

MEDIA REVIEW: Disability in Dangerous Times

"Disability in Dangerous Times" is based on a public lecture given by Catherine Frazee for the Disability Studies Speaker Series, 2009, Ontario Institute for Studies in Education, and New College, University of Toronto, November 5, 2009. Dr. Frazee is former chair of the Ontario Human Rights Commission and Professor of Distinction with Ryerson University's School of Disability Studies. In her lecture, given to an audience of disabled academics, activists, advocates and community members, she engages with past and immediate media stories. Dr. Frazee wedges the concerns of developmentally disabled people into these urgent public discussions. In doing so, she exposes the ways in which "public health crises" ignore and sacrifice disabled people. She ends hopefully, urging us to use the stories we hear through the media as an opportunity for empathy.

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1. Prologue

You are, you know, a tough crowd. And that is as it should be, on this day of action,¹ this day of making visible our claims, our solidarity, our insistence. Tough is what it will take, if we are to sever the ever-tighter hold that binds privilege to education, class to health, self-interest to sustainability, profit to dignity. Tough we must be, if we are to awaken the moral outrage of fellow citizens who have been lulled into a dreamless and compliant sleep, wrapped in blankets of "common sense" and liberal reason. Tough is the ticket that gets us through the turnstile, one obstruction closer to the table we demand—and deserve—a seat at.

But forgive me if I cannot help but notice also that you are a tough crowd for me to face this afternoon. You are a formidable presence, the *Sandinistas* of Disability Studies in Toronto and beyond. How shall I enter this gathering of savvy revolutionaries, your minds already so finely attuned to the mighty thoughts and dazzling scholarship of Michalko and Titchkosky? What can I possibly add to a conversation that trembles with the intensity of justice on the rise? In the blink of a mere three weeks, you have mounted a fierce and unstoppable campaign worthy of the man it honours and the program it defends.² You have gathered momentum and global support, you have mobilized passion and argument, you have secured moral and tactical ground. I applaud what

1 For some context for the timing of this address, see Canadian Federation of Students – Ontario, "Mass Rallies Throughout Ontario Call on McGuinty to Drop Tuition Fees and End Poverty" (2009), http://www.cfs-fcee.ca/html/english/media/mediapage.php?release_id=1070.

2 John Bonnar, "Students Protest Proposed Cuts to Disability Studies Program at U of T," *Rabble.ca* (2009), <http://www.rabble.ca/blogs/bloggers/johnbon/2009/11/students-protest-proposed-cuts-disability-studies-program-u-t>

you have achieved and I thank you—*Disability Studies thanks you*—for your fury on behalf of our colleague, mentor and friend.

But truly, against the strong angles of your activism, my brain feels soft, my temperament heavy. What can I possibly say to you about *disability in a dangerous time*? What can I offer, in support of your school, your faculty and your defence of both?

Only this, my breath. What I have of that precious resource is yours for the next 30 minutes.

2. Soliloquy for Soft Brain

These fragile bodies of touch and taste
This vibrant skin—this hair like lace
Spirits open to the thrust of grace
Never a breath you can afford to waste

*Bruce Cockburn,
from Lovers in a Dangerous Time*

I am naked, and the waters are rising. A woman leans in toward me, presses, pulls, turns. Her touch is sure and linen-crisp. Tender but firm attention from warm, unsentimental hands. It is the way I like it, for my morning hour.

I am naked, and she is not. We repeat this encounter every day, while my lover swallows coffee and buttered toast in the next room. Sometimes we proceed silently through my daily routine of waking, bathing, dressing and emerging. Sometimes we talk. The years have made friends of us.

On this day, like everyone else, we are talking. It is the summer of 2005. The levees have failed, and the bodies of 34 drowned residents have been found in what remains of St. Rita's Nursing Home in Saint Bernard Parrish, Louisiana.³

Shelley is outraged. I am lying on my side, a position in which clear speech is difficult. But clear speech will be difficult for all of us today.

I make sounds to assure her that I share her distress.

I also, evidently, make assumptions about the precise nature of that distress. "They've got no business," Shelley continues. "No business judging those women. Those women have families just like me. What do they expect? Forget your family and do your job? I'm here to tell you, there's no way I'd be staying behind. No way."

My eyes scramble across the ceiling for something solid to fix to. I wish that I were not quite so naked.

The waters have risen. We are intimates in a dangerous time, Shelley and I. That much is clear.

