Re-shaping, Re-thinking, Re-defining:

Feminist Disability Studies

by Rosemarie Garland-Thomson

Barbara Waxman Fiduccia Papers on Women and Girls with Disabilities

Center for Women Policy Studies
2001

About the Center for Women Policy Studies

Since its founding in 1972 as the nation's first feminist policy research organization, the Center for Women Policy Studies has been on the front lines of efforts to promote justice and equality for women.

The Center's multiethnic and multicultural feminist research, policy analysis and advocacy bring women's diverse voices to important debates – on women and AIDS, violence against women and girls, welfare reform, access to health care, educational equity, employers' work/family and workplace diversity policies, reproductive rights and health, and much more.

The Center is a unique resource for policy makers, advocates and community leaders.

We . . .

IDENTIFY cutting edge issues and trends and shape multiethnic feminist responses.

ADDRESS the combined impact of gender, race/ethnicity and economic status on issues affecting women and girls.

ENSURE that our staff, Board and programs reflect women's diversity – by race and ethnicity, economic status, disability, sexual orientation and age.

GROUND our work in the belief that all issues affecting women are interrelated.

The Center . . .

CONDUCTS RESEARCH
We conduct qualitative and quantitative research, using focus groups, in-depth interviews, surveys and secondary data analysis.

ANALYZES POLICY AND LEGISLATION
We analyze federal and state policies and legislative initiatives and develop policy options.

CONVENES LEADERS
By sponsoring seminars, symposia, conferences and think tanks, we bring together creative thinkers and experts to address cutting edge issues and trends.

PUBLISHES REPORTS
We publish reports, newsletters, policy papers, research papers, action alerts, press releases and op-eds to bring our research findings and policy analyses to wide and diverse audiences.

CONDUCTS ADVOCACY
To influence policy change, we share our work with policy makers and advocates, participate in coalitions, and conduct public education and media outreach programs.

Additional single copies of this publication are available for $14.00 each. Bulk rates are available.

PUBLICATIONS
Center for Women Policy Studies
1211 Connecticut Avenue, NW, Suite 312
Washington, DC 20036
202-872-1770 *phone*
202-296-8962 *fax*
cwps@centerwomenpolicy.org *email*
www.centerwomenpolicy.org *website*

ISBN #1-877966-74-6

TABLE OF CONTENTS

PREFACE

In 1999, at the urging of our sister/colleague Barbara Faye Waxman Fiduccia, the Center for Women Policy Studies launched a new series of publications on women and girls with disabilities – beginning with two groundbreaking reports, *Violence Against Disabled Women: Research and Data in Brief* and *Women and Girls with Disabilities: Defining the Issues – An Overview*. Barbara envisioned and co-authored both of these reports and together we began to make plans for several additional reports and for a larger program of policy leadership and training for activist disabled women.

Sadly, we lost Barbara in April of 2001 and we will always miss her great and powerful spirit and her passion to ensure the full human rights of women and girls with disabilities. We continue this work, therefore, in her name, in her feminist spirit, and in her memory.

This report, written by leading Feminist Disability Studies scholar/activist Rosemarie Garland-Thomson, launches the Center's **Barbara Waxman Fiduccia Papers on Women and Girls with Disabilities**.

As Barbara and I noted in the Introduction to *Women and Girls with Disabilities: Defining the Issues – An Overview*:

> "Disabled women and girls are of all ages, all racial, ethnic, religious, and socioeconomic backgrounds and sexual orientations; they live in rural, urban and suburban communities. . . Disabled women and girls live at the corner of disability and womanhood – with two 'minority' identities, a double dose of discrimination and stereotyping and multiple barriers to achieving their life goals. . . While many women with disabilities derive enormous strength, resilience and creativity from their multiple identities, they also face the consequences of discrimination. . .
>
> Yet, the self-defined needs of women with disabilities remain on the margins of the social justice movements that should represent them – the women's movement, the disability rights movement, and the civil rights movement – leaving disabled women and girls of all backgrounds essentially invisible."

The Center for Women Policy Studies presents the **Barbara Waxman Fiduccia Papers on Women and Girls with Disabilities** as our small contribution to ending this invisibility and bringing the self-defined needs of women and girls with disabilities to policy makers, advocates, educators, and the general public.

We are especially grateful to Susan O'Hara and the True North Foundation for their generous support for the development and production of this series of reports. And we remain grateful to Felicia Lynch, former president of Women and Philanthropy, for her visionary leadership in bringing the self-defined needs of women with disabilities to philanthropy.

Leslie R. Wolfe
President
Center for Women Policy Studies
September 2001

INTRODUCTION

DISABILITY STUDIES:
The broad cultural impulse toward "minority" enfranchisement and inclusion that produced the civil rights movement in the 1960s and the feminist movement in the 1970s led as well to the disability rights movement – expressed by the Americans with Disabilities Act of 1990, the most comprehensive civil rights bill yet for people with disabilities. This landmark law requires both the public and private sectors to accommodate the corporeal and functional differences we think of as disabilities.

As disability has been recast as a civil rights issues, the emergent academic discipline of Disability Studies also has reframed the concept of disability by placing it in a social context – what is called an ethnicity model – showing that the social problems and judgments of inferiority that disabled people face are produced by their interaction with a cultural environment, both material and psychological, that is at odds either with the functioning or the configuration of their bodies. Disability Studies views the condition of having a disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy.

Disability Studies originally arose in the academy from Sociology and has developed more recently in the Humanities where it is an area of critical inquiry that is parallel to, informed by, and overlapping with Feminist Studies. In its broadest sense, Disability Studies in the Humanities undertakes a radical critique of disability. The fundamental premise of Disability Studies is that disability is a culturally fabricated narrative of the body, a system that produces subjects by differentiating and marking bodies.

This comparison of bodies legitimates the distribution of resources, status, and power within a biased social and architectural environment. As such, disability has four aspects: first, it is a system for interpreting bodily variations; second, it is a relationship between bodies and their environments; third, it is a set of practices that produce both the able-bodied and the disabled; and fourth, it is a way of describing the inherent instability of the embodied self.

