Colin Barnes: "'Emancipatory' Disability Research"

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Abstract: This presentation provides a broad based overview of the development of emancipatory disability research in the United Kingdom since its emergence in 1992. Drawing on personal experience in the field, the author responds to several important considerations that need to be addressed before considering adopting this controversial perspective. The presentation is divided into two main sections. The first part provides a concise introduction to the thinking that underpins the concept of emancipatory disability research. The second section discusses key elements of this approach including: the problem of accountability; the social model of disability; choice of methods and; empowerment, dissemination and outcomes. The paper concludes by suggesting that whilst there has been considerable progress over the last decade the future of emancipatory disability research remains precarious.

"From Participation to Emancipation: Disability Research in the UK"

This presentation will, first, trace the history of disabled people's involvement in social research in the UK from its origins in the 1960s and, second, discuss the principal features of participatory/emancipatory disability research.

Early influences 1

Disabled people's involvement in disability research in the UK began in the 1960s with the work of Paul Hunt and residents in the Le Court Cheshire Home for physically disabled people.

See for example:

- Hunt, P. ed. 1966: 'Stigma: The Experience of Disability'
- Miller, E. J. and Gwynne, G.V. 1972: 'A Life Apart'.

Early influences 2

The 1970s saw the emergence of user led organisations such as the Spinal Injuries Association (1974), and UPIAS (1974) and user led services.

1981 witnessed the publication of Hunt's stinging critique of Miller and Gwynne's 1972: A

Life Apart entitled: 'Settling Accounts with the Parasite People', and the conceptualisation of the Social Model of Disability by Mike Oliver (see Oliver 1981: 'A New Model of the Social Work Role in Relation to Disability').

A year later the *Committee on Restrictions Against Disabled People* (CORAD) Report was produced based on research commissioned by the CORAD committee chaired by a disabled person and activist Peter Large.

Early influences 3

The Voluntary Organisations for Anti Discrimination Legislation (VOADL) was formed in 1985. This stimulated two reports on discrimination in employment and politics respectively by the Spastics Society (now known as (SCOPE) and the demand for a more comprehensive *user led* research project on discrimination against disabled people.

The outcome of which was Barnes C. 1991: 'Disabled People in Britain and Discrimination: the Case for Anti Discrimination Legislation'.

Other important developments included the establishment of the journal *Disability*, *Handicap and Society* in 1986 by Len Barton and Mike Oliver (renamed *Disability and Society* in 1993) and several empirical disability research projects conducted by disabled people.

These included Oliver M. et al.,1988; 'Walking Into Darkness: The experience of spinal cord injury', Morris, J. 1989; 'Able Lives: Women's Experience of Paralysis' and Barnes, C. 1990; .Cabbage Syndrome: The Social Construction of Dependence'.

The Emergence of Participatory Emancipatory Research

In 1991 the Joseph Rowntree Foundation (JRF) funded a series of seminars on disability research which culminated in a special issue of the Journal *Disability*, *Handicap and Society* entitled 'Researching Disability' (1992) and the notion of emancipatory disability research.

The 1990s

During the 1990s the momentum for greater involvement by disabled people in disability research intensified with:

 the formulation of the BCODP Research Unit in the School of Sociology at the University of Leeds in 1990, later known as the Disability Research Unit (DRU) (1992) and since 2000 the Centre for Disability Studies (CDS). several research projects sponsored by the BCODP and other user led organisations such as Shaping Our Lives formed in 1996.

An international conference on researching disability hosted by the DRU here at Weetwood Hall (Leelds) n 1996 (see Barnes, C. and Mercer, G. (eds.) 1997: 'Doing Disability Research').

The recognition of the importance of user involvement and participation in disability research by independent funding agencies such as the Joseph Rowntree Foundation and the Big Lottery.

Principal features of participatory/emancipatory research?

- Accountability
- The social model of disability
- Choice of methods
- Empowerment, dissemination and outcomes

Examples of 'emancipatory' disability research 1

- Barnes, C. 1991: Disabled People in Britain and Discrimination. London: Hurst and Co., in association with the British Council of Organisations of Disabled People (Available at: http://www.disability-archive.leeds.ac.uk/).
- Barnes, C. 1992: Disabling Imagery and the Media: An Exploration of Media Representations of Disabled People. Belper: The British Council of Organisations of Disabled People (Available at: http://www.disability-archive.leeds.ac.uk/).
- Barnes, C. (ed.) 1992: Making Our Own Choices: Independent Living, Personal
 Assistance and Disabled people. Belper: British Council of Organisations of
 Disabled People (Available at: http://www.disability-archive.leeds.ac.uk/).
- Barnes, C. and Mercer, G. 2006: *Independent Futures. Creating user-led disability services in a disabling society.* Bristol: The Policy Press.
- CHANGEpeople 2009: Talking About Sex and Relationships: The views of young people with learning disabilities. Leeds: CHANGEpeople. (http://www.changepeople.co.uk/show Page.php?id=9)

Examples of 'emancipatory' disability research 2

 Inclusion Europe, 2008: The Specific Risks of Discrimination Against Persons in Situations of Major Dependence or with Complex Needs: Report of a European

- Study, Volume 3: Country Reports, Brussels: Inclusion Europe (Available at: http://www.inclusion-europe.org/documents/CNS%20Volume %201.pdf
- Oliver, M. and Zarb, G. 1992: Personal Assistance Schemes in Greenwich: An Evaluation. London: University of Greenwich.
- Oliver, M. and Zarb, G. 1992: Ageing with a Disability, London: University of Greenwich (Available at: http://www.disability-archive.leeds.ac.uk/)
- Zarb, G. and Nadash, P. 1994: Cashing in on Independence: comparing the costs and benefits of cash and services. Derby: The British Council of Disabled People. (Available at: http://www.disability-archive.leeds.ac.uk/)
- Examples of user led research with people with mental health concerns can be found on: http://www.mentalhealth.org.uk/searc h?q=user+led+research&submit.x =9& submit.y=9

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- Hunt, P. (ed.) 1966: *Stigma: The Experience of Disability*. London: Geoffrey Chapman, http://www.disability-archive.leeds.ac.uk/
- Hunt, P. 1981: Settling Accounts With The Parasite People: A Critique of 'A Life Apart' by E. J. Miller and G. V. Gwynne. *Disability Challenge*, 1, 37-50. http://www.disability-archive.leeds.ac.uk/

- Miller, E. J. and Gwynne, G. V. 1972: A Life Apart. London: Tailstock.
- Morris. J. (ed.) 1989: Able Lives: Women's Experience of Paralysis, London: The Women's Press.
- Oliver, M. 1981: A New Model of the Social Work Role in Relation to Disability. In
 J. Campling (ed.), The handicapped Person: A New Perspective for Social
 Workers. London: RADAR, 19-32 http://www.disability-archive.leeds.ac.uk/.
- Oliver, M. et al.1988: Walking Into Darkness: The Experience of Spinal Cord Injury, Tavistock: Macmillan.

Eine kurze Dokumentation über den Besuch von Prof. Colin Barnes u.a. an der Universität Hamburg finden Sie unter dem folgenden Link: http://www.zedis.uni-hamburg.de/?p=1414