

Scaffolding for empowering research

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What I will cover

1. Background to radical emancipatory research, an example and criticisms
2. Background to liberal participatory research and some criticisms
3. Scaffolding to support inclusive research

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The radical discourse

- Loss of Grand Theory
- Challenge to meta-theory and positivism
- Power suffuses all life and interaction at all levels (Foucault); Human interests should be emancipatory (Habermas); social action including research should be transformative (Freire)
- Competing voices vie for ascendancy, recognition and funding

The radical discourse

'...emancipatory research is as much a form of political action as it is research', (Walmsley, 2001).

- Politicisation and transformation of lives
- Based on social model which views medical models of disability as socially created and as leading to oppression
- By transforming the social and material relations of research production

Radical discourse

Barnes and Oliver – The characteristics of emancipatory research:

- Being commissioned by democratic organisations of disabled people
- Being a tool for improving live
- Providing opportunities for dis-abled researchers
- Involving reflexive stance around relations of power and channels for dissemination
- Being accountable to democratic organisations of disabled people.

The liberal discourse

- Rise of consumerism (rights, participation, choice, redress)
- Localisation of services within community teams
- Person-centred services giving voice to each individual
- Recognition of socially valued roles including within the research process

Radical discourse

- Emancipatory
- Ownership and accountability held by dis-abled people
- Independent dis-abled researchers

Liberal discourse

- Participatory
- Partnership, consultation, involvement and participation
- Co-researchers seen as part of a team

Problems for the emancipatory research

- The majority of research claiming to be emancipatory seems to ignore the interests of people with intellectual disabilities (Chappell, 2000)
- Where are the commissioners of research with dis-abilities?
- Many groups do not seem to recognise their own oppression

Problems for the emancipatory research

- If interests are represented by products of people with intellectual disabilities a substantial proportion of them are tied to services.
- Researchers judging their own research feel despite aspirations that it does not meet the emancipatory ideal

Rodgers (1999) Trying to Get it Right: Undertaking research involving people with intellectual disabilities:

Aim: To examine health of people with learning difficulties (note the phrase 'learning difficulty' here) from their own point of view using focus groups:

- Research was suggested by a group of women with intellectual disabilities

But also reflected interests of researcher and local health service managers

Rodgers (Cont'd)

- There was much success in developing questions for the focus groups with people with intellectual disabilities acting as consultants.

However,

- Accommodations were requested between the various partner organisations that funded the research in terms of employment and support for people with intellectual disabilities,

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Rodgers (Cont'd)

- Permissions were required from ethics committees, GPs, parents and services.

Goodley and Moore in research on participation in performing arts say of their experience that:

'...the parameters of the contract we signed up to with funding bodies emphasised our role as 'consultants' and 'experts'...This prohibited adopting an emancipatory position' (2000, p.862)

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Rodgers (Cont'd)

- Despite people with intellectual disabilities being employed as co-interviewers in Focus Groups, the researcher found herself asking most of the questions,
- Because the research design was emergent analysis had to be undertaken between Focus Groups. This excluded the consultants to a huge degree

Rodgers (Cont'd)

However

- The people with intellectual disabilities` were very much involved in developing the plain language report and in dissemination

Overall,

There was a 'flight of power' (Walmsley and Johnson, 2003) back to researcher control because of the context and the way research is organised and undertaken.

Flight of power

- The study of Direct Payments by Swindon People First published with two discourses.
- A study around day services by a group in Sheffield simply not published because no agreement could be developed over content after eighteen months.

'The rhetoric of participation sounds very rosy; the reality on the other hand can be quite different' (Walmsley and Johnson, 2003).

Further criticisms of emancipatory research

- The extent to which all voices can and are taken into account
- Alliance with specific forms of data collection strategies
- Cost (The CHANGE bid was \$922k) for time and planning for the work,
- Cost of organising it properly and working with people with intellectual disabilities
- The assumption that 'noble intent' is the preserve of emancipatory research,
- Conviction and personal values as the sole arbiter of validity. Experience as the sole evidence of expertise.

