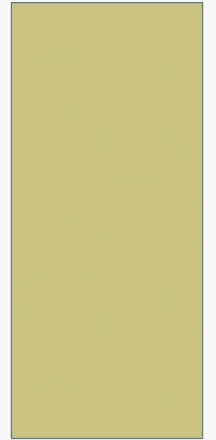


INCLUSIVE RESEARCH PAST PRESENT AND FUTURE

JAN WALMSLEY
VISITING PROFESSOR, OPEN UNIVERSITY
UK



AIMS FOR TODAY

- Define Inclusive Research
- Past - Reflect on its origins
- Present - Consider where it is now, what it has achieved and its limitations
- Future – look at future directions
- Inspire and inform!

QUESTIONS

- What is inclusive research?
- Why did inclusive research emerge in the 1980s?
- What has it achieved?
- What are its limitations?
- How might it develop?

LEARNING DISABILITIES

Past, Present and Futures

Jan Walmsley and
Kelley Johnson



INCLUSIVE RESEARCH

WALMLSEY AND JOHNSON 2003

INCLUSIVE RESEARCH

From passive beneficiaries or objects of study to the people who frame the questions

Defined in 2003 as:

A term which embraces participatory and emancipatory approaches to research

Walmsley and Johnson 2003

INCLUSIVE RESEARCH

- Owned (not necessarily initiated) by people with learning disabilities
- Furthers the interests of disabled people, researchers on the side of people with learning disabilities
- Collaborative
- People with learning disabilities exercise control over process and outcomes
- Outputs are accessible
- Walmsley and Johnson (2003) *op. cit.*

CARLISLE RESEARCH COLLABORATIVE DEFINITION

- Person led research is research started and controlled by people who have learning difficulties
- Rejected research is where people with learning difficulties are not part of the research when it is about them... Where they are not completely included they are rejected
- Townson et al 2004 page 73

PAST

TRADITIONAL / INCLUSIVE RESEARCH

Traditional

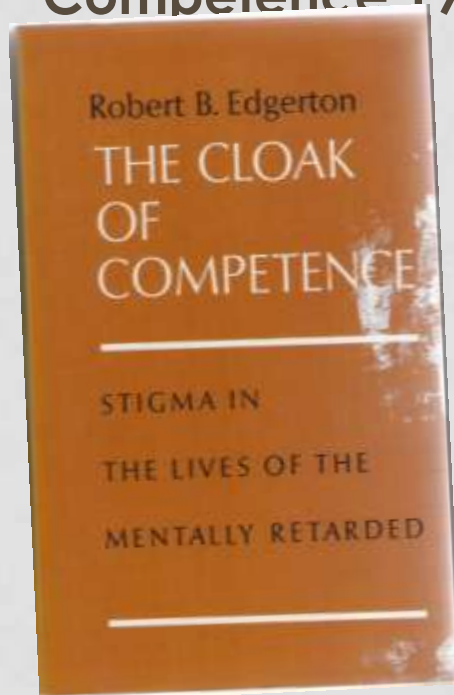
- Researchers decide on the questions to ask, and the methods
- People with learning disabilities as objects of research
- Research not designed to be used by people with learning disabilities
- Reports not accessible

Inclusive

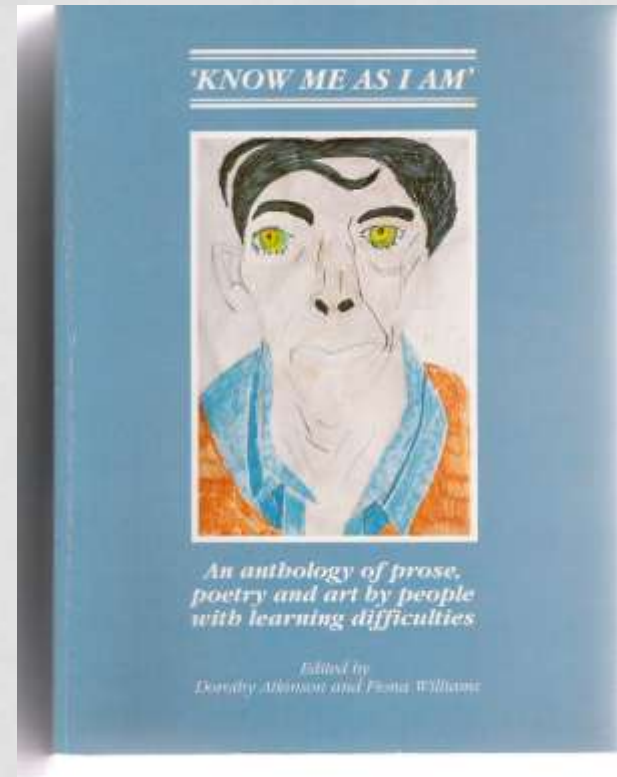
- People with learning disabilities help decide topic, questions, methods
- People with learning disabilities carry out some research tasks
- People with learning disabilities use the results
- Accessible reports

