

マーシャ・サクストン著 「女性障害者の権利と胎児スクリーニングおよび 選別中絶への視座」の紹介

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ここに紹介するマーシャ・サクストン (Marsha Saxton) の論文「女性障害者の権利と胎児スクリーニングおよび選別中絶への視座」(Disabled Women's Rights and Views of Screening and Selective Abortion) は、2008年11月1日に明治学院大学社会学部附属研究所の研究プロジェクトとして開催したセミナーの発表原稿を『研究所年報』に掲載するために、若干、加筆していただいたものである。

セミナーではサクストンさんのプレゼンテーションのあと、事前にこの論文を読んで参加した研究者、大学院生と活発な議論が交わされた。その議論が活発になったのは、プレゼンテーションの質の高さもあったが、サクストンさんが英語を母語としない参加者にわかりやすい英語で、なおかつ注意深く単語を選んで表現したためだと思う。そこで、ここにその論文を英語のまま紹介したい。

その前に、マーシャ・サクストンさんの紹介と、このテーマについての解説、およびセミナーにおいて議論になった点の説明を加えておきたい。

マーシャ・サクストンはカリフォルニア州のバークレーにある世界障害研究所の研究員であり、カリフォルニア大学バークレー校において障害学プログラムも教えている。彼女は二分脊椎の障害をもって生まれた。大学では遺伝カウ

ンセラーの資格を取得し、その後 PhD を得た。また、女性と健康の運動に加わり、女性障害者の視点を女性運動に反映させてきた。

彼女の著作は、英語論文は、文献リストにくっつか記されているため、日本語で読める論文を紹介しておきたい。まず、体外受精などの生殖技術についてフェミニストの視点から論じた『試験管のなかの女』(アルディッティ他編、共同通信社)に「生まれる子と生まれない子」が所収されている。また、最近「障害者コミュニティのメンバーは、なぜ出生前検査と選別中絶に反対するか」(青海恵子翻訳・解説)が雑誌『インパクション』169号(2009年)に掲載された。ぜひお読みいただきたい。

医療機器や検査技術の発達によって、先天的な障害や疾患、または将来的に発症する可能性のある遺伝性の疾患について、生まれる前、つまり胎児やさらには受精卵が細胞分裂(分割)しはじめた時期に検査(着床前検査)できる。検査の方法は、子宮から羊水を採取して、その成分や羊水中に含まれる胎児由来の細胞を検査する羊水検査、胎盤の絨毛の細胞(胎児由来)を採取して細胞の染色体や DNA を調べつ絨毛検査、あるいは妊娠するとほとんど必ず実施される超音波検査でも胎児の障害がわかることもある。

論文の題名にあるスクリーニングとは、医療

においては、一定の条件で選別するといった意味である。この論文では、妊娠中の女性の血液中の成分から胎児に染色体異常の一部や二分脊椎などの障害がある確率を求める母体血清マーカー検査を指す。胎児に特定の障害がある確率が高いという結果がでると、さらに確実な結果が得られる検査が「選択肢」として提示される。ハイリスクの妊婦をスクリーニング（選別）する検査と呼ばれているが、それは検査によって胎児を「選別する」ことでもある。

出生前検査や着床前検査と呼ばれるこれらの検査は、そのあとの診断によって障害や疾患がわかったとしても、その状態を改善したり、悪化させたりしないような医学的な対処ができる状態は限られている。胎児治療は実験段階であるだけでなく妊娠している女性の負担も大きい、胎児の状態を事前に把握することによって、出産時や出生後の対応を準備し、状態を悪化させないことができる場合もある。ところが、多くの場合に、なんの対処もできないために、胎児の状態を把握した上で、妊娠を継続しない、つまり人工妊娠中絶をするという決定がなされることがある。そのために出生前検査が「問題」として立ち上がる。