Disability is a broad term within which cluster ideological

categories as varied as sick, deformed, ugly, old, maimed, afflicted, abnormal, or debilitated – all of which disadvantage people by devaluing bodies that do not conform to certain cultural standards. Thus, disability functions to preserve and validate such privileged designations as beautiful, healthy, normal, fit, competent, intelligent – all of which provide cultural capital to those who can claim such status and reside within these social identities. It is, then, the various interactions between bodies and world that create disability from the raw material of human variation and precariousness.

Disability demands a reckoning with the messiness of bodily variety, with literal individuation run amok. Because disability is defined not as a set of observable, broadly predictable traits, such as femaleness or skin color, but rather as *any* departure from the physical, mental, and psychological norms and expectations of a particular culture, disability highlights individual differences. In short, the concept of disability unites a heterogeneous group of people whose only commonality is being considered abnormal. As the norm becomes neutral in an environment created to accommodate it, disability becomes intense, extravagant, and problematic.

Disability, then, is the unorthodox made flesh, refusing to be normalized, neutralized, or homogenized. More important, in an era governed by the abstract principle of universal equality, disability signals that the body cannot be universalized. Shaped by history, defined by particularity, and at odds with its environment, disability confounds any notion of a generalizable, stable physical state of being. The cripple before the stairs, the blind person before the printed page, the deaf person before the radio, the amputee before the typewriter, and the dwarf before the counter are all proof that the myriad structures and practices of material, daily life enforce the cultural standard of a universal human being with a narrow range of bodily and mental variation.

We need to study disability in the context of what we take to be the body of knowledge that tells the story of our world and lives – the Humanities. This study is essential not to make students and teachers feel more comfortable in their skins, but rather to direct the formidable critical skills of higher education toward reimagining disability, seeing it with fresh eyes and in new ways. This is an important

educational goal not only for people with disabilities, but for everyone.

The constituency for Disability Studies is all of us – as disability is the most human of experiences, touching every family and potentially touching us all. This universality of disability experience is reflected in the term "temporarily able-bodied" (TAB), which serves as a reality check to those who perceive themselves to be immutably able-bodied.

FEMINIST STUDIES:
In the 30 years during which feminism has been a part of the academic conversation, it has proved to be flexible, diffuse, and – perhaps most significantly – self-critical. Thus, we speak now of "feminisms," "conflicts in feminism," "hyphenated feminisms," and even "post-feminism."[1] Historically, academic feminism combines the highly political civil rights and accompanying identity politics impulses of the 1960s and 1970s with postructuralism's theoretical critique of the liberal humanist faith in knowledge, truth, and identity – often adding an insistence on materiality gleaned from Marxist thought. The focus of feminist conversation has shifted from early debates between liberal and radical feminisms, which focused on achieving equality, to later formulations of cultural and gynocentric feminisms, which highlighted and rehabilitated female differences.[2]

Most recently, the debate between those who would minimize differences to achieve equality and those who would elaborate differences to celebrate the feminine has been eclipsed by an investigation of how the gender system itself operates and by its profound challenge to the very notion of "woman" as any kind of unified identity category or sociopolitical group.[3] By complicating the shared identity "woman" and recognizing that all women have multiple identities, academic feminism has generated an array of critical areas of study – Black Feminist Studies, Lesbian Studies, Latina Studies, and so on – each an acknowledgement that every woman is never simply a "woman," but is multiply identified across a spectrum of cultural categories, many of which are extrapolated from human physical differences.[4]

Most of these areas of study within feminism arise from conflicts between overarching feminist assumptions of the universality of women's experience and the experience or

perspectives of women who are members of other oppressed or stigmatized groups, in addition to being female. The points of view underpinning these diverse feminist analyses take issue with a homogeneous category of women and focus on the essential effort to understand just how multiple identities intersect.

Both inside and outside the academy in 2001, feminism is still struggling to articulate both theory and practice that adequately address cultural and corporeal differences among women. In its effort to highlight gender, feminism has sometimes obscured other identities and categories of cultural analysis – such as race, ethnicity, sexuality, class, and physical ability. As feminism recognizes this omission, however, the voices of and for women with disabilities are beginning to be heard across the Humanities.

The strands of feminist thought most applicable to Disability Studies are those that go beyond a narrow focus on gender alone to undertake a broad sociopolitical critique of systemic, inequitable power relations based on social categories grounded in the body. Feminism becomes a theoretical perspective and methodology for examining gender as an ideological and material category that interacts with but does not subordinate other social identities or the particularities of embodiment, history, and location that informs personhood. Briefly put, feminism's often conflicting and always complex aims of politicizing the materiality of bodies and rewriting the category of woman combine exactly the methods that should be used to examine disability.

FEMINIST DISABILITY STUDIES

Feminism and Disability Studies converge in Feminist Disability Studies. Just as Women's Studies expands the lexicon of what we imagine as womanly and seeks to understand and destigmatize the identity "woman," so has Disability Studies examined the identity "disability" in the service of integrating disabled people more fully into our society.

Feminist Disability Studies brings the two together to argue that cultural expectations, received attitudes, social institutions, and their attendant material

conditions create a situation in which bodies that are categorized as both female and disabled are disadvantaged doubly and in parallel ways. Feminist Disability Studies interprets disability as a cultural rather than an individual or medical issue and insists on examining power relations rather than assigning deviance when analyzing cultural representations of oppressed groups.

Feminist Disability Studies emphasizes changing public policy and cultural institutions rather than viewing the problems of disabled women as residing in their own supposedly inferior bodies. Within the critical framework of Feminist Disability Studies, disability becomes a representational system rather than a medical problem, a social construction instead of a personal misfortune or bodily flaw, and a subject appropriate for wide-ranging intellectual inquiry rather than a specialized field within medicine, rehabilitation, or social work.