3. Not So Clear, but Still Present

Don't the hours grow shorter as the days go by
You never get to stop and open your eyes
One day you're waiting for the sky to fall
The next you're dazzled by the beauty of it all

*Bruce Cockburn,
from Lovers in a Dangerous Time*

The days have gone by. The sky has not fallen. And wishing that I were not quite so naked has given way to a kind of astonishment, though not from beauty. It is striking to me that at what one might consider a safe distance of over 2,000 km from those broken levees, I could feel the waters rising—a generous interpretation might suggest this to be empathy. But in the panic occasioned by our clash of subjectivities, I could in an instant descend to a staggering *failure of empathy* in relation to those workers whom Shelley had championed: a clutch of faceless women, likely racialized, working poor, and caught up in a swirling horror. What did I feel entitled to expect, and from whom? Would I have braved the waters for them? Shelley was certain of her answer. I am not, cannot be. In that we differ. But a difference in style of certainty is surely not of great moral significance.

What is of significance, is this.

Framings of personal tragedy are every bit as distorting, destructive and deceptive when applied to catastrophe as they are when applied

3 Gardiner Harris, "In Nursing Home, a Fight Lost to Rising Waters," *New York Times* (2005), <http://www.nytimes.com/2005/09/07/national/nationalspecial/07chalmette.html>

to impairment, and for some of the same reasons. They overlook the social dimension, constructing a scenario that pits simple villains against single victims, colluding with the larger forces of power and structure and governing relations that constitute the stage upon which the characters, including ourselves, perform our parts.⁴

We figured it out, slowly, in the post-Katrina discourse. When we recovered our grasp on the big picture, we turned our gaze from the workers of St. Rita's to the stewards of the levees, from the crumbled and rotting nursing homes to the rooms behind closed doors on distant higher ground where decisions could have been made so very differently. And as good disability scholars, we looked up from the bodies of those 34 residents, from the images of victims slumped in wheelchairs, and we opted out of the vulnerability narrative. In and of itself, vulnerability explained nothing. Instead, it demanded its own explanation, its own unpacking from the baggage of social policy and neglect. It was *social* frailty, not impairment, that accounted for those deaths. It was not the workers who abandoned those residents. It was America. As Laura Hemingway & Mark Priestley concluded, "Disabled people have been *made* more vulnerable to natural hazards." As a consequence of generations of exclusion, impoverishment and overlooking, disabled people's experience of disaster is more acute, more long-lasting, more catastrophic.

While calamity may be random, its impacts never are. For the most part, catastrophe stalks by category, and disabled people figure prominently on its radar. My soft brain settles on the notion of a social model of dangerous time. Thanks to Shelley for the jolt, and to Christopher Johnstone for his phrase, "disasters are complicated affairs."⁵

4 Laura Hemingway and Mark Priestley, "Natural Hazards, Human Vulnerability and Disabling Societies: A Disaster for Disabled People?," *Review of Disability Studies* 2.3 (2006).

5 Christopher Johnstone, "Disability Studies and Disaster Services: Putting the "DS" in "DS"," *Review of Disability Studies* 2.3 (2006).

4. The Trouble with Normal

Strikes across the frontier and strikes
for higher wage
Planet lurches to the right as ideologies engage
Suddenly it's repression, moratorium on rights
What did they think the politics
of panic would invite?
Person in the street shrugs—"Security
comes first"
But the trouble with normal is it always
gets worse.

*Bruce Cockburn,
from The Trouble with Normal*

The other trouble with normal is the trouble of bedfellows. I move now from Shelley at my bedside with clothes on, to my new bedfellows, the entire Calgary Flames hockey team.⁶ Me and the Flames, we are high-risk and therefore vaccinated. For now, it seems, we have been cured of our *vulnerability* to H1N1. We are joined in this category by residents of Vancouver's downtown Eastside, but not, to my knowledge, by Toronto's homeless population.⁷ They are classed with the general population, not with the high-risk high-rollers.

Meanwhile, whatever our category, we are all washing our hands. It's the perfect metaphor. We began by washing our hands of the pandemic's origins on the factory farm—leaving the barn door still open on the known hazards of industrial-scale animal production. "A necessary evil," we shrug, "to keep meat prices competitive." Yet according to Gwynne Dyer's calculations,⁸ factory farming is saving the average consumer \$29 US a year, or about \$2.40 a month.

