idea is that discrimination comes when the requirement, the college degree, or being a certain height isn't really related to the task of the job. So firefighter job descriptions have been changed so that you don't have to be a certain height, but you have to lift a certain weight. The rules have to really fit the situation. The workplace has to change not only for women who are pregnant, but for all

⁵ *Critical Race Theory* is the school of thought that holds that race lies at the very nexus of American life. It is an academic discipline that challenges its readers, whether proponents or dissenters, to consider the relationship that exists between race, the justice system, and society.

⁶ In the *Minority group model* minority status that is applied to subjugated, powerless, and/or oppressed segments of a society, who are singled out for unequal treatment and discriminated against by the dominant segments of society.

⁷ The *United States Congress* is the legislature of the United States federal government. It is bicameral, comprising the House of Representatives and the Senate. The House of Representatives has 435 members, each representing a congressional district and serving a two-year term. House seats are apportioned among the states by population. Each state has two Senators, regardless of population. There are 100 senators, serving staggered six-year terms. Both Senators and Representatives are chosen through direct election.

⁸ The *Supreme Court* of the United States is the highest judicial body in the United States and leads the judicial branch of the United States federal government.

people who are parents. I'll talk about this more later, but it's not just women who are mothers. In many instances, men are fathers, and anyone who is raising children should have a workplace that recognizes family responsibility. Well, that's a good example I think of how men or women didn't set the rules that govern work. And if...if we had, those rules I think would be very different from the rules we've got.

Anna: You've written about the omission of women with disabilities from much mainstream feminist work on issues like reproduction, motherhood, discrimination, sexuality. How have you tried to explain those connections between gender, sexuality, and disability to those who had overlooked them?

Adrienne: My colleague, Michelle Fine⁹, and I edited a book on women with disabilities in the mid...and it came out in the late 1980s. And what we tried to do was figure out whether women with disabilities had been discriminated against in ways that resembled or differed from other women's discrimination. Or than other men with disabilities. And what we've found in our work was that women with disabilities were in some ways doubly discriminated against. They didn't have as, as Michelle Fine wonderfully described, the pedestal of other women.

Anna: Um-hum.

Adrienne: And they did have all the discrimination that women had. They didn't have the...When people studied—and this is still true today—when people study women and achievement, say, or look at women in corporations, or want to look at women in academia, they may look at how many women of color are there, or they may look at the class origins of women. But they don't look at whether those women have disabilities. Disability is still not a category that is comfortable for lots of people within feminism, or anywhere else, to think about. As a political category, it's all in this sort of category of misfortune rather than politics. So we're much more comfortable now than we were even when the feminist movement got started with sexual orientation but that same comfort of thinking about, again, disability as something that affects, say, 15 percent of the population in the United States, and maybe more worldwide, it's a large category. And the...a world that really took people with disabilities into account would look quite different in some ways from the world that we have. Not only would it have more ramps and curb cuts, but flexible hours at work would be much more common to accommodate all sorts of people who need breaks to rest their hands or change positions if they have back problems, or all kinds of things than we now have. But we don't take account of people with disabilities as members of society trying to do all kinds of things. And in fact, the definition of disability in a lot of countries, certainly in the United States, is as a person who can't work. And so you have this kind of irony. There's a sense...the typical census questions ask you things about, do you have a disability that prevents you from keeping house – this is a sexist question too...ah...

⁹ *Michelle Fine* is a professor in the Social/Personality Psychology Program at City University of New York and previously taught for 12 years at the University of Pennsylvania. Her research program surrounds questions of community development with a particular emphasis on urban youth and young adults.

Anna: [laughs]

Adrienne: ...going to school or working at a job. Well, what if you have a disability that is considered a health problem, like just deafness or blindness or paraplegia, but you are going to school, keeping house or working at a job. How do you answer that question? I usually confound the census people by answering no.

Anna: [laughs] That reminds me of the bumper sticker, if gays and lesbians are given civil rights then everyone will want them. So like if...if people with disabilities are given accommodation, then everyone will want them [laughs].