- Ok, now further consideration of the liberal discourse

Widely accepted in UK Policy

- All Wales Strategy for the Development of Services for Mentally Handicapped (sic) People (Welsh Office, 1983)/Valuing People (2001)
- NHS Plan (DoH, 2000)
- Research and Development for a First Class Service: R & D Funding in the new NHS, (Department of Health 2000)
- Grant and Ramcharan (in press) Valuing People and Research: The Learning Disability research Initiative

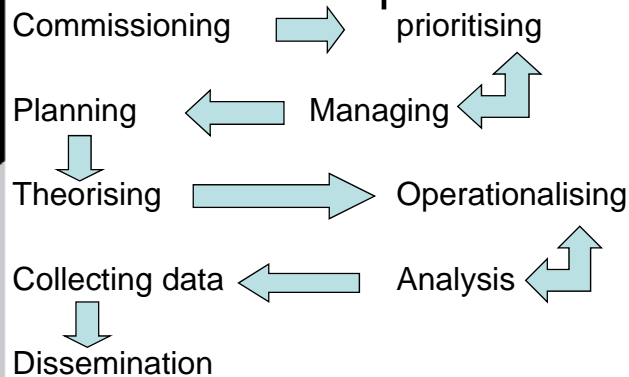
The liberal discourse

Inclusive research:

- Different perspective
- Research priorities important to consumers
- Less waste of resources on research that has little or no relevance
- Outcomes of consumers and not just academics and professionals
- Helps in recruiting peers for research projects
- Better access to marginalised groups (hard to find)
- Help in dissemination of research
- Empowered through taking part
- Aids the further involvement of service users around the services they use.

(*Involve* – Formerly Consumers in the NHS, 2001)

Involvement in Research – The options



Project Steering and Management

Summary of User Involvement in research projects listed on INVOLVE website

Stage on involvement	Number of projects	%
Prioritising research topic	120	66
Planning Research	139	77
Managing Research	91	50
Designing research instruments	131	72
Undertaking research	94	52
Analysing research	85	47
Writing publications	61	34
Disseminating	101	56
Implementing action	63	35

(Secondary analysis undertaken December 2004)

Grant, G. and Ramcharan, P. (2006) User Involvement in Research. In K.Gerrish and A. Lacey. The Research process in Nursing (5th Edn). Oxford: Blackwell Publishing.

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The non-emancipatory model

Telford et al. (2004):

- Research roles of consumers and researchers agreed
- Budgets should include all costs of consumer involvement in the research
- Researchers respect the differing skills, knowledge and experience of consumers
- Consumers are offered training and support
- Researchers should have necessary skills to involve consumers in the research process
- Involvement in recruiting consumers
- Consumer involvement described in the research reports
- Research findings made available in formats and language that is understandable to them

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Criticisms of the liberal model.

Of liberal approaches Oliver (1999) argues in 'Final Accounts and the Parasitic People':

'It attempts to deal with the problem of emancipation by sharing or attempting to share responsibility and, indeed, blame with the research participants. The worst example of this is the attempt to do participation by employing a few disabled people as researchers, often without much support or understanding of what that means...'

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Criticisms of the liberal model

Commissioning

prioritising

Planning

Managing

Theorising

Operationalising – planning research instruments

Collecting data

Analysis

Dissemination

Project steering

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Criticisms of the Liberal Model

- Very few details (e.g. INVOLVE WEBSITE)
- Very few details of the research process and participation in reports from studies
- Where there are examples reported the experience is never straight forward

Criticisms of Liberal model

There is still a flight of power

- Sleight of hand by academics - Claiming inclusion without handing over power
- Maintaining the interests of researchers, services and professionals
- Continued iatrogenesis

