Emancipatory /Participatory Research

Professor Nicola Martin

martinn4@lsbu.ac.uk

Dr Mitzi Waltz

The SAGE Dictionary of Social Research Methods. (2006)Victor Jupp

- **EMANCIPATORY RESEARCH**
- Gayle Letherby
- Research that seeks to empower the subjects of social inquiry. It is now commonly recognized that power is a fundamental aspect of all research relationships. Traditional research processes have been criticized for their objectification of respondents. One response has been to argue for an emancipatory research process: one which recognizes this power imbalance in research and aims to empower respondents through research. Traditional research processes argued for the objective and value-free production of knowledge: a 'scientific' social science. From this perspective the research process is value-free, coherent and orderly – in fact 'hygenic' (Stanley and Wise, 1993; Kelly et al., 1994).

Voice

Quick fire……When thinking about the involvement of disabled people in research which impacts on their lives what comes to mind straight away?

Subject or participant?

Levels of participation?

Degree of control.

Reimbursment-pay-acknowledgement ….

Voice

How about when thinking specifically about children?

Agency, informed consent, ethics

Voice

- What about the participation of people (of any age) who may have difficulties with conventional forms of communication and understanding?

Agency, informed consent, ethics

Voice

- How about the idea of 'marginalised people'?

Agency, informed consent, ethics, marginalisation

Emancipatory /Participatory Research

- Useful?

- Problematic?

- SWOT

- Emancipatory v participatory methodology-what's the difference?
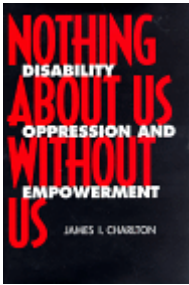
Emancipatory Research

- Useful?

- Problematic?

Mike Oliver says that research should make **things better**, not be about just finding things out.

Abstract Important methodological questions are raised by the act of researching disablement. Disability research has attracted much methodological criticism from disabled people who argue that it has taken place within an oppressive theoretical paradigm and within an oppressive set of social relations. These issues are of heightened significance for non-disabled researchers and bear many similarities to those faced by researchers investigating barriers to the social inclusion of women, Black and 'Third World' peoples. Such challenges have led to the development of an 'emancipatory' research paradigm. Six principles of emancipatory research are identified and the authors' own research projects are critically examined within this framework. A number of contradictions are identified and an attempt made to balance the twin requirements of political action and academic rigour.
Stone and Priestley 96

- adoption of a social model of disablement as the epistemological basis for research production

- surrender of claims to objectivity through overt political commitment to the struggles of disabled people for selfemancipation

- willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers

- evolution of control over research production to ensure full accountability to disabled people and their Organizations

- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual Experiences

- willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

Stone, E. and Priestley, M., 1996. Parasites, pawns and partners: disability research and the role of non-disabled researchers. British Journal of Sociology, pp.699-716.

6 core principles

Insider perspective

- 'It is a hot summer day in London in the late 1980s. Gathered together in one of the capital's most venerable colleges is a large number of academics, researchers and representatives of research funding bodies. Their purpose? A symposium on researching disability comprising presentations on a variety of different methodological and other themes, given and chaired by a panel of experienced disability researchers.

- CHAPTER 2 (in 'Doing Disability Research' edited by Colin Barnes and Geof Mercer. Leeds, The Disability Press, pp. 15-31).Emancipatory Research: Realistic goal or impossible dream?

- What credibility can such a seminar muster, they ask, when none of those chairing or presenting papers are themselves disabled? What does it say about current understanding of disability research issues that such an event has been allowed to go ahead in this form, when a Symposium on researching gender issues given entirely by men, or race relations research given entirely by white people, would have been laughed our of court?' (Ward and Flynn, 1994: 29).

social model

In the broadest terms, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment- whether sensory, physical or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media-films, television and newspapers.' (Oliver 2009:47)

Oliver , M (2009). Understanding Disability. Palgrave.

Can disability studies and psychology join hands?