FROM ACADEMIC GAZE TO SPEAKING FOR YOURSELF

Edgerton, Cloak of Competence 1967



Atkinson and Williams, Know Me As I Am 1990





FROM THIS

CLASS AT LEAVESDEN HOSPITAL, HERTFORDSHIRE, ENGLAND. 1960S



TO THIS

GRUNDTVIG PARTNERSHIP WORK GROUP IN ICELAND C. 2007

PRESENT

INCLUSIVE
RESEARCH
WHERE IT CAME
FROM

- Participatory Action Research
- Normalisation / srv – valued social roles
- Social model of disability -reducing barriers
- Co – production - changing professional practice

PARTICIPATORY ACTION RESEARCH

Assumption about the nature of the problem	Communities know what they need but lack the resources to address their problems through research
Intervention	Researchers support communities to define what matters to them, find solutions which fit their context
Expected Outcomes	Practical solutions to people's real problems Skilled people in communities
Success Measures	Increased capacity in communities and groups to identify and tackle problems of real concern

MY LIFE MY CHOICE ANNUAL HEALTH CHECKS IN OXFORDSHIRE

- Sponsored by NHS Trust and self advocacy group (MLMC)
- In Oxfordshire only 26.1% of people had a health check in 2009/10.
- Carried out by MLMC and myself
- Easy Report, full Report and Launch
- MLMC campaign to increase health checks (in 2012 50%)

26.1



STORIES OF CHERRY ORCHARD, HEAVERS FARM, AND WAYLANDS

Mark Towers

Yeah, laundry. Go out in the mini bus and pick the washing up from Thornton Heath.

Pat Hall

We done the Laundry right up to 20 to 4. Then we use to go home then. We use to get 4 pounds and at Christmas time we use to get bonus, didn't we? We use to get 12 pounds bonus at Christmas.



SOCIAL ROLE VALORISATION

Assumption about the nature of the problem	Labelling leads to societal devaluation, denial of access to valued social roles
Intervention	Involvement in research provides valued social roles in valued settings with valued people
Expected outcomes	Increased social value for people with learning disabilities, both participants, and as role models for others
Success Measures	Societal perceptions of people with learning disabilities change

CENTRAL ENGLAND PEOPLE FIRST RESEARCH OWN HISTORY

- Philip visits Northamptonshire Archives



YOUNG PEOPLE AT CHANGING OUR LIVES INTERVIEW STAFF AND RESIDENTS OF FORMER HOSPITAL



THE SOCIAL MODEL OF DISABILITY

Assumption about the nature of the problem	Disablement is the result of barriers in society - to full participation, citizenship, and inclusion
Intervention	Change in the social relations of research production. Disabled people in charge of research, deciding the questions, designing the process, receiving and using the results
Expected outcome	Research that is framed around disabled people's concerns, finding solutions which reduce barriers to participation and inclusion
Success Measures	Fewer barriers, greater inclusion

SELF ADVOCACY WHERE NEXT?



