Towards Inclusive Research: Our Clients, our collaborators

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Outline

• What is inclusive research?
• Research participants as partners and collaborators
• Why Inclusive research?
• Issues, challenges and paradoxes involved in inclusive research
• Examples/case studies of research with marginalised communities particularly people with disabilities in different contexts and across cultures
WHAT IS INCLUSIVE RESEARCH?

• An umbrella term for research which employ methodologies which involve the people or community in the process and production of knowledge.
• Partnership and service users involvement in research
• Research which engages with the people rather than on the people or community.
• Inclusive researchers are committed to engage with minority and marginalized groups and to allow for their voices to be heard in the generation of knowledge, theory and practice about their lives.
Research which engages with the people

• A range of research methods mostly in the qualitative research orientation
  - Action research
  - Participatory research
  - Emancipatory research
  - Life stories / life histories
  - Narratives
  - (auto)-biographical research
  - Ethnographic research
People as active participants

A Continuum

**Participatory Research**
- The traditionally researched e.g. people with disabilities are involved in the research process
- Researcher seeking out the researched as knowledge producer
- Researcher bent on understanding the insiders’ experiences
- Service users having a ‘voice’
- Researchers and the researched working together

**Emancipatory Research**
Feminist research (Reinharz, 1992)
Emancipatory Disability Research (Oliver, 1992, Barnes 2003)
The researched have full control of the research - set the agenda, decide on the methods and interpret and analyse the findings of research
Active doer of research
Criteria for Inclusive Research

- Research themes must be of clear relevance for people with disabilities
  - Goal: Improvement of the quality of life
  - Perspectives and experience mark the starting point
  - Researching together to achieve collaborative results
  - People with disabilities should have some control over the research process
  - People with disabilities should be able to make active contributions as researchers
  - Accessibility of the research and its findings
Why Inclusive Research?

• What is research for?
• Generation of knowledge
  ➢ Knowledge which can make a difference in the lives of the people
  ➢ Knowledge to inform practice and policy
  ➢ Theory building
Emancipatory research can, and has made a difference

- M. Oliver (1992) emancipatory research
- Barnes (2003) in ‘What a Difference a Decade Makes: reflections on doing ‘emancipatory’ disability research
  
  E.g. British Council of Disabled People (BCODP) studies on discrimination has played a crucial role in getting the anti-discrimination legislation (Barnes, 2003) following in the UK

- Research process – DPOs control research agenda and dissemination of findings – is empowering

- ‘Empowerment is not something that can be given, it is something that people must do for themselves’ (Barnes, 2003: 12)

- Asnarulkhadi Abu Samah (2007) – Malaysia: Involving older persons in research in order to empower them
- Potential of older people to exert influence on policy which may affect their lives.
Why Not?

• In line with social work principle of promoting social inclusion.
• “Nothing about us, without us” (disability rights movement)
ISSUES, CHALLENGES & PARADOXES involved in inclusive research

Where do we begin?

• Begin with the premises that our clients’ knowledge counts
• legitimize grassroots knowledge which becomes the source of empowerment
• “…social work practice, if it truly takes place in solidarity with the oppressed, also must value the knowledge of the people with whom we work; they have a wisdom and an expertise which we do not, just as because of our professional education, we may have particular knowledge and skills that they do not. Social work practice requires the two sets of wisdom and knowledge be brought together in a form of dialogical praxis” (Ife, 2000:6).
• Can we know what our clients know?
• How do we know what they know?
• This requires different methods of research, & different ways of knowing.
Some interesting anecdotes…

A researcher conducting a household survey in a village standing on the sea.

Researcher: what is the land size of your house?

Respondent: Land size? You have to measure the size of the sea!

Researcher: Aaaa?!
One more...

The number of livestock

- **Researcher:** Tell me then how many chickens you reared?
- **Respondent:** I don’t really know
- **Researcher:** How about we throw the chicken feed out so that when they come we can start counting them’.

When that was done, many chooks and chicks came. The researcher began to count them...

- **Respondent:** I have to tell you some of them belong to my neighbours, and to be honest, I really don’t know how many are mine and how many are theirs…”
Whose Reality?

- Researchers: land possession, monetary income, ownership of assets irrelevant to the lifeways of the people studied.

- Concepts and categories do not reflect the world view and experiences of the people studied. For example, self-esteem and independence are culturally based norms, either alien or differently interpreted in different cultures.

