

## **Interconnectedness and Women's Leadership: Disability Rights Through the Lenses of Emancipatory Spirituality and Liberatory Theology**

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### **Abstract**

While “women’s leadership” may seem, at first glance, to be incongruous to the subject of disability rights through the lenses of emancipatory spirituality, chaos theory and wisdom traditions, just the opposite is true. Chaos theory, with an emphasis on the interconnectedness of all people and living beings, sheds new light on emancipatory ideologies for all individuals, particularly women who have disabilities. Native sciences and other wisdom traditions also present themes of “interdependence and respect [for all living beings]”... (Cajete 2000, 13). Women with disabilities have long been denied “equality of respect.” From segregation in schools to discriminatory policies from employers, the women with disabilities among us have systematically faced exclusion from most of our institutions. Drawing on the works of Nancy Eiesland, Michael Lerner, Nancy Mairs and Greg Cajete, as well as my own experiences raising a daughter with a disability, I explore notions of disability rights and models of leadership that embrace the inclusion of individuals with disabilities into all facets of our society.

*The Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency.*

Americans with Disabilities Act of 1990

*Women with disabilities face double discrimination--discrimination based on gender and discrimination based disability. Women of color who are disabled face yet a third type of discrimination...The limited available statistics suggest that economically, socially, and psychologically, women with disabilities fare considerably worse than either women who are nondisabled or men who are disabled.*

(Women and Disability Awareness Project 1989)

### **Introduction**

I would like to begin with an essay my daughter, Heidi Comfort, wrote. In her own words, this is what Heidi would like people to know about being a woman with a disability.

By Heidi Comfort

## Forum on Public Policy

*My name is Heidi and I have Williams syndrome. I am eighteen-years-old and I like lots of things. I like jewelry a lot, make-up, clothes, shoes, music a ton and nail polish. I love animals a lot and I like to cook.*

*Williams syndrome is actually a gene that is missing. When you have Williams syndrome you are so nice that people appreciate it. You talk a lot and sometimes say things you don't mean. Having Williams syndrome makes me special but sometimes I wish I didn't have it. I wish I was just a regular person. I can't get a tattoo because I have a heart problem. Everything is hard because I have Williams syndrome. I don't know how to speak to boys sometimes. Sometimes kids tease me. They say bad things. They make fun of how I act. It makes me sad to talk about it. I don't feel normal and I don't like how I act sometimes.*

*I get to do lots of good things where I really have fun. I've met lots of famous people like Jennifer Aniston, Mathew Perry, Melissa Ethridge (she is really tight) and Courtney Cox. I got to be in a documentary with Oliver Sacks. Making the documentary was fun.*

*I want people to know that I can do lots of stuff. Nobody should make fun of me. If they do, I will cry. We should treat people with disabilities with respect. I will have Williams syndrome forever. Nothing can change that. I want a good life doing lots of good things. I want to take care of animals and have a good life and still be happy even with a disability.*

### **Themes of Interdependence and Interconnectedness**

Having a daughter with a disability propelled me into the disability rights movement and into the world of the "other." I have spent much of my time searching for

ways to create opportunities for inclusion and leadership for Heidi; unfortunately, this has proved to be a difficult task. While searching for inclusive philosophies, I became intrigued with ideas of emancipatory spirituality and what this ideology has to offer in the way of creating more opportunities for people with disabilities. While “women’s leadership” may seem, at first glance, to be incongruous to the subject of disability rights through the lenses of emancipatory spirituality, chaos theory and wisdom traditions, just the opposite is true. Chaos theory, with an emphasis on the interconnectedness of all people and living beings, sheds new light on emancipatory ideologies for all individuals (Briggs and Peat 1999). Greg Cajete points out that native sciences and other wisdom traditions also present themes of “interdependence and respect [for all living beings]” (13). Women with disabilities have long been denied “equality of respect.” From segregation in schools to discriminatory policies from employers, the women with disabilities among us have systematically faced exclusion from most of our institutions. Drawing on the works of Nancy Eiesland, Michael Lerner, Nancy Mairs and Greg Cajete, as well as my own experiences raising a daughter with a disability, I explore notions of liberatory theologies that embrace the inclusion of women with disabilities into all facets of our society.

