Having a Say in Care/Care Full Deliberation: older people participating in decision making

Marian Barnes Professor of Social Policy University of Brighton, England Marian.Barnes@brighton.ac.uk



Sites and models of older people's participation in the UK

- Locality based older people's forums.
- Officially sponsored consultative committees.
- Pensioners convention: national and local groups.
- Service focused initiatives.
- Participatory research.



Deliberation: a good way to have a say?

Deliberative democracy requires spaces:

"...where rational debate amongst equals can happen; where citizens, politicians and 'experts' can meet without one group dominating another, where all have equal opportunity to pursue their arguments and challenge others, and where the intentions of all are focused on achieving the best possible outcomes, rather than pursuing self interest."

Critics point to:

- The impossibility of a level playing field.
- Emphasis on rational debate may exclude those whose communication styles are different.
- The importance of 'greeting, 'rhetoric' and 'narrative'.
- The place of emotion as well as reason in debates about policies and services.



Emotional morality



- Issues are emotionally charged: pain, fear, loss, anger.
- Don't rule emotional content 'out of order'.
- Recognising and respecting the emotional content of experiences.

Designing spaces for older people to have a say about care: Fife User Panels

- 7 panels throughout the region.
- Facilitated by development officer, part time project worker, support from secretary.
- Members recruited through service providers, churches other local contacts.
- 35 out of 62 aged over 80.
- Range of health problems and services used
- Practical issues: venues, transport, reminders, refreshments, notes.



Ways of working

- Starting with open discussions
- Identifying important issues
- Focussing in and coming up with ideas
- Inviting service providers to come and meet them
- Involvement in working group
- Responding to issues brought to them



Learning from Fife User Panels project:

- Greeting through valuing, recognition, expressed in practical arrangements and the nature of interactions.
- Story telling as making sense of experience.
- Building a collective story which plants the seeds of change.
- Leveling the playing field building strength-'courage' amongst older people before meeting officials.
- Importance of positive emotional experience of participating in sustaining engagement.

An ethic of care: principles

- Attentiveness
- Responsibility
- Competence
- Responsiveness
- Trust





Deliberating with care (1):

Dialogue about experiences deriving from the process of ageing can encourage attentiveness to such experiences and give recognition to them.

Direct testimony from older people makes it hard to continue to ignore their individual and collective agency.

Attending to voices expressed in unfamiliar ways and which demand a response because of what is said, can encourage responsibility to act to ameliorate the situations being described.



Deliberating with care(2):

- Such attentiveness focuses attention on the consequences of decision making. I.e it highlights when there is a lack of competence in the way in which services are provided, as well as the response of older people to the nature of the care provided.
- Officials' experiences of engaging in dialogue with people who may be angry or upset by the way in which they have been treated, or whose styles of communication are different, enable them to confront their own competence in relating to others who are different from them. Ie. It can help official learning.



Researching with care with older people

- Attending to differences, support needs, practical details.
- Balancing responsibility to 'get the job done' with acting on attentiveness to needs.
- Ensuring competent organisation to meet the aim of involvement.
- Inviting feedback from older researchers, being aware of impact of involvement.
- Recognising different powers, creating safe environment.



Conclusion

- Having a say about care requires care full deliberation.
- Rational argument is not enough –emotional content and expression can enable learning.
- Ethical approaches can be applied in different contexts in which older people can have a say.