Adrienne: Well, and the thing is every...If you're...we talk about accommodation as though it's only something we do for people with disabilities. But that's preposterous. We accommodate one another in day-to-day life all the time. If you have a friend who's a vegetarian, you don't make steak for dinner when you...when you invite her over. And that doesn't get a medal and it doesn't get called reasonable accommodation. It's just you took your friend's concerns and needs into account when you made the plan. And the same is true in...in any work situation. Even if you have ten people doing the same job, people do it differently, and some people know that...some faculty members really like to serve on committees and have the temperament for it, and some people know that other faculty members would rather do anything that serve on committees, so they'd rather write more articles, and people try to...even though faculty members have to both serve on committees and write articles, people try to accommodate, if you will, the individual personalities and preferences of people. But when it comes to a person with a disability, we call it a reasonable accommodation and think it's a totally different thing than any other accommodation we have done...

Anna: Um-hum.

Adrienne: ...of people in ordinary day-to-day life.

Anna: I was talking to someone who had mentioned that...who called a stroller for a child a mobility-assisted device.

Adrienne: That's right.

Anna: Or a...or a typewriter, a prosthesis for writing.

Adrienne: Well, that's right.

Anna: You know, because of course we use these things all the time.

Adrienne: And because the majority use them, we don't think of them as accommodations. I know someone with a disability who always...who uses a wheelchair, who points out that she's the only person who brings her own chair to meetings.

Anna: [laughs] One...one partic—somewhat poignant example that you wrote about was...at a...I think the setting was a feminist conference and the topic was sexual harassment, and the feminists who understood themselves as not disabled were talking about, you know, being sexually harassed and how terrible this is. And one women who was using a wheelchair pointed out that she's never sexually harassed. And the point was that she's not considered an object of sexual attention at all. And it wasn't something that had appeared at all in the discussion of sexual harassment as it had been going on before she interjected that.

Adrienne: That's right. And it's...in I'd say several realms, the perspective of women with especially readily apparent disabilities is often overlooked. Sexuality is one, people with disabilities, women with disabilities and...and men too, but particularly women I think, are perceived as either not attractive or not interested, which is preposterous. And in fact I don't know anybody with a disability or not who doesn't have some interest in the topic one way or the other.

Anna: [laughs]

Adrienne: But people may feel not that they're...not that they have no desire but they are not desirable, or not...And they may feel desirable, but they don't feel desired. There's a very...You can internalize the fact of not being desired to not being desirable, but you don't have to. And so in fact lots of people don't. They know that they are desirable, but they also know that they're not desired. That's a very painful thing. Similarly, many people with disabilities who are parents, just as people with disabilities who are workers, defy the stereotype of a person who can take care of themselves and take care of someone else. So many of my friends who are parents are always...who have disabilities are always having strangers come up and well-meaning acquaintances of their children come up and say, "Oh, do you take care of your mother? Isn't that nice?" Well, no, the kids don't take care of their mothers, their parents take care of them the way other parents take care of their children. And it's very insulting, not to mention confusing to a five-year-old kid to think that they're taking care of their mother.

Anna: [laughs]

Adrienne: Another kind of example is, think of all the times that friends are, oh, you know, going through a bad time—they're moving or they're sick or they're something, and you can offer to bring somebody dinner or pick up something for them. The number of times that people with disabilities will not be accepted or women with disabilities are not accepted as help givers, you're only a help receiver. And...and that really leaves out people with disabilities and women with disabilities from a role that you may want to assume. I mean, no, women don't want to be self-sacrificing martyrs, disabled or not...

Anna: Um-hum.

Adrienne: ...but you want to be able to give help in the same way that you want to be able to take help. It's no fun to take help if you aren't respected as someone who can also provide it. So you're not nurturant, you're not sexual, you're not a mother, you're not a worker. At which point if you're an adult, you have no social role left to you.

Anna: Do you consider yourself a feminist?

Adrienne: Yeah. I'm not sure everybody considers me a feminist, but I consider myself one.

Anna: [laughs] Why do you say that?