Feminist Disability Studies also seeks to augment and correct traditional feminism, which sometimes ignores, misrepresents, or conflicts with the concerns of women with disabilities. For example, disabled women must sometimes defend against the assessment of their bodies as unfit for motherhood or of themselves as childlike objects who occasion other people's virtue. Whereas motherhood is often seen as compulsory for women and therefore potentially oppressive, the opposite is true for disabled women, who are denied or discouraged from this reproductive role. Perhaps more problematic still, the pro-choice rationale for abortion rights seldom questions the assumption that "defective" fetuses, destined to become disabled people, should be eliminated.[5]

The controversial feminist ethic of care also has been criticized by feminist disability scholars for undermining symmetrical, reciprocal relations among disabled and nondisabled women as well as for suggesting that care is the sole responsibility of women. Making disabled women the objects of care risks casting them as helpless in order to celebrate nurturing as virtuous feminine agency. Philosopher Anita Silvers explains that "far from vanquishing patriarchal systems, substituting the ethics of caring for the ethics of equality threatens an even more oppressive paternalism."[6]

One of the most pervasive feminist assumptions that undermines some disabled

women's struggle is the liberal ideology of autonomy and independence that fuels the broader impulse toward women's empowerment. By tacitly incorporating the liberal premise that levels individual characteristics to posit an abstract, disembodied subject of democracy, feminist practice often leaves no space for the needs and accommodations that disabled women's bodies require.[7] Prominent disability rights and feminist activist Judy Heumann's angry and disappointed words reflect the alienation that results: "When I come into a room full of feminists, all they see is a wheelchair."

ASPECTS OF FEMINIST DISABILITY STUDIES:
The major work of Feminist Disability Studies is to undertake a complex critique of gender and disability as intertwined exclusionary and oppressive systems rather than as the natural and appropriate order of things. The fundamental premises of feminist disability critical theory are: that representation structures reality; that the margins define the center; that gender and disability are ways of signifying relationships of power; that human identity is multiple and unstable; and that all analysis and evaluation has political implications. Feminist Disability Studies can be divided into four aspects, in which these premises operate: representation, the body, identity, and activism.

Representation: Feminist Disability Studies probes the issue of representation in its broadest sense to understand the saturating of the material world with meaning. Indeed, human language itself, which enables thought and knowledge, *is* representation. In this sense, disability and gender are stories we tell about bodies and are our systematic ways of representing bodies. Disability and gender are representations that historians can chart over time, interpretations that philosophers can query, images that religious scholars can trace, concepts that geographers can probe, traditions that rhetoricians can contest, and fictions that literary critics can reveal.

These narratives shape the material world, inform human relations, and mold our sense of who we are. Many cultural stories simplify disability's complexities, limit the lives and govern the bodies of disabled women. Indeed, these stories ultimately undergird the exclusionary environment and the employment discrimination that disabled women face and warrant

the flight from disability so characteristic of our cultural moment. Feminist Disability Studies seeks to challenge our collective stories – our cultural representations – about disabled women.

Cultural stories about women and disability go back to the beginnings of western civilization. Classical thought has long defined women and disabled people as being the same. For example, Aristotle defined women as "mutilated males," thus suggesting that women be seen as disabled men. Indeed, Aristotle describes women in exactly the same terms we now use to describe disability; femaleness is "a departure from type" and women have "improper form." We are, in a word, "monstrosit[ies]."[8] According to this view, women are literally the first freaks or what Nancy Tuana calls "misbegotten men."[9] The tradition that Aristotle initiated envisions women as what we might now call "congenitally deformed" as a result of their "genetic disability."

The feminist investigation of gender since Simone de Beauvoir's landmark 1949 study, *The Second Sex*, reveals how women are assigned a cluster of ascriptions, such as Aristotle's, that mark us as the "Other." What is less widely recognized, however, is that this collection of interrelated characterizations is precisely the same as is attributed to people with disabilities.

Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority.

Indeed, equating femaleness with disability is common, sometimes to denigrate women and sometimes to defend them. Examples abound: Freud delineated femaleness in terms of castration; late 19th century physicians defined menstruation as a disabling and restricting "eternal wound"; Thorstein Veblen described women in 1899 as being literally disabled by feminine roles and costuming. And 20th century feminists invoke negative images of disability to describe the oppression of women; for example, Jane Flax asserts that women are "mutilated and deformed" by sexist ideology and practices.[10]

This persistent intertwining of disability with femaleness in the western tradition provides a starting point for Feminist Disability Studies, as bodily functioning and configuration anchor the way western tradition defines both femaleness and disability. Most fundamentally, both women and disabled people are imagined as being pure body, unredeemed by mind or spirit. Women are cast as tethered to materiality, to "immanence," in Simone de Beauvior's analysis.[11] Moreover, this sentence of embodiment is conceived as either a lack or an excess. Women, for example, are imagined as castrated or "penis-poor" in Marge Piercy's wonderful term.[12] They are hysterical or have overactive hormones.

Women have been imagined as alternately having insatiable appetite in some eras and as pathologically self-denying in other times. Similarly, disabled people are portrayed as having extra chromosomes or limb deficiencies. The differences of disability are cast as atrophy, meaning degeneration, or as hypertrophy, meaning enlargement. Women with abundant body hair are described as having hypertrichosis. People with disabilities have aplasia, meaning absence or failure of formation, or hypoplasia, meaning underdevelopment. What Susan Bordo calls the "too-muchness" of women also makes disabled people equally threatening in the cultural resonances we give to differences.[13] Think of the excess embodied in the figure of the monster, the witch or the madwoman – all enduring cultural images of disability and often in its female form.

Each of these perspectives measures women and disabled people against a normative standard body and finds them wanting. Either they are not enough, or they are too much. Whether cast as superfluous or inadequate, women and disabled people are always wrong. Theirs are supposedly the ungovernable, helpless, dependent, weak, vulnerable, and incapable bodies. This cultural narrative merges the female body and the disabled body and produces an ideology that renders women and disabled people both redundant and expendable. Thus, they are the objects of female infanticide, selective abortion, eugenic programs, assisted suicide, bride burning, honor killings, domestic violence, and the classical practice of exposing disabled infants to die.

Another aspect of this condemnation to materiality that defines women and disabled people is their role as spectacles. Women are the proper object of the male gaze, while disabled people are the proper object of the stare.[14] Beauty contests, girlie shows, freak shows, telethons, and medical theater all testify to an appropriating to-be-looked-atness that supposedly inheres in the female and or the disabled body. Leering at women and gawking at disabled people are historical practices that constitute female and disabled personhood in the social world.

