Doing what it takes: involving people with dementia in decision-making

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Aims

• Set the issue in a disability rights context: “reasonable accommodation”
• Look at 2 attempts the Alzheimer Society of Ireland made recently to involve PWD
• What might “reasonable accommodation” might look like for PWD?
Why?

• Good person centred practice
• A human right, supported by law
  – UN Convention on the Rights of People with Disabilities
  – New Irish Capacity legislation
  – European Convention on Human Rights
  – EU and national anti-discrimination laws
What is reasonable accommodation?

• Making adaptations to enable a person with a disability to access employment or use a service

• Based on individual's needs

• Limits: "disproportionate burden"

• Requires identifying barriers and taking steps to remove them.
What excludes people with dementia from participation in decisions?
What excludes people with dementia from decision making?

1. Perception of disability
2. Lack of opportunity to participate
3. Lack of involvement
What excludes people with dementia from decision making?

• Construction of what decision making involves: definition of capacity

• Emphasis on rationality

Really? Is that how we do it?!
Lack of involvement

Inaccessible process

Cognitive Impairment

Lack of right supports

Lack of involvement
Case study 1

• Consultation on National Dementia Strategy (August 2012)
• How could we incorporate the voices of as many people with dementia as possible in the most meaningful way possible?
Consultation on National Dementia Strategy: Focus Group for PWD

- Needed leadership commitment
- Wide outreach
- Clarity of purpose
- Based on trusting relationships
- Lots of information given in advance, lots of phone calls
- Venue choice
Consultation on National Dementia Strategy cont.

- Staff/participant ratio
- Design of process “Cara pairs”
- 3 themes
- Carers and PWD separately
- Thank you event and further follow-up
Key learning

- Carers and people with dementia must both be included in the process but they have different things to say and need separate spaces to say them.
Tip of the iceberg..

Focus group

Building trust with carers and referrers

Design and logistics

Building trust with PWD
SUMMARY SUBMISSION ON THE NATIONAL DEMENTIA STRATEGY AUGUST 2012

RECLAIMING DEMENTIA
TRANSFORMING THE LIVES OF PEOPLE WITH DEMENTIA

The Alzheimer Society of Ireland welcomes the opportunity to make a submission to the Department of Health on the National Dementia Strategy. The submission is based on a wide range of perspectives of the lived experience of dementia gathered over three decades of organisational development and through an extensive internal consultation process.

“I thought to myself – What can I do now? What do I do now? What I do now is walk around with a smile on my face because I'm still alive and I'm still happy, enjoying my life.”
(Person with Dementia)

“Having a diagnosis under 65 means you don't fit into any box in the health service, it's not considered a disability and under 65s are not covered by older persons services.”
(Family Carer)

“It is hard at times because of the things you can no longer do. You definitely feel different.”
(Person with Dementia)

“People should be encouraged to maintain their independence for as long as possible; continue with their hobbies, and clubs to have a greater awareness of the condition; integrate people with dementia into society rather than keeping them on the periphery.”
(Family Carer)

“I stay positive because I made a decision to keep a positive attitude”
(Person with Dementia)
Case Study 2: “Decisions Month” at Failte Day Centre

• Aim: to try to find out from people with moderate-advanced dementia what helps them in relation to making decisions (in context of new capacity legislation)

• To observe and document what worked well in helping people express their views
Talking about decisions

• Staff briefed:
• Take every opportunity to talk to people about what they find difficult or helpful when they have to make decisions
• Note the circumstances in which conversations happen (book in staff room with easy to use record sheets)
Learning:

- Difficult for staff to commit time: need a lot of support.
- Time- needs to be ongoing priority
- Major issue: majority of people not aware of dementia
- Where they persisted, some significant breakthroughs:
“Margaret”

- Early June in group discussion: no awareness of dementia, not engaging with questions.
- Early July, while one staff member bringing her to toilet: spoke about having Alzheimer’s, being so upset when she was told. Hates that her husband picks out her clothes.
Reasonable Accommodation for People with Dementia

• Might not need any!
• Clearly presented information
• Format - written or oral or both?
• Opportunity to go over information in own time
• Prompts
• Breaks/pauses
• Non-distracting environment
• Based on relationships
mauruuru, Kiitos, mahalo, Köszí, Merci, спасибо, Grazie, Thank you, Dank U, obrigado, Takk, Děkuju, Dziękuję, Gracias, danke