Adrienne: Well, I have quirky views. I taught at a women's college, Wellesley, for many years and I loved teaching at Wellesley, but I didn't attend a woman's college and I'm not really entirely sure I believe in women's colleges.

Anna: [laughs]

Adrienne: In fact, I'm pretty sure I don't. Because I'm not a separatist.

Anna: Right, yeah, that's...that integrationist view is really coming...coming through all the way it seems like.

Adrienne: So I was in a department of Women's Studies and I think there's a need for Women's Studies, but only...only until theories of every discipline take the experiences and lives of women into account. Then there should be no need for women's studies. So I'm interested in things like women's studies or disabilities studies or ethnic studies or whatever only until the elites recognize that they're only a teeny part of the story. Then I want to get rid of women's studies and any kind of separate stuff. So I'm a feminist in the sense of believing firmly in women's equality and options for women and I love it that, you know, now you have assembly races and senate races where two women are up against each other and nobody thinks about it anymore. But I remember when Bella Abzug¹⁰ was running for Congress, it was a big deal in New York. Um, and, you know, I...I was not a great celebrator of Geraldine Ferraro¹¹ for vice president in 1984, but that's not that I didn't want a woman for vice president, I just didn't really think Geraldine

¹⁰ *Bella Savitsky Abzug* (1920–1998) was a well-known American political figure and a leader of the women's movement. She famously said, "This woman's place is in the House—the House of Representatives," in her successful 1970 campaign to join that body.

¹¹ *Geraldine Anne Ferraro* (born 1935) is a politician from New York, serving in the United States House of Representatives and who received the nomination of the Democratic Party to run for Vice President of the United States. Ferraro is the first (and, to date, only) woman to be so nominated on a major party ticket, and is the best-known woman to have run for the Vice Presidency. She and fellow Democrat Walter Mondale were defeated in a landslide by the re-election campaign of President Ronald Reagan and Vice-President George H. W. Bush in the 1984 election.

Ferraro had very good politics. And in the same way that I don't think we want to celebrate feminists should celebrate Margaret Thatcher¹². She didn't do anything for women or anybody else.

Anna: Right.

Adrienne: I'm not interested in celebrating victories for women if they have terrible ideas. So I'm happy to see a woman president, but only if I believe in her politics.

Anna: Have your views about feminism changed over the years?

Adrienne: Well, that particular view I don't think has changed. Um, I think feminism changes as...as the world changes. I mean, many of the feminists who fought for reproductive freedom, which often meant the freedom not to reproduce and legal abortion, now are very proud parents, mothers, they would describe themselves. And they're very involved in, I mean not all of them, but many of them are involved in celebrating motherhood, or celebrating the notion of having it all. Actually one...one way that I...I find...I found my Wellesley students very distressing. Here were these high powered women planning to get an education and become doctors and lawyers and investment bankers, and still seeing child raising as primarily women's work. Motherhood was really differentiated from fatherhood. And I think that feminism has not done a good job of keeping the notion of gender equality and parenting and gender equality in...in family relations really front and center. There's so much appreciation of what pregnancy and motherhood can mean for women's bodies, that there is sometimes a kind of glorification of, and a sort of essentializing of women and pregnancy and breast feeding as these transformative experiences that make women really different from men.

Anna: Um-hum.

Adrienne: I'm not a difference person, I'm a similarity person.

Anna: [laughs]

Adrienne: And I'm probably someone who understates difference, because I think that in overstating difference we do ourselves a great disservice. So I'm in the...I'm in the understating of difference camp.

¹² *Margaret Hilda Thatcher*, Baroness Thatcher, (born 1925) was Prime Minister of the United Kingdom from 1979 to 1990. Thatcher was the longest-serving British Prime Minister since Gladstone, and had the longest continuous period in office since Lord Liverpool in the early nineteenth century. She is also the only woman to have served as Prime Minister or as leader of a major political party in the UK, and, with Margaret Beckett and Condoleezza Rice, is one of only three women to hold any of the four major offices of state.