Points to consider

- It must at all times be possible to say what is being gained by undertaking any form of inclusion
- It must be made clear that involvement is not a form of validity
- Show how and why the research will challenge oppression of both users and academic researchers
- Explain how the research findings will affect the work of professionals and the lives of disadvantaged and vulnerable people
- Explain how participation will be meaningfully accomplished
- State clearly the values underpinning the research
- Publish work not only for other academics and professionals but in ways that make the findings available to the users themselves
- Establish a reflexivity to all processes involved in the research to identify and challenge inequalities between those involved
- Budget for meaningful involvement

There is also a **scaffold** upon which the approaches build.

Scaffolding

1. Research funding

Joseph Rowntree Foundation

<http://www.jrf.org.uk/>

Joseph Rowntree

- Does not fund knowledge for its own sake
- Funds practice and development activity that is directly commissioned, i.e. emphasis on action
- Encourages beneficiary-led projects.

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The Big Lottery Fund (Cont'd)

- Grants are given to the NGO
- Researchers are partners and reflect the voluntary sector interest.
- Beneficiary involvement is **expected**
- Maximum grant of £500,000 but most around £180,000

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Valuing People, 2001

It was written in 2001, and it was the first White Paper (policy) for people with intellectual disabilities for 30 years. It covers England.

It is based on people having:

- their rights as citizens
- inclusion in local communities
- choice in daily life
- real chances to be independent
- It was written with help from people with intellectual disabilities, family carers, and people who work in services or other organisations for people with intellectual disabilities.



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Valuing People

- It came with an easier to understand version, as well as a report from the service users advisory group called 'Nothing about us without us',



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Two key issues

1. Research funding
2. Place of self advocacy

The Learning Disability Research Initiative

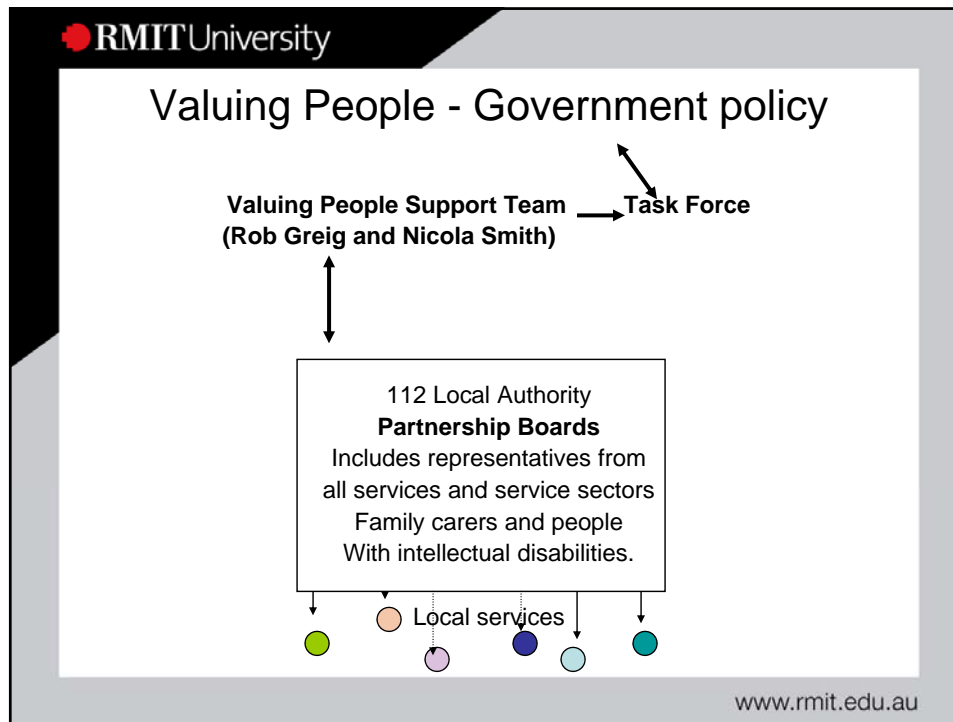
Gordon Grant and Paul Ramcharan co-ordinated the LDRI

