

Disability and Diversity: Challenges to Normalisation and Sameness

By Susan Hawthorne

What is the velocity of a falling body? a body moving through space, sensing neither the relative time, nor the relative motion of its fall.

*How long does a body falling into a seizure take to fall?
(Hawthorne 1999: 90)*

I want to begin by introducing myself.

I grew up in rural Australia in the 1950s. This was not a great time to be different. My difference was suffering from epilepsy, and I was told by my mother that no one knew about this distinction. My response was deep silence. Only my mother and the doctor knew. I thought it must be pretty dreadful if that was the case. Somehow I had even told myself that my father knew nothing. I wondered for a long time why it could not be spoken about.

When I was 14, my mother told me the word "epilepsy," explained a few things, and gave me a *Life* magazine article to read. By this time I had internalised the silence so much that I continued to not speak about it to anyone. I attended a school where I knew a girl, similar in age, who took the same pills, Dilantin. For four years we met in the line each day and for four years we remained silent. Even curiosity did not break the spell.

In 1973 I joined a Women's Liberation consciousness-raising group, and there, for the first time, finally spoke about it. I shook with

fear, expecting my friends to get up and leave the minute they knew about my affliction. Instead, they stayed, they asked questions, and to my amazement they continued to be friends.

When I began to write my first novel *The Falling Woman* (1992), I began with an autistic character. It took me about a year to realise that my main character did not suffer from autism, but from silence and epilepsy.

*Orpheus sings as he returns
from the dead.*

*Eurydice cries out, Don't
leave me here like this.*

*Eurydice's eyes are dry
with fear and anger*

*As darkness closes in on her
once again.*

(Hawthorne 1999: 46)

For me the silence was not eternal. For Eurydice, and for those like José Flores, a deaf Latino, who is not only poor, but also cannot

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speak or sign, who is confined to jail for his disability because he cannot communicate (Davis 1995: 170), silence, and the darkness of incommunicable experience, is.

Many of the most marginalised peoples with disabilities are excommunicated from society because they cannot communicate in the ways designated by the "hegemony of normalcy" (Davis 1995: 170).

Normalising

The experience of normalisation is a familiar one for most people with a disability. The process was what my mother endlessly hoped for: that no one would notice, that no one would ever know. The sense of disengagement this process leaves one with is profound. I write about this in my collection of poems, *Bird and Other Writings on Epilepsy*.

*There's a hyphen between me
and the rest of the world,
breaking us apart
(Hawthorne 1999: 39)*

Normalisation is also a problem of the ways in which support groups for people with disabilities sometime function. As a lesbian, and as a feminist, I was appalled by some of the gratuitous put-downs of others in the Epilepsy Foundation's Newsletter *Epiletter* when I subscribed to it during the 1980s. I cancelled my subscription, and it has taken until the late 1990s for the organisation to have a more inclusive outlook. This process of normalisation has the effect of making everyone little models of sameness. On a small scale it is like the "monocultures of the mind" that Vandana Shiva writes about (Shiva 1993), like the process of global cultural homogenisation, but instead of countries homogenising, it is individuals. And those individuals are pushed to homogenise in the direction of the dominant culture.

This is so even within the discourse of disability. The marked body is outside what is regarded as the norm: it is too thin, it is too fat, it is crippled (Mairs 1992), it is mad (Jeffs: 2000), it is unpredictable (Hawthorne: 1996). The able body is the neutral body.

Lennard Davis in his book *Enforcing Normalcy: Disability, Deafness and the Body* (1995: 11) uses an example of visualising the normal, which marks his consciousness as a member of four powerful groups (male, white, middle-class and heterosexual) and one powerless group (the disabled). He writes:

... if I ask you to think about the nude in art, chances are good that you will visualise a specific kind of body. Chances are remarkably good that the body will be female, white and not visibly impaired. Few readers would imagine an Asian woman or a woman of color, even fewer a nude using a wheelchair.

What is interesting about his example is the way it is framed. He is politically aware of the categories "disability" and "race" or "culture," but he appears to be utterly unaware of the categories of sex and sexuality. And when it comes to class, it is rendered utterly invisible, unmentioned. It has become a kind of *terra nullius* of the body, empty land, not inhabited. It does not occur to him that the body could be male, could be poor, could be a lesbian.

The pressure to sameness goes in two directions. One, as above, is the dominant culture's process of normalising which comes out in patronising sentences like, "You're not that different, dear."

The other pressure is the urge to sameness within the disability rights movement. The strategic need to forge unity sometimes causes activists to assume a universal experience. For example, I suffer epilepsy, but I have no idea what it is like to be affected by something which makes mobility difficult. And yet, we share our marginalisation. What we share is membership of a group which I have come to call the "diversity sector." It is comprised of groups and individuals who for a range of reasons are considered to be "outside the mainstream." This group comprises poor people from the world over, indigenous peoples, migrants, refugees, most women, most blacks. It is also made up of ethnic groups who are marginalised because of their culture, the locale, their traditions. Gays and lesbians often fall into this group. As do the mad, the unpredictable, the body disabled by injury or simply by fate. Indeed, among the disabled are every other kind of person. And the disabled tend to be at the receiving end of the worst treatment in most of these settings, and if the person with disability is female, oppression layered upon

oppression is the result.

