

Health Activism – Patient Rights Movements

SLIDE 1: LECTURE OUTLINE

Intro:

- **With exception of First Nations Peoples, have been talking to you as if ‘patients’ are a monolithic group** – next section of the course is going to break this down a bit – looking at health as it intersects with economic & social status, looking at global health inequalities
- **Today want to present another facet of way in which people rewrite bio-medical scripts – activist patient** – point here is that there are is the grand narrative of western biomedicine, there is the big pharmaceutical companies, state medical systems – but **patients not just pawns** in this system.

SLIDE 2: ACTIVIST PATIENT

- **Activist patient = one who challenges medical establishment & the cultural mainstream** - how? Re how his/her situation is **defined** – both in medical terms and in broader cultural context. Re nature of medical practice – i.e. **treatment**. Re how their illness is dealt with in **everyday life**. - Activist patients are often labeled **‘bad patients’**
- Define **patient rights movement – groups of activist patients with similar issues – concerns**.

- Today am talking re patient rights movements – decided to **focus on 2 groups**: one that I think makes us **uneasy**, the second one which I think **terrifies us**.
- What groups am I talking about?: **disabled people, people with cancer**.
- Each of these groups have over the last half century – risen up to challenge social norms and biomedical orthodoxy – **2 successful illustrations of patient movements – patient activism**.

SLIDE 3: DISABLED PIC & QUOTE

- In case of **disabled people** – activism focused around **redefining disability – not in biomedical terms as sickness, but as people who have to live in a society that disables them**.

SLIDE 4: CANCER PATIENTS & POINTS

- Same but different in case of cancer – crit of **biomed interpretations, treatment & research, crit of closeted ‘hidden’ nature of disease**.
- **Format for today** – shorter lecture on disabled activism – break – shorter lecture on breast cancer activism

SLIDE 5: DISABILITY HISTORY

The Disability Rights Movement:

Historical Context:

- History of disabled rights groups in western world – **older groups in U.K. & U.S. date back to 1890s**, i.e. British Deaf Association, National League of Blind People, militant, linked to early labour movement.
- **New groups emerging in 1970s**, inspired by the U.S. **Civil Rights Movement** & peopled by survivors of **1950s polio epidemics & Thalidomide babies** late 1950s/early 60s
- Also medical advances meant some disabled people able to live longer, more access to education, employment & community facilities, **more able to organize**.
- **1981** = Big turning point, **designated International Year for Disabled People by the United Nations** – big outcry by disabled groups changed title from **for** to **of** – global expression of disabled peoples wish for self-definition

SLIDE 6: REDEFINING DISABILITY

Issues:

- 1) **Redefining disability – impairment vs disability**

- **Discarding the medical model (disability as an individual health problem)**, disabled theorists differentiate between impairment & disability.
- **Point here is that disability is defined within social & cultural contexts** – until the 1940s community of **Martha's Vineyard** on eastern seaboard of the U.S. included significant number of deaf people – whole community knew sign language, hearing people used it among themselves so it was an ordinary way of communicating, hearing and hearing-impaired intermarried, hearing impaired not considered different or special.
- **So when does an 'objective' impairment become a disability?** - Disability activists & scholars say this depends on **the environment, the expected daily activities, & the attitudes of other people** – disability = **more than limitations** of a person's sensory, motor, cognitive, or other capabilities –

SLIDE 7: PIC STAIRS & WHEELCHAIR & QUOTE

- - An impairment is the loss of some physiological or anatomical function, impairment is relatively verifiable in 'objective' terms. - But a disability is the consequence of such an impairment, i.e. the inability to climb up stairs independently, for example.
- **Disability re interaction between individual's condition & the environment** (the place where the

individual lives), **both physical & attitudinal** – impairment is universal, but social & cultural responses & the ‘design’ of social environments vary – so unlike standard biomedical model of disability - medical sociologists focus, not on the disabled person, but on **disabling attitudes & environments** – question of whether a disabled person is ‘sick’ or ‘well’ does not come into it.

SLIDE 8: DISABLING PRACTICES

2) Disabling Practices:

- **Disabling Practices – significant critique from the disabled movement about practices which result in social marginalization:** – Lack of access to activities, places considered ordinary by those who are well, i.e. use of public toilets, use of public transit. – i.e. disabled people find it harder to get work & are often at low end of income scale.
- Argument is one that sets out our society (the public world) as being structured around the premise that everyone is fully able - can walk, hear and see well, can work without stopping, shop without sitting down – this relates not just to architectural design but also the whole physical & social organization of life – **disabled people are trying to bring the private world of illness, pain & an ‘imperfect’ body into the public world.**

SLIDE 9: QUOTE RE IND LIVING

3) Independent/Integrated Living vs Institutional Living

- **Independent/Integrated Living vs Institutional Living - OVERHEAD** – quote by John Evans - right to control where they were living central core of new disability movement, important aspect of the medical model to be discarded.

SLIDE 10: HISTORY IND LIVING

- Disabled activists proposed & established various **innovative housing schemes**, i.e. **Centre for Independent Living** - grew out of scheme at University of Berkeley in California in 1973 – within 10 years there were 200 CILs across US.
- **English Grove Road Scheme** - started 1979 by severely disabled people who wanted to move out of the institution where they lived & get married - model included able-bodied + disabled in apartment block, able-bodied providing help - **health & welfare professionals thought unrealistic** - **interesting stat** that disabled couple estimated would need 20 hrs/wk help, in reality after 1 year required 1.5 hours.

SLIDE 11: CAMPHILL

- **Camphill**, est in North Yorkshire after WW2

SLIDE 12: MAINSTREAM CULTURAL ATTITUDES

3) Mainstream cultural attitudes toward the disabled:

- **Push to change mainstream cultural attitudes toward the disabled:** - disability scholars argue that that disabled **category is a nebulous one – are disabled people healthy or sick or something else? –** it may be this **shifting line between ‘normal’ & disabled that makes people uncomfortable** with disabled people.
- Disabled scholar **Sue Halpern** argues able-bodied capable of **feeling sympathy for the disabled but not empathy** - unable & unwilling to imagine themselves as disabled - **if able-bodied saw disabled as potentially themselves/future selves would think disabled people should be fully integrated & contributing members of society.** EXPAND