1. The origins of inclusive research
2. How participation is defined at the different stages of the research process
3. Methodological issues
4. Distinct characteristics and limitations and barriers
Dominant Paradigm:

The characteristics of traditional research in intellectual disability (learning difficulties, learning disabilities, mental retardation, etc.) are:

- Positivist approach
- Medical model of disability
- Research on people with intellectual disability
- The views of people with intellectual disability are not examined or explored
The inclusion of the voices of People with intellectual disability: Early studies:

› Bogdan and Taylor’s (1976) life-history of Ed Murphy

› The longitudinal work of Edgerton (Edgerton, 1967; Edgerton & Bercovici, 1976; Edgerton, Bollinger, & Herr, 1984; Edgerton & Gaston, 1991)

(...) it was not possible to include in this book all the people who shared their lives with us, but we would like to take this opportunity to express our sincere thanks to all of them. Most of all, our deepest gratitude goes to the people whose lives appear here -whose friendship, patience, and teaching has made our research and this book possible

(Edgerton and Gaston, 1991, p xi, emphasis added).

› In this type of research people with intellectual disabilities are informants (rather than active participants in the research process)
The catalysts (according to Jan Walmsely and Kelley Johnson, 2003):

› Feminist (and other) critique of positivist quantitative research and its challenge to research objectivity (e.g., Oakley, 1981)

› Influence of the principles of Normalization/social role valorization (e.g., Bank-Mikkelson, 1969; Nirje, 1980; Wolfernsberger, 1972) in the provision of services for people with intellectual disability

› The social model of disability and participatory and emancipatory research (e.g., Zarb, 1992; Oliver, 1992)

› Self-advocacy movement (for a critique from an self-advocate and researcher, see Aspis, 2002)
The critique of traditional research:

› Disability is socially constructed and this should be recognised in research that is value driven and of benefit to people with disability

› Acknowledgement that research can be oppressive (as well as empowering) and has silenced the voices and perspectives of oppressed groups, including people with disability

› Involvement in research has been of no or little benefit for participants (objects of research), while it advances the knowledge, standing, and careers of (able-bodied) researchers

› Topics of research may be irrelevant or of little interest to people with disability
Disability Research:

Participatory Research

- Participatory research aims to challenge social divisions and the power relationships of researcher-researched, and give the participants of the research a voice.

- Participatory research is considered as “compatible with the social model of disability but not dependent on it” (Finkelstein, 1999, p. 863).

- It doesn’t not seem as necessarily changing the social and material relations of research (which is the ultimate role and aim of emancipatory research).

Emancipatory Research

- Influenced by the work of Paulo Freire (1970).

- In emancipatory research the researcher devolves his/her control to disabled people throughout the research process, including the stages of research design, collection of data, analysis and dissemination.

- As Stone and Priestley argued, the emancipatory model “requires full ownership of the means of research production – ownership by the research participants, not the researcher” (1996, p. 709).
## Participatory research and emancipatory research

(From: Walmsley, 2001, p. 196):

<table>
<thead>
<tr>
<th>Participatory research</th>
<th>Emancipatory research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Methodology</strong></td>
<td>Phenomenological (getting inside the experiences of research subjects), qualitative methods</td>
</tr>
<tr>
<td><strong>Ideology</strong></td>
<td>Not prescribed; likely to be either normalisation or social model of disability, and to promote positive images of disabled people</td>
</tr>
<tr>
<td><strong>Who is in control?</strong></td>
<td>Researcher in partnership with disabled people, particularly at data collection stage</td>
</tr>
<tr>
<td><strong>Role of researcher</strong></td>
<td>Expert, sharing expertise with research subjects; sometimes also an advisor /supporter</td>
</tr>
<tr>
<td><strong>Subject matter</strong></td>
<td>Issues relevant to the lives of disabled people</td>
</tr>
<tr>
<td><strong>Accountability</strong></td>
<td>Accountable to funders</td>
</tr>
</tbody>
</table>
The position of people with intellectual disability in the social model of disability:

- The social model of disability centers on physical and sensory disabilities.
- References to intellectual disability tend to be limited and an ‘afterthought’ (Chappell, & Lawthom, 2001).
- People with intellectual disability have experienced exclusion from the broader Disability Movement.
“‘Inclusive research’ is a term used here to refer to a range of research approaches that have traditionally been termed ‘participatory’ or ‘emancipatory’, broadly speaking research in which people with learning difficulties are involved as more than just research subjects or respondents.