Olkin, Rhoda; Pledger, Constance

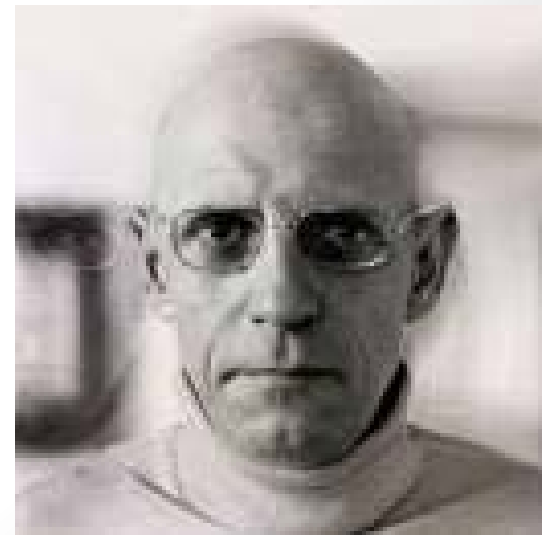American Psychologist, Vol 58(4), Apr 2003, 296-304

Abstract

Although the field of disabilities studies incorporates psychology within its interdisciplinary purview, it embodies a distinct perspective consonant with the new paradigm of disability. This perspective is contrasted with that of psychology, and the place of disability within psychology is examined. Although psychology has begun to embrace diversity, disability has remained marginalized. Four areas are presented in this article: (a) the foundational ideas of disability studies, (b) training in disability within psychology, (c) the paradigms of disability

- 'language has always had power to define cultural groups' (Haller et al 2006:61)Haller, Beth, Bruce Dorries, and Jessica Rahn. "Media labelling versus the US disability community identity: a study of shifting cultural language." *Disability & Society* 21.1 (2006): 61-75.

- 'The constant division between the normal and the abnormal… the 'othering' and exclusions of "incompatible" persons…'

Foucault ,M (1977) Discipline and Punish: The Birth of the Prison. Pantheon

Othering

Disability studies and the social studies of childhood, whilst both different in their approaches and ideologies, share some common themes; both are driven by a desire to turn those they work with, children and disabled people, from the objects of study to the subject and to present them as active agents, and both approaches are also firmly wedded to the concepts of rights and participation. There are, however, differences in their approaches. In contrast to many of the writings found in the social studies of childhood, disability studies, through the ideas contained in the social model of disability, accentuate the material.

Watson 2012

What is Critical Disability Studies Theory?

- If in the late twentieth century disability studies was associated with establishing the factors that led to the structural, economic and cultural exclusion of people with sensory, physical and cognitive impairments, then disability studies in the current century might be seen as a time of developing nuanced theoretical response to these factors.

Goodley 2013 p631

Recently there has been discussion about the emergence of critical disability studies. In this paper I provide an inevitably partial and selective account of this trans-disciplinary space through reference to a number of emerging insights, including theorizing through materialism, bodies that matter, inter/trans-sectionality, global disability studies, and self and Other. I briefly disentangle these themes and suggest that while we may well start with disability, we often never end with it as we engage with other transformative arenas including feminist, critical race and queer theories. Yet critical disability studies reminds us of the centrality of disability when we consider the politics of life itself. In this sense, then, disability becomes entangled with other forms of oppression and revolutionary responses.
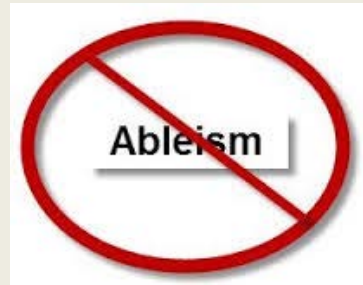
Goodley 2012

Preamble of UN Convention on the Rights of Persons with Disabilities (2006):

– 'disability is an **evolving** concept...results from **interaction** between persons with impairments and attitudinal /environmental barriers that hinder full effective participation in society on an equal basis with others'

- Article 1 of the Convention states:

– '*p*ersons with disabilities **include** those who have long-term physical mental intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'

The violence of disablism. Goodley D. Runswick-Cole K (2011)

Abstract

This article addresses the multi-faceted nature of violence in the lives of disabled people, with a specific focus on the accounts of disabled children and their families. Traditionally, when violence and disability have been considered together, this has emphasised the disabled subject whom inevitably exhibits violent challenging behaviour.