障害者がその社会に生まれ、生きることを障害者自身は、どのように感じたり考えたりしているのか。障害のある子どもを産むこと、育てることをその親はいかに経験して、どのように考えているのか。同様に、これから障害児・者の親や家族になるかもしれない人はいかに考えているのか。医療者はどう考えているのか。人工妊娠中絶について社会の人々がいかに受け止めているのか、とくに女性が望まない妊娠をしたとき、産めない・産みたくない・育てられないと思ったときに、人々はその女性の決定をいかに受け止めているのか。社会制度はどうなっているのか。このように、出生前検査を受け

る・受けないの決定、検査の結果によって産む・産まないの決定に影響する要因は、さまざまにある。

サクストンの論文では、胎児の障害が見つかれば人工妊娠中絶する状況を、批判的に述べながらも、中絶する決定を単純に問題としているわけではない。障害者の権利運動は、障害者への差別がスクリーニング検査をもたらしたと批判した。ところが初期の障害者の権利運動には女性の視点が含まれていなかった。アメリカでは1973年以降、人工妊娠中絶の賛否をめぐる激しい攻防があり、女性が中絶する「権利」はつねに危機にさらされてきた。そのために彼女は、障害者へのまなざしが女性に出生前検査を受けさせていると批判しながらも、障害のある胎児が中絶されることへの批判が中絶をする女性への批判や中絶を制限することの主張へとつながる危険について注意をしている。これについては、日本とアメリカの中絶をめぐる状況に違いがあるため、セミナーでも議論になった。

アメリカで、1960年代にはじまった女性の健康に関する運動にも障害者の視点が含まれていなかったことから、サクストンさんは両方の視点をもつ立場から、スクリーニング検査に対して発言し、女性の中絶の権利の重要性を主張してきた。

もうひとつ、サクストンさんが日本の出生前検査の受検率が低いことに関心をもち、それも話題になった。私もかかわった調査研究の結果について簡単に報告した。その詳細は『妊娠』（柘植・菅野・石黒共著、洛北出版、2009年）として出版されたので、最後に紹介させていただきたい。

注 「障害」ではなく「障碍」や「障がい」と記すようになってきたが、出生前検査について論じるときには、障害と記述したほうが議論が明確になると考えた。

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Perspectives on Disability Rights, Prenatal Testing and Abortion

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Many disability rights activists have a critical view of prenatal testing with intent to abort because the pregnancy might result in a child with a disability. In the United States, the general public seems to accept these reproductive screening technologies based on the assumptions, regarded as “common sense,” that prenatal screening and selective abortion can reduce the incidence of disease and disability and thus improve the quality of life. I’d like to offer a deeper look into the general public’s, as well as the medical system’s views of disability, along with several other social factors which contribute to discriminatory attitudes about disability and how they affect the use of these tests. There are several common assumptions I would like to challenge.

Disabled people, in the last few decades, are connecting with other disabled people and recognizing the experience of discrimination. Effective medical resources, antibiotics and improved surgical techniques have helped to alleviate previously fatal conditions. Disabled people are living longer and healthier lives. Many have access to powered wheelchairs,

lift-equipped vehicles, and computer and communication technologies, which enable access to education and employment. Effective community organizing by blind, deaf and mobility impaired citizens and disabled student groups flourished in the '60's and 70s, resulting in the passage of new civil rights legislation in countries around the world. Today, many disabled people view themselves as part of a minority group and reject the common stereotypes of disabled people as defective, burdensome and unattractive. It is ironic that just when disabled citizens have achieved so much, new reproductive technologies are promising to eliminate births of people with Down syndrome, spina bifida, muscular dystrophy, sickle cell anemia and hundreds of other conditions.

Reproductive Rights in a Disability Context

A dangerous void of real information about disability is the social context of common attitudes about prenatal diagnosis and selective abortion.. These attitudes include the belief that the quality and enjoyment of life for disabled people is necessarily inferior, that raising a child with a disability is a wholly undesirable experience, that selective abortion will save mothers from the burdens of raising disabled children, and that ultimately we as a society have the means and the right to decide who is better off not being born. I hope to explain how selective abortion or eugenic abortion, as disability activists have called it, oppresses not only people with disabilities, but additionally hurts all women.