Introducing a new term may seem to create unnecessary complications. However, it has the advantage of being less cumbersome and more readily explained to people unfamiliar with the jargon and nuances of academic debate, including people with learning difficulties”

Characteristics of Inclusive Research:

- Inclusive Research:
  - Owned but not necessarily initiated by people with intellectual disability or their organisations
  - Promotes the interests of people with intellectual disability
  - Researchers act as allies
  - Common aims, shared expectations and collaborative working practices
  - Shared control over process and outcomes
  - Outputs are presented in accessible ways
Selected practices used in inclusive research:

- Common, complementary or dual aims for the research, but explicitly shared and agreed
- Reference Group
- Relationships (from Walmsley & Johnson, 2003):
  - Researcher as teacher and coach/person with intellectual disability as learner or student
  - Researcher as consultant/people with intellectual disability as employers
  - Co-researching: trained researchers and people with intellectual disability
- Working together on outcomes
- Accessible outputs (plain English, visuals, videos, etc.)
- Financial aspect of research –Funding, payment of co-researchers
Examples from Research Projects:

1. Quality and capacity in inclusive research with people with learning disabilities (Melanie Nind & Hilra Vinha, 2012)
   › Website: http://www.doingresearchinclusively.org/
   › Report: http://www.southampton.ac.uk/education/research/projects/quality_and_capacity_in_inclusive_research_with_learning_disabilities.page

The academic journal:

2. National Institute for Intellectual Disability (Trinity College Dublin, Ireland)
   › Research with People with Intellectual Disabilities: Inclusive Research:
     - Website: http://www.tcd.ie/niid/research/irn/

“From the outset, my co-researchers presented at conferences and university seminars with me. These presentations were well received and I noted that quite a few of the participant group had a flair for, and really enjoyed, public speaking. We developed a proposal that was eventually funded by a member of the host organisation and seven young people were recruited and paid to work with specialist consultants to become trainers in Down syndrome and disability issues. They have since developed workshops for undergraduate social and health care professionals. The young people use presentation software and DVDs (very enabling technologies), as well as role play exercises with students, to augment and enrich their communication and messages. Thus from an initial process of research inclusion, has blossomed an interesting and affirmative role for some young people with an intellectual disability and, equally, some memorable learning for university students”

(Stevenson, 2010, p. 45).
“This journal has been publishing articles related to the lives of people with learning disabilities over a number of decades. In recent times, some of these articles have been written in partnership. […] However, we also think it is time that people with learning disabilities became involved in *more than just* co-writing and research. We wanted to see a partnership approach to the whole process of peer review and publishing research. We bear witness to learning disabled researchers finding it difficult to access their rightful place in discussion within academia despite government departments, research councils and the larger charities demanding that inclusive/service user involved, or partnership research, is the ethical way of working. With this idea in mind, we met with the editor of the journal, Professor Duncan Mitchell to ask whether our group could, for the first time in the UK, complete the whole process for a special edition of the journal: that is, to peer review articles and write the editorial in partnership”

(Blunt, et al., 2012, p. 83, emphasis added).
Mencap. Make it Clear: A guide to making information easy to read and understand.

http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication
The case of children and inclusive research:

› Inclusive research has been conducted predominately with adults

› There are research studies that use participatory action research with children with disability but they do not call their approach inclusive research

› An example: Gray & Winter (2011):

› Thirty-six young children with and without a disability were engaged in all aspects of research project. A range of disabilities were represented. “Matched according to age and gender, six dyads of children attending four early years settings in Northern Ireland chose the research question, selected the research methods, gathered the data and disseminated their findings” (Gray & Winter, 2011, p. 309).

› Ann Lewis and Jill Porter (2004) have proposed a set of guidelines for conducting research with children with intellectual disability
Bibliography:


