Members of the CDS Inclusive research network
49th ASID Conference, Esplanade Hotel, Fremantle, 5-9 November, 2014

On becoming an inclusive researcher
Evolution of inclusive research

James L. Charlton

NOTHING ABOUT US

WITHOUT US

DISABILITY OPPRESSION AND EMPOWERMENT

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

STUDS TERKEL
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
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).
Is the research agenda based on a social model of disability?

Does the researcher have a commitment to disabled people’s self-empowerment?

Will the research contribute to the removal of disabling barriers?
- Will the research be accountable to disabled people and their organisations?

- Will the research give voice to both the individual and shared experiences of disabled people?

- Will the choice of research methods be determined by the understanding of the participants?
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.
What is inclusive research?

Research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers, and disseminators of research.

Jan Walmsley

Kelly Johnson
How do you go about it?

- Ownership of questions
- Collaborate
- Some control over processes
- Access reports
- Further interests
- Participatory or emancipatory in nature

People with disability being

Advisory group members

Co-researchers

Collaborators
Living safer sexual lives (Johnson, Frawley, Hillier & Harris (2001))

ADVISORY GROUP ROLE

- People with disabilities members of a advisory group with service providers and advocates
- Guidance in design of interviews & recruitment.
- 25 people contributed their life stories
- Advisory group involved in analysis.
Team work from the advisory committee (Johnson, Minogue, & Hopkins, 2014)

- Researchers contributed their knowledge of research methodology; people with disabilities their lived experience; advocates support change.
Involving people with intellectual disabilities as co-researchers
NIID research network
Marie Curie Transfer of Knowledge Grant

- 4 year UN contract
- 4 post grad fellows, for up to two years each
- 6 Experienced researchers for up to 6 months each
- Purpose was to explore what was meant by inclusive disability research
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 Loneran
from Moorehaven Centre in Tipperary Town

Where we Live
A National Study done by
Members of the Inclusive Research Network

CDS
Centre for Disability Studies

AN AFFILIATE OF
THE UNIVERSITY OF SYDNEY
All We Want to Say Study

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The University of Sydney
Research questions

How life is like in Ireland for people with intellectual disabilities?

How life could be better?
Focus Groups

23 in total
• 16 in Ireland
• 7 in Northern Ireland
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:
Where We Live

House by Shane Lonergan
from Moorehaven Centre in Tipperary Town

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The Inclusive Research Network
A Participatory Action Research Project

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Disability
Studies
Where We Live

Are you able to use the kitchen when you want?

We did surveys:
43 in total all in Ireland
27 females
16 males
Only half of the people chose where they live.
Relationships and Supports Study
Why we wanted to study relationships?

- Because people should have relationships –
- It’s part of everyday life
- Families should support people to have relationships, to have their own lives
Research questions

- What do you think makes a good friend?
- What do you think about having a boyfriend / girlfriend?
- What supports do you need?
We did 16 focus groups
Focus group facilitation (running a focus group) was new to me so it’s a milestone to me in my career as a researcher. I feel more confident, less nervous.

Brian Donohue, Co-researcher, National Federation of Voluntary Bodies, Galway
Who took part in the focus groups?

- 97 people took part, 45 men and 52 women.
What do you think about having a boyfriend or a girlfriend?

Treat each other well

If you bring a girl any girl out, you are going to treat her to something anyway whether it’s a mineral* or a bloody ice-cream or whatever you like to give a girl you give it to her, whether it’s a smart or a kiss.

* soft drink in Ireland
Inclusive research - What questions need to be considered?

- How can one ensure that the research topic is of interest and will further the interests of people with disabilities?
- How can we build capacity to support stakeholders to engage in inclusive research?
- Is co-researching the same as collaboration?
- Where does research start and finish advocacy begin?
What does the NDIS mean for me?: An Inclusive Research approach to exploring the views of people with disability

by
The Centre for Disability Studies Inclusive Research Network
Affiliate of The University of Sydney, NSW, Australia

ASID 49th Annual Conference
Fremantle, Australia
November 2014
What is the Centre for Disability Studies Inclusive Research Network?

- Thank you to NSW RUN projects and ASID

- We are a group of co-researchers with intellectual disabilities, their supporters and university researchers from CDS, Sydney. We do research together.

- We have been working together since 2010

- Our members have changed over time but we are still very keen to do research together

“Nothing About Us Without Us”
Some of Our Inclusive Research Network Members
Workshops and monthly meetings over the years

Beginning skills in
- Developing research questions
- Ways of gathering information
- Research ethics
- Developing interview guides
- Interviewing skills
- Analysing the interview information (data)
- Preparing presentations
- And now – focus group skills
What is our research about?

