

# Why consult and involve people with dementia?

- Rethinking nature of dementia
- Policy & legislation
- Social inclusion
- Pressure from people with dementia

*“Oh, I like to use my own mind – not what others think, what I think. I have a brain of my own.”*

participant with dementia  
from Allan (2001)

*Hearing the Voice of People with Dementia:  
Opportunities and Obstacles*  
by Malcolm Goldsmith (1996)

- Literature review
- Large scale consultation exercise with workers in field
- Interviews with persons with dementia and family carers

# Goldsmith's conclusions




- **Communication is possible**
- **People with dementia are disempowered**
- **Need for attention to issues of timing and pacing**
- **Need to recognise impact of environment**
- **Importance of nonverbal communication**
- **'Challenging behaviour' – a form of communication**

***It is possible to be involved in meaningful communication with the majority of people with dementia but we must be able to enter into their world, understand their sense of pace and time, recognise the problems of distraction and realise that there are many ways in which people express themselves and it is our responsibility to learn how to recognise these.***

**Goldsmith (1996: 163)**

***Communication and Consultation***  
***Exploring ways for staff to involve people***  
***with dementia in developing services***  
**by Kate Allan (2001)**

**Explored how to carry out consultation work in ordinary service settings by:**

-  supporting staff in trying out various approaches**
-  learning about experiences of staff in undertaking this kind of work**
-  looking at barriers to work**

# Examples of initiatives

- **Use of visual stimuli – pictures, objects, word cards**
- **Use of ‘3<sup>rd</sup> person’ approaches**
- **Exploring role of activities**
- **Attention to nonverbal communication**

# **Allan's conclusions**

- Lots of different ways to encourage people with dementia to express their views – approaches need to be individualised**
- Consultation work needs to be integrated with everyday approaches to communication with service users**
- Timing is crucial**
- Staff need support to try things out and reflect on their experiences**

***‘Including the perspectives of people with dementia in designing and delivering care: “I need to be me!”’ by Elizabeth Barnett (2000)***

**In-depth exploration of experiences of residents in a care home which:**




- **used discourse analysis to find meaning in the words of people with dementia including ‘memory stories’**
- **Dementia Care Mapping**
- **sought views of staff & relatives**

**Barnett discusses both positive potential and costs of such work**

## **Other examples of consultation work**

**Sue Heiser (2002)**

**People with dementia expressing their views of homecare**

-  **group situation**
-  **relevant objects like bucket, mop, rubber gloves, polish etc used**
-  **participants very forthcoming**

**McAndrew & Taylor (2006)**






**Involvement of service users in strategic planning using person-centred planning approach**

-  **one-to-one interviews carried out by staff with service users and carers**
-  **workshop event, using graphic recording**

***‘Listen to us: Involving people with dementia in planning and developing services’***

**Caroline Cantley, Janet Woodhouse & Monica Smith (2005)**

**From Dementia North, this report looks at:**

-  context & challenges**
-  what it means to involve people with dementia – wide range of different activities**
-  ethical issues including consent**
-  management issues**
-  practice matters**

# Organisational change

## The Alzheimer's Society – 'Living with Dementia'

The 'Living with Dementia' project began in 2000 run by Rachel Litherland. Its aims were to:

- “help people with dementia to learn to live with the disease and to achieve the highest level of self determination and active participation in their care as possible”
- “develop the organisational attitudes and structures within the Alzheimer's Society so that it is responsive to the needs of people with dementia and enables their involvement”
- “develop user centred services”

# **Living with Dementia Project**

**Alzheimer's Forum:  
A website produced by  
and for people with  
dementia**

**Living with Dementia  
newsletter published  
regularly**

***DEMENTIA IS NOT JUST A STATE  
OF MIND IT'S A WHOLE NEW  
WAY OF LIFE"***

Barry, 2006

# Organisations created and run by people with dementia

Scottish Dementia Working Group,  
Alzheimer Scotland



Delaware Dementia Advocacy and Support Network  
International

PROF (People Relying on People) Group,  
Doncaster



# Including people with dementia in research

**People with dementia as:**

- **participants**
- **funding panel members**
- **project advisors**
- **co-authors**
- **co-presenters**

**? Not yet as researchers**

**More recently – progress on ways of dealing with issues of consent – see workshop**

**So, lots of positive findings and useful learning.**

**But...**

**Large scale study of communication in various kinds of services for people with dementia**

**Ward, R., Vass, A.A., Aggarwal, N., Garfield, C. & Cybyk, B.**

**Findings published in 2005-6**

## Ward et al (cont)

- On average, each person with dementia spent no more than 2% of the day communicating with a member of staff
- 78% of interactions were concerned with specific care tasks and took place mainly in silence. Where there was verbal input, this was mostly routinised “carespeak”
- Encounters characterised by warmth were infrequent
- Much of the behaviour of care staff seemed to avoid rather than encourage communication

**Attention given to experiences of staff and their “*hidden workload*” in dealing with their own emotions and those of people with dementia.**

**Staff described as an “*overlooked workforce*”.**

**Evidence for meaningful communication if it is looked for properly, including in people with little language.**

***Evidence from our study suggests that the development of skills and of the potential for expertise in communication remains submerged and unsupported in dementia care settings. There is little opportunity for workers to share their insights or even to articulate what it is they do. The way care homes are organised fails to promote communication as a crucial dimension of care practice.***

Ward et al(2006b: 24)

***What do I wish for now? What message would I like to convey about people with dementia? We can learn from care workers and from those with dementia themselves. I would say - SLOW DOWN!***

***If we could slow down, focus on what is important - and really LISTEN to one another - perhaps we would value one another more, and find happiness without having to be smart or clever or super-intelligent.***

***It has taken some time for me to reach this stage in my thinking. I am humbled by the goodwill and love which is all around us. My hope would be for us all to find it, and to give it as well as receive it.***

**Ian McQueen (2001)  
man with early onset dementia**