- For example, independent living for adult PwDs – Is it about them living apart from their parents? Or rather the concern is: will my non-disabled children take care of the disabled child when I am gone?

- Experiences of minority groups continue to be masked by imposing mainstream/dominant/western concepts and assumptions.

- Marginalisation and even exclusion of culturally diverse interpretations of reality and human experiences.
Multiple realities...

• Barnes, C (2003) cautions against the representativeness of individual experiences; while it is important that “any discussion of disabled persons’ experiences, narratives and stories are couched firmly within an environmental and cultural settings that highlights the disabling consequences of a society around the needs of a mythical, affluent non-disabled majority’, however, these experiences may not be representative of all DPs who are from diverse backgrounds in terms of class, gender and ethnicity. Neither do the experiences represent those in the global south.
Who is a disabled person?

Relative invisibility of DP in Sarawak (experiences of MMU, UK-UNIMAS, Sarawak collaborative research project, 2008-2010)

DPs unseen? Hidden? Reluctance to report? Or is it possible that certain impairment may not be considered a disability in Sarawak?

Disabilities in UK may not be disabilities in Sarawak, Malaysia.

Disabilities in an urban setting may not a disability in a rural village, and vice versa.

Example, someone who may have a learning disabilities and is engaged in farm work in a rural setting and well integrated, but will not be able to hold down a job if in a urban setting.
Cultural meanings of impairment

- ‘cacat’ (in Malay / Iban)
- chan chiek’ 殘疾人 in Chinese
- implied diseased ‘spoilt/broken and lacking’ 

The meanings of disability varied and diverse

- ‘This child is a God’s gift’ (Malay families)
- ‘Could this be bad feng shui?’
- ‘May be something I did wrong in my past lives (Chinese families)’ (Ling, 2007)
- ‘This person is handicapped because her parents had broken certain taboo when her mother is pregnant with her. It is a curse!’ (Iban villagers/Terence Mamba, 2010)
- ‘This is God’s testing for me’ (both Muslim and Christian/Chan, 2011)
Making sense of meaning – So what?

• Meaning the research participants attached to their own lived experiences
• Whether seeing disability as personal tragedy or god wills – how do we move them beyond from ‘personal to political’?
• Do Disabled persons have a shared identity?
• Shakespeare (2006) discusses the inclusive view of disabled identity (you are disabled if you said you are) and concluded that this is problematic. Some like to identify as disabled, but do not have the experience of oppression, or some who may experience oppression, but subjectively refused to identify themselves as that.
Many ways of knowing

• PAR can overlook the nuances and multiple voices that emerged from communities, in trying to capture a commonality of experiences (Healy, 2001)

• The possibility of ‘untold truth’ and ‘variant truths’ (Fenge, on a PAR with Older lesbian and Gay Men)

• The need to have ‘many ways of knowing’ (Hartman, 1990) ‘each is grounded in, and an expression of certain ontological, epistemological, and value assumptions’ – different culture and world view
Ling, H.K. & Fejo-King, C (Forthcoming) argued for culturally congruent research methodology

- Valuing indigenous knowledge
- Embracing local communication patterns
  
  e.g. Research on help-seeking experiences of local people (Ling, 2001): most interviews in village settings done in the open - family members or neighbours coming and going freely.
- Acknowledging spirituality
Relationship between the Researcher & the Researched

• Relationship is not individualised, but governed by a person’s social position and roles in a network of interconnection.

• How might entering into a research/participant relationship change existing patterns of relationship in a community? It may involve role reversal; the social roles expected of younger and older persons in a community may define the social interaction between them differently.
• The notion of a contractual relationship is alien to non-western cultures. It is more difficult to enter into a community as a stranger to conduct research. There needs to be an extension of friendship, and the need for mutual exchange and reciprocity.

• The norms governing interactions and communicative processes. There may be the issues of what can or can't be asked, who can ask what to whom, and of whom
WHERE DO WE GO FROM HERE?

Some suggestions, as well as some questions to ponder, on developing inclusive research

• Research methods need to take into consideration the cultural nuances, the local pattern of communication, the concepts used in a different culture.

• Research methods need to be able to incorporate or acknowledge the diversity and multiplicity of different contexts within and across cultures/countries.

• Develop a way of knowing which respects and embraces differences.
• We need to think not just the ‘what’ of research (the techniques) but more the ‘how’ of research (the process)

• We need to reflect on different ways of thinking about knowledge and engage in other ways of knowing in order to search for an indigenous research paradigm to uncover local knowledges.
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Thank You
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