All these social scripts, these systems of representation, these collective cultural stories about disability and femaleness shape the material world, inform human relations, and mold our senses of who we are. For example, the voice that rings through the head of Virginia Woolf's famous character, Lilly Brisco, in *To the Lighthouse*, insists that: "Women can't paint; women can't write."[15] Think of what the concept of "throwing like a girl" tells us about how women learn that their bodies are objects not actors in the world.[16] Consider the racialism and stigma embedded in a term such as "mongoloid idiot."[17] Look at what Harlan Hahn calls the pervasive "asexual objectification" of disabled people, the assumption that they are sexless or are inappropriate sexual partners.[18] These stereotypical, often unexamined stories ultimately undergird exclusionary environments, economic discrimination, sociopolitical marginalization, and violence.

Feminist Disability Studies has challenged these tired but persistent narratives by focusing on gender and disability as representational systems, as ways of giving meaning to human variations. From the earliest "images of" surveys to the most nuanced poststructuralist critiques of identity, perhaps the most fundamental goal of Feminist Disability Studies is to reimagine women and people with disabilities. All the tools of critical theory are being recruited to show that gender and disability are discourses to be charted over time, aesthetic motifs to be probed, rhetorical traditions to be contested, metaphors to be deconstructed, performances to be analyzed, and fictions to be revealed.

The Body: A second aspect of Feminist Disability Studies is its focus on the body. While confronting issues of representation is certainly crucial to Feminist Disability Studies' cultural critique, the field does not

focus exclusively on that issue. In fact, what distinguishes both Feminist Studies and Disability Studies from many other academic critical paradigms is that both scrutinize a wide range of material practices involving the lived body.

Perhaps because women and disabled people so often are closely associated with the body in western thought, their actual bodies have been subjected relentlessly to what Michel Foucault calls "disciplining."[19] In other words, tremendous social pressures enforce practices that shape and regulate both female bodies and disabled bodies. The many practices directed at making female and disabled bodies conform to cultural expectations fall into two broad interrelated and ideologically loaded categories: medicine and appearance.

The Politics of Medicalization: Feminist Disability Studies undertakes a wide-ranging critique of the medicalization of female and disabled bodies as both women and disabled people have been imagined as medically abnormal – as the quintessential sick ones – which has entailed distinct consequences in everything from epidemiology and diagnosis to prophylaxis and therapeutics. The goal of medicine has been to cure, fix, eliminate, or control these ostensibly deviant bodies. This ideology of cure is not isolated in medical texts or charity campaigns but in fact permeates cultural attitudes and practices about disability.

Women have endured clitoridectomies, ovariotomies, unnecessary hysterectomies, radical mastectomies, and drugs to regulate their supposedly deviant sexualities and personalities. Disabled people as well are routinely subjected to invasive surgical procedures and medication intended not to improve their lives, but rather to standardize their bodies and eliminate any physical differences from ostensibly normal people.

Research on women's health has been inadequate or brutal, just as funding to enhance the economic status of disabled people is always outstripped by investments in medical procedures to normalize disabled bodies. Both women and disabled people have been institutionalized, forcibly sterilized, euthanized, mutilated, and literally reshaped in the name of "their own good."[20]

Congenitally disabled people are particularly objects of these normalizing procedures. Two

examples of this will-to-correct the disabled body are the treatment of conjoined twins and the treatment of intersexed individuals, better known as hermaphrodites, who display ambiguous genitalia and gender characteristics. Both of these forms of embodiment are congenital variations that spectacularly violate sacred ideologies of western culture. Conjoined twins contradict our notion of the individual as discrete and autonomous – actually, quite similarly to the way pregnancy does.[21] Intersexed infants challenge our insistence that biological gender is unequivocal.[22]

So threatening to the order of things is the natural embodiment of conjoined twins and intersexed people that they are almost always surgically normalized through amputation and mutilation. So intolerable is their insult to the dominant ideologies that the testimonies of adults with these forms of embodiment who say that they are happy the way they are is routinely ignored in establishing the rationale for medical treatment.

Feminist Disability Studies focuses as well on several other aspects of embodiment. A disability perspective on such reproductive issues as genetic testing and selective abortion complicates much of the feminist rhetoric about these practices.[23] Some disability activists argue that the "choice" to abort fetuses with disabilities is a coercive form of genocide against the disabled. Similarly, genetic testing and such enterprises as the Human Genome Project are often critiqued as enactments of eugenic ideology, what Evelyn Fox Keller calls a "eugenics of normalcy."[24] Aging is also at once a women's issue and a disability issue, since a significant majority of elderly people are disabled women.[25] Depression, anorexia, and agoraphobia are psycho-physical disabilities that are linked to gender roles.[26]

In addition, the politics of prosthetics, a disability concern, enters the purview of women's studies when we consider the controversial use of breast implants and prostheses for breast cancer survivors or other cosmetic prostheses such as corsets.[27] Obesity is a disability that qualified women to be freak show performers in the 19th and early 20th centuries; to quote Susie Orbach – "fat is a feminist issue."[28] Indeed, the tyranny of slenderness is perhaps the most virulent of the ideologies of beauty used to discipline and control the female body.

The Politics of Appearance: Given that the medicalization of female and disabled bodies is very often employed in the service of the politics of appearance, beauty is a value system that Feminist Disability Studies examines and critiques. We have been taught to assume rather uncritically that beauty is a relatively fixed property of the female body, even though most of us recognize the historical and cultural relativity of appearance standards. Beauty has been traditionally framed as an aesthetic quality, whether universal or subjective, and imagined as free from political implications or relations of power.

While many are willing to challenge impossible beauty norms, most still tend to think of beauty in terms of personal adequacy or inadequacy. Beauty, we have learned from our culture, is something corporeal that one has or does not have – just like a disability. But whereas having a disability seems a disadvantage, having beauty seems an advantage.