Themes of interdependence and interconnectedness play important roles in developing a worldview that includes, rather than excludes, people who have disabilities. In the same way that many groups have been relegated to being “other” based on race, ethnicity, religion, or sexuality, individuals with disabilities are often relegated to the boundaries of society and community.

## Forum on Public Policy

Michael Lerner (2000), in his essay “Emancipatory Spirituality,” explores the notion of a worldview that offers “the immortality of being part and parcel of the Totality of All Being” (33). If people see themselves as part of the “Totality of All Being,” it becomes possible to see the universe as “a vast system of cooperation” (33). While Lerner does not specifically address disability, his arguments can easily be applied to the liberation and inclusion of such individuals in our churches and in our communities. Lerner notes several characteristics of “Emancipatory spirituality,” including the following:

Cultivating our capacities to see each other as ends, rather than as means. Every single person on this planet is to be treated as valuable and deserving of love, respect, and solidarity.

Emancipatory spirituality affirms the equal worth of every human being, regardless of race, gender, sexual orientation, nationality, religion, cultural ties, or anything else [disability] that has been used to deny equality of respect (36).

While Lerner does not explicitly provide analysis of the relationship between “churches” and those with disabilities, Nancy Eiesland (1994) does just that in her text *The Disabled God: Toward a Liberatory Theology of Disability*. Eiesland, herself a woman with a disability, writes with eloquence and power about the systematic “...injustice [against people with disabilities] in the church and the world” (111). Eiesland compares the disability rights movement to other struggles for civil rights:

The liberatory impulse evidenced in the disability rights movement has propelled people with disabilities to resist their marginal status in the full range of social institutions, including the Christian church.... People with disabilities have protested restrictive ordination requirements. We have resisted our experience being reformulated to conform to crippling theological categories. We have recovered our

## Forum on Public Policy

hidden history and exposed the church's complicity with our marginality (20).

One of the ways in which the church has exacerbated the marginalization of individuals with disabilities is found in the language imbedded within the very structures of church doctrine. According to Eiesland, "The Christian interpretation of disability has run the gamut from symbolizing sin to representing an occasion for supererogation. The persistent thread within the Christian tradition has been that disability denotes an unusual relationship with God and that the person with disabilities is either divinely blessed or damned: the defiled evildoer or the spiritual superhero" (70). Of course, neither of the aforementioned stereotypes is accurate nor do such generalizations represent the lives of those with disabilities. Eiesland traces biblical references that seem to support connections between one's morality or lack thereof and disability:

Leviticus 21: 17-23 prohibits anyone 'blind or lame, or one who has a mutilated face or a limb too long, or one who has a broken foot or a broken hand, or a hunchback, or a dwarf, or a man with a blemish in his eyes' from the priestly activities of bringing offerings to God or entering the most holy places in the temple.... The New Testament also supports this theme of a link between sin and disability. The account of the man with paralysis who was lowered into the house where Jesus was speaking in Luke 5:18-26 has often been interpreted as a story of heroic helpers and a crippled sinner. Here forgiveness of sin and physical healing are represented as equivalent (71).

Other notions of disability that are sometimes fostered by the church are notions of "virtuous suffering" (Eiesland 1994, 73), which can lead to defining disability as "divine testing"; of course, there is also the idea that trials help people grow closer to God as they rely less on themselves and more on their faith. An ideological sentiment that I have heard far too often, and that I consider offensive, is the idea that "God" chooses certain people to parent children with special needs because we are somehow

special—as if we as parents should consider ourselves—to use Eiesland’s words—“divinely blessed” because we parent a child who is, according to certain measures, different than her peers. While my daughter has “blessed” and enhanced my life in ways I cannot begin to express, I do not see an image of divine blessing liberating for people with disabilities or for those of us who parent children with disabilities. These images of suffering or divineness must be revised in order to come to an inclusive understanding of disability and to honor the “ordinary” lives that most individuals with disabilities live every day. Emancipatory spirituality recognizes and celebrates the divineness of all people recognizing that our “ordinary” lives are the manifestation of our spirituality.

