Encouraging user involvement of older people in technology, including users with cognitive impairments
End user groups and how to involve them

AAL Forum 09 Wien

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Major challenges

- Doubling of number persons with dementia in 20 years
  - Quickest growing group of users in care services

- Imminent care crisis
  - Not enough persons to help
  - Too expensive to help
  - Too much political attention on adding more nurses
  - Not enough attention on how to adapt environments and use technology to make the world dementia friendly
Combined efforts needed

Medical care and nursing

Adapted housing

Supporting

Memory
Independence
Orientation for time and place
Activity and entertainment
Wellbeing

ICT and other technological solutions
Why are these basic needs important?

Memory
Independence
Orientation for time and place
Activity and entertainment
Wellbeing
Because active participation and inclusion give better quality of life and health for all people
Why in relation to persons with dementia?

- When these needs are not met, it can lead to feelings that have undesired effect on their dementia and on helpers
  - Unhappiness and depression
  - Frequent feeling of failure
  - Frustration
  - Sometimes unacceptable behaviour
  - Sometimes passivity and resignation
If ICT supports people with dementia in relation to all these needs, it can benefit

- Other groups of old people
  - Also with cognitive and physical impairments
- Family carers
  - Reduces burden of care
- Professional carers
  - Supports and supplements their care work
- Stakeholders
  - Can give long term cost benefit

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Methods to involve users aim at achieving AIDA
Attention

- Meet the users with respect for their own reality and situation
  - Problems and needs
  - Past history
Interest

- Make them understand that there is a possibility to meet their needs
  - But don’t promise too much!
  - Listen to and respect their objectives
  - Define user requirements
Desire

- The users must desire to discuss concepts and to try something new
  - This is where users agree to take part in user trials
Accept

- Having tried prototype and found it to be useful
- User friendly
- Acceptable
The AIDA steps

- Each step requires some similar and some different methods for each different user group
- But to achieve relevance and involvement, always ensure
  - Thorough knowledge about each user group and how to communicate with them
  - State of the art knowledge
Involving users with dementia

- There is a common assumption that
  - They cannot express their opinions
  - It is unethical to involve them because they will become confused and frustrated
  - You cannot reason with them
But remember

- They are a varied user group
  Remember ethics when involving all of them
  - Early stage dementia (at home)
    - Want to be heard, express opinions, active but worried, active participation has positive effect
  - Medium stage dementia (at home + at day centre)
    - ”I’m still me”, important to prevent dependency,
  - Late stage dementia (in nursing home)
    - Expression through non-verbal communication, like facial expression, passive behaviour, anger
Example of AIDA

User involvement in a day care centre for people with early dementia

Over several short sessions but several months
Parallell user groups involved

● Primary users, with early dementia

● Secondary users
  – family carers (of primary users or Alzh.org)
  – professional carers (of primary group or others)

● Stakeholders; local authorities, politicians, designers/producers
Involving user group in day care centre for persons with early dementia
Attention

- Observation and building up confidence in the whole user group
- Tell them why you are there
- Participation in activities in centre
- Conversation through participation
- Focus on expressed problems and needs
Interest

- Choose a group of 5 or 6 persons
- Listen to their ideas and dreams
- Everything is possible at this stage !!
- Present some concepts and functions to discuss if they are of interest
Desire

- Show some sketches of ICT that **might** meet their needs
- Or rapid prototypes
- Let them choose which seems best and that they would like to try
Accept

- User trials of well functioning prototypes over several months
- Thorough trial design and followup
- Adaptation and redesign
- Hopefully they find the ICT:
  - Useful
  - User friendly
  - Acceptable
Success criteria

- Old people like to be involved and are a resource in development work
- Early involvement in the design process is important, and pays off
- Have and show respect for all opinions