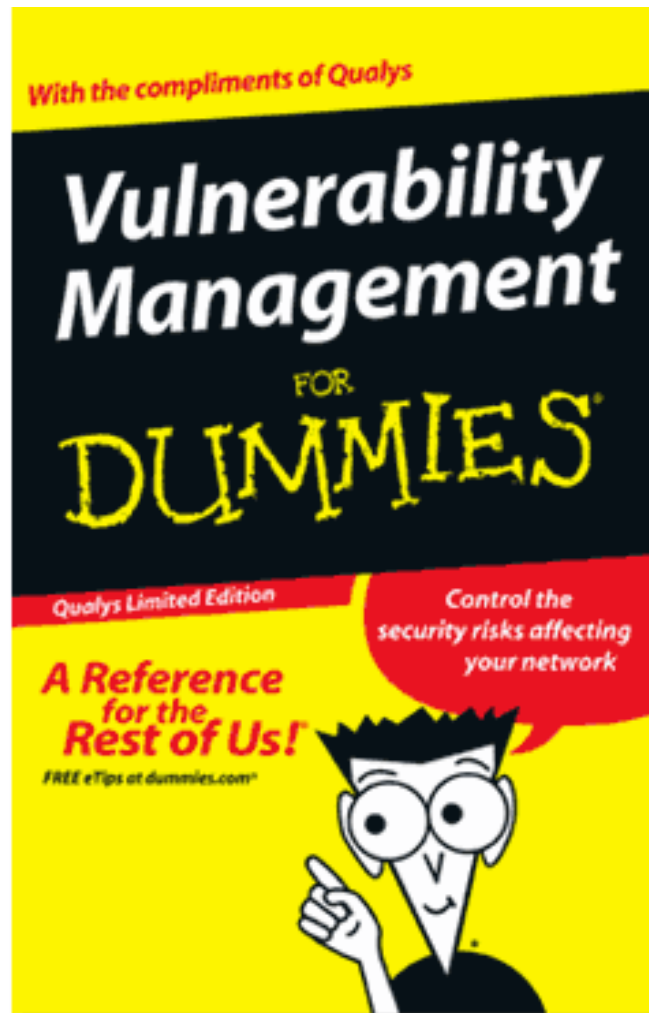


Whose vulnerability counts?

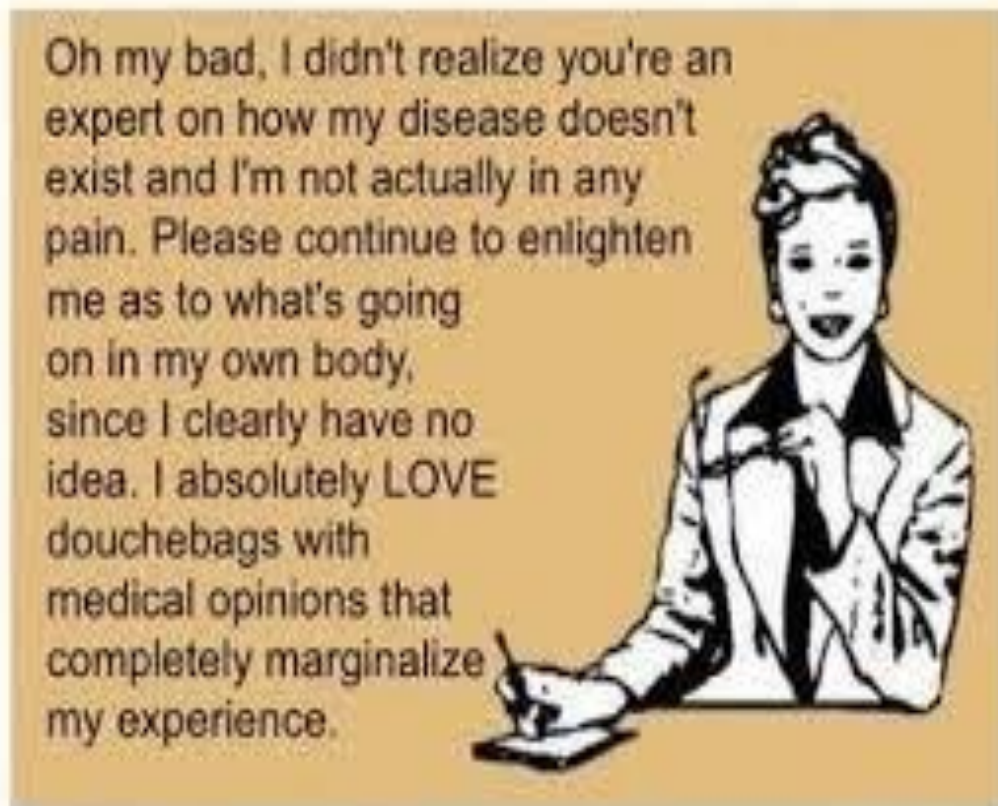
Fern Brunger, PhD
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What is 'vulnerability' good for in research ethics?



What is 'vulnerability' good for in research ethics?