Eugenics and The Birth Control Movement

Eugenic ideology, or the “science” of selective breeding of human beings, has operated in reproductive politics for more than a century. In the late 1800’ s, eugenicists in the United States embraced the idea that undesirable traits, such as poverty and thievery, as well as such desired traits as musical ability, and "good character" were hereditary. They sought to perfect the human race through controlled procreation, encouraging those from "healthy stock" to mate, discouraging reproduction of those defined as the socially "unfit." American eugenicists were successful in enforcing a program of social engineering through a series of laws and court decisions. Leaders in the early birth control movement in the U. S. including a much admired ,woman Margaret Sanger, embraced a eugenic view, encouraging white, affluent women to reproduce, while discouraging reproduction among non-white, immigrant and disabled people. Proponents of eugenics portrayed disabled women as particularly unfit for procreation. In 1919 The American Birth Control League (ABCL) created an alliance with the director of the American Eugenics Society, Guy Irving Birch. The resulting coalition supported the forced sterilization of people with epilepsy, and those diagnosed as mentally retarded and mentally ill. By 1937, in the midst of the Great Depression, 28 states had adopted Eugenics Sterilization Laws. These laws sanctioned the sterilizations of over 200,000 women between the 1930's and

the '70's. Nazi Germany’ s extreme implementation of eugenic ideology, aimed at Jews, as well as disabled people and many other groups, sadly, was inspired by thinking that originated in the United States. While today's feminists are not responsible for these eugenic biases, some of these prejudices have persisted in the reproductive rights movement today. It is clear that some medical professionals and public health officials are promoting prenatal diagnosis and abortion with the intention of eliminating categories of disabled people, people with Down Syndrome and my own disability, spina bifida. For this reason, many disability activists and feminists have come to regard prenatal testing as "the new eugenics".

The Role of Disability Pride in Critiquing Prenatal Testing

Many disabled people have a growing sense of pride as "citizens with disabilities." With decades of hard work, disability activists have fought institutionalization, discrimination in employment and education, transportation and housing. We have fought for rehabilitation and Independent Living programs, and proven that disabled people can participate in, contribute to and lead society. In the United States, we fought for and won one of the most far-reaching pieces of civil rights legislation ever, the Americans with Disabilities Act (1990) sadly repeatedly weakened in congress and the Supreme Court. Despite the inevitable set backs of a successful movement, we are growing. Many disability activists see the next

generation of disabled children as "the youth" of the movement, who offer hope that life will continue to improve for people with disabilities for generations to come. Many parents of disabled children validate the joys and satisfactions of raising a disabled child. A large literature of books and articles by parents confirm the view that discriminatory attitudes in schools and the community, and under-funded services make raising a disabled child much more difficult than the actual logistics of their care.

The Pressure to Test and Abort

How do women decide about tests and how do attitudes about disability affect women's choices? I will describe the common arguments supporting prenatal testing, and what is insufficient or dangerous about these perspectives, not only for disabled women but for all women. Women are increasingly pressured to use prenatal testing with the argument that these tests are the "responsible thing to do." Strangers in public will even ask a woman with a pregnant belly, "Did you get your amnio?" The justification is "reassurance that the baby is fine." But the underlying communication to the mother is clear: screening out the disabled fetus is the right thing, "the healthy thing", to do. As feminist biologist Ruth Hubbard put it, "Women are expected to implement society's eugenic prejudices by "choosing" to have the appropriate tests and "electing" to terminate pregnancies if it looks as though the outcome will offend."

Often prospective parents have never considered the issues of disability until they are raised in relation to pre-natal testing. What comes to the minds of parents at the mention of the term "birth defects"? Usually the most stereotyped visions of disabled people derived from telethons and charity appeals. This is not to say that all women who use selective abortion do so based on, mindless stereotypes. I have met many women who have aborted on the basis of test results. Their stories and their difficult decisions were very moving. They made the decisions they felt were the only ones possible for them, given information they had been provided by doctors, counselors and society.

