Inclusive research with people who have left a licensed boarding house

Mr Paul Jones
Mr Jeffrey Martin
Dr Gabrielle Drake
University of Western Sydney
Overview

- Licensed boarding houses in NSW
- Inclusive research
- The inclusive research projects
- Barriers to inclusive research
- The team approach
Licensed Boarding Houses

- People who live in licensed boarding houses are people with disability.
- Licensed under the YACS Act 1973
- Administered and monitored by FACS- Ageing, Disability and Home Care
- About 30 left in NSW with approximately 700 people
Licensed boarding houses

- Transinstitutionalisation – many people have moved from one type of institution to another.

- Third tier of homelessness – no tenancy rights.

- Subject of recent Coronial Inquest
Inclusive research...

‘a range of research approaches that traditionally have been termed ‘participatory’, ‘action’ or ‘emancipatory’. Such research involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users’ (Walmsley & Johnson 2003; p.10).
Approaches to Inclusive research

• Advisory

• Collaborative

• Leading and Controlling (Bigby et al 2012)
Phase One

• Working out what, why and how we are going to do it...
  – Identifying an inclusive research method

• Interviews and focus group

• Human Research Ethics Committee Application
Phase Two

• Conducting the research

• Project Partners
  – People with Disability Australia
  – UnitingCare Disability Services
  – University of Western Sydney
Phase One- Experience of inclusive research

- Interviews with four men who have left a licensed boarding house.
  - Variety of experiences as participants, consumer consultants and consumer educators.
  - None of the men had been involved with an inclusive research project before.
  - Identified lots of experiences of not being heard, valued or taken seriously.
No other research projects but sometimes the consumer consultants get us to fill in surveys.

Focus group participant
Phase One- Asking the experts *what, why and how*

- Focus group with men who lived in a licensed boarding house.
  - Discussed what we want to find out and why we are interested in doing this research.
  - Identified **how we** are going to do the next project.
  - Recruited two co-researchers for Phase Two of the project.
What we want to do?

• Learn about the experiences of people who have left a licensed boarding house.
  – What supports people received to move out
  – How did moving out impact on quality of life?
Why we want to do it?

- Identify the best ways to support people leave licensed boarding houses.

- Draw on our experiences to support others and advocate for change!
The managers would say you won’t make it on the outside. They would say we would suicide if we went out on our own.

Focus group participant

I’d love to contribute in any way I can. I just want to make a difference for the people who are still living in licensed boarding houses.
How we are going to do the next project:

- Individual interviews with people who have left a licensed boarding house (and their family/friends/partners and support workers - if the person thinks this is a good idea).
- “Talk to people - they feel involved”
- “Think about location, make them feel comfortable”
- “Ask people about life after leaving a boarding house”
- Payment of $50 per interview
Ethics Application

• Human Research Ethics Committee Application
  – What benefits can people get out of participating?
    • Opportunity to share their experience
    • Can hear from other people who are living in their own place
    • Listened to, treated with dignity and respect.
    • Choice about where we meet for the interview
    • $50
Ethics Application

- Recruitment - how we invite people to be interviewed.
  - PWD and UnitingCare Disability Services
  - Community Organisations (e.g. ALI services)
  - Community Mental health teams and ADHC teams
  - NSW Council for Intellectual Disability
Being a co-researcher

- Set the research agenda
- What we should do
- Why we should do it
- How we are going to do it
- Ethics application
- Collecting data
- Report writing
- Dissemination of findings (conference presentations, journal articles, future meetings with ADHC/Minister)
Barriers to inclusive research

• Institutional processes
  – Funding grants
  – Human Research Ethics Committee’s application process

• Values and attitudes
  – Being a ‘successful’ academic
  – What skills and abilities are valued?
One thing we noticed with the owners and it was consensus is that they try and give the residents; it's almost a psychological stand over technique; or they create the illusion that our opinions don't really matter or if we do have an opinion it's swept under the carpet. “You're mentally ill. No one is going to take you seriously”.

Co-researcher
Barriers to inclusive research

• Multiple experiences of being devalued and ‘not taken seriously’.

• Knowledge of, and access to, the ‘research world’.
The team approach

• Shared passion for change
• Commitment to social justice
• Commitment to hearing and valuing people’s experiences
• Valuing of individual’s knowledge, skills and experience.
• Trust and respect- space to challenge each other
Thank you!!

g.d Drake@uws.edu.au