



# LGBTQ Health and the Disabled Community

Lessons learned/Implications for  
future research

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# How I got here

- My own story- briefly
- My many hats/contradictions
- Wry Crips/ World Trust/Fabled Asp
- Ph.D. Integral Studies
- Studies in wellness, resiliency, coping, rehabilitation and recreation therapy
- Transformative learning- challenging underlying assumptions/disorienting dilemmas

# Who's missing?

- Look around the room and tell me if you notice any segment of the lgbtq community that is missing?

# Why are we missing these people?

- What makes it normative for us to miss people?

# Why does it matter?

- What is health and wellness in it's broadest sense- both for us as individuals and for us as a community?
- Why should we include disabled lgbtq folks in our research? What can we learn?

# Barriers to Health Care for lgbtq people with disabilities

- When we think of lgbtq people with disabilities who do we generally think of?
- What leads us to ignore the needs of people with physical disabilities in healthcare?
- Why don't lgbtq people with disabilities get appropriate treatment?
  - Isolation- differences in generations- some informal findings from our oral histories
  - Fear of medical treatment based on bad experiences

# Paradoxes and Complexities of Disability/Difference

- Visibility/Invisibility- everyone stares at you but no-body sees you
- Dependence/Independence
- Isolation/Community
- Perceived Entitlement/Assumptions-work ethic- valued based on perceived productivity
- Physical Barriers
- Barriers to friendship
- Economics of health care/Social Security
- Issues of loneliness and devaluation of people who look different-- lessons from Fat Studies/Disability Studies
- Vulnerabilities/Strengths

# Risks

- Risks -e.g. vulnerabilities around sex in lgbtq disabled community = need for sex education/disease prevention
- Alcoholism/addiction rates. Are they significantly higher in the lgbtq disabled community?
- Suicide amidst lgbtq disabled/chronically ill folks
- MCS/EI-- how do you get people to “give up” something-e.g. scents or perfume in order to enable full inclusion
- Depression-- research into the effects of social isolation, separation from work world, operating outside the norm

# Challenges to equitable access

- Barriers or attitudes? What is really a disabling condition?
- Funding-- how do you thrive if you are trying to survive?

# What is a community based model of wellness?

- What does it look like?
- Personal example of growing up in a Jewish intertwined neighborhood in N.Y.

# Inclusion: A guiding principle

- What does it mean to create healthy inclusive community?
- What can we learn from disabled queers and disabled lesbians?

# What is working?

- In the lesbian community- groundbreaking feminist emphasis on inclusivity- 70's and 80's-sign language, wheelchair access, healthcare, sliding scales, examining/dialoguing about issues of race, class, gender and overcoming systems of inequity- an understanding of bias
- Carol Gilligan's research- studied women's development- Ethic of Care
- LGBTQ- our experiences with Aids/Hiv/Cancer
- Emphasis on compassion/support services
- Barter system/Volunteering/Mentoring
- Diversity Training
- Dialogue with a capital D - David Bohm- ideas that support mutuality of respect
- "Field of Mutuality"- Joanne Gozawa- a field of mutuality that gives groups of diverse participants the safety in which to question their deep assumptions
- Theater, art, dance, culture-- physically integrated dance- The Gimp Project, AXIS, Sins Invalid, Wry Crips, Fat Lip, creative expression, self-expression- community appreciation- changed attitudes

# What is possible

- Looking at the lesbian, women's and lgbtq community models/exemplars/services- as a framework for care--
- Model programs--BHAWD, Charlotte Maxwell Clinic, Women's Cancer Resource Center, Special Needs Comprehensive Services Gay Day, Operation Concern/New Leaf

# What if...

- What if the people we value the least are actually the most important to our own survival?
- Resiliency resources/Hardiness Studies/Perceived Challenge/Control/Commitment- Kobasa and Maddi
- Flow studies/Optimal Health- balance between anxiety and boredom- Csikzentmihalyi
- Wellness studies/Role of fun/social support/partners/spouses
- Stress studies/Coping
- Research into marginalized communities of marginalized communities
- Research model populations- Learning from survivors/thrivers-- lesbian community- Dalai Lama studied Jewish summer camps-- to learn how to keep cultures intact what can we learn from folks who have had to be resilient?

# The movement towards Interdependence

- Independence- stepping stone- e.g. Grocery store- do you want someone to get your groceries off the top shelf- or do you want to be able to get them yourself?-- this is the move toward independence-- do you want people clearing chairs out of the way or do you want to just be able to get to where you are going-- fundamental principle of Universal Design-- good for everyone
- So what is interdependence and why is it important for healthcare-- what if we accept the notion that at some level we all need each other-- lesbian, feminist community has been a model for this

# Challenges/ Opportunities/Implications

- Medical model/holistic model-- difference between quality of life and searching for a cure
- Disparities in funding for Aids vs. Cancer- women involved in Aids- radical notion that lesbians care for each other--
- Where do we fall short around lgbtq folks with disabilities and where do we need to grow?
- differences in care, differences in caring (temporary vs. permanent disability, short-term illness vs. chronic illness, where is that bowl of soup when you need it?)
- Lotsa Helping Hands- communities of care- internet- expanding the concepts that work to our most marginalized communities