Anna: So there's been a lot of, in the media about this supposed conservative turn among younger women of these issues that you...it sounds like you've encountered that some with your students. How did you...how did you talk to them about it?

Adrienne: Well, I kept talking about...I mean, I taught a course at Wellesley called Women and Motherhood, and one of the things I tried to raise is should...do we want to think about motherhood as different from fatherhood. Should we be talking about parenthood? In my view, Nancy Chodorow¹³ had it right when she wrote her book *Reproduction of Mothering*, in 1978. Now she seems to have moved away from some of her own views then about equality in parenting, and in children's needs for...for recognizing that men and women can be gentle and strong. Men and women can be nurturant and separate. I think those are important ideas. But...and so do many young women think that. Until it gets down to the crunch of imagining whether they or their male partner, if they're heterosexual, will stay home with their sick five-year-old, and then they just somehow naturally assume they're going to stay home. And I would say, why? Why is it your job? Why isn't it just as much your partner's job as yours? It's your child, both of your child. I find that appalling.

Anna: So let's get to some more questions about motherhood and reproductive rights. And, you know, a lot of feminists are loathe to abandon the position that abortion should be available without regard to the reasons why a women might be wanting to choose an abortion, and...and they don't want to start it all down the slippery slope of questioning why, weighing a woman's reason for having an abortion. But you also argue eloquently that it's really hard to say that it's okay to abort fetuses with Down Syndrome, for example, but also that people among us who have Down Syndrome¹⁴ are full and equal citizens, that those...those two things don't sit very well together. So what are you thoughts on that, this difficult question of prenatal testing and abortion?

Adrienne: It's difficult [laughter]

Anna: It's difficult [laughing]. Is that right?

Adrienne: I guess I'll say...I'll try to say three things, since I've spent a lot of ink on this topic.

¹³ Nancy Chodorow is a feminist sociologist and psychoanalyst born 20 January 1944 in New York City. She has written many influential books, including *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender* (1978); *Feminism and Psychoanalytic Theory* (1989); *Femininities, Masculinities, Sexualities: Freud and Beyond* (1994); and most recently *The Power of Feelings: Personal Meaning in Psychoanalysis, Gender, and Culture* (1999).

¹⁴ *Down syndrome* (also Down's syndrome) or trisomy 21 is a genetic condition resulting from the presence of all or part of an extra 21st chromosome. Down syndrome is characterized by a combination of major and minor irregularities of body structure and function. Among features present in nearly all cases are impairment of learning and physical growth, and a recognizable facial appearance usually identified at birth.

Anna: Right, right.

Adrienne: Condense it. But I think that as long as women...as long as women bear children, as long as women are pregnant people, women should decide whether they want their bodies to sustain life. And if they don't, they should have abortions available to them for whatever reason they want. But for the same reason that I think women and feminism critique the notion that women in Western countries or other countries choose to abort female fetuses, as...for the same reason that feminism is skeptical of that act, it may tolerate it, but it is skeptical of it...I think feminism should be skeptical of the act of aborting fetuses because of particular characteristics, whether they're sex or Down Syndrome, rather than...It's very different to say, "I did want to be pregnant, and I did want to raise a child, but now I have found out that this fetus I'm carrying is a girl and I really only want a boy." Or "Now I'm carrying a fetus that has cystic fibrosis¹⁵ or Down Syndrome and I don't want that." Well, the question I want women to ask themselves is, why don't they want that? How much do they know about life with cystic fibrosis or Down Syndrome? If...if they say that it's legitimate to be a person with cystic fibrosis or Down Syndrome, why isn't it legitimate to be the parent of such a person? If they...if they say, well, of course they believe in women's equality, why should women abort female fetuses, or male ones for that matter. When you abort a fetus because of a characteristic, you're...you're making an assumption that that characteristic in some way is very dominant and controlling of what your life is...what the life of that child, if it comes into being, is going to be. And I don't think that's true. Even sex, being male or female, only tells you one thing about a person. It tells you something about how they may be treated and it tells you something about their reproductive capacities, but it doesn't tell you what they're going to be interested in. It doesn't tell you what their personality is going to be like. The same thing is true for somebody with Down Syndrome or cystic fibrosis or deafness or muscular dystrophy¹⁶. It tells you some things about limitations and impairments, but it doesn't tell you who that person with muscular dystrophy will be. Are they going to be energetic, or are they going to be quiet, or are they going to be interested in things their parents are interested in? Or are they going to be interested in totally different things? Those are the kinds of questions I would like people to ask themselves before women automatically rush to the abortion clinic when they get a prenatal diagnosis of spina bifida¹⁷ or Down Syndrome or cystic fibrosis or a sex they think they don't want. I think abortion has to be available to women as long as women are the pregnant people who bear children. If they don't want to be going through gestation, they

