



# **Growing older: Issues for people who use AAC**

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# Background

- Little is known about older people with lifelong disability who use AAC
- People with lifelong disability are living longer
- We are now seeing a 'healthy survivor cohort'
- We can expect this number to increase and numbers of people with severe levels of disability to increase in the future



# Sad truths

- We live in a society that values youth
- We perpetuate myths about ageing
- We have different expectations for older people with and without lifelong disability
- The community has little understanding of disability and almost none about older people who have a lifelong disability and who use AAC



# Is ageing for people using AAC different

- Yes and no
- People with cerebral palsy think their age earlier
- People with Down syndrome have a high risk of dementia
- People with intellectual disability more at risk for mental health disorders



# May not have AAC

- Impact of diagnosis
  - Refrigerator mother
- Negative early experiences with technology
- Lack of appropriate or adequate service now



# Good old age

- Social connectedness
- Good health
- Financial security
- Remember the healthy survivor cohort
- Women with cerebral palsy 3 times at risk of death from breast cancer
- Adults with lifelong disability are hospitalised 2+ times as often as other older adults



## What do people who use AAC say about health as they age?

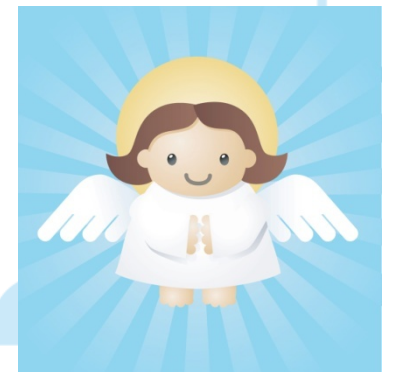
- More pain- back, joints and neck
- Lack of information
- Changes in eating and drinking
- 70+% take medication
- Experience difficult in getting care and services they need
- Not included in health choices and decisions





# Going to hospital

- Lack of information
- Nurses have no time
- Have to rely on families
- No dignity
- Early discharge
- Staff do not understand AAC or lifelong disability
- High risk of adverse events
- But there is always one good nurse





# Going to the Doctor

- No time for consultation
- Doctor may speak to support person only
- Lack of knowledge
- Lack of holistic health care
- Seen as a 'disability' not a person



# What may REALLY help

- Education?
- Policy Changes
- Self Advocacy
- Early Practice
- Early involvement
- Literacy



# The rest of the story

- Social connectedness
  - Loneliness
    - Partners
    - Children
    - Parents
    - Siblings
    - Friends



# Loneliness

- People who use AAC may be more lonely than people without a disability
- Level of severity may impact positively on feeling of loneliness
  - Amount of in house support
- Inequality of relationships
- Community attitudes
- Changes in service delivery
- Lack of information
- Lack of opportunities
  - e.g., volunteering



# Grief and loss

- Additional dimensions
  - Life is growing smaller
  - Diminishing control
  - Loss of hope
  - Opportunities never realised
  - Role of the GATEKEEPERS
  - Younger people in nursing homes and ageing in place?



# Families

- May not promote the use of AAC
  - Poor early experiences
  - Difficulty in accessing services
  - Cannot see the point
  - Technophobia
- This may be particularly true for people with ASD



# Siblings

- Siblings relationships are the longest we experience
- Tend to become closer in adulthood and as siblings grow older
- How the relationship develops as children impacts' on how it will be later after parental death





# The way forward

- We need more research
- We need to focus carefully on young AAC users
  - Communicative competence
  - Educational Integration
  - Community participation
  - Self Advocacy
  - Health
  - Employment



## Cont.

- Better attitudes- for most ageing is preferable to dying
- Ageing with AAC must be on the agenda
- New research methods
- European studies



# Life course paradigm

- Elder's life course paradigm
  - historical timing -Major historical events have a relatively uniform affect on all individuals experiencing them
  - social timing – at what stage did these events occur
  - linked lives -a person's network of shared inter-generational relationships of family and friends over the lifespan
  - human agency -individuals exercise choice and make compromises within the limitations of their social, familial and historical context



# Conclusion

- Many adults who use AAC do so now after a long struggle to communicate
- Are we able to learn from them to avoid making the same mistakes
- Can younger people who use AAC look forward to a happy and productive life as they age?