- Build on our previous work on the everyday experiences of people with intellectual disabilities on rights in the UN Convention on the Rights of Persons with Disabilities

- NDIS is a major change in Australia involving, amongst other things, how support to people with disabilities is provided

- The NDIS represents major changes for people with intellectual disability

- We were interested to find out how people with intellectual disabilities thought the NDIS might impact on them and their everyday lives.
The Two Parts to our Study

Part 1 – NDIS Information Sessions

- Four Information Sessions on NDIS for people with intellectual disability involved with organisations that we have contact with

- Material covered basic information on the NDIS around choice, voice and control

- People at information sessions were invited to take part in later focus groups
Part 2.- Focus Groups

- Four focus groups to explore the perceptions of people with intellectual disability on the impact of NDIS on them

- Focus group participants in the main, but not exclusively, were people who came to the information session

- The conduct of and findings from the focus groups is the subject of this presentation

- Research question: How do people with intellectual disability see the impact of the NDIS on their lives?
How we did the research

- We decided that focus groups were the best way to get the information we needed because they encourage discussion among group members.

- We developed a series of questions around the NDIS to guide the discussion.

- Focus groups were conducted by researcher teams consisting of both members with and without intellectual disability.

- The study was approved by the University of Sydney’s Human Research Ethics Committee.
Who were the focus group participants?

- Twenty eight people in all took part in the four focus groups
- All were receiving support from a disability organisation ranging from 24 hour to “drop in” support
- Age range from young adulthood to middle-aged and older adults
- Some were in part-time employment, others in community participation programs
- Transcripts of recordings of the focus group were our data
Three Themes

- What I know or don’t know about the NDIS
- What I think the NDIS might do for me
- My worries about the NDIS
So where does all the money go to? … does the service hold that, or do you get it all put into your account, or what happens to it?

we know a little bit about the NDIS, but we don’t know a lot and we’re a little bit unsure about what it will mean for us.

to sort themselves, settle themselves down so that they don’t put too much pressure on them.

When will it be out? This year? ... next year.

I mean most important getting the right information to the right people.
What I think the NDIS might do for me

It will help us like with budgeting, like life choices and stuff, so you’re in control of what you want to do. So yeah I think control with the NDIS would be good.

… one system not a whole system but going into one simple, under one system now that can be easier for people to understand and work with

….that we don’t have people saying we can’t use that money. It’s up to us

like we want to go to go out and do things and have support staff and help like get my shoes on for work and things like that, and support with like the budgets and banking, things what we need

In a way it’s sort of makes you think a little bit more about you actually want to do
My Worries about the NDIS

... there could be a problem with like maybe having it too open for your choices, so like you end up maybe choosing the wrong thing, like you want to have a limit to what you could choose, like you don’t want to be choosing a wrong path.

People might not be confident to speak up and voice their opinions.

We should be told that before it rolls out everywhere that it can’t be cut out

Because everyone gets elderly, look at Ellen, she’s 68, she’s got a disability so I think they should up the age.

we should understand that the government is always talking about cutting down every department funding.
Reflections on Our Work

Our participants told us that:

- They need clear, easy to follow information and time to think about the information and how the NDIS will affect them.
- They see opportunities for themselves with the NDIS, but they have concerns or worries.
- People with an intellectual disability want to learn more about the NDIS and how it will affect them as an individual.
- The NDIS is a time of significant change that brings with it some anxiety.
- In all, major policy change such as the NDIS has a substantial impact at the individual level.
What was it like doing the focus group work

- It was a new experience
- Good to learn new skills
- Enjoyed getting people to think about the NDIS
- Everybody in the group was different, with different things to say
- The focus group was more relaxing than doing interviews
- It was a lot of work, but it was worth it!
Thank you for your attention
Members of Our Group

- Susan Adrian
- Jodie Airey
- Sarah Butler
- Alex Butters
- Julie Deane
- Robert Griffiths

- Shane Godbee
- Suzie Jessep
- Marie Knox
- Lesley Lewis
- Michael Mcdonald
- Megan Noyeaux

- Bruce O’Brien
- Patricia O’Brien
- Glen Pudney
- Mark Walters
- Leigh Worrall
- Elizabeth Young
For more information please contact the
Inclusive Research Network

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What needs to happen in your organisation so that inclusive research can occur?
In Relation to:

- Delivering training workshops and deciding what to research
- How to gather information
- How to analyse information and share findings with others