

Responses to combined questions 2 and 3 of Women's Health Movement Roundtable

February 21, 2013
Selling Sickness Washington DC

Question #2

The current struggles of the Feminist Health Movement are similar to the past in terms of our mission to educate and empower women about issues of safety and harm. However, now instead of the paternalism and sexism of the past (and of course some elements are still pretty evident right now) we are faced with powerful marketing machines that appropriate feminist language peddling "awareness" campaigns that "offer" women harmful and/or unnecessary tests and treatments. How do we educate about these pharma tactics and help give voice to other perspectives?

This question is about how the nature of the struggle has shifted from structures and systems that peripheralized and denigrated women and women's health issues to marketing strategies which seem pro-women but actually result in the harms of over-diagnosis and over-treatment. The discussion related to this question will likely be about how current mobilizations/groups/networking entities/researchers/allied medical professionals etc. analyze and resist these marketing ploys and reveal the iatrogenic outcomes of selling sickness. The issue of astro-turf groups could emerge here or in question 3.

Question #3

What kinds of alliances can we and should we be building as we move into the future while at the same time grappling with cutbacks, hostile political environments, and burn-out, especially of vulnerable survivors of pharma-harm?

This question will likely evoke discussions concrete examples of coalition projects that are currently in evolving, and the kinds of projects that advocates and activists are undertaking. Social justice issues, social determinants of health, issues of powerholding and disempowerment may emerge. These are often subtle and complex terrains. Is it time to bring back the "consciousness-raising group" to be able to better hear and analyze silenced voices, questions and concerns?

Notes taken by Adrienne Shnier and Richard Lee with a bit of editing by HR

Kay Dickerson: CUE Consumers United for Evidence-based healthcare = a model

- women's health, family health etc
- a coalition of groups coming together, asking questions that might remain unasked or in the hands of men
- build a coalition of women who can be leaders in their fields
- important to work on release of pharma documents

Cindy Pearson: more analysis needed of marketing and advertising that draws in women and co-opts for enhancing profits

- the power of the story has been co-opted by pharma!

- alliances can draw on people's natural skepticism and caring and make links with organizational allies
- need for new institutional allies
- increase access to data needed; create a generalist group searching for a window of opportunity to generate more access to information

Anne Rochon Ford: must start with kids, add to elementary school curricula ways to critically analyze/address advertising, develop critical skills

- teach children to deconstruct advertising, learn how ads lie, prevent tidal wave of belief that there is a pill for everything
- if kids grow up without a critical lens very difficult to develop one as adults
- telling stories to understand need for skepticism in school setting
- seek alliances between chemically harmed and pharma-harmed; people should not have to advocate by themselves for themselves.
- another alliance→occupational health and enviro health
- important to learn from DES as case study

Colleen Fuller: alliance from within WHM i.e. breast cancer and unions who represent women in occupational roles who have various cancers and illnesses

- form broader alliances to take on industries
- people tend to want to focus on own specific issue, but need to break through segregation of issues and see over-arching role of pharma---i.e. the same master in different diseases
- decrease fragmentation in pharma-harmed mobilization which interestingly parallels fragmentation in medical profession
- bring (back) public funding for advocacy and increase advocacy around public interest issues like housing

Gail Hornstein: importance of psychiatric survivor movement has not been a focus of WHM

- importance of grassroots alliances of survivors; struggle against astro-turf groups sponsored by pharma
- increase respite care and community centers with supportive environments that allow women to deal with psychiatric illness within a safe environment
- understand that help does not mean being on a drug permanently and the drugs for life pharma narrative rarely examined/countered

Some Highlights from Discussion with Audience

Warren Bell: all evidence comes from the story; aggregate data can be used to suppress the story

Kay: drug companies love personalized medicine; use the story to further marketing

Gail: story is a part, but what is defined as a story must be in context with full disclosure and transparency; cannot be stripped because loses complexity

- be careful pharma loves the story

Leonore Tiefer: Booktivism (at Selling Sickness) is an example of where to look for alliances, create local action that can evolve; the power of the book club

Response by Colleen to Kate Ryan's question about power and control over women's bodies

- role of unions in negotiating over formularies; membership education about drugs listed on formularies

- Listening for Direction-what needs are and are not being met? Housing?
- question role of pharmaceuticalization in situations where elderly living in sub-par housing, overcrowded or women without childcare/support-→ read as depression but real diagnosis is needs for support

Harriet Rosenberg: move from knowledge activism to actual physical clinic for pharma harmed, where protocols would exist on how to treat medically induced harm

- physical presence, actual site important = advance in patient care

Cindy response to audience member about daughter's death from 3rd generation synthetic hormone IUD contraceptive...what does "choice" mean in this context, since not informed by data/evidence, choice is not informed choice in this context:

- there is a struggle to have effective testing, devices/drugs need to be compared to other contraceptives rather than placebo or the supposed "harm" of pregnancy

Harriet: The Struggle Continues!