¹⁵ *Cystic fibrosis* (CF) is a common hereditary disease that affects the entire body, causing progressive disability and early death. Breathing difficulties are the most common symptom and result from frequent lung infections, which are treated, though not always cured, by antibiotics and other medications. CF is a multi-system disorder of exocrine glands causing the formation of a thick mucus substance that affects the lungs, intestines, pancreas, and liver. A multitude of symptoms, including sinus infections, poor growth, and infertility, can result from the effects of CF on other parts of the body.

¹⁶ The *muscular dystrophies* are a group of genetic and hereditary muscle diseases characterized by progressive skeletal muscle weakness, defects in muscle proteins, and the death of muscle cells and tissue. In some forms of muscular dystrophy, cardiac and smooth muscles are affected.

¹⁷ *Spina bifida* is a Latin term which means "split spine" and describes birth defects caused by an incomplete closure of one or more vertebral arches of the spine, resulting in malformations of the spinal cord. The spinal membranes and spinal cord may protrude through the absence of vertebral arches (called clefts).

shouldn't have to. But I think they should think about, well, if they did want to be pregnant, why don't they want to be pregnant with a fetus that has this particular characteristic? Isn't that a kind of discrimination and stereotyping that they don't like in their own lives?

Anna: It sounds like you would want the practice of, say, being a genetic counselor to be pretty different than it currently is.

Adrienne: That's an understatement.

Anna: Yes [laughs]. Well, in your...in your ideal world, both...it seems that both the world would be a better place where...for people with all kinds of disabilities, so that perhaps some of the challenges wouldn't happen to people who want to parent children with disabilities, but also that people's understandings of what those challenges might be, would be...would be quite different than they are.

Adrienne: Yes. And I think that genetic counselors¹⁸ are getting better, but still have trouble both in terms of how much time they are given to work with prospective parents and in terms of how much information they get in their own education, and in terms of how the encounter with prospective parents is structured. There are a lot of barriers to doing good genetic counseling, but I would say that genetic counseling should be giving information about the realities, sometimes very harsh ones of life with disabilities, and the rewards of families of people with disabilities. But parents of kids with disabilities should be routinely part of the genetic counseling encounter whenever you get a positive, so-called positive test result, that reveals that your fetus will...has a disabling characteristic or an impairment. You as a prospective parent should have the opportunity to meet with someone who's raising a child with that impairment, or to meet an adult with that impairment, and that should be routine parts of the genetic counseling experience. But it typically isn't. And the materials that genetic counselors give parents should be entirely different from the ones that are. They should talk about life with cystic fibrosis, not simply the numbers of medications that a child with cystic fibrosis will take.

Anna: So do the current materials just list all of the medicalized ver—you know, lists of all the clinical problems and medications, and this is what you'll have to do, and that sort of thing?

¹⁸ *Genetic counseling* is the process by which patients or relatives, at risk of an inherited disorder, are advised of the possible consequences of the disorder, the probability of developing or transmitting it, and the options open to them in management and family planning in order to prevent, avoid or ameliorate it. This complex process can be seen from diagnostic (the actual estimation of risk) and supportive aspects. Practitioners must be certified by the American Board of Genetic Counseling. Genetic counseling can occur before conception (i.e. when one or two of the parents are carriers of a certain trait), during pregnancy (i.e. if an abnormality is noted on an ultrasound or if the woman will be over 35 at delivery), after birth (if a birth defect is seen), during childhood (i.e. if the child has developmental delay), or even adulthood.