- Central England People First commissioned Ian Davies (former chair) and me to find out how other self advocacy groups work and report back
- Used results to change the way they work



CLARE INCLUSIVE RESEARCH GROUP, IRELAND

WE HAVE A RIGHT TO RELATIONSHIPS: USING DRAMA TO GET THE MESSAGE ACROSS



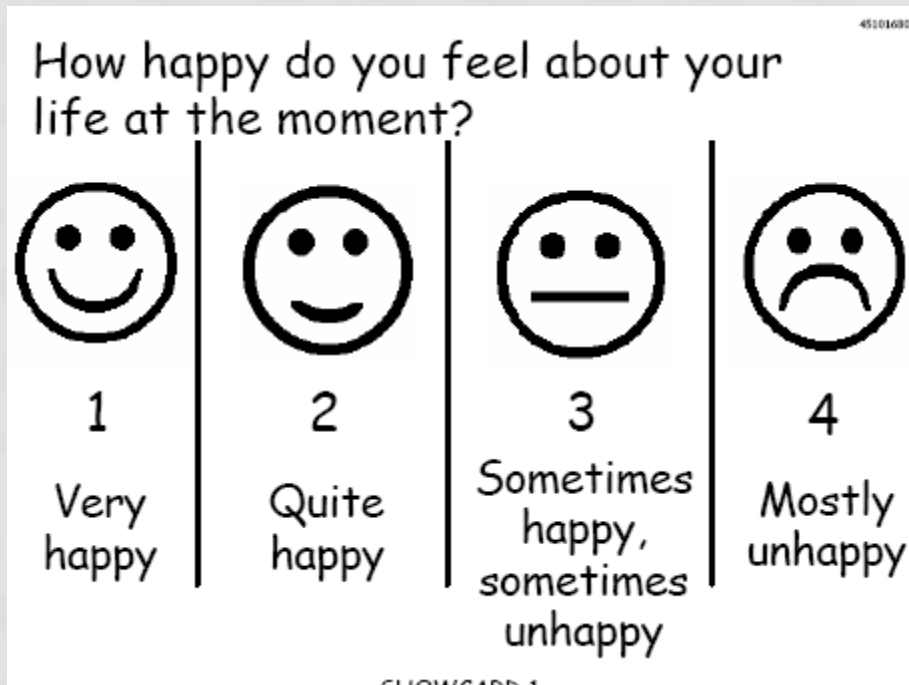
CLARE INCLUSIVE RESEARCH GROUP

RESEARCH INTO THE BARRIERS TO TRAVEL IN RURAL IRELAND, USING
DRAMA TO PRESENT FINDINGS

CO-PRODUCTION

Assumption about the nature of the problem	People are the most important resource for health and care, but professionals do unto, rather than work in partnership
Intervention	Research partnerships between professionals and people who need to use services to research real needs people have of support
Expected Outcomes	Service users empowered, professional roles changed from relieving to enabling
Success Measures	Professionals as enablers Improved service outcomes Lower costs???

FRAMING THE RESEARCH QUESTIONS



http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4120033

FINDING THE RIGHT WORDS

The terms people use to discuss research is shaped by past experience. This in turn shapes the role they feel they can take in research. In our research project on adult protection policy we found the terms risk and abuse in particular are shaped by past experience.



Extracts from accessible summary p. 143

We have found that by NOT asking people their story but sharing one of our own meant people that came to our research sessions felt able to share what they wanted about their story, in the way they wanted to without feeling put on the spot.



Brookes I, Archibald S, McInnes K, Cross B Finding the words to work together: developing a research design to explore risk and adult protection in co-produced research *BJLD* 40 (2) 143-15.

INCLUDING PEOPLE WITH HIGHER SUPPORT NEEDS

Sue Ledger combined interviews with information from those in the person's network and 'mobile interviews' to enable people with higher support needs and challenging behaviour to contribute to Life Maps like these



The research helps explain why some people did not get placed out of borough.

It can be used to reduce out of borough placements and to develop personalised services with people who have high support needs

FUTURE DIRECTIONS?

