

I don't know how radical you are or how radical I am. I am certainly not radical enough; that is, **one must always try to be as radical as reality itself**

Imagining, knowing and changing disability



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Outline of presentation

- Ways of thinking about disability
- What we do when we do disability studies
- *Disability Rights and Wrongs*
- Example: quality of life in restricted growth
- Identity politics, and other dangers
- Example: *WRDR*

Disciplinary approaches

- Medical sociology: chronic illness approach (Bury, G.Williams, S.Williams, Charmatz)
- Sociology of the body (Hughes & Paterson)
- Bioethics
- Special education
- Ageing research
- Mental health research



New directions

- Materialist disability studies (UK)
- Disabilities studies in the humanities (US)
- Normalisation research, self advocacy research
- Nordic disability research
- Deaf studies

Interrogating research

- Does it involve disabled people?
- Does it take a structural analysis?
- Does it have a political engagement?
- Does it provide sound empirical evidence?
- Does it rely on good argumentation?
- Does it ask deeper questions?
- *Does it make a difference?*

How should we do disability studies?

1. *Disability studies is not activism by other means*
2. *Disability studies is about understanding the experiences and views of disabled people*
 - What it is like to have a particular impairment;
 - What people with different impairments think and say about their lives;
 - What impact impairment has on family life, on self-esteem, on participation etc.
3. *Disability studies is about society's responses to the challenges of impairment and inclusion*
 - medical, psychological, educational, social, legal, economic, political
4. *Disability studies depends on sound empirical research and normative argument*
 - not slogans or ideologies or anecdotes (Vehmas: science vs ideology)
5. *Disability studies researchers should be engaged and committed, but their first duty is to the truth*
6. *Good Disability studies research will lead to better Disability Politics*

Disability Rights and Wrongs (2006)

- Increasing frustration with social model dominance and identity politics ideology
- Rejection of 2001 paper by *Disability & Society*
- Wanted to promote debate and open up possibility of new ways of thinking
- Very critical reaction from materialist disability studies: reviews in *Disability and Society*
- Very positive reaction from other disability researchers, philosophers etc: reviews in *Journal of Medical Ethics*
- Wider impact: too early to tell?

Disability as an interaction

Intrinsic factors	Extrinsic factors
Type of impairment	Physical environments
Severity of impairment	Social arrangements, structures
Motivation, attitude to impairment, goals	Expectations and roles
Self-esteem, confidence	Cultural meanings, representations

What do we know about impairment

- Not easy to define;
- Part of human condition;
- Complex: scalar, multi-dimensional;
- Not necessarily a tragedy, but rarely neutral;
- Often a predicament;
- Rarely is it only social and cultural context which makes impairment a problem;
- Does not have to dominate or determine an individual's experience or identity.

Example: Quality of life in restricted growth

- Managed by DPO
- Collaboration of clinician and sociologists
- Quantitative and qualitative methods
- Impairment specific
- All dimensions of life with RG
- Respondents identified as 'different' not 'disabled' (until impairment increased)
- Complex interplay of medical, psych, structural factors

Anecdote

- Became paralysed over 3 days, August 2008
- Multiple impairment puzzled professionals
- Positive experience of nurses, physios, some OTs
- Positive experience of benefits, services, attitudes
- Impairment, not barriers, as major problem
- Now very interested in rehabilitation...

Having a disability does not mean you are right about disability

- Slogans are not enough
- Assumptions need to be tested
- Research is not the plural of anecdote
- Activist positions are sometimes wrong
- Activists are rarely representative of the wider population
- Non-disabled researchers are welcome



So the Emperor walked under his high canopy in the middle of the procession, through the streets of his capital and all the people standing by, and those at the windows, cried out, 'Oh how beautiful our emperor's new clothes are!'

H.C.Andersen

Naked emperors?

- Social model of disability (UK)
- Supported decision making
- Impairment relativism
- Employment as an option for all people with intellectual disability
- ?Nothing about us without us?

The value of extremism

- Motivates activism
- Generates change
- Empowers individuals
- Pushes people in right direction
- Is often right!
- When wrong, can make moderate radicalism appear reasonable

The danger of extremism

- Critique of identity politics by Nancy Fraser (1995)
- Undermines cause
- Alienates potential support within constituency
- Alienates potential support from outside constituency
- Stresses divisions, what separates...
- Becomes inward looking
- Unrepresentative of wider constituency
- Dangerous consequences if taken seriously

Research relationships

- Engagement
- Need for partnership, division of labour
- Accountability to research participants, rather than to the partner DPO
- Asking difficult questions
- Abandon all assumptions
- Methodological pluralism
- Commitment to truth (or as close as we can get)
- Reflexivity

What do we need to know?

- What disabled people think... (about ethical issues, identity, health)?
- What happens in... (education, rehabilitation, support services etc)?
- What works in... (education, rehabilitation, support services etc)?
- How we can change... (professionals, environments, attitudes)?

World Report on Disability and Rehabilitation

- Commissioned by World Health Assembly of WHO
- Chapters on data, health, rehabilitation, support services, environments, education, employment
- Global coverage
- ~100 authors
- Absence of good quality global evidence on what works to improve the lives of disabled people
- We need: numbers, data, evidence!

Thank you for listening!

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