CDS
Centre for
Disability
Studies

THE UNIVERSITY OF
SYDNEY

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

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asid
research to practice

Run Projects

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

Developing Research Skills

- 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.

NDIS
National
Disability
Insurance
Scheme
www.ndis.org.au

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

The Two Parts to our Study (cont'd)

Part 2.- Focus Groups

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

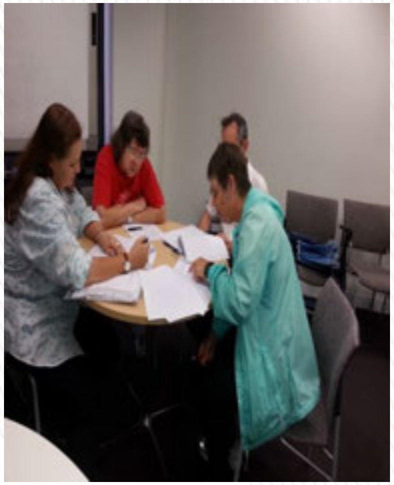
- Focus group participants in the main, but not exclusively, were people who came to the information session

- 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

What we found out

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

What I Know and Don’t Know about the NDIS

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

have time to 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

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?

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.

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

… 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

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 understand that the government is always talking about cutting down every department funding.

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 be told that before it rolls out everywhere that it can't be cut out

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

More Reflections on Our Work

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 Jessup
- Marie Knox
- Lesley Lewis
- Michael Mcdonald
- Megan Noyeaux
- Bruce O'Brien
- Patricia O'Brien
- Glen Pudney
- Mark Walters
- Leigh Worrall
- Elizabeth Young

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