- *Practising Inclusive History: Moving on from 'nothing about us without us'*
- *Recognition that multiple perspectives are required*
- *Working alongside people with learning disabilities, carers and advocates to frame the research questions that are important for them*

SOCIAL HISTORY OF LEARNING DISABILITY RESEARCH GROUP

[HTTP://WWW.OPEN.AC.UK/HSC/LDSITE/](http://www.open.ac.uk/hsc/lbsite/)

***Practising Inclusive History: Moving on
from 'nothing about us without us'***



Going in and getting out after 20 years by Kevin Chettle

AIMS

- To encourage historians, researchers and people with learning difficulties to work together on the history of learning disability
 - To develop methods of historical inquiry that combine oral history, biography and archive research
 - To find ways and means of making history available and accessible to all who are interested
 - To make links between the history of learning disability and broader social policies.



STAFF STORIES AND STORIES ABOUT STAFF JULY 2010 THE OPEN UNIVERSITY, MILTON KEYNES



The leopard has changed its spots

Daniel Docherty

In this paper I am going to describe my Experiences of support staff in the early 1970s when I was living in Calderstones Hospital. I am going to compare these experiences to the approach taken by the staff who support me now.

People with learning difficulties are Supported better than they were 27 Years ago. The leopard can change its spots

LYNNE AND SUE DUMBLETON



STAFF AS LIBERATORS: LIBERATION FROM WHAT?

- My paper will suggest that for some staff the romance of history, of the exciting challenge of practice 20 or 30 years ago, might get in the way of providing good support in the twentieth century
- As has so often been the case my professional knowledge and practice have been challenged by what I have learnt as a parent



WHAT HAS BEEN ACHIEVED?

- Valued social roles - contributions named and recognised
- Gains in self confidence and opportunities
- Insight into life stories, what people want from life, how services are experienced, how to communicate
- Imaginative ways to include people in different aspects of research – transferable to professional practice
- Finding the right words – transferable to practice
- Some knowledge transfer
- A place in the research pantheon

A DEFINITION OF SUPPORT



- Support is a role that bridges the gap between what people want to be doing, and what they are rejected from doing by the way things are (Chapman and McNulty 2004 p.84)

CQC EXPERTS BY EXPERIENCE

"I'm pleased about being an expert by experience. Because I know hopefully this will make a difference to people's lives." [Expert by experience]

Everyone involved has increased their understanding of engagement and communication with people who use services, and it has made them more aware of their own practices. Service providers and managers told us that they thought experts by experience are good role models for people who use services.



GOVERNMENT REPORTS IN EASY READ VERSIONS



What we found when we looked at the services

- there were some good services, for example Osborne House and the day centre at Orchard Hill Hospital
- we found that people were looked after in a way that was easy for the staff but that was not always what was best for the people living there
- people did not have a lot to do and sometimes only had four hours a week of doing activities such as learning new things, painting or listening to music. Most of these activities were at the hospital



- most of the houses were not suitable because it was difficult for people who use wheelchairs to get around
- we found that sometimes people were not given the privacy they need because there was not enough space
- sometimes people were not treated in a respectful way such as not being told what was happening or why something was happening
- many people did not get the chance to see staff who have special training and are good at understanding what help people need such as help with feelings and behaviours, and help with eating and drinking

LIMITATIONS

- New social roles primarily for an elite
- Exclusion of people with higher support needs
- One sided advocacy
- Over reliance on 'easy read'
- Lack of clarity about its 'added value'
- More emphasis on process than outcomes
- Limited recognition that people with learning disabilities need knowledge and skills, as well as life experience
- Not enough transfer to practice

WHAT OF THE FUTURE?

- Build on successes – BJLD, JARID, right language, nature of support relationships
- Sharing leadership, team approach, organisational relationships
- Knowledge transfer
- Help people to ask research questions for others to address
- Acknowledge that staff, families, professionals and researchers have contributions to make to understanding the past and forging a better future

TOWARDS A NEW THEORY OF CHANGE?

Assumption about the nature of the problem	How to bridge the gap between what people want to be doing, and what they are rejected from doing by the way things are
The Intervention	Inclusive research to experiment with different models of personal and organisational support relationships, and spread the results to policy makers and to services
Expected Outcome	Improved understanding of what constitutes effective support to be used to train and develop staff, volunteers, and advocates to work alongside people with learning disabilities
Success ?	People are supported to bridge the gap as they define it