Feminist Disability Studies shifts our received assumptions about beauty by suggesting that beauty has a political dimension. Social discrimination and political subordination are linked to the cultural valuing and devaluing of bodies on the basis of their appearance. Focusing on appearance enables us to critique not only the system of standards called beauty, but also to consider how appearance norms contribute to sexism, racism, ableism and other forms of social oppression. Beauty, then, can be seen in this way as a coercive cultural ideology, a set of values and practices that, like disability, has consequences in the material world.

Lynn S. Chancer asserts that the ideology of beauty produces what she calls, not without irony, "looks-ism," which she defines as "a discriminatory phenomenon [that] sets up categorical divisions, placing far greater importance for one sex than the other on the cultivation and maintenance of particular bodily appearances to gain love, status, and recognition." Moreover, she continues, these "beauty expectations are systemic"; that is, they are a "social fact," to use Emile Durkheim's term for an aspect of culture that "exist[s] above and beyond the ability of individuals to control."[29]

Like disability, beauty is a system of representations, a set of practices and meanings, and an historically shifting ideology of the female body that we receive upon entering the world. As such, it is

a way of looking at, thinking about, and interpreting bodies that is at once culturally determined and yet by no means unalterable.

Feminist Disability Studies "denaturalizes" beauty and normalcy to transcend the usual way of thinking about these value systems – as an aesthetic quality of bodies. Feminist Disability Studies moves us from thinking about bodies as naturally having certain meanings to seeing them as social products that are informed by our cultural interpretations of them. Feminist Disability Studies shows that beauty and normalcy are a series of practices and positions that women take in order to avoid the stigmatization of ugliness and abnormality.

Appearance norms have a long history in western culture. While the classical ideal was designed to be worshipped rather than imitated, the notion of an ideal has migrated to become the standard which we are expected to achieve. The ideological systems called beauty and disability both posit a certain kind of body, a malleable body that can in some sense assume any identity or form that it chooses. This fantasy of the malleable body conforms to modernity's notion that the body is a neutral instrument of the omnipotent individual will, an instrument of agency that is both pliable and invulnerable, that we can control and alter. This notion is manifested today in the institution of cosmetic and reconstructive surgery, as is the belief that the body is not only imagined to be but literally *is* plastic, almost infinitely transformable, not just in its actions or gestures, but in the very form of its flesh.[30]

Such plasticity takes on moral dimensions in a society devoted to the fantasy of self-improvement inflected by the duty to consume that is characteristic of late capitalism. Think, for example, of the moral injunction against fat that is so common today.[31] What is most important for the politics of appearance that includes both beauty and disability in its purview is that cultural practices shape bodies according to a strict standard of normalcy that is not only privileged but that also is framed as a moral imperative.

The particularities we call disability, race, and ethnicity generally resist this coercive standardization more stubbornly than the bodies we imagine as being nondisabled, white, or beautiful. They often are not so plastic or require more invasive or extreme standardization

procedures. Moreover, postmodern culture draws a line between what it posits as fitness or cosmetic disciplinary procedures, which it often challenges, and the normalizing procedures it imposes upon impaired bodies under the almost never questioned ideological banners of health, reconstruction, or rehabilitation.

Cosmetic surgery, which is used overwhelmingly to standardize women's bodies, now enforces feminine beauty standards. Reconstructive surgery, which is used exclusively to eliminate disability, enforces the standards of normalcy. Both procedures commodify the body and are presented as enhancements that correct flaws or improve the psychological well being of the patient.

The twin ideologies of normalcy and beauty posit female and disabled bodies both as spectacles to be looked at and as plastic bodies to be shaped infinitely to conform to a set of standards called "normal" and "beautiful." In the language of cosmetic surgery, for example, the unreconstructed female body is persistently cast as having "abnormalities" that can be "corrected" by surgical procedures which "improve" appearance by producing "natural looking" noses, thighs, breasts, chins, and so on. Thus, women's and disabled people's unmodified bodies are presented as unnatural and abnormal while the surgically altered bodies are portrayed as normal and natural.

Beauty ideology, and with it normalcy, has become more coercive over the last 25 years. Ironically, this rising concern with beauty has occurred exactly at the same time as the legal and social changes wrought by feminism. This escalation can be documented by the dramatic increase in the occurrence and reporting of eating disorders and the recent burgeoning commercialization of beauty practices such as dieting (a $33 billion a year industry), cosmetics (a $20 billion a year industry), and cosmetic surgery ($33 million and growing, with nine times more women than men as clients). Naomi Wolf has convincingly shown that the social demand to configure our bodies according to beauty's standards and to create its effects with commercial products has escalated dramatically in the 20th century, not only as capitalism has demanded expanded markets for beauty products but, more interestingly, as women have achieved political gains and more equality.

Now that women have access to the vote, education, employment opportunities, and legal freedoms, Wolf argues, beauty has come to be the last restrictive institution and has consequently had to take over the repressive work that an entire system of restraining institutions accomplished in the 19th century and before.[32] While women have been liberated from many restrictions, they have not been freed from the social mandate to pursue beauty.

Feminist Disability Studies does not suggest that women and disabled people should not use modern medicine to improve their lives or help their bodies function more fully. Rather, it illuminates and explains instead of enforcing set orthodoxy. Feminist Disability Studies offers a counter logic to the powerful cultural mandates to be normal/beautiful at any cost.

The ideology of beauty in the context of disability raises critical issues that are complex and provocative. For example, questions about gender, sexuality, and disability were raised by the photo spread of Ellen Stohl, a paraplegic actress who appeared as the nude centerfold of *Playboy* magazine in 1987. Stohl wrote to editor Hugh Hefner that she chose to be in *Playboy* because "sexuality is the hardest thing for disabled persons to hold onto."[33]

The 1990s version of Ellen Stohl is Aimee Mullins, a champion runner, fashion model, celebrity, and double amputee – who also was one of *People* Magazine's 50 Most Beautiful People of 1999. An icon of disability pride and equality, Mullins exposes – in fact calls attention to – the mark of her disability in most photos, refusing to normalize or hide her disability in order to pass as nondisabled. Indeed, her public version of her career is that her disability has been a benefit – she has several sets of legs, both cosmetic and functional, and is able to choose how tall she wants to be.[34] This narrative of advantage works against the traditional narrative of overcoming that is usually ascribed to disabled people in the public sphere.