Feminism

My understanding of issues around disability was made possible for me through my reading of books on feminism. It was, of course, accompanied by my own experience. And it was within the women's movement that I first began to see the ways in which those living with disabilities very different from my own, were able to articulate this, verbally and through their actions.

An analysis of power, discrimination and oppression began to shape itself as a mosaic of patterns which applied themselves to our lives in different ways.

And it was within a feminist discourse that I first encountered protests about abortion, about prenatal testing, and a range of biotechnological interventions which the scientists claim would reduce the incidence of disability. I know that under a eugenics programme, I would be eliminated. Under a regime like Nazism, I would be eliminated (on two counts: as an "epileptic" and as a lesbian). Under the Inquisition or in the time of the Witch Hunters, I would be eliminated.

*Yesterday you brushed past death,
galloping faster this time, although
your head
lay in the snow.
(Hawthorne 1999: 77)*

Such issues are important for all women to understand. These debates are certainly not over, and with increasing intervention through genetic engineering, and its resulting social engineering, the likelihood of those of us with disabilities being excluded from health services is a genuine

prospect (Klein: personal communication). Especially if we have not undergone the required prenatal testing.

The interventionist approach gets at women in two ways. It blames women for disabilities that are the result of birth, so women are driven in fear to take tests that then throw them into ethical quandaries, often not knowing enough to make a judgement. And for the women who refuse such tests, the result then, too, is to blame. And the girls born with disabilities, in many countries, become a "burden" on the family, because the culture has deemed girls worthless. Simply being a girl is considered a sufficient defect to abort in China, India and elsewhere; in these circumstances a disabled girl will be lucky to make it through her childhood.

*The new technologies
I speak empty breath.
My tongue fallow, no
harvest of words*

*Only a dead-eyed
gaze and muscles that
cringe convulsively.
(Hawthorne 1999: 73)*

As is clear from the above, I am no fan of biotechnologies, and there are developments in information technologies that I have similar qualms about.

Among my worries are the normalising forces behind the way in which information technology is promoted to people with disabilities. No one will know that you have cerebral palsy on the Internet. No one will see your wheelchair before they engage with your mind, your personality. These are old sentiments dressed up in

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shiny new technological finery. No one could see my invisible disability (until I had a highly visible seizure in their presence) but I still felt the pressure.

I can see the usefulness of the technologies, but I distrust the rationale.

And the Internet is a fabulous tool for activism (see Hawthorne and Klein 1999) for making connections with like-minded people. It enables frequent communication for those who have access to the technology and its expensive hardware and software. For me, it has meant that some of my poems have been read much more widely than I ever dreamt possible when I first wrote them. It allows me to search for the work of others, and to join chat groups if I want to, thereby forming an electronic community.

But even with all these advantages, I am suspicious of how it can be used as a medium of control. What I want is a world filled with richness, texture, depth and meaning. I want a world in which everyone is special, valued, treasured, loved. I do not long for masks. I want the multi-

faceted parts of my being, and yours, to be recognised and celebrated. I want diversity with all its surprises and variety. I want an epistemological multiversity which values the context and real-life experiences of people. I want a world in which relationship is important, and reciprocity is central to social interaction. I want a language with which these things can be spoken.

My tongue has blossomed in my
mouth
It is filled with language
It spreads like a big red balloon
With language caught inside.

A language that can't distinguish one
thing from another
A language that does not care for past
or future
A language tense with the present

The language in my tongue dissolves
all history
It dissolves all expectation of the
future
The language in my tongue is a big
red balloon

There's a language in my body too
A language in the arch of my back
A language in the froth from my
mouth
A language in my clenched fist
A language in the cry from my lungs
There's a language in my bleeding
tongue

The language in my body and in my
tongue
is the language they spoke in Delphi.
The language of the seizure that
dispels time,

that defies death, that returns the
orator
to the world of light, that single point
that
draws me back from the inertia, the
gravity
field of a hole so black, nothing exists
and nothing matters.
(Hawthorne 1999: 53) ♪

Susan Hawthorne is the author of two books which touch on the subject of epilepsy, a novel *The Falling Woman* (1992, Spinifex) and a collection of poems, *Bird* and other writings on epilepsy (1999, Spinifex). She has also contributed artwork to an exhibition *Seize*, held in Melbourne in 1999, and has created an aerials performance around her poem "The Language in my Tongue." She is also currently completing a PhD on *Wild Politics: Feminism, Globalisation and Biodiversity* at the university of Melbourne. She has (co-)edited or authored 10 books.

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