

Exploring Ethical Issues in Ageing: An Australasian Perspective

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Workshop Overview

- Background
- Key Issues (Family, Retirement, Health & End-of-life)
- Common Themes
- World Café
- Summary & Close

Background

- August 2016, ASID NSW hosted a forum on Ethical Issues in Ageing.
- Four topics:
 - 1) Family
 - 2) Health
 - 3) Retirement
 - 4) End-of-life
- Invited speakers from US, Australia and New Zealand
- Workshop participants discussed the ethical issues for each topic.

Family (Invited speaker Dr Angela Dew)

Key Issues:

- Who is responsible for services and supports?
- What happens when family members don't agree?
- Why don't families plan for the future?
- What happens when parents age and roles change?
- How does a person with disability help his/her ageing parents?
- Is Family-centred planning possible in the NDIS?

Retirement (Invited speaker Prof Roger Stancliffe)

Key Issues:

- Who decides when and how a person with a disability retires?
- Who should provide information, education and support about retirement?
- What happens when retirement activities are based on what is available not what the person wants or is interested in?
- How do we know if a person is making an informed choice about their retirement?

Health (Invited speaker Dr Stuart Wark)

Key Issues:

- Is it ok to put a person with disability into hospital or a nursing home if they need special nursing care?
- As a person gets older, is it more important to have a LONG life or to have a GOOD life?
- Who should be involved in making health decisions about a person with intellectual disability?
- How can these decisions include what the person wants?
- What supports would help people and agencies maintain the health of a person with intellectual disability?

End-of-Life (Invited speakers Dr Michele Weise & Ms Sharon Brandford)

Key Issues:

- How, when and what do we tell a person with disability who is dying?
- How can make sure a person has the time and support to know about their dying?
- How do we know if a person is making an informed choice about their end of life plans?
- How do we support a person to make choices when there may not be many good service options at the end of life?
- How do we balance the rights of the dying person with the rights of others?

Common Themes – Ethical Questions

Three common themes emerged from the discussions of the 4 topics:

- 1) Self-determination and supported decision making
- 2) Accessible Information
- 3) Changing nature of services

World Cafe



World Café – How it works

- There are 3 questions – one for each of the common themes
- Participants work in small groups led by a ‘host’
- Each group discusses the same question and records (written or drawing) responses, suggestions and ideas
- After 15 minutes each group will provide feedback which will be graphed by our graphic facilitator
- We will then introduce a new question
- You will get to have your say on each of the 3 questions
- At the end, our graphic facilitator will reveal the group feedback to the 3 questions.

Self Determination & Supported Decision Making

Case Study & Question 1

Case Study – Tony

Tony, aged 65, has lived with his mother, in the family home in a small country town all his life. He loves to play lawn bowls and is a long-standing member of the local club. Tony and his much-loved dog Blue, walk around town everyday chatting to the locals. Tony, who has an intellectual disability, requires some assistance with daily living tasks, particularly in relation to monitoring his diabetes and handling money.

A few weeks ago, Tony's mum moved into a nursing home due to advancing dementia. To provide temporary support to Tony his sister, Mary, travelled the four hours from Sydney to stay with him.

Mary now needs to return to her own home and is keen for Tony to move closer to where she lives. She has approached AAA Disability Service which has a position available in a group home in Sydney. Tony says he doesn't want to move, he wants to stay in his home and community with Blue.

Question 1: How should major life choices and decisions of people with intellectual disability be made - particularly as they age and the family support system changes?

Accessible Information Case Study & Question 2

Case Study – Jo

Jo turned 60 this year, she has an older sister who she sees regularly, their parents are both dead. Jo lives with two other people with disability in a flat where they get drop in support.

Jo has an intellectual disability and cerebral palsy and her communication difficulties and physical limitations have made it hard for her to access regular public health screening programs such as mammograms.

During a routine GP visit, Jo's doctor finds a lump on her left breast. Further investigations reveal breast cancer at an advanced stage. The prognosis is not good and Jo may not have long to live.

Question 2: How much information should Jo receive about her diagnosis, its prognosis and treatment options?