Identity: A third aspect of Feminist Disability Studies is an inquiry into how identity operates in society. The most productive challenge that feminist thought has faced is the challenge to the unity of the category "woman," on which the entire feminist enterprise seemed to rest. Recognizing that all women have multiple identities compelled feminists to turn away from an exclusive male/female focus.

Feminism began instead to look at the exclusionary, essentialist, oppressive aspects of the category "woman" itself.

The kind of rigorous self-critique feminism has undertaken is at once humbling and heartening. Expanding our understanding of how various registers of identity such as gender, race, class, and sexuality intrude upon and inflect one another sharpens feminist analyses and critiques. Disability is, of course, one such identity category that complicates the idea that all women are essentially alike and illuminates the workings of gender in particular ways. Indeed, disability disrupts the unity of the category "woman" and challenges the primacy of gender.

As a category of analysis, disability poses invigorating questions to feminism about issues such as power relations among women, the status of the lived body, the privileges of being normal, the social construction of the able-bodied, and the uses of identity politics. In turn, gender complicates Disability Studies in equally productive ways by introducing such concerns as power differentials within the disability community, reproductive and sexuality differences, and the ways that gender scripts inflect disabled identity.

For example, Feminist Disability Studies illuminates the ways that identity categories operate and interact within a political and economic context by looking at the Americans with Disabilities Act of 1990. This historic piece of civil rights legislation creates the legal category of "the disabled" by broadly defining a person as disabled if she has a condition that substantially limits a major life activity or – in a gesture toward a social model of disability – is *perceived* as having such a condition.

The courts, of course, are scurrying to limit and clarity this definition on a case-by-case basis. Who is disabled and who is able-bodied is being determined just as race was legally codified in the 19th century, although of course for different ends. Is one disabled, for instance, if function is normalized by prostheses such as glasses, hearing aids, or canes? Is one disabled by a facial deformity that makes one "ugly" but does not affect functioning? What about premenstrual syndrome, depression, HIV infection, infertility, aging, chronic pain, fetal alcohol syndrome? Suddenly, "them" and "us" are not

so clear – and gender is implicated throughout.

Feminist Disability Studies pressures both feminist theory and Disability Studies to acknowledge physical diversity more thoroughly in the task of exploring identity. Perhaps feminism's most useful concept for Feminist Disability Studies is standpoint theory, which recognizes the immediacy and complexity of physical existence. Emphasizing the multiplicity of women's identities, histories, and bodies, this theory asserts that individual situations structure the subjectivity from which particular women speak and perceive.[35]

Incorporating postmodernism's challenge of the objective Enlightenment viewpoint – the supposed view from nowhere – feminist standpoint theory has reformulated gender identity as a complex, dynamic matrix of interrelated, often contradictory, experiences, strategies, styles, and attributions mediated by culture and individual history. This matrix cannot be separated meaningfully into discrete entities or ordered into a hierarchy.

Acknowledging identity's particular, complex nature allows characteristics beyond race, class, and gender to emerge. Standpoint theory, and the feminist practice of explicitly situating oneself when speaking, allow for complicating inflections such as disability or, more broadly, body configuration – attributions such as fat, disfigured, abnormal, ugly, or deformed – to enter into our considerations of identity and subjectivity. Such a dismantling of the unitary category "woman" has enabled feminist theory to encompass, although not without contention, such feminist specializations as, for example, Patricia Hill Collins' "Black feminist thought" or my own explorations of a "feminist disability studies." So just as feminist theory can bring to disability theory strategies for analyzing the meanings of physical differences and identifying sites where those meanings influence other discourses, it can help articulate the uniqueness and physicality of identity as well.

Feminist Disability Studies focuses on the singularity and perhaps the immutability of the flesh, and at the same time questions the identity it supports. For example, Nancy Mairs explores the politics of self-naming, a common feminist theoretical practice, in regard to women with disabilities. Mairs claims the appellation "cripple" because it demands that others

acknowledge the particularity of her body. "People…wince at the word 'cripple'," Mairs contends. Even though she retains what has been a derogatory term, she insists on determining its significance herself: "Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger."

Mairs is not simply celebrating the term of otherness or attempting to reverse its negative connotation; rather, she wants to call attention to the material reality of her crippledness, to her bodily difference and her experience of it. Mairs chooses here to define her identity in terms of the significance of her pain and her struggle with an environment built for other bodies.[36]

Activism: Feminist Disability Studies also focuses on activism for change, which augments and remedies the accompanying focus on negative representations of women and disabled people, the pathologizing of their bodies, and the politics of appearance. Important activist strands have developed in both feminism and Disability Studies that shift them from the constant task of exposing just how relentless and pervasive oppression has been – and is.

This is a different kind of activism from demonstrations and marches. While less theatrical, the activism focused on integrating education, in the very broadest sense of that term, is no less ardent. And higher education is the grass roots of the educational enterprise. College and university teachers shape the communal knowledge base that is disseminated from kindergarten through the university. Activist academic practices include exposing the workings of oppression, constructing a tradition of disability culture, historical and textual retrieval, canon reformation, finding and being role models, mentoring, curriculum reform, course and program development, and integrating disability into existing syllabi.

Part of the activism inherent in Feminist Disability Studies emerges in its commitment to study the lives and artistic products of women with disabilities. To analyze who disabled women are and what they create expands our understanding of human variation and enriches our collective

knowledge of humankind, especially the ways that gender operates. For example, the judgment that the disabled woman's body is asexual and unfeminine creates what Michelle Fine and Adrienne Asch term "rolelessness," a social invisibility and cancellation of femininity that can prompt disabled women to claim the female identity that the culture denies them. Cheryl Marie Wade insists upon a harmony between her disability and her womanly sexuality in a poem characterizing herself as "The Woman With Juice."[37]

As Mairs' exploration of self-naming and Wade's assertion of sexuality suggest, a feminist disability politics would uphold the right of women to define their physical differences and their femininity for themselves rather than conforming to received interpretations of their bodies. Wade's poem of self-definition echoes Mairs by maintaining firmly that she is "not one of the physically challenged." Rather, she claims, "I'm the Gimp/I'm the Cripple/I'm the Crazy Lady." Affirming her body as at once sexual and different, she asserts, "I'm a French kiss with cleft tongue." Resisting the cultural tendency not only to erase her sexuality but to deprecate and objectify her body, she characterizes herself as "a sock in the eye with gnarled fist." This image of the disabled body as a visual assault, a shocking spectacle to the nondisabled eye, captures a defining aspect of disabled experience.