Nancy Mairs (1996), who has Multiple Sclerosis, explores the historical role of the church and she considers biblical references with regard to healing individuals with disabilities in her text *Waist High in the World* :

In biblical times, physical and mental disorders were thought to signify possession by demons. In fact, Jesus’ proficiency at casting these out accounted for much of his popularity among the common folk...People who were stooped or blind or subject to seizures were clearly not okay as they were but required fixing, and divine intervention was the only remedy powerful enough to cleanse them of their baleful residents. Theologically as well as medically, this interpretation of the body in trouble now seems primitive, and yet we perpetuate the association underlying it (56).

Mairs is pointing out that this is a primitive theology, which has outlived its usefulness. With the renewal of fundamentalism, we may be in danger of reviving such an outmoded and dangerous theology.

While one might think that the church, of all places, would be the one place for all people to find acceptance and love, the words of Mairs and Eiesland quickly prove that the church is no more inclusive than the rest of society. Eiesland includes the story of

Diane DeVries—a woman born “without lower limbs and with above-elbow upper extremity stumps” (33). DeVries faced years of marginalization and segregation from many people in her rural Texas community, including people in the church she attended. In addition to the physical barriers of the church (lack of ramps, bathrooms not wheelchair accessible, etc.), DeVries was prohibited from singing in the church choir because of the “minister’s concern [with] shielding the congregation from her appearance” (35).

Despite years of discrimination, DeVries came to understanding of her body as “attractive, whole, and integrated” (39). Notions of the mind-body connection are certainly not unique to people writing about disabilities. The idea of the connectedness between mind and body—the wholeness between mind and body—is central to many of the teaching of wisdom traditions. Greg Cajete (2000) explores the mind-body connection in indigenous spirituality in his text *Native Science*. Cajete points out that “the body...is a central consideration of Native Science.... Tribal use of the metaphor [of the body] describes not just the physical body, but the mind-body that experiences and participates in the world” (25). His Holiness the Dalai Lama (2000) also probes the “intimate connection between physical well-being and emotional well-being”(3)--the connections between the mind and the body-- in his work *Transforming the Mind*.

His Holiness points out another aspect of Buddhist thought that may lead to a more realistic and inclusive view of disability, particularly physical disabilities. As His Holiness says, “[through meditation]...we come to realize that both happiness and suffering are subject to change and are impermanent” (22). As non-disabled individuals recognize the impermanence of their “able” bodies, perhaps they will realize that at any

time, they too might become "disabled" as a result of illness, aging, an accident, or any other of a number of reasons. Nancy Mairs asserts that one reason able-bodied people shun and ignore the disabled is to pretend that they are in no danger of becoming disabled themselves. Mairs' "descriptions and self-revelations disclose disability as part of an ordinary life. Mairs plumbs the social fears that 'this could happen to me' by acknowledging that it well could. [Mairs] offers few soothing words to those who would shield themselves from their bodies. [Mairs] moves toward the realization that she can live in her 'crippled' body and urges her readers to accompany her" (44-45).

In conversations with other parents of children with disabilities, I have shared and been told stories of parents of non-disabled children who shy away from engaging with *us* in dialogue. Parents of children who are not disabled, or people who do not yet have children but are planning to, often avoid interaction with those of us who live with the needs of our children who have disabilities every day. By confronting parents like me, people must acknowledge the fact that many people take care of themselves, get prenatal care, don't abuse drugs or alcohol, have typical pregnancies, and still can give birth to a child that many see as "abnormal." Often, because of the segregation of people with disabilities, those not involved in the world of disabilities may not know how to approach the subject. They may fear that they will insult us and choose, rather, to avoid interaction.

Nancy Mairs discusses issues of avoidance and alienation by non-disabled persons. Like Eiesland, Mairs writes of being a woman with a disabled body. Mairs has written a number of texts about being a woman in our society with a "damaged" body. In American society, woman's bodies are subjected to constant and often brutal scrutiny.