Recently, however, more attention has been paid to violence experienced by disabled people, most notably in relation to hate crime. This article embraces theories that do not put the problems of disablism or violence back onto disabled people but magnify and expose processes of disablism that are produced in the relationships between people, which sometimes involve violence

Goodley and R-C

This, we argue, means taking seriously the role of social relationships, institutions and culture in the constitution of violence. Disabled children, we argue, are enculturated by the violence of disablism. We follow Žižek's advice to step back from the obvious signals of violence to ' perceive the contours of the background which generates such outbursts', and identify four elements of the violence of disablism which we define as real, psychoemotional, systemic and cultural. We come to the conclusion that violence experienced by disabled children and their families says more about the dominant culture of disablism than it does of the acts of a few seemingly irrational, unreasonable, mean or violent individuals. We conclude that there is a need for extensive cultural deconstruction and reformation.

Think about

- **The phenomenology of the researcher(s)**

recognising the significance of our embodied, intersubjective lifeworld.
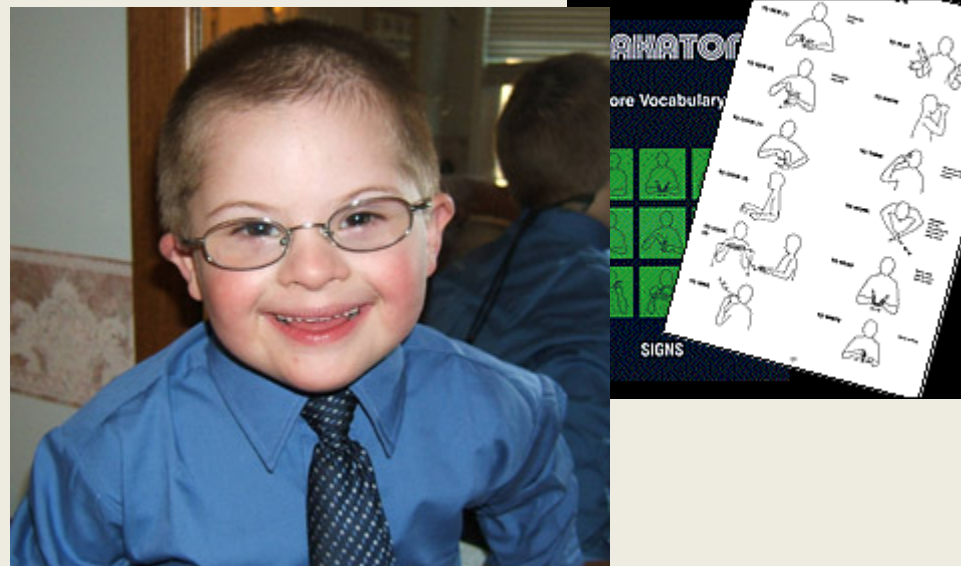
Giorgi (1989) One type of analysis of descriptive data: procedures involved in following a phenonenological psychological method. Methods 1, 39-61.

- **Participation of people with communication difficulties**

- **Emancipatory principles**

Walmsley, Jan. "Normalisation, emancipatory research and inclusive research in learning disability." Disability & Society 16.2 (2001): 187-205.