Whereas feminists claim that women are objects of the evaluative male gaze, Wade's image of her body as "a sock in the eye" subtly reminds us that the disabled body is the object of the stare. If the male gaze makes the normative female a sexual spectacle, then the stare sculpts the disabled subject into a grotesque spectacle. The stare is the gaze intensified, framing her body as an icon of deviance. Indeed, as Wade's poem suggests, the stare is the gesture that creates disability as an oppressive social relationship. And as every person with a visible disability knows intimately, managing, deflecting, resisting, or renouncing that stare is part of the daily business of life.

One example of academic activism that is exemplary in Feminist Disability Studies is what might be called a methodology of intellectual tolerance. This is not tolerance in the more usual sense of tolerating each other – although that would be useful as well. Rather, it is the intellectual position of tolerating what has

previously been thought of as incoherence.

As feminism has embraced the paradoxes that have emerged from its challenge to the gender system, it has not collapsed into chaos, but rather has developed a methodology that tolerates internal conflict and contradiction. This method asks difficult questions but accepts provisional answers. This method recognizes the power of identity at the same time that it reveals identity as a fiction. This method both seeks equality and claims difference. This method allows us to teach with authority at the same time that we reject notions of pedagogical mastery. This method establishes institutional presences even while it acknowledges the limitations of institutions. This method validates the personal but implements disinterested inquiry. This method writes new stories and recovers traditional ones.

Considering disability as a vector of identity that intersects gender is one more internal challenge. While it threatens the coherence of the category "woman," Women's Studies can accommodate such complication and the contradictions it creates. Indeed, Feminist Disability Studies strengthens the critique that is feminism and deepens the critique that is Disability Studies.

Feminist Disability Studies contends that integrating the study of disability – as a category of analysis, as a historical community, as a set of material practices, and as a representational system – into gender studies and all educational enterprises will help integrate the sociopolitical world for the benefit of everyone.

Disability, like gender and race, is everywhere, once we know how to look for it. Integrating it will enrich and deepen all our teaching and scholarship to include, for example, the history of the vibrant and variegated disability rights and independent living movements into studies of other social justice movements. Ethics is a disability issue, as is the feminist ethic of care. Literature, art, and music also have been shaped by disability experience – from Oedipus to Audre Lorde, from Rembrandt to Toulouse-Lautrec to Frida Kahlo, from Beethoven to Stevie Wonder. Many of our most developed historical fields, such as women's, labor and immigration history, are deeply informed by disability.

As with gender, race, and sexuality, to understand how disability operates is to understand what it is to be fully human.

NOTES

1. See Diane Price Herndl and Robyn Warhol, *Feminisms* (2nd ed., New Brunswick: Rutgers University Press, 1997); Marianne Hirsch and Evelyn Fox Keller, eds., *Conflicts in Feminism* (New York: Routledge, 1990). "Hyphenated Feminism" is used by Judith Grant, *Fundamental Feminism: Contesting the Core Concepts of Feminist Theory* (New York: Routledge, 1993), p. 3; Brigitta Boucht et al., *Postfeminism* (Esbo, Finland: Draken, 1991).

2. For an overview of the history of academic feminist theory, see Elizabeth Weed, "Introduction: Terms of Reference," in Elizabeth Weed, ed., *Coming to Terms: Feminism, Theory, Politics* (New York: Routledge, 1989), pp. ix-xxxi. For discussion of these debates and bifurcations in feminism, see Linda Alcoff, "Cultural Feminism Versus Post-Structuralist Feminism: The Identity Crisis in Feminist Theory," *Signs*, 13 (3): 405-36; Hester Eisenstein, *Contemporary Feminist Thought* (Boston: G.K. Hall, 1983); and Josephine Donovan, *Feminist Theory* (New York: Continuum, 1992).

3. Spelman, Elizabeth V. *Inessential Woman: Problems of Exclusion in Feminist Thought* (Boston: Beacon, 1988).

4. See Collins, Patricia Hill. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment.* (Boston: Unwin Hyman, 1990).

5. Parens, Erik and Adrienne Asch. *Prenatal Testing and Disability Rights.* (Washington, DC: Georgetown University Press, 2000).

6. Silvers, Anita. "Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities." *Hypatia* 10, no. 1 (Winter, 1995): 30-55.

7. Fine, Michelle and Adrienne Asch, eds. *Women with Disabilities: Essays in Psychology, Culture, and Politics.* (Philadelphia: Temple University Press, 1988); Wendell, Susan. *The Rejected Body: Feminist Philosophical Reflections on Disability.* (New York: Routledge, 1996).

8. Aristotle. *Generation of Animals*. Trans. A.L. Peck. (Cambridge: Harvard University Press, 1944).

9. Tuana, Nancy. *The Less Noble Sex: Scientific, Religious, and Philosophical Conceptions of Woman's Nature.* (Bloomington: Indiana University Press, 1993).

10. See Patricia Vertinsky, "Exercise, Physical Capability, and the Eternally Wounded Woman in Late Nineteenth-Century North America," *Journal of Sport History* 14 (1): 7; Thorstein Veblen, *The Theory of the Leisure Class* (1899; reprint, Boston: Houghton Mifflin, 1973); Jane Flax, *Thinking Fragments: Psychoanalysis, Feminism, and Postmodernism in the Contemporary West* (Berkeley: University of California Press, 1990), p. 136.

11. de Beauvoir, Simone. *The Second Sex.* 1952. Trans. H.M. Parshley. (New York: Vintage Books, 1974).

