

Whose agenda for disability research?  
Participation, partnership and progress

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Themes

- Challenges to traditional research
- Power, politics and the researcher
- Participation and 'emancipatory' research
- A European research agenda

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Past problems

'As disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than part of the solution... Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.'



(Oliver 1992: 105)

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**The parasite people**

'It was clear to us that [the researchers] were definitely not on our side. They were not really on the side of the staff either...They were in fact basically on their own side, that is the side of supposedly 'detached', 'balanced', 'unbiased' social scientists, concerned above all with presenting themselves to the powers-that-be as indispensable. Thus the fundamental relationship between them and the residents was that of exploiters and exploited.

(Paul Hunt 1981: 38)

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**Whose side are we on?**

(Becker)

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**A different way of doing things?**

Emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. To do this researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this.

(Barnes, 1992: 12)



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**A different way of doing things?**

Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how.

(Zarb 1992: 128)

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**Emancipatory Research?**

(six challenges)

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Is the research agenda based on a social model of disability?

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Do the researchers have a commitment to disabled people's self-empowerment?

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How will the research contribute to this, or to the removal of disabling barriers?

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How will the research be accountable to disabled people?

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Will the research give voice to the individual and shared experiences of disabled people?

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Will the research methods be shaped by the needs of the participants?

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Centre for Disability Studies

...supersizing the emancipatory research menu



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About our project

- Funded by the European Commission (FP7) 'Science in Society' programme
- 'Capacity building activities for civil society organisations...  
...and development of cooperative research activities'
- Three partners:
  - European Disability Forum
  - University of Leeds
  - Maastricht University
- February 2008 – August 2009 (18 months)

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Aims and focus

1. Identify and communicate the research priorities of disabled people's organisations in Europe
2. Develop knowledge in civil society about research in European countries
3. Start new research collaborations with European research teams

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Activities

- review current issues (EDF, DPI, EC, UN Convention, etc.)
- consult EDF members (questionnaire)
- share priorities (civil society, researchers, policy makers)
- research summer school (civil society and researchers)
- observation at research conferences ('researching the researchers')
- online training (research methods and knowledge)
- identification of funding opportunities (FP7 and others)
- initiation of research funding collaborations (matching and meeting)

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### The Survey

- Online questionnaire (English and French, online and paper)
- Presented at EDF Annual General Assembly (Slovenia, May 2008)
- Information, research experiences, priorities, motivation
- Responses from 68 organisations in 25 countries
- ...in seven languages
- Mostly national or European organisations, ontrolled by disabled people

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### The Survey Results

- Strong interest in research (and experience of collaboration)
- Lack of resources for own research
- Very positive about potential for academic collaborations...
- ...BUT... Universities do not 'understand research needs'
- Civil society have clear priorities and strong ideas (many ideas!)

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### The Research Priorities

- First steps towards a user-led agenda for disability research in Europe?




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The 'Top 10'

- Non-discrimination and human rights
- Education
- Mainstreaming disability in policies
- Support for independent living
- Social exclusion and poverty
- Employment
- Health care
- Information and communication
- Bioethics and rights to life
- Transport, mobility or tourism

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The 'Top 10' for DPOs?

- Non-discrimination and human rights
- Support for independent living
- Education
- Information and communication
- Bioethics and rights to life
- Health care
- Mainstreaming disability in policies
- Organisations of disabled people
- Urban and built environments
- Parenting and family life

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Developing ideas at the Summer School



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### The Summer School

- 11 national or European organisations (8 women, 3 men)
- 11 researchers (6 women, 5 men)
- 15 countries represented
- 5 different academic disciplines (different methods)
- Shared commitment to disability equality and participation
- Meet the researchers ('presentations' of research activity)
- Doing disability research ('theory', politics, methods?)
- Developing ideas (group work and informal discussion)

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### Who does what?

- Setting the agenda (funding and ideas)
- Formulating the questions
- Choosing the methods
- Access to people and knowledge
- Analysis of data
- Validation of results
- Dissemination and communication
- Practical implementation

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### Roles for disabled people?

- Research 'subjects' and participants
- Project reference group
- Consultants and advisors
- Peer interviewers
- Co-researchers
- Academics
- Project co-ordinators
- Employers

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## Questions and discussion

What are the priorities for research in Ireland?

- ...for the researchers?
- ...for disabled people?

How can disabled people be more involved in the research process?

What are your own research interests?

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Mark Priestley  
Centre for Disability Studies  
University of Leeds  
[m.a.priestley@leeds.ac.uk](mailto:m.a.priestley@leeds.ac.uk)

[www.eurade.eu](http://www.eurade.eu)

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