Adrienne: They tend to be very medicalized. They don't tend to include...any stories about life with these conditions. There's a big difference between what parents are told after a child is born, which is much more life-oriented and what they're told prenatally, which is much more avoidance oriented.

Anna: Um-hum.

Adrienne: And I...I think that's...I think that's bad. I think people need to have a familiarity with the genuine struggles. I mean, I was talking with someone just this morning who said, "Well, I don't have the money to raise a child with a disability. And she's a very well educated and sophisticated person. I said, "Do you know how much it costs to raise a child with a disability? Which disability? Why do you think it costs more?" And she, like most other people, doesn't really know. She's going on a kind of stereotype public image that might be true, but might not.

Anna: I'd be interested to know, have you ever had the opportunity to address a group of genetic counseling students or...or...

Adrienne: Yes. I have.

Anna: Yeah. How did that go?

Adrienne: Not well.

Anna: [laughs] What [laughs]...what did you say to them?

Adrienne: The same kind of thing I'm saying to you. But it challenges...I mean, maybe that I haven't said it gently and kindly enough and I'm trying to do that. I have sympathy for how difficult it is to do this work. But I have no sympathy for people telling me that parents aren't interested in this information or it's not appropriate to give them the kinds of information that I'm describing. I think in fact that's what genuine information is.

Anna: Um-hum.

Adrienne: And I have no sympathy with the creators of the Genetic Counseling Code of Ethics that don't have anything about teaching about life with disability in their Code of Ethics. There's nothing in the genetic counseling curriculum that requires that students get to know people with disabilities outside of medical settings. So that even in genetic counseling curricula there are culturally sensitive and sensitive to the range of families in the United States now, and I think those are good things. There's no requirement to really learn about the lives of people with disabilities from any kind of social model.

Anna: Hm.

Adrienne: None.

Anna: That is interesting.

Adrienne: And that I have no sympathy for, no patience with, and I'm infuriated by. And in case anybody wants to miss my indignation...

Anna: [laughs]

Adrienne: I wouldn't want you to miss it.

Anna: Um, so...so backing up to some larger issues about motherhood. Of course feminist research has always considered motherhood to be a critical site for understanding gender. And we've seen recently, the media never seems to lose interest in reporting on the "mommy wars", quote-unquote, generally represented as a conflict between White professional working mothers and their stay-at-home counterparts. And of course now we've seen rounds and rounds of this over the past few decades. But what do you wish we would focus on instead in a national conversation about motherhood?

Adrienne: Parenthood, first of all. I'd like to get rid of motherhood.

Anna: Um-hum.

Adrienne: Let's talk about fathers. Don't they count? I mean, there are plenty of families that now don't have two parents, one of each gender. That's fine. But in the families that do, let's talk about fathers. They count. Let's talk about raising children and parenthood, and recognize that people of either sex can be parents. One person can be a parent. And, as scandalous as this might sound, five people could be parents. Sometime, you know, there's a reason why Hilary Clinton wrote her book called *It Takes a Village*. There are...most two-parent families would tell you that they wouldn't mind a little more help.

Anna: [laughs]

Adrienne: I'm not saying that we...that children need one, two, or any particular number of adults to help them grow up. I think parents...I think people who are involved in raising children should recognize that it's a complicated enterprise and children need all kinds of adults to help them. So the first thing I would get rid of is the focus on motherhood as some kind of sacred, natural state. I would get fathers into the act. I would expect women to get fathers into the act. Not in a punitive way, and not just talking about deadbeat dads and divorced fathers who don't pay child support. I mean, those are very bad things. But don't talk about daycare as a woman's issue. Don't talk about flexible hours at workplaces as a woman's issue. Don't talk about school rooms as places only for women as...as aids to teachers. This is incredibly regressive. So that's the first thing I