12. Piercy, Marge. "Unlearning to Not Speak." *Circles on the Water*. (New York: Knopf, 1985) p. 97.

13. Bordo, Susan R. *Unbearable Weight: Feminism, Western Culture, and the Body*. (Berkeley: University of California Press, 1993), pp. 160-161.

14. Kaplan, E. Ann. "Is the Gaze Male?" In Ann Snitow, Christine Stansell, and Sharon Thompson, eds., *Powers of Desire: The Politics of Sexuality*. (New York: Monthly Review Press, 1983), pp. 309-25; Laura Mulvey. "Visual Pleasure and Narrative Cinema" (1975) in *Feminisms*, eds. Robyn Warhol and Diane Price Herndl. (2nd ed., New Brunswick: Rutgers University Press, 1997); "Staring Back: Self-Representations of Disabled Performance Artists." *American Quarterly* 52, 2 (June 2000): 334-8.

15. Woolf, Virginia. *To the Lighthouse*. 1927. (New York: Harcourt Brace and World, 1955), p. 75.

16. Young, Iris Marion. *Throwing Like a Girl and Other Essays in Feminist Philosophy and Social Theory*. (Bloomington: Indiana University Press, 1990).

17. Berube, Michael. *Life As We Know It: A Father, A Family, and an Exceptional Child*. (New York: Pantheon Books, 1996).

18. Hahn, Harlan. “Can Disability Be Beautiful?” *Social Policy* (Fall 1988): 26-31.

19. Foucault, Michel. *Discipline and Punish: The Birth of the Prison*. Trans. Alan M. Sheridan-Smith. (New York: Vintage Books, 1979).

20. Ehrenreich, Barbara and Deirdre English. *For Her Own Good: 150 Years of the Experts’ Advice to Women.* (Garden City, N.Y.: Anchor Books, 1979).

21. Clark, David L. and Catherine Myser. “Being Humaned: Medical Documentaries and the Hyperrealization of Conjoined Twins.” Thomson, Rosemarie Garland, ed. *Freakery: Cultural Spectacles of the Extraordinary Body.* (New York: New York University Press, 1996), pp. 338-355.

22. Dreger, Alice Domurat, ed. *Intersex in the Age of Ethics.* (Hagerstown, MD: University Publishing Group, 1999). Fausto-Sterling, Ann. *Sexing the Body: Gender Politics and the Construction of Sexuality.* (New York: Basic Books, 2000); Kessler, Suzanne. *Lessons from the Intersexed*. (New Brunswick: Rutgers University Press, 1998).

23. Hubbard, Ruth. “Who Should and Should Not Inhabit the World.” *The Politics of Women’s Biology.* (New Brunswick: Rutgers University Press, 1990), pp. 179-198; Parens, Erik and Adrienne Asch. *Prenatal Testing and Disability Rights*. (Washington D.C.: Georgetown University Press, 2000).

24. Keller, Evelyn Fox. *Refiguring Life: Metaphors of Twentieth-Century Biology*. (New York: Columbia University Press, 1995).

25. Woodward, Kathleen, ed. *Figuring Age: Women, Bodies, Generations.* (Bloomington: Indiana University Press, 1999).

26. Bordo, Susan R. *Unbearable Weight: Feminism, Western Culture, and the Body.* (Berkeley: University of California Press, 1993).

27. Lorde, Audre. *The Cancer Journals*. (San Francisco: Aunt Lute Books, 1980).

28. Orbach, Susie. *Fat is a Feminist Issue: the Anti-diet Guide to Permanent Weight Loss.* (New York: Paddington Press, 1978).

29. Chancer, Lynn S. *Reconcilable Differences; Confronting Beauty, Pornography, and the Future of Feminism.* (Berkeley: University of California Press, 1998), p. 83.

30. Bordo, Susan R. "'Material Girl': The Effacements of Postmodern Culture." *Unbearable Weight: Feminism, Western Culture, and the Body.* (Berkeley: University of California Press, 1993); Featherstone, Mike. "The Body in Consumer Culture." *The Body: Social Process and Cultural Theory*, eds. Mike Featherstone, et al. (London: Sage, 1991).

31. Brown, Catrina and Karin Jaspers, eds. *Consuming Passions: Feminist Approaches to Weight Preoccupation and Eating Disorders*. (Toronto: Second Story Press, 1993); Seid Roberts Pollack. *Never Too Thin: Why Women Are At War With Their Bodies.* (New York: Prentice Hall, 1989).

32. Wolf, Naomi. *The Beauty Myth: How Images of Beauty Are Used Against Women*. (New York: William Morrow, 1991).

33. "This Sunny Californian Isn't About to Let Disability Diminish Her Lust for Life." *Playboy* (July, 1987), p. 68.

34. Johnette Howard. "She's Got Legs." http://cnnsi.com/womens/features/1997/magazine/gotlegs2.html

35. Collins, Patricia Hill. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment.* (Boston: Unwin Hyman, 1990).

36. Mairs, Nancy. "On Being a Cripple." *Plaintext: Essays.* (Tucson: University of Arizona Press, 1986), pp. 9-21.

37. Wade, Cheryl Marie. "I Am Not One of Them." *Ms.* 11, no. 3 (Nov/Dec, 1991), p. 57.

ABOUT THE AUTHOR

Rosemarie Garland-Thomson is Graduate Associate Professor of English at Howard University in Washington, DC, specializing in American literature, feminist theory, and disability studies. She is the author of *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (Columbia University Press, 1997), the editor of *Freakery: Cultural Spectacles of the Extraordinary Body* (New York University Press, 1996) and co-editor of *Enabling the Humanities: A Sourcebook for Disability Studies in Language and Literature* (Modern Language Association Press, 2001).

In 2000, Garland-Thomson co-directed the first National Endowment for the Humanities **Summer Institute for Disability Studies in the Humanities**. She has held fellowships from the National Endowment for the Humanities, the Andrew Mellon Foundation, and the American Association of University Women, for example. Her essay on Toni Morrison won the 1989 Modern Language Association's Florence Howe Award for Feminist Scholarship.

She currently is writing a book on the dynamics of staring and one on the cultural logic of euthanasia.

Garland-Thomson serves on the Research Advisory Board of the Center for Women Policy Studies.