Mairs writes of “the Western dichotomy between mind, and active and in control, and body, that wayward slug with which it is afflicted” (41). Mairs also probes ideas of ways in which Western culture fosters “self-loathing” (47) of one’s body for many women, particularly women with disabilities, or to use Mairs’ term, “crippled” bodies. This is a societal ideology, rather than an individual ideology; however, the societal ideology shapes individual thought about responses to disabilities:

Illness and deformity, instead of being thought of as human variants, the consequence of cosmic bad luck, have invariably been portrayed as deviations from the fully human condition, brought on by personal failing or by divine judgment. The afflicted body is never simply that—a creature that suffers, as all creatures suffer from time to time. Rather it is thought to be ‘broken,’ and thus to have lost its original usefulness; or ‘embattled,’ and thus in need of militaristic response, its own or someone else’s to whip it back into shape; or ‘spoiled,’ and thus a potential menace to the bodies around it.... To embrace such a self requires a sense of permission some people achieve more readily than others (47-48).

As a society, we need to move away from this idea that a disabled body is a broken body. We begin to do this by having conversations like this at conferences, in our churches, in the classroom, and in our homes. In order to move past assumptions of brokenness, disabled and non-disabled communities must join together to educate one another.

Such education might begin with a recognition that all women, to some degree, suffer from the unrealistic societal standards about our bodies. For women with disabilities, society’s images are even more unrealistic and unattainable. In addition to struggling with images of our bodies as imperfect, women with disabilities face other, even more pressing challenges. (There are over 28 million women in the United States living with a disability (<http://www.infouse.com/disabilitydata/womendisability/>) and an estimated

600 million people with disabilities worldwide.) Some of the challenges faced by women with disabilities include:

- “physical barriers (poor access to enter buildings, a lack of transportation and support services to keep appointments, run errands, or receive medical care). [There has, of course, been some progress in removing physical barriers in many parts of the world.]
- financial barriers (having lower wage jobs and no health insurance). [In an age of globalization, many people are facing financial burdens and lack of healthcare. These problems are exacerbated for people with disabilities.]
- lack of reliable health information and services that address their needs”

(<http://www.4woman.gov/wwd/>) .

Women with disabilities also face a high risk of abuse in their homes and communities. According to a study conducted by the Center for Research on Women with Disabilities:

Women with disabilities face the same risks of abuse that all women face, plus additional risks specifically related to their disability. It is notable that women with disabilities tended to experience abuse for longer periods of time [than women without disabilities], reflecting the reduced number of escape options open to them due to more severe economic dependence, the

## Forum on Public Policy

need for assistance with personal care, environmental barriers, and social isolation. It is difficult to separate the effect of disability from the effects of poverty, low self esteem, and family background in identifying the precursors to violence against this population [http://www.bcm.edu/crowd/national\\_study/ABUSE.htm](http://www.bcm.edu/crowd/national_study/ABUSE.htm).

Until we, as a society, recognize role that poverty plays in limiting opportunities for parents of children with disabilities and for people with disabilities, we will continue to witness disparities and biases against those living with disabilities. Financial resources lead to expanded opportunities, better healthcare, stronger education and job training. The lack of such resources leads to continued violence and limited opportunities. In the United States, people with disabilities are often forced to remain in poverty as their benefits are reduced or eliminated if they earn wages or have assets of more than \$2,000. Poverty can also cause women with disabilities to become trapped in violent situations. Women with disabilities may not have the option of escaping such a situation because they are more likely to make less money than their non-disabled peers. Less than one-quarter of women with severe disabilities have a job or business (<http://www.infouse.com/disabilitydata/womendisability>).

One possible reason for high rates of unemployment among people with disabilities is that, as Mairs points out, we live in a about “society that equates ‘disability’ with ‘sickness’ and ‘helplessness.’ [Many disabled people raised in such a society] especially among the congenitally disabled, cannot envision any productive roles for themselves. Without a new model, which defines people with disabilities precisely in

terms not of what they cannot do but of what they can, will the world stop imposing this unwholesome sort of dependency” (93).

