

Third Sector Research Forum Conference Feb 1st 2018: Researching Together

Presentation Title: Coproducing Research with Disabled People: Disability research into independent living and learning

Presenters: Prof Kirstein Rummery, Dr Jim Elder-Woodward OBE

Handout

Questions of disability: impairment or society?

Questions of impairment (e.g. OPCS)	Questions of society (e.g. the work of Mike Oliver & Paul Abberley)
Can you tell me what is wrong with you?	Can you tell me what is wrong with society?
Does your health problem / disability prevent you from going out as often or as far as you would like?	What is it about the local environment that makes it difficult for you to get about in your local neighbourhood?
Have you attended a special school because of a long term health problem or disability?	Have you attended a special school because your educational authority's policy of sending people with your health problem / disability to such places?

Goodley, D (2017) *Disability Studies: An Interdisciplinary Introduction* (2nd edition) Sage, London, p 32

Research as knowledge, participation and emancipation:

Disability studies research might be conceived as a continuum ...

Knowledge research	Shared Knowledge	Co-produced action research
e.g. an (individual) academic challenges the constitution of normalcy ¹	e.g. researchers work with a self-advocacy group to develop inclusive research practices ²	e.g. disabled people's organisations work with researchers to measure and eradicate disablism ³
Non-participatory	Participatory	Emancipatory
Research-led, university-based, generating social theory for those in the academic field	Researcher invites participants into the research, breaking traditional boundaries	Co-researchers co-producing knowledge and practice

Goodley, D (2017) *Disability Studies: An Interdisciplinary Introduction* (2nd edition) Sage, London, p 29

¹ Michalko, R (2002) *The Difference that Disability Makes*, Temple University Press, Philadelphia

² Docherty, D, Hughes, R, Phillips, P, Corbett, D, Regan, B, Barber, A, Adams, P, Boxall, K, Kaplan, I, and Izzidien, S (2005) 'This is What We Think.' In D Goodley and G Van Hove, *Another disability reader? Including people with learning difficulties* (pp17-30) Garant Publishers, Antwerp

³ Arthur, S and Zarb, G (1995) *Measuring Disablement in Society: Working Paper 3*

Disabled People and the Citizen's Charter, <http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Zarb-meas-work-paper-3.pdf> (accessed 20/12/2017)

Participatory Research vs Emancipatory Research

Participatory Research ⁴	Emancipatory Research ⁵
<ol style="list-style-type: none"> 1. Clarity about what participation is being offered, and what its limits are; 2. Participation from the beginning in ways which are central to agency structures and processes but which are also flexible; 3. Tangible goals for participation; 4. Participation from black and minority perspectives; 5. Individual and collective perspectives; 6. Provision of time, information, resources and training; 7. Openness to advocacy; 8. Clear channels of representation and complaint; 9. Involvement of key participants, not just some; 10. Open agendas; 11. Facilitation of attendance 	<ol style="list-style-type: none"> 1. As per Participatory Research; but also... 2. Accountability to the disabled community is a key component. 3. Founded on the social model of disability. 4. Researchers must make their position clear at the outset, ensuring that disabled people's choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny 5. In terms of the choice of data collection methods, from the point of view of the emancipatory model, all data collection strategies have their strengths and weaknesses. 6. In terms of 'the role of experience', it is important that discussions of disabled people's experiences, narratives and stories are couched firmly within an environmental and cultural context in order to highlight the disabling consequences of a society that are increasingly organised around the needs of a mythical, affluent non-disabled majority. 7. In terms of practical outcomes, emancipatory disability research can and has offered something different and positive. 8. Doing emancipatory research cannot be conceived in terms of a single project or even a collection of projects, but is a continuous process and the organisation and content can only be determined by disabled people and their organisations. 9. The evaluation of the effectiveness of the research can, ultimately, only be determined by disabled people and their organisations.

Adapted from Swain J. and French S. (2004) 'Researching Together: A participatory approach'. In French S. and Sim J. (eds.) *Physiotherapy: A psychosocial approach* (3rd Ed.) Butterworth-Heinemann, Oxford.

⁴ Braye, S. and Preston-Shoot, M. (1995) *Empowering Practice in Social Care*, Open University Press, Buckingham, p118

⁵ Barnes, C. (2001) 'Emancipatory' disability research: project or process? Public lecture for the Strathclyde Centre for Disability Research, University of Glasgow, pp 20-23 www.leeds.ac.uk/disability-studies/archiveuk/index. (accessed 30/12/17)