- race, gender, ethnicity, physical or mental (dis)ability, disease status, occupation, class...
- actual or perceived power imbalance
- may be historical or symbolic
- may be based on implicit or explicit researcher exploitation



<https://noonegetsflowersforchronicpain.com/2013/10/16/do-not-lose-your-sense-of-humor/>

How ‘vulnerability’ as a concept may play out in the lives of researchers, community members, and REB members

STORY 1

“1, 2, 3, 4, we can’t get through the friggin’ door”

STORY 2

“What do they (really) mean by partnership?”

“1, 2, 3, 4 – we can’t get through the friggin’ door”

- D. Gustafson, F. Brunger, “Ethics, ‘vulnerability,’ and feminist participatory action research with a disability community”. Qualitative Health Research. 2014; Vol. 24 Issue 7, pp. 997 – 1005

➤ community rejects “vulnerability”



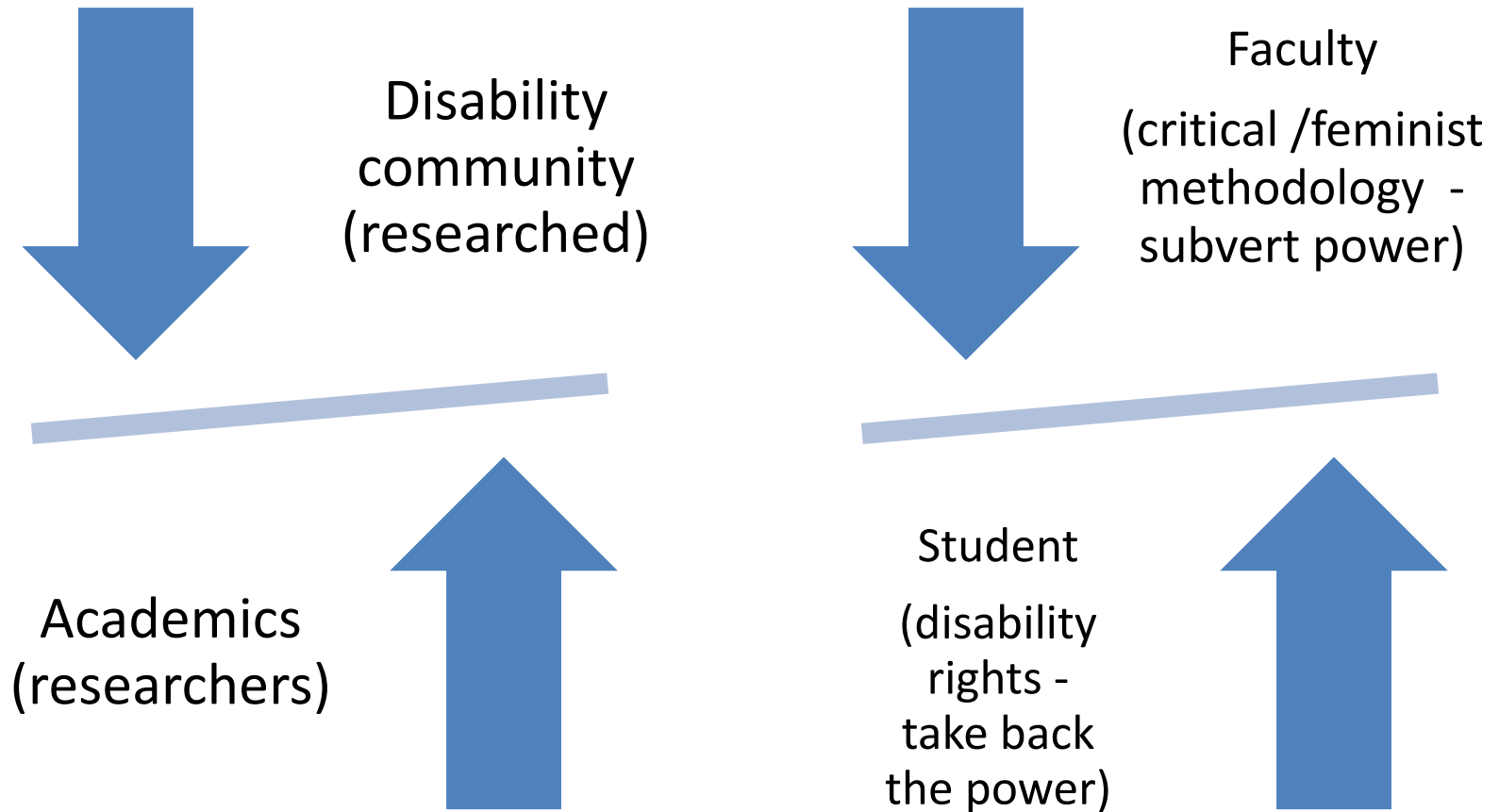
Friggin' door (1)