Such exclusion, from work, from school, from social opportunities can lead to “learned helplessness” (Seligman, 1975), which often exacerbates feelings of helplessness and dependency among women with disabilities. My daughter has, on more than one occasion, said, “I can’t do math [or read, or clean my room by myself]. I have Williams syndrome.” At a very young age, Heidi had already “learned” that the outside world focuses on what she cannot do rather than what she can do. At a parent/teacher conference when Heidi was in the second grade, the teacher commented (with Heidi in the room) that “Heidi cannot do anything the other children can do. She can’t read, write, do basic addition. She won’t stay in her chair. She cannot be in this classroom.” When I posed the question, “What can Heidi do well?” the teacher was unable to answer. The teacher’s notion of disability was so completely limited to the deficit model—what Heidi was unable to do—that she could not even fathom a way to verbalize Heidi’s abilities. While I quickly moved Heidi into a different class with a different teacher, it was too late to undo some of the damage that had been done to Heidi’s belief that she is a capable, self-sufficient individual, who can become a leader. Learned helplessness stems from exclusion from the workforce, from not being schooled with non-disabled children and from not being encouraged, or even allowed, to see one’s self as worthy and whole.

Obviously, we are not living in an inclusive time or place. The societal model currently in place is one of exclusion, one in which differences are seen as negative rather than positive. In their text *Seven Life Lessons of Chaos*, Briggs and Peat (1999) note that “Difference, which is a form of complexity, can engender feelings of apprehension and

uncertainty. We may simplify those differences into something awe-inspiring, creating celebrities and heroes, or stigmatize them into negative stereotypes” (94). In *Native Science* Greg Cajete provides an idea of what a truly inclusive community might include, a community that provides leadership opportunities for all its members. He presents an analysis of “communal environmental ethics that stemmed from the broadest sense of kinship with all life” (95). One important aspect of such kinship is the diversity of communal living. “In the close-knit interdependent community, children were exposed to people of all ages, married and singles, as well as varied personalities, the *handicapped* [italics added] and the ‘contraries.’ Children interacted with all types of people on a daily basis in the course of living in community” (96). Integral to indigenous communities is the clarity of roles for each person. “Everyone knew his/her relationship to other people, nature, and the things of their society. Relationship was the basis of the community” (96). Carol Locust (1994) notes in her exploration of American Indians with disabilities that “If the lives of the disabled Indian individuals mentioned in this paper were to be analyzed, the criteria for them **not being classified as disabled** [emphasis Locust’s] may include several factors: 1. The ability to contribute to tribal society; 2. the tribe did not view the individual as having a disability; and 3. being able to maintain harmony despite physical impairment” (21). In the Hopi village of Moencopi, Ellie’s ability to make piki bread, indeed her status as the “best piki maker,” led her to become a “living legend among her people” (2). Ellie was “not as tall as an eight-year-old, [had a] spine that was terribly twisted and a huge hump on her neck. [Yet, the villagers] seemed oblivious to the way her tiny neck was buried in her hunched shoulders and the strange gait of her walk. She was an excellent piki maker. That’s who she was” (3). Locust

## Forum on Public Policy

notes that Ellie was not perceived as disabled; thus, she lived a full life: getting married, raising a family, contributing to the village by making piki. Had Ellie grown up somewhere else, her life may well have been defined and limited by her physical appearance. Ellie was a leader, respected and valued in her community because of her strengths; she was not dismissed as an unproductive or defective individual.

Notions of leadership models based on interconnectedness and interdependence are in direct contrast to many Western ideas of individualism. As Lerner says, "In the contemporary world, it's easy to sustain the consciousness of ourselves as separate beings, but it's very hard to develop a sense of ourselves as part the Unity of All Being" (33). Many children with disabilities remain separated from non-disabled children. Because of the segregation of disabled children into "special" classes, non-disabled children often do not feel connected to their disabled peers. This "dis-connectedness" fosters a sense of superiority and domination over people who are disabled. While the inclusion model has taken place in some areas (or the "mainstreaming model") there is still the sense that difference is somehow not ok. Proponents of inclusion (placing children with disabilities in regular classes, with modification and support) argue that all children, disabled and non-disabled, can learn from one another and will benefit from being part of an accepting, inclusive community; however, inclusion faces many opponents and we are not yet at a place in our churches or our schools where acceptance of difference and diversity is the rule rather than the exception. Fostering a liberatory pedagogy requires the same sort of paradigm shift that is necessary for a liberatory theology.