Another common justification for selective abortion is that it "ends suffering." Women as care-givers, and medical providers as guardians of health, are both vulnerable to this message. Health care providers are trying, despite the profit-based health care system in the U. S., to improve life for people they serve. But the medical system takes a very narrow view of disease and "the ending of suffering." What is rarely taught in medical training and treatment are the social factors that contribute to suffering. Physicians encounter disabled persons with health problems, complicated by the stresses of a marginalized life, perhaps additionally made worse by poverty, race or sex discrimination. Because of their training, they tend to assume that the individual's overall struggle is caused by disability. Doctors do not often get to see ordinary disabled individuals living in their communities among friends and family.

Conditions receiving priority attention for prenatal screening include Down's Syndrome, spina bifida, cystic fibrosis, and Fragile X, all of which are associated with mildly to moderately disabling clinical outcomes. Individuals with these conditions can live good lives. Of course, there are severe cases, but the medical system tends to underestimate the functional abilities, and overestimate the "burden" and suffering of people with these conditions. Among the priority conditions for prenatal screening are diseases that occur very infrequently. Tay-Sachs disease, for example, a debilitating, fatal disease that affects primarily Jews of eastern-European descent, is often cited as a condition that justifies prenatal screening. But as a rare disease, it's a poor basis for a treatment policy.

Those who advocate selective abortion often raise economic factors, or cost benefit of screening. Of course, women can be directly pressured or subtly intimidated by this notion. But it is notable that families with disabled children who are familiar with the actual impact of the disabilities tend not to seek the tests for subsequent children. The cost benefit argument fails when we consider the huge cost of disability discrimination which keeps disabled people from working, participating fully and contributing to society. We spend enormous resources to test for a few rare genetic disorders. It is also important to recognize that promotion and funding of prenatal tests distract attention and resources from addressing environmental and social causes of disability and disease. We must remember that the major causes of suffering,

and of illness and disability in the world are poverty, lack of education, lack of public health, poor nutrition and unclean water, and war, not genetic disease.

Separating Out Patriarchal Control and Eugenics from Reproductive Freedom

My challenge here is not just about the rights or considerations of disabled people. Women's rights and the rights of all human beings are important here. When disability rights activists question the practice of selective abortion many feminists react with alarm. Some feminists say they feel "uncomfortable" with language that accords human status to the fetus. One woman said: "You can't talk about the fetus as a being supported by advocates. It's too much like the 'right to life' movement. In the disability community we make a clear distinction between our views and those of anti-abortion groups. There may have been efforts to enlist disabled people to support anti-abortion ideology, but anti-abortion groups have not taken up the issues of expanding resources for disabled people or parents of disabled children, nor lobbied for disability rights legislation. So their efforts have not been successful.

A crucial issue compels us to risk making people uncomfortable by discussing the fetus. We must clarify the connection between **control of "defective fetuses" and the control of women as vessels or producers of quality controllable products**. This continuum between control of women's bodies and

control of the products of women's bodies must be examined and discussed if we are going to challenge the ways that reproductive technologies increasingly take control of reproduction away from women and place it within the commercial medical system. If a condition (like Down's Syndrome) is unacceptable, we are setting the stage for experts to use selective abortion to manipulate -- eliminate or enhance -- other (presumed genetic) socially charged characteristics: sexual orientation, race, attractiveness, height, intelligence and other traits. Pre-implantation diagnosis, now used with in-vitro fertilization, may signal the prospect of "admission standards" for all fetuses.

Some of the pro-screening arguments masquerade today as "feminist" when they are not. Selective abortion is promoted as a "reproductive option" and "personal choice". But as anthropologist Rayna Rapp notes, "private choices always have public consequences." Consider sex selection. The feminist community generally regards the abortion of fetuses on the basis of gender as furthering the devaluation of women. With sex-selection, typically favoring male offspring, women are pressed to "choose" to perpetuate the devaluation of females, and thus their own devaluation.