Think about

- Methodology (mixed methods)

- Practical applications

- Limitations

- Hard to reach participants

- Research participants v research subjects

One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder

Tonje Gundersen
Norwegian Social Research (NOVA), Oslo, Norway

Abstract The internet has democratised access to health and diagnostic information, enabling patients to mobilise social support from peers and advocate their interests in encounters with medical personnel. Research has shown that these possibilities are particularly important for patients and caregivers confronting a rare medical condition. However, little research has focused on how the act of searching for and accumulating information via the internet can be important for coping emotionally with a situation characterised by uncertain prospects and inadequate information from health personnel. This paper explores the experiences of 10 Norwegian parents whose children have different rare genetic disorders and who used the internet as a resource. The analysis draws on the theoretical framework of the medical sociologist Aaron Antonovsky, who emphasises people's inherent ability to manage extremely stressful life experiences. Analysing the process of adjusting to and coping with life parenting a child suffering from a rare genetic disorder, this study shows that becoming knowledgeable about a child's condition is essential for gradually comprehending and managing a situation that initially seems unmanageable and distressful. It also suggests that as parents adjust, so do the frequency and purpose of their internet searches.
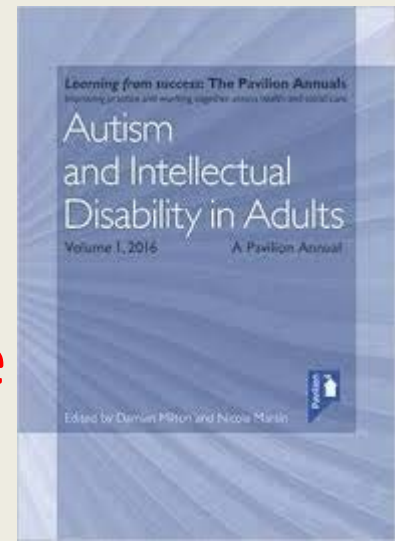
Think critically about…

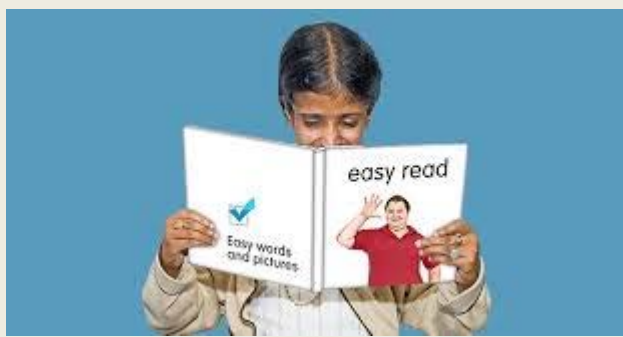Purpose, ethical issues, methodology, potential impact…

contact a family
for families with disabled children

PARC

- **Participatory Autism Research Collective**
- Convened at LSBU by Dr Damian Milton
- Includes autistic scholars and allies
- Aims to ensure autistic representation in research
- Emancipatory principles emphasise control of the research process, usefulness and insider perspective
- Funding is a thorny issue
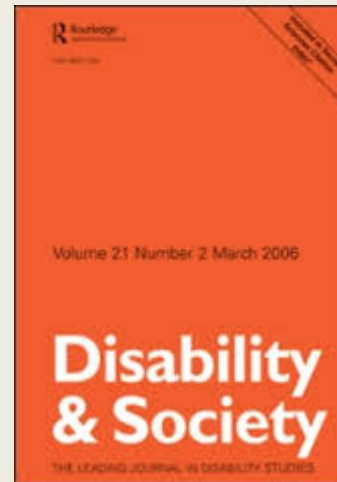- Disabled people often find that their participation in research is unfunded

Voice

- Consider the inclusion in research of disabled people who do not use voice or the written word as a means of communication

Issues	Sollutions

Disability Rights UK

drill
Disability Research on Independent Living & Learning

Levels of participation

- **User-controlled research**
- **Research 'Partners'**
- Consultants or Advisory Group members
- Respondents or interviewees

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THE LEADING JOURNAL IN DISABILITY STUDIES

THE SOCIAL MODEL OF DISABILITY AND DYSARTHRIA

The Disabled Person's Point Of View; The Personal And The Academic

ABLEISM

easy read
easy read ✓ ✓

There is no such thing as a single-issue struggle because we do not live single-issue lives.

Audre Lorde