- Department of Health
- \$5m for thirteen research projects
- People with intellectual disabilities involved in Commissioning, reviewing bids and Reference Group
- Fully paid at consultancy rates and supporters too
- Easy words and pictures dissemination
- A user group project made up of self advocates to research the involvement of people with intellectual disabilities in each of the research projects

Scaffolding through funding

- Pressure on funding bodies to see the relevance of inclusive research
- Convince public funding agencies to empower NGOs not academics
- Make arguments about the importance of different forms of knowledge
- Build an alignment between an agenda set by NGOs, people with intellectual disabilities, family carers and their advocates and research funding
- Research which measures outcomes important to people not services

But the above cannot be shaped without either a strong movement of self advocates nor leadership from the NGO sector generally



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Valuing People – Commitment to Advocacy

'Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs. Both citizen advocacy and self-advocacy are unevenly developed across the country. Barriers to future development include: insecure funding; limited support for local groups; and potential for conflicts of interest with statutory agencies who provide funding. This must change', (Valuing People, Paras 4.5 to 4.7).

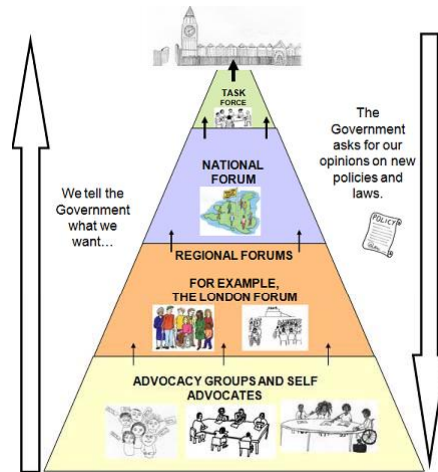
And

'to have a range of independent advocacy services available in each area so that people with learning disabilities can choose the one which best meets their needs.'

- \$3.25m per year over three years for development of self- and citizen advocacy.
- January 2007 to December 2008, £900,000 will be given out each year.

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UK advocacy policy participation framework



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- **The National Forum works with the Learning Disability Task Force and has the job of telling the Government how Valuing People is working for people with intellectual disabilities.**
- **The National Forum is made up of a group of about 25 people who represent the nine regions of England.**

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How the process works – An example

Local advocacy groups were alarmed at the number of people who had said they had been the victims of crime. A national report found that 34% claimed to have been a victim of crime, abuse and hate crimes in the past year. This was reported to the Regional forum

Some Minutes from a Regional Forum:

The Crown Prosecution Service

- The Crown Prosecution Service want to know what you think about their ideas as to how they will prosecute people who carry out Hate Crimes against people with intellectual disabilities.
- Helen and Jane are going to ask for an extension of the consultation time so that people with intellectual disabilities can respond

ACTION

- To invite someone from the Crown Prosecution Service to the next National Forum meeting

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Task Force Minutes

National Forum Feedback:

They asked **Task Force** members, in their groups, to think about some of the main things on the Forum's plan:

- What would happen to Valuing People after 2006
- Transport
- Autism
- **Hate Crime**

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Hate Crime

- Mary said that every council has to make a crime and disorder strategy. These are then sent to the Home Office. Maybe the **Task Force** should see how it could get involved in that process. It might be a good idea to ask the Home Office official who came to the June 2004 meeting to come to the TF again.
- The Employers Forum on Disability has a Police Disability Network. They could be asked to send LDTF 10 March 2005 out messages about intellectual disability and hate crime.
- Karen said that Victim Support Schemes do not always understand how to help people with intellectual disabilities.