To blame women's oppression on the characteristics of the fetus distracts us from the core of the "choice" position: women's control over our own bodies. It also obscures the different access to "choice" of different groups of women. I've been asked "Would you

want to force a poor woman to bear a disabled child?" That is a fundamentally confused question. It reinforces what many feminists in the U. S., particularly women of color, have been saying all along. It is primarily white women who have "choice." It is the middle- and upper class women in the U. S. who can purchase these "reproductive choices". It's not poor women, and it is not families with problematic genetic traits who are asking for or creating the market for tests. Women who hope for and expect the "perfect baby" are establishing new "standards of care." Responding to the lure of consumerism of new reproductive technologies, they are helping create a profitable market that exploits the culture's fear of disability and expands the lucrative reproductive technology industry.

Some proponents argue that prenatal tests are feminist tools because they save women from the excessive burdens associated with raising disabled children. To me this sounds like calling the washing machine a feminist tool. New technologies in the home may "save time", even allow women to work outside the home, but it has not fundamentally changed who does the housework. The fact is, women still do the vast majority of the cleaning and the childcare. Housework and child care are still not valued as real work (or worth paying housecleaners or teachers or day-care workers well.) Selective abortion will not challenge the sexism of the family structure in which women provide most of the care for children, for elderly parents, and for those disabled in accidents or from non-genetic diseases. We are being sold an illusion that the "burden" and

problems of motherhood are being alleviated by medical science. The job of helping disabled people must not be confused with the traditional devaluing of women in the caregiver role. Indeed women can be overwhelmed and oppressed by their work of caring for disabled family members. But this is not caused by the disabilities of those needing extra help. It is caused by inadequate community services, and by the sexism that isolates and overworks women caregivers.

I do believe that at this point in history, the decision to abort a fetus with a disability even because it "just seems too difficult" must be respected. A woman in a position to make this decision must be allowed to assess her own resources. We must propose a policy of forcing women to complete a pregnancy. She must be allowed to decide for herself about her own body. But it is important for her to realize this "choice" is actually made under duress. Our society profoundly limits the "choice" to love and care for a baby with a disability. This failure of society should not be projected onto the disabled fetus or child. No child is "defective." A child's disability doesn't ruin a woman's dream of motherhood. Our society's inability to appreciate and support people is what threatens our dreams.

In our struggle to lead our individual lives, we all fall short of adhering to our own highest values. We forget to recycle. We ride in cars that pollute the planet. We buy sneakers from "developing countries" that exploit workers and perpetuate the distortions in world economic power. Everyday we have to make judgment calls as we assess own

ability to live well and right, and it is always difficult, especially in relation to raising our own children -- perhaps in this era more so than ever, to include a vision of social change in our personal decisions.

Women sometimes conclude that, " I 'm not saintly or brave enough to raise a disabled child." This distorts the experience of mothers of disabled children. They're not saints, they're ordinary women, as are the women who care for spouses or their own parents who become disabled. It doesn't take a "special woman" to mother a disabled child. It takes a caring parent to raise any child. If her child became disabled, any mother would do the best job she could caring for that child. It is everyday life which trains people to do the right thing, sometimes to be leaders. Do I think a woman who has utilized selective abortion intended to oppress me, or wishes I were not born? No, of course not. No more than any woman who has had an abortion means to eliminate the human race. In resisting the tests, we do not aim to blame any individual woman or compromise her individual control over her own life or body. We do mean to offer information to empower her and to raise her awareness of the stakes involved for her as a woman and member of the community of all women.

Conclusions

In concluding, here are some things I have learned while working to educate others on this issue. I try to be patient with people who don' t agree with me about these complex

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issues. I try not to get defensive when people show their confusion or disagreement. I must remember that these issues are hard to understand. My perspectives may seem contradictory to widespread assumptions about people and life.

Here is an important point to understand about the disability community and prenatal testing. The message at the heart of selective abortion is the greatest insult to the community of people with disabilities. The message is that some people would be "too flawed" at their very core, their DNA, to exist, they would be unworthy of being born. This message is painful to confront. But fighting for our right and worthiness to be born and to be welcomed, is the fundamental challenge to disability oppression; it underlies our most basic claim to justice and equality: We are, all of us, worthy of being born, we are worth the help and expense, and we know it! There is a great opportunity here to think clearly and take leadership where feminism, reproductive rights, disability rights and human liberation meet.

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