would do. The second thing I would do I think is get rid of this notion that motherhood is about making sure your child has everything, does everything, is everything. This is especially hard in affluent communities that have a lot of resources and a lot of options. Follow the lead of, and the capacities and the interests of your child. Do some shaping, sure. But recognize that your child is an individual from the day your child comes into the world. And start noticing not only what you want for your child but what your child also wants. And respect those qualities of your child. That's true for mothers and fathers. It's true whether you've used assisted reproduction or ordinary reproduction. But it's related to the prenatal testing notion. We want prenatal testing because we want to give our children the best, and we're convinced that disability or the wrong sex, whatever it is, isn't going to be best for them and the best for us. But that's not focusing on the unique characteristics of your child. Every child is going to be different in some ways from the child you want. And you can do as a parent, and you should do things, to instill values and preferences into your children. That's...that's fine. But at some point your children are going to reject some of your values and some of your preferences, and that's valid. Peop—parents forget what they did to their own parents.

Anna: Um-hum.

Adrienne: And I wish people remembered their own adolescence when they were parents. And how to respect for the ways that they listened to and didn't listen to their parents, and mostly came out okay.

Anna: Yeah, it seems like now parents have taken so seriously the tabula rasa...that I can make my child, a wonderful ballet dancer, or a star soccer player, you know, if I just try hard enough, or...we just start the lessons early enough [laughs]

Adrienne: Right. That's...your child may say, "Thanks for all those lessons, dad, mom, I'm not interested."

Anna: That's what happened to me. I went to a couple lessons and it was hopeless and that was the end of that.

Adrienne: Well, and the other thing I think I want to say is that I...I said motherhood or parenthood takes a village. The society has to change to appreciate the work that child raising is. Workplaces have to change to...to give people more options. It has to be legitimate for men as well as women to take parental leave. It has to be legitimate for men as well as women to go to a child's after school activity or a parent-teacher conference.

Anna: How well, do you think we're doing on that?

Adrienne: Badly. We're doing better than we used to, but I don't think it's still the social norm and I don't think it's the workplace norm. That's why we have the mommy wars, that's why we have women getting off the tenure clock or...You know, why aren't men

getting off the tenure clock? Or...or the corporate ladder clock in law or whatever the analogous things are in nonprofessional jobs? Unions have to take this seriously. Employers have to take this seriously. I mean, it may be fine for movie theaters and restaurants to have some hours where they say, you know, no children or whatever, but children are a part of life, and I think it's got to...You know, I do think it's...it's much better that breastfeeding women can go to restaurants or theaters and...You know, some of those things are better. But we have a long way to go before American society really is child friendly. We celebrate children, but we don't cele—we don't create a society where children's needs are taken into account. And motherhood and parenthood is about children. It's not about adult satisfaction, or at least not only about adult satisfaction. It's about who individual unique children are.

Anna: So we heard that you're writing a book on assisted production. Can you give us a little preview of what you argue in that book?

Adrienne: Well, some of the things I'm saying here. But I'm also talking about the ways that reproductive technology makes the...makes children even more kind of consumer products, available to the affluent, not available to the not-so-affluent, if you're infertile, for example. I want to try to talk about the problems that I see in buying sperm online or...and buying characteristics of those sperm. Or looking at egg donor profiles.

Anna: How does that...can you talk about how some of that works?

Adrienne: That would take a whole other conversation, but...

Anna: [laughter] I'm just trying to picture that what a website like that looks like [laughs].

Adrienne: Well, there are catalogues. You can go to sperm bank catalogues and infertility clinic catalogues and read...pic—you know, get bios and self descriptions of egg donors and sperm donors. They really should be called “sellers” because they're generally being paid for their sperm or their eggs. And women who gestate children who are either called surrogate mothers or contract mothers, you can find catalogues of all these people who are willing to do these things, and pick the characteristics that you want, thinking foolishly that because some woman has 1500 SAT¹⁹ scores that her eggs are going to give you a child that's going to get 1500 on his SATs. There's a kind of genetic determinism²⁰ that's not, just not true. It's making us...it's making people think that we are our genes. I mean, genes play a role in our lives, but so does environment.