6 Josh Wingrove, Anna Mehler Paperny and Dawn Walton, "Hockey Players Jump the Flu Queue—and Land on Thin Ice," *The Globe and Mail* (2009), <http://www.theglobeandmail.com/life/health/h1n1-swine-flu/hockey-players-jump-the-flu-queue-and-land-on-thin-ice/article1351587/>

7 Andy Blatchford, "H1N1 Outbreak Could Be 'Dangerous' for Canada's Homeless: Advocates," *CTV news* (2009), http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20091025/swineflu_homeless_091025/20091025?hub=Health

8 Gwynne Dyer, "Of Pandemics, Pork, and Factory Farms" *Georgia Straight*. (2009), November 4, 2009, <http://www.straight.com/article-222087/gwynne-dyer-pandemics-pork-and-factory-farms>

With clean hands and outstretched arms, we welcome and applaud big pharma. Never mind the profit windfall occasioned by pandemic. Never mind those antiviral patents they so jealously guard. As we line up for our shots, we wash our hands of the great big messy truth. To quote Priscilla Wald, “nothing [would] go further to contain the spread of disease than a healthy population with access to health care.”⁹ “Later,” we urge, right now this virus is our #1 public health priority.

We wash our hands of the fact that First Nations communities were, quite predictably, hit first and hardest by H1N1. As Kevin Patterson¹⁰ wrote in the *Globe* earlier this fall, “the main reason *native* people die of infections, at rates that would be inconceivable and entirely unacceptable to other Canadians, is because they are poor. The poor die of everything—heart attacks, diabetes, suicides, homicides, drowning, house fires—at rates that would not be permitted along the various Bridle Paths of the nation.” Patterson concludes, “The most effective vaccine against any infection is affluence.”

And still we wash.

So, what about disabled people?

This is where I’m supposed to blow you away with the results of my investigations, arm you with facts and figures to take to the streets. But as every good disability scholar knows, pay attention to the absences, and that’s where you’ll find disability. Translation: there’s not much to report, but I do have questions. Some I’m hoping you can help me with:

- How is Wheeltrans accommodating its riders’ vaccine wait times?
- Is the Ministry of Health keeping its ASL bulletins up to date?

- What is the status of prevention efforts among Toronto’s homeless?
- What research is underway to protect persons with impairments or sensitivities for which the vaccine is contraindicated?
- How are our Survivor communities being resourced for pandemic education and self-advocacy?
- Likewise how are our People First and AAC networks being resourced for pandemic education and self-advocacy?

In a blog posting just over a month ago,¹¹ Dick Sobsey, whom most of you know is a prolific disability scholar and our country’s most vigilant watchdog on matters of life and death for people with intellectual disabilities, flagged some important numbers emerging from US fatality data: “67% of the children who have died from H1N1 in the US ... are children (under 18) with significant pre-existing health conditions.”¹² That is perhaps what we might have expected, given the designation of certain impairments as high risk. But the second statistic is both alarming and unexpected: almost all of these deaths (92%) involved children with some degree of intellectual impairment. This must surely make them one of the highest risk groups, although any public health recognition of this reality is hidden within the generic category of “chronic health condition.” This, despite the fact that in 2005 in the US, “neurodevelopmental conditions” were expressly added to the list of conditions “that should prompt seasonal influenza prevention and treatment.”

Our chronic health conditions got us to the front of the vaccine line, but it appears that we part company with the Calgary Flames at the top of another list—the exclusion criteria list in Critical Care Triage Protocols. If it weren’t so deadly serious, we might think of this as the list of who gets voted off the island first, if and when critical care

9 Priscilla Wald, “Let’s Not Panic over the Pandemic – Let’s Just Focus on Global Poverty,” *The Globe and Mail* (2009), <http://v1.theglobeandmail.com/servlet/story/RTGAM.20090430.wcopandemic01/BNStory/PRISCILLA+WALD/PRISCILLA+WALD>

10 Kevin Patterson, “Influenza Has a Cure: Affluence,” *The Globe and Mail* (2009), <http://www.theglobeandmail.com/news/technology/science/influenza-has-a-cure-affluence/article1276838/>

11 Dick Sobsey, “Medical Fragility & Pandemic Planning,” *Dick Sobsey’s MECP2 Duplication Blog* (2009), <http://mecp2.wordpress.com/2009/09/21/medical-fragility-pandemic-planning/>.