- REB: student's membership on the board of directors = conflict of interest
 - recruitment of participants from *vulnerable population* is potentially coercive
 - REB recommendation -- student should step down for the duration of the study
- Community: rejected that recommendation and its underlying assumptions:
 - Unlike the institutionalized assumption that a disability community was vulnerable and in need of protection, the disability community regarded itself as capable of making informed choices about the degree of risk that participation may involve
 - Moreover, the disability community questioned who had the authority to determine whether or not a group was being exploited
 - These assumptions held by the disability community were consistent with the principles of the independent living movement on which the Centre was founded
 - The university partners were regarded as overreaching their authority
 - The board of directors insisted the student continue to serve on the board as a condition of engaging in the research

Friggin' door (2)

- Disability community was being constructed as vulnerable and in need of protection by the academic community
- Academic community was being constructed as paternalistic in relation to the disability community
- The crux of the discussions concerned:
 - what constitutes a vulnerable population in need of special protection; and
 - who has the authority to define a population as vulnerable

The complexities of power, representation, authority, risk



“What do they (really) mean by partnerships?”

- F. Brunger, T. Russell, “Risk and Representation in Research Ethics: The NunatuKavut experience,” Journal of Empirical Research on Human Research Ethics 2015; 10(4): 368-379.
- F. Brunger, D. Wall, “‘What do they really mean by partnerships?’ Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research,” In press, Qualitative Health Research.
 - (a) Our community is vulnerable and so should be consulted
 - (b) Our community is being rendered vulnerable by researchers trying to ‘empower’ us

A. Vulnerability denied – (What community? What vulnerability?)

ONE RESEARCHER'S STORY

...I had that little project where I wanted to look at the meaning of health care and how health care was talked about in communities across Newfoundland and Labrador, rural communities... And I got this publicity.... and so people in Labrador started to contact me and say, “I’d like to participate in your research”....

So I contacted them all back and said, “Okay, as soon as I know my schedule and I have all the approvals in place I will get in touch.” I had started to send [a notification] to all the different health regions as a courtesy



[I]n fact I didn't really say anything about wanting to talk to Aboriginal people....

For me this was not about Aboriginal identity



So I was a bit surprised when there was this – “Well, you have to get this one [community consent] and you have to get this one and you have to get this one”

So I did the whole thing and submitted it, and then got this call ...

“Sorry, no, your project, we’re not going to give ethical approval”the population of Labrador was already over researched and they had to protect their population....

... vs community voices

- I think that from the early 1970's onward there was a tremendous amount of study done on Labrador with the exclusion of our people ... did a lot to harm good, balanced research on our aboriginality and our indigenous character...
- ...[research that had been done which dismissed the southern Inuit as not being aboriginal and not worthy of study] recreated what the identity is, recreated the land use patterns, recreated our whole relationship with Labrador...
- ...So the picture coming out of [research] was there was a vacuum of our people



<http://www.nunatukavut.ca/home/album-10>

I sit at a lot of provincial tables with other Aboriginal groups at the table...and you do get the sense of that people look at us and we're not as Aboriginal as Nunatsiavut or Innu

[T]he province has a little bit of difficulty accepting the fact that we're here and that we're Aboriginal. ...

We were told by the archeologists who actually worked on the [Muskrat Falls] project at times they were told just look for Innu artifacts



<http://halifax.mediacoop.ca/fr/story/true-cost-muskrat-falls-renewable-energy/20382>

B. And on the other hand – vulnerability reinforced by researchers, in the guise of empowerment and capacity building -- The active under-resourcing of communities by universities

- *The most evident example of, and metaphor for, ongoing colonialism in research is that Aboriginal communities are under resourced and doing volunteer work for publically funded researchers with rarely financial remuneration for time spent.*

- Brunger & Wall, in press



<http://theindependent.ca/2012/12/03/federal-support-for-muskrat-furthers-ire-in-labrador/>

Q. How can we retain the necessary elements of “vulnerability” (basic principles of ethics that are necessary to safeguard) while accounting for its complexity?



“Getting in” vs “Getting Consent”

Idea and design



Proposal



REB review



Community:
getting in
and consent



How academia imagines the process:
the “consent” model



Re-imagining the process: a network of inter-related relationships (non-linear research process; non-linear consultation process)



Reflections for REBs

A research ethics policy that directs researchers to negotiate collective consent requires that researchers and REBs explicitly attend to the *politics of risk*-- the ways in which collective identity and research risks are co-constructed.

- Need to pay attention to how the communities themselves define their own vulnerability; a one-size fits all paternalism is not appropriate in 2016.
- Communities are complex – “which” community is labelled as vulnerable affects whether and how paternalism should be invoked

Recommendations

- Be explicit about the nature of the research relationship and have in place community-researcher agreements that detail the nature of that relationship, including explicit discussion of power relations, roles and expectations of the various partners with regard to research process, ownership of data, and dissemination of results

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- Darlene Wall (Manager, Health and Social Sector) and Todd Russell (President) – NunatuKavut
- Diana Gustafson, Professor, Social Science and Health, Division of Community Health and Humanities, Memorial University
- Sarah Smith (previously, medical student trainee, history of “vulnerability” concept in research ethics) – Resident Physician, University of Toronto