## Forum on Public Policy

For Eiesland, moving toward a “liberatory theology” requires seeing individuals with disabilities as similar to minority groups. “The concept of the minority group provides a theoretical lens for understanding how such factors as negative stereotypes, prejudice, and discrimination affect the lives of persons with disabilities. Such understanding is the first step toward real communication and a change in the negative attitudes toward and differential treatment of persons with disabilities.... The minority group model gives people with disabilities and able-bodied individuals and institutions committed to social equality—those others who care—a framework in which to envision change and feasible ideas for bringing it about” (66). The disability rights movement (both in and out of churches) closely resembles other civil rights struggles. According to Eiesland, however, even though other factions of society have begun to acknowledge new models for understanding disability, “this movement has been largely ignored by the Christian church...In many denominations, discrimination against people with disabilities continues to be condoned” (67).

The very fact that many people, in addition to Eiesland, have begun a movement toward liberatory theology is encouraging. The number of texts written about the church’s role in creating an inclusive community is growing. Ideas from the new sciences and wisdom traditions regarding interconnectedness and community may create environments in which all individuals are seen as equally “valuable.” The works of Cajete and Lerner both support Eiesland’s theme of “liberatory theology” without specifically grappling with notions of disability. Community and a relationship with others are an integral part of Eiesland’s proposed theology. Eiesland asserts that “any theology that seeks access for people with disabilities must necessarily come from a

liberatory voice that continues to be constituted by a dialogue within the community of people with disabilities that locates us at the speaking center. It must come from the perspective of persons with disabilities and address other people with disabilities as the center of its concern. Likewise, it must appreciate the diversity within this community and its ever-changing character” (83).

### **Conclusion**

There are a number of organizations, led by women with disabilities that are changing the limited roles women with disabilities have often been forced to play. One such organization, Mobility International USA (MIUSA), was co-founded by Susan Sygall, who uses a wheelchair and “is an internationally recognized expert in the area of international educational exchange and leadership programs for persons with disabilities” (<http://www.miusa.org/>). MIUSA is a grassroots association that has worked to change the lives of women with disabilities throughout the world. One of their activities is a Women's Institute on Leadership and Disability, which “bring[s] together 30 new grassroots women leaders with disabilities from around the world, to build skills, exchange experience and strategies, create new visions and strengthen international networks of support to improve the lives of women and girls with disabilities.... MIUSA creat[es] opportunities for women with disabilities to take integral roles in the development process, empowering themselves and their communities” (<http://www.miusa.org/>).

MIUSA is the picture of leadership based on interconnectedness. I wish to add my voice to the voices of Susan Sygall, Nancy Eiesland, and Nancy Mairs and to the many other voices of those people who are committed to creating inclusive communities and

churches, which, in turn, would lead to increased leadership opportunities for all women. Wisdom traditions and chaos theory offer us new ways to think about our minds/bodies, our communities and our responsibilities to others. By integrating notions of interconnectedness and respect for all life, we will move toward the kind of liberatory and emancipatory theology Eiesland and Lerner and propose. Roger Gottlieb (2000) ends his essay *Caring for the Disabled* with the following quote from medieval Catholic priest Thomas à Kempis:

God has furnished us with constant occasions of bearing one another's burdens. For there is no one living without failing; no person that is so happy as never to give offense; no person without a load of trouble; no person so sufficient as to never need assistance...therefore, we should think ourselves under the strongest engagement to comfort, and relieve, and instruct, and admonish and bear with one another. (79)

Within a context of interconnectedness, the words of Thomas à Kempis can be read afresh, presenting a new, more inclusive, way to think about our relationships with all living beings and rethink narrow definitions of who is qualified to be a "leader."

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