12 Centers for Disease Control and Prevention, “Surveillance for Pediatric Deaths Associated with 2009 Pandemic Influenza A (H1N1) Virus Infection – United States, April–August 2009,” *Morbidity & Mortality Weekly Review* 58.34 (2009).

units of our public hospitals enter what is called pandemic surge, and there is insufficient capacity, personnel, medication or equipment to save all of the lives that seek to be saved. (Some are urging, as an aside, that our courts as well will need to equip themselves for pandemic surge, as these triage exclusions are implemented.¹³)

In post-SARS Ontario, there's already been a good deal of attention paid to questions of triage in a worst-case scenario. Last year's Ontario Health Plan for an Influenza Pandemic,¹⁴ which appears to be the current document of reference, included a Draft Critical Care Pandemic Triage Protocol to guide hospitals in making those life-and-death judgments. They articulate, in vivid black-and-white, the "exclusion criteria" for critical care services:

We are there; the Flames, incidentally in this instance, are conspicuous by absence. The criteria specify that patients will be excluded from admission/transfer to Critical Care if any of a number of conditions are present, including the following:

- Advanced untreatable neuromuscular disease.

Severe and irreversible neurologic event/condition.

- Severe cognitive impairment.

Nothing fudgy or generic here. Spelled out quite clearly, in fact. There it is, that same familiar melody, that cold and clammy farewell handshake, utilitarian-style. Sorry, we've done all that we could for you and your kind. But the waters are rising, and there are others in desperate need. There are others that we must save, because they will live long and rich lives (homonym intended). Difficult choices must be made. Surely you understand.

Yes, I believe we do understand. Just keep washing our hands.

13 Juliet Guichon and Ian Mitchell, "The Courts Need Surge Capacity," *The Globe and Mail* (2009), <http://www.theglobeandmail.com/news/opinions/when-a-pandemic-comes-our-courts-need-surge-capacity/article1305911/>

14 Government of Ontario, *Ontario Health Plan for an Influenza Pandemic* (Toronto: Government of Ontario, 2008).

5. Lovers of Whom? Lovers of What?

When you're lovers in a dangerous time
Sometimes you're made to feel
as if your love's a crime—
But nothing worth having comes
without some kind of fight—
Got to kick at the darkness 'til it
bleeds daylight
When you're lovers in a dangerous time
Lovers in a dangerous time
And we're lovers in a dangerous time
Lovers in a dangerous time

*Bruce Cockburn,
from Lovers in a Dangerous Time*

There's a Jewish teaching that if you put one human life on one side of a scale, and you put the rest of the world on the other side, the scale is balanced equally.

Believe it or not, I learned that teaching from Peter Singer,¹⁵ who was quick to dismiss it as a "feel-good claim." Singer acknowledged the teaching as perhaps having "symbolic value in particular circumstances," but as a guide to social conduct, he rejected it as "deeply unethical."

Perhaps, I say, but the realm of the symbolic may be a good place to start.

I don't have the sharp clean formula to rebut the ubiquitous QALY,¹⁶ the measurable criteria that will more fairly guide critical care triage. I just don't think we're ready for that invention. We've got too much unfinished business, too much history to settle, too many symbols to unpack, too much handwashing to correct.

I hear Elie Wiesel urging us to "always think higher and feel deeper."¹⁷ That is what we do in Disability Studies.

15 Peter Singer, "Why We Must Ration Health Care," *The New York Times Magazine* (2009), <http://www.nytimes.com/2009/07/19/magazine/19healthcare-t.html>

16 Stephen Strauss, "Health Reporting Needs the Qaly Treatment," *Science Friction* (2007), http://www.cbc.ca/news/viewpoint/vp_strauss/20070517.html

17 Susannah Tully, "On Forming Connections, Succeeding for Others, and Being Bold in Thought and Spirit: Excerpts from Graduation Speeches," *Chronicle of Higher Education* (2009).

I leave you now, still wrestling with what is for me the pivotal question of empathy.

In times of calamity, humans are called to serve. Some will serve on the front lines of direct relief. Some will serve through duty of witness and reporting: journalists, bloggers and YouTube aficionados come to mind. Some will serve as truth-tellers and way-finders, performing the vital tasks of observation, commentary, advocacy. Essential to all of this work is empathy, a new strain of empathy that must evolve as our human state has evolved, to a response that is activated by *knowing*, and no longer requires the proximity of immediate encounter.¹⁸ If we can cultivate that human power, and if we can remain vigilant and active in framing danger not as a site for individual tragedy, but rather as a place where nature meets the social, then perhaps it will be possible to kick some ethical daylight back into the darkness of dangerous times.

On this day of action and in the many days of struggle ahead, I shall cast my lot with the likes of you, my fellow lovers of justice in a dangerous time.

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¹⁸ The author's thinking in this regard is much influenced by the contributions of New York Times columnist Nicholas Kristof. See, for example, his observations on the subject in the documentary film *Reporter*, dir. Eric Daniel Metzgar, 2008.

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