¹⁹ The *Scholastic Aptitude Test* (SAT or SAT I to distinguish it for the SAT subject tests) is a standardized test frequently used by colleges and universities in the United States to aid in the selection of incoming students. In the U.S., the SAT is administered by the private College Board, and is developed, published, and scored by the Educational Testing Service (ETS).

²⁰ *Genetic determinism* is the idea that genes determine a physical or behavioral phenotype. The term may be applied to the mapping of a single gene to a single phenotype or to the idea that all phenotypes are determined by genes. While the former is well established, the latter is generally rejected by biologists, and is poorly defined.

And there are different prices for sperm from different people and eggs from different people. And do we really want to put prices on the characteristics of future individuals? I think that's very dangerous to respecting all people as equals and moral equals, even if they have different kinds of endowments. So those are some of the kinds of things I want to talk about. I also want to talk about the very complicated question of access to these reproductive technologies and regulation of the reproductive technologies. Should they be available to anyone who wants them? Should they be available as they are now basically on...based on who can pay for them? I think that's obviously stratifying more things in society than should be stratified. There are big problems if you had the state regulating reproductive technologies. You could enshrine a lot of prejudices against older women or single women or lesbian couples or gay male couples. I wouldn't want to see that. At the same time, if we don't do some kind of regulation of these technologies, we keep having all the worst of the free market. You think about a free market in work and unregulated workplaces. There are lots of reasons why we have minimum wages laws²¹ and work and hour laws and set working conditions.

Anna: Um-hum.

Adrienne: And there are lots of problems with regulating reproduction and access to reproduction, but there are lots of problems that come from not regulating them too. So that's the kind of thing I'm going to try to talk about...

Anna: Um-hum.

Adrienne: ...in this book.

Anna: What would you say is the most pressing bioethical problem we're facing today and how should we be approaching it?

Adrienne: I'm not sure I can link it to one. I think there are two, uh, bioethical problems. One is a straight access problem of access to quality healthcare for everyone in this country. That we have 45 million uninsured people, many of whom work. That health

²¹ *The minimum wage* is the minimum rate a worker can legally be paid (often per hour) as set by statute. Each country sets its own minimum wage laws and regulations, and while a majority of industrialized countries have minimum wage laws, many developing countries do not. Minimum wage laws were first introduced nationally in the United States in 1938. During his presidency, Bill Clinton gave states the power to set their minimum wages above the federal level. As of 2004, 12 states had done so; and on November 2 of that year two additional states (Florida and Nevada) approved increases in statewide referendums. Community organizing efforts initiated by ACORN were responsible for the Florida and Nevada increases. Some government entities, such as counties and cities, observe minimum wages that are higher than the state as a whole.

insurance and healthcare comes as a...as a benefit of employment largely, and it's not a national responsibility for all citizens I think is something that is front and center one of the nation's greatest social problems and bioethical problems. I also think the increasing notion of autonomy that I just talked about in terms of reproduction – it's my body, it's my right, I can do what I want"—that notion leads to I think the worst excesses of consumerism and, um...And so you...you have in...in the medical establishment, increasing amounts of cosmetic surgeries – breast reductions, breast enlargements, you have growth hormone for short children. You have all kinds of modifications that have nothing to do with ameliorating an impairment, and a lot to do with making people fit in to some narrower and narrower notion of what people are supposed to be. And the notion of autonomy leads to that kind of consumerism. There isn't enough social justice discussion in bioethics, whether it's about healthcare or about the equality of all people with their different characteristics. I'm looking for a society that respects the uniqueness and the contributions of every individual, and the capacity of each individual to contribute according to their abilities, and...and to be provided for according to their needs. And that's an old socialist-Marxist notion, but it's the society I'm interested in creating. And I'd like a bioethics along with a feminism that was interested in creating that. I think that's out of fashion but that's really what I'm looking for.

Anna: Is there anything else you'd like to add?

Adrienne: No, that probably will do it.

Anna: [laughs] Great. Thank you so much!

The End