Inclusive research: Opening up a new frontier
Evolution of inclusive research

Nothing About Us
Disability Oppression and Empowerment

James L. Charlton

"Jim Charlton in a deeply moving work demolishes old myths about disabilities. He reveals in startling oral histories, conducted in ten different countries, possibilities yet untapped."

STUDS TERKEL

Centre for Disability Studies

An affiliate of The University of Sydney
Disability Rights Movement of 1990’s
Participatory research: Research with rather than on people

- People with disabilities are part of the design, conduct and evaluation of research, with the construction of non-hierarchical research relations (Zarb, 1992).

- Participatory research, attempts to change the social relations of research processes.
(Research needs to be...) More relevant to the lives of disabled people and more influential in improving their circumstances. The two key fundamentals on which such an approach must be based are empowerment and reciprocity (Oliver, 1996, p. 141)
Due to a combination of factors including the burgeoning disabled people’s movement and the activities of a small but influential group of predominantly disabled writers and researchers the space has been created within the research establishment for researchers to pursue an implicitly, if not explicitly, emancipatory disability research agenda....this is not a particularly easy task.
Research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers, and disseminators of research.
Principles of inclusive research

- People with disabilities have ownership over research questions
- Are collaborators in doing the work
- Exercise some control over the process and outcomes
- Can access questions, reports and outcomes
- Outcomes further their interests

- Outcomes most commonly associated with participatory action or emancipatory paradigms (Walmsley & Johnson, 2003, pp. 9-10)
- Search engines
- Pro quest
- ERIC
- Google scholar
- Intellectual disability
  - /And
- Inclusive research
- Participatory research
- Collaborative research
- Emancipatory research
- Co-research
- Co-designed research
- Nothing about us without us
Topics

- Communication
- Quality of Life
- Spirituality
- Person-centredness
- Leisure & Sports
- Sterilization
- Self-advocacy
- Exploration & Inclusive Research Process

- Employment
- History
- Parenting by PWID
- Family/Carer issues
- Transition
- Grief & Death

- Health & wellbeing
- Education
- Social Inclusion

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The work of Irish researchers with intellectual disabilities

All We Want To Say: Life in Ireland for People with Intellectual Disabilities
December 2009

National Institute for Intellectual Disability
School of Social Work and Social Policy
Trinity College Dublin
&
Co-Researchers with Intellectual Disabilities from Ireland

House by Shane Lonergan
from Moorehaven Centre in Tipperary Town

Where we Live
A National Study done by
Members of the Inclusive Research Network
More dialogue
All research is based on vision of the world
Research method depends upon one’s epistemological viewpoint

Epistemological Foundations
- **Positivist**: objective reality & pre determined
- **Interpretivist**: multiple realities
- **Constructivist**: create your own reality
Is there a divide between the three epistemological presuppositions?
Is dialogue between paradigms possible within the area of inclusive research?

A MULTI-PARADIGM PERSPECTIVE

Kuhn (1971)

Presence of a single paradigm characterizes normal science while the coexistence of different paradigms can be symptomatic of periods of scientific revolution.
Ownership & collaboration

- Positivist
- Interpretivist:
- Constructivist

Control over outcomes

- Interpretivist:
- Constructivist

Accessible reports; Outcomes further interests.

- Interpretivist:
- Constructivist
Another aspect of world view relates to place in the world

HUMAN RIGHTS PERSPECTIVE

- Therefore people with intellectual disability should be involved in research

SOCIAL MODEL PERSPECTIVE
To have better lives, people needed to be:

- a self advocate
- a house owner, flatmate
- a paid employee
- a partner in a relationship
- a good communicator
- a money manager
- a respected citizen
We did a DVD and a report with the findings:

All We Want To Say:
Life in Ireland for People with Intellectual Disabilities

December 2009

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Components of a collaborative group model (Bigby, Frawley & Ramcharan, 2014, p. 56)

- Shared and distinct purposes - equally valued
- Shared involvement and distinct contributions – equally valued

Scaffolding for inclusion

- Working as a group with trusting relationships and dispersed power
- Flexible adapted research methods.