Changing Nature of Services Case Study & Question 3

Case Study – Sandra

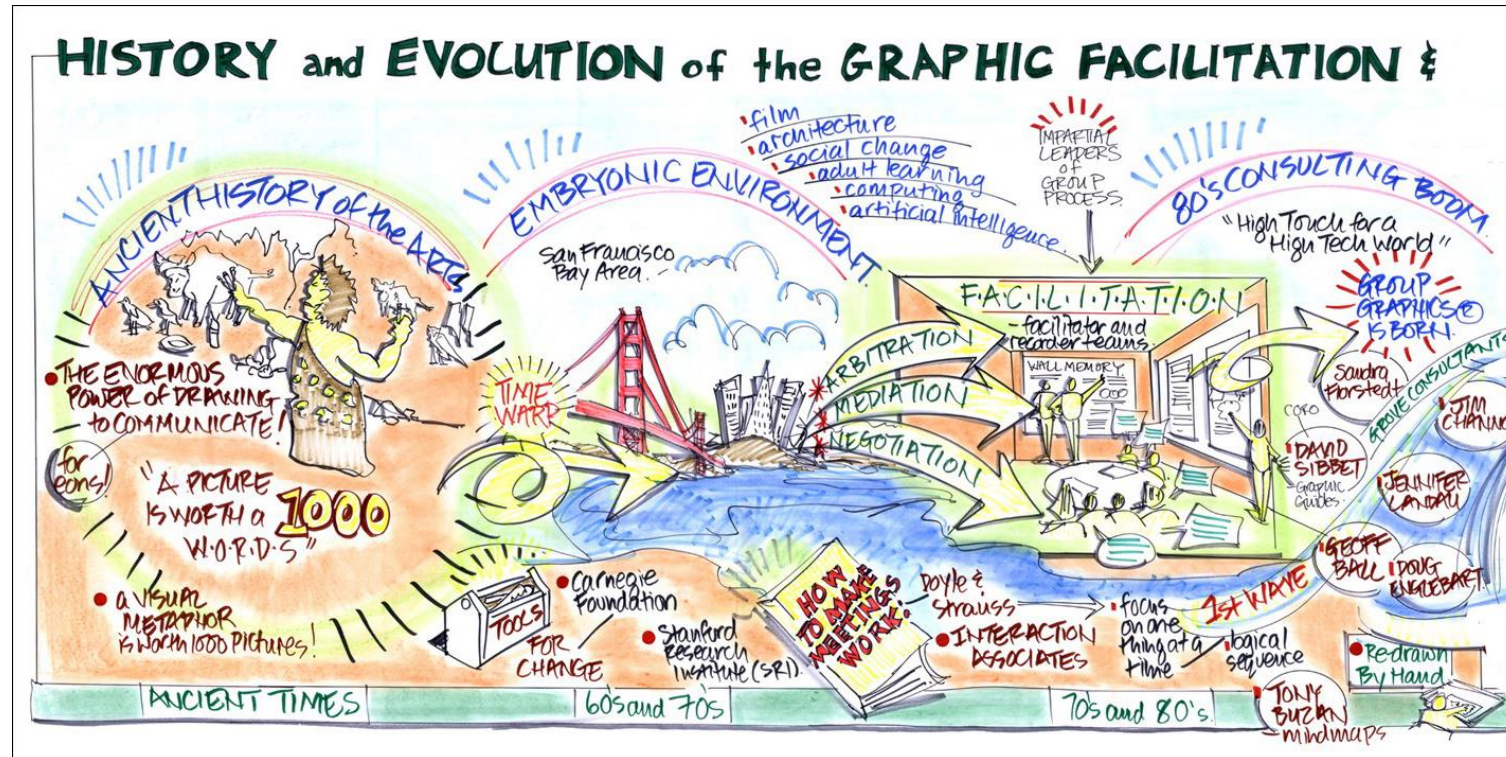
Sandra celebrated her 64th birthday earlier this year. Recently when Sandra was looking through the photos from the party, she told a staff member that it wasn't her party as she couldn't remember it. Sandra has Down syndrome and, for the past 25 years, has lived in a group home with the same three other ladies.

Sandra's forgetfulness seems to have been getting worse. In January this year, her GP referred her for a baseline cognitive assessment. There are concerns that she is developing dementia.

Sandra loves where she lives. Group home staff have expressed concerns about their capacity to continue to support her if she does have dementia. The NDIS doesn't come to Sandra's area until after her 65th birthday. In Australia, age 65 is when people usually transfer from disability funding (NDIS) to aged care funding, unless they are already in the NDIS system.

Question 3: Should Sandra be able to continue living in her home?

Graphic Feedback



Next Steps

