



Putting People First in Disability Research

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Social v Natural Research

Social Research Natural Research

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social world natural world

• •

what humans do & world humans live in
create together

• •

families, work, social mountains, rivers, minerals,
services electricity

• •

sociologists, anthropologists, geologists, physicists, biologists
psychologists, philosophers mathematicians



Disability Research- Natural or Social Science?

Disability research – natural or social science?
depends

•

Which model of disability are you working from

•

individual medical model social model

• •

cause & cure disabling society

rehabilitation & care exclusion, social

oppression



Defining Disability

Individual Medical Model



impairment = disability



what is wrong with you?



I'll do this to you to fix you



Social Model



impairment + disability



part of body or mind negative social response
to impairment



social oppression



Disability Research

Objective, detached & balanced social scientists



Benefit themselves + oppress disabled research subjects



[By]presenting themselves to the powers that be as indispensable in training 'practitioners' to manage the problem of disabled people in institutions.

(Paul Hunt, 1981 cited in Oliver, 1999, p.9)



Debate!

Who should be doing disability research?


Who should set the research agenda?

Why/reason they are doing it?

How are they doing it?

Who is benefiting?

Who should benefit from disability research?



Social Model = New Disability Research Agenda

... it is not disabled people who need examining but able-bodied society; it is not a case of educating disabled and able-bodied people for integration, but of fighting institutional disablism; it is not disability relations which should be the field for study but disablism. (Oliver, 1992, p. 112)



Emancipatory Research

Emancipation = achieving freedom & equity

Emancipatory research = is done to increase the control, freedom and equity disabled people experience in their lives



Emancipatory Research

- Research subjects have complete control over the research process
- Social researcher puts her/his skills at the disposal of, say, People First and they decide what research will be done



This means

People First/people with learning difficulties as co-researchers

- define the topic
- decide who is going to be on the research team
- make up the questions
- help collect the data
- help analyse the data
- decide what goes in the final report
- own & control the data, the report and any publications



Ethical research and Intellectual Disability

Ethics = all about telling the difference between good & bad, right & wrong

= treating others as you would have them treat you



Participatory research

+

Collaborative learning

□

people with learning difficulties

□

research advisors

interviewers & life historians

□

reliable informants

“best authorities on their own lives, experiences,
feelings and views”

(Stalker in Mercer 2004, p.126)




Researching learning disability in Aotearoa New Zealand

- NZ ASID Conference, 2009 – 26 papers & workshops
- Making Inclusive Education Happen Conference, Te Papa, Sept 2009 – 66 papers & workshops
- The Donald Beasley Institute



Some examples of intellectually disabled adults as researchers

- Robertson, A., Frawley, P. & Bigby, C (2008) Making life good in the community: When is a house a home? School of Social Work and Social Policy, La Trobe University. Viewed 24 August 2009. <http://www.dhs.vic.gov.au/data/assets/pdf/file/0008/179243/When-is-a-house-a-home-final-web.pdf>
- Marks, G. (2009) 'I'd like to write an organ symphony of my life': Co-researching with people with intellectual disabilities. Paper presented at Disability Studies Australia Conference, UNSW, Sydney 26-27 June, 2009.

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- Colin Gladstone, Andrew Dever, Caroline Quick (2009) “My Life When I Leave School” Transition Project: Self- determination and young intellectually disabled students in the transition from school to post school life. Paper presented at From Theory to Practice: Knowledge and Practices NZ ASID Conference, 2009
 - Graeme Parish & Cindy Johns (2009) A place of my own. Paper presented at From Theory to Practice: Knowledge and Practices NZ ASID Conference, 2009



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