Bay Tree Voices
Inclusive practice in the involvement of people with dementia in practitioner education

Dr Andrea Capstick,
Bradford Dementia Group, UK
The short history of involvement of people with dementia in practitioner education

- Patient and Public Involvement Initiative (2005) does not make specific recommendations for the involvement of people with cognitive difficulties

- Survey of HE finds that dementia-related involvement is almost entirely family carers

(Thompson et al, 2007)
Current situation

• ‘Experts by experience’
• Dementia Engagement and Empowerment Project (DEEP)
• ‘Professional patients’, ie predominantly white, male and/or former professionals
• Involvement is not very inclusive!
Callaghan and Light’s criteria for authentic service user involvement

- co-operative – working in partnership as equals
- comprehensive – across all components of education
- effective – ensuring meaningful change
- ongoing – across the lifespan of the programme
- inclusive – representative of all stakeholders
- reflexive – critically aware of its own assumptions
Bradford Dementia Group’s 3-level strategy 2007-2012

• Level 1 - Involvement of PWD in direct teaching

• Trevor Jarvis, expert by experience, teaches on the MSc Dementia Studies Training pathway
Level 2: Outreach work in the community

- Participatory photography and video in a day centre
- People with early onset dementia created learning resources for students (Capstick 2011)
Level 3: Bay Tree Voices: aims of the project:

• To involve people with more severe dementia, those in long-term care, or with reduced verbal communication, in educating practitioner-students in Dementia Studies
Format

• 10 short 2-3 minute film clips incorporated into undergraduate module ‘Approaches to dementia’
• Delivered on-line via Blackboard VLE site and Vimeo
• Self-study followed by discussion groups
Process 1: Getting to know you – first film clip plays here

- People with dementia in a local care facility
- 10 visits May to July 2011
- Alternate visits filmed
- Naturalistic encounters – not staged or scripted
Process 2: Finding the voices – second film clip plays here

- Approaches used included walking interviews, photo-elicitation, sensory approaches, digital storytelling
Confidentiality and consent – third film clip plays here

- Relatives consulted by Bay Tree
- Ongoing process consent
- Individual decisions about inclusion of real names and images
- No filming of people in negative states/apparent ill-being/‘improvable practice’
- Actor reconstruction of scenes where consent not possible
Benefits to participants (fourth film clip plays here)

• People with dementia who were less engaged got involved
• Students took a personal interest in the film’s ‘characters’
• Observation skills improved
Initial evaluation and post-pilot follow up

- More students engaged in on-line discussion compared with previous delivery
- More in-depth engagement with exercises and on-line discussion when film clips were used
- Students communicated directly with participants in the film (eg ‘Can you tell Tom…’)
- Viewing of film by Bay Tree participants and staff November 2011
- Module evaluation questionnaires
Ethical and methodological issues

• Informed consent: do participants really understand what the film is being used for?
• Continuity: difficulties in keeping contact with the same participants due to frequent moves within the care system and funding issues.