Further developments

1. There is a growing movement to see **everyday lives** as the focal point for resistance.
2. There are some truly exciting moves coming from within the independent advocacy movement:
 - Parliaments – Ten in operation at last count largely led through self-advocacy movement
 - Development of easy words and pictures dictionaries.
 - Education, training and consultancy (human services, universities, police and communities)
 - Links with commerce – the mystery shopper project, consultations with Chambers of commerce (with 20% of the population having a disability they would do well to heed this voice!!)
 - Disability art, theatre and writing.



Parliaments



Education and teaching by people with intellectual disabilities



Theatre and the arts



Research

CHANGE Research (con'td)

- Paul Ramcharan and Penny Curtis visit CHANGE in Leeds proposing to look at the maternity care experiences of women with intellectual disabilities
- Over a period of several months CHANGE tell us that their work has been on mothers who have had their children taken away.
- They now want to do research about sexuality and relationships of young people with intellectual disabilities because this is where they see the problem as originating.

CHANGE Research (con'td)

- Paul and Penny acquiesce. They write a detailed technical proposal.
- CHANGE have been developing theatre. They want the theatre to be used in the research.
- Paul and Penny acquiesce.

CHANGE Research (con'td)

- In collaboration over a period of months CHANGE with Paul and Penny decide to recruit 20 young people with intellectual disabilities between 14 and 25 from schools and colleges.
- Their work using interactive theatre around the issues of relationships and sexuality will be the centre-piece of the research
- The work will involve 20 weeks forming the interactive theatre troupe and 20 weeks working around issues of sexuality. The final dissemination of this part of the research will be a play.

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CHANGE Research (con'td)

- There will be Focus groups with teachers and governors at schools and colleges
- There will be individual interviews with 20 parents
- There will be a national questionnaire to colleges drawing from findings of interview data about what sexuality and relationship training is provided

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CHANGE Research (con'td)

- The theatre will be managed by one non-disabled member of CHANGE staff (part time) and two people (part time) with an intellectual disability. They will be paid a researcher's salary
- The University will employ one Research Assistant

CHANGE Research (con'td)

- Thematic analysis of theatre sessions, interview and Focus Group data will be undertaken by CHANGE with the RA.
- The RA and his/her supervisors will carry out additional thematic analysis and statistical analysis of the questionnaire data.

CHANGE Research (con'td)

- This will be the first project nationally to be operated on a plain language policy and it will use the CHANGE Picture Bank for this. However, an illustrator (part time) will also be hired to undertake some of this work.
- The proposal was submitted as a plain language document. The academic proposal was appended to this.

CHANGE Research (con'td)

Dissemination will be:

- Theatre performance
- Five plain language leaflets on sexuality and relationships
- Two regional gatherings to politicise and operationalise the research with key invitees from amongst organisations of disabled people and national policy advisors
- An article in a popular young people's magazine
- A five thousand word plain language report for the funding agency
- Academic articles.

Features of the research

- Focus collaborated over, but users kept control
- People with intellectual disabilities to be involved in data collection
- People with intellectual disabilities to be involved in analysis
- People with intellectual disabilities to be involved in dissemination
- People with intellectual disabilities to own the results and take it forward to make policy and political change
- Good quality support for self advocates and co-researchers

Scaffolding – The NGO sector

- To become research active
- Partnerships between universities
- Leadership around the development and use of knowledge

Scaffolding – Easy information

We need to...

- talk a different language and to communicate in easy words and pictures
- commit time to often long and tough support and negotiation
- run all meetings and events in easy language as a matter of course
- Restructure what we see as good dissemination
- Establish an RQF that sees products other than peer reviewed articles as important in making change for the most disadvantaged members of our society.
- A new ethics for inclusive research

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Items for the future

- Looking to the future there are a few priority areas around inclusive research. These include:
 - *making visible hard to reach groups*
 - *equality of arms*
 - *addressing the systemic-individual nexus*
 - *measuring performance on basis of outcomes set by people with intellectual disabilities*

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Thanks for listening!!