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# ETHICAL ASPECTS OF THE USE OF ASSISTIVE TECHNOLOGY

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# Outline

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- What is Assistive Technology?
- What is Ethics?
- Ethics and Assistive Technology.
- Dilemmas.
- Conclusions.

# Assistive Technology (AT)

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- Any item, piece of equipment or product system, whether acquired commercially, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with disabilities.

*(The US Assistive Technology Act of 1998, Section 3)*

- AT has the potential to help people with disabilities to live in the least restrictive environments and attain their personal and vocational aspirations.

*(Peterson DB, Murray GC. Ethics and assistive technology service provision. Disability and Rehabilitation: Assistive Technology 2006;1:59-67)*

# AT and Telecare

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- AT&T = the delivery of health and social care to individuals within the home or wider community outside formal institutional settings, with the support of devices enabled by information and communication technologies

*(Tang P, Curry R, Gann D. Telecare: new ideas for care and support @ home. Bristol: The Policy Press, 2000.)*

# Facts about AT

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- Assumption: Disabled and elder people wish to lead independent lives in a familiar environment.
- AT are not new and their use has never been uncontroversial.
- Technological advances will considerably expand the areas in which AT are used.
- Literature is critical of the technology-driven nature of AT development.
- Care should be taken that AT supports communication.

# AT – universal design

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- Assistive technology which is not guided by the universal design concept may benefit people with disabilities but result in separate and stigmatising solutions, for example, a ramp that leads to a separate entry to a building from the main stairway. Universal design strives to be a broad-spectrum solution that helps everyone, not just people with disabilities and it recognises the importance of how things look.

*(Perry J, Beyer S, Holm S. Assistive technology, telecare and people with intellectual disabilities: ethical considerations. J Med Ethics 2009;35:81-86.)*

# Advantages and disadvantages of an AT device

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- Advantages

- It can always be there
- It can be powerful

- Disadvantages

- It may not always work as intended in every possible situation
- It doesn't "grow" with the client
- It may break
- It may encourage the consumers to rely on (imperfect) technology instead of developing their own skills

# Use and abandonment of AT

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- Studies show that up to 75% of AT devices are abandoned within 3 years.
- This may be a positive thing.
  - Consumer no longer needs AT.
  - Consumer needs a more complex device.
- However, it is often a negative thing.

# Why abandon AT?

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- Not well matched to individual.
- Little or no training provided.
- Families not accepting of technology.
  - Family members from different cultures may have diverse perceptions of the need for technology.
  - Consumer or his/her family doesn't want to "stand out" by using the technology.
- School or workplace not accepting of technology.

# What do we mean by ethics?

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- Ethics is the systematic reasoning of and critical reflection on morality.

*(Leubben 2003)*

- Ethics is sometimes thought to be only a matter of individual preference or cultural convention. Although ethical judgments may indeed express personal preferences, and may be connected in complicated ways with cultural conventions, ethics itself is a form of rational inquiry that concerns how we should live and what we should do.

*(Australian Health Ethics Committee 2004)*

# Ethical Issues

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- Responsibility.
- Autonomy, dependence and care.
- Socio-ethical issues.
- Data protection and invasion of privacy.
- Implementation in the living environment of disabled and elder people.

# The 4 ethical principles

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- The principle of non-maleficence.
- The principle of beneficence.
- The principle of justice.
- Respect for person's autonomy.

*(Pellegrino, Thomas & David, 1989)*

# The principles defined

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- Non-maleficence simply means “do no harm”.
- Beneficence means striving consciously to be “of benefit” to the person. To aim to do good.
- Autonomy refers to respecting the person’s rights to things like self determination, privacy, freedom, and choice. Includes informed consent.
- Justice means treating everyone fairly.

# Ethics in professional practice

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4 components:

1. Moral sensitivity (recognition of ethical issues).
2. Moral judgement (making decisions about right and wrong).
3. Moral motivation (prioritisation of ethical values).
4. Moral courage (taking of moral actions even in adversity).

*(Swisher, 2005)*

# Ethical reasoning – making moral judgements

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- What should be done?
- What is the right thing to do?



# Ethical questions related to AT

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- What forms of personal care and contact are abandoned with the use of AT?
- What consequences arise when responsibility for the monitoring and quality of intervention is delegated to machines and informal carers?
- Which services must be established or made accessible to ensure that persons receive integrated care and that technologies can be embedded in the domestic environment?
- Which particular problems arise in terms of data protection?
- What is necessary to ensure that all those in need have access to AT and that no one is disadvantaged?
- What requirements does technological development need to meet from an ethical perspective?

# AT Provider vs. User

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- Privacy: personal data protection! (Privacy Laws: personal/medical information of individuals).
- AT: from non-invasive (without operation/intervention into the body) to invasive (operation: integrated circuits, pumps etc.: invasion in the integrity of human being).
- Position: provider is in a superior position towards the user (inferior position).
- Power: provider has power over the user (weakness).
- Reliability: Providing regular and irregular services/repairs (for software and hardware).

# Informed consent – always needed!

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- Most technology to support people with disabilities is user activated.
- Newer technologies work ‘passively’ and no user input is required.
- If informed consent can’t be obtained, using passive technologies can create ethical dilemmas:
  - Would using it without consent be an invasion of privacy, or in the best interests of e.g. someone with dementia?
  - Can it ever be used in an ethical way for people who can’t give informed consent to its use?

# Ethical conflicts that arise may depend on

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- The purpose for which technology is introduced.
- Degree of involvement of the person, especially where his/her capacity or judgement may be limited.
- Degree of involvement of significant others including family, friends, neighbours and professional care staff.
- Effect on person.
- Availability and the funding to provide AT.

*(CSIP, 2005)*

# Ethical guidelines for the use of AT

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- Privacy: an individual shall be able to control access to his/her personal information and to protect his/her own space.
- Autonomy: an individual has the right to decide how and to what purposes he/she is using technology.
- Integrity and dignity: individuals shall be respected and technical solutions shall not violate their dignity as human beings.
- Reliability: Technical solutions shall be sufficiently reliable for the purposes that they are being used for. Technology shall not threat user's physical or mental health.
- E-inclusion: Services should be accessible to all user groups despite of their physical or mental deficiencies.
- Benefit for the society: The society shall make use of the technology so that it increases the quality of life and does not cause harm to anyone.

*(Ikonen V, Kaasinen E, Niemelä M, and Leikas J, "Ethical Guidelines for Mobile-Centric Ambient Intelligence", Tech. Rep., 2008.)*

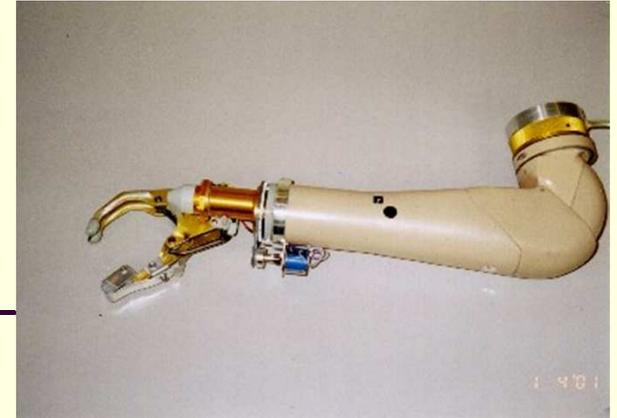
# Dilemmas

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- To build or not to build...
  - Are there alternatives to AT?
  - When are the alternatives appropriate?
  - When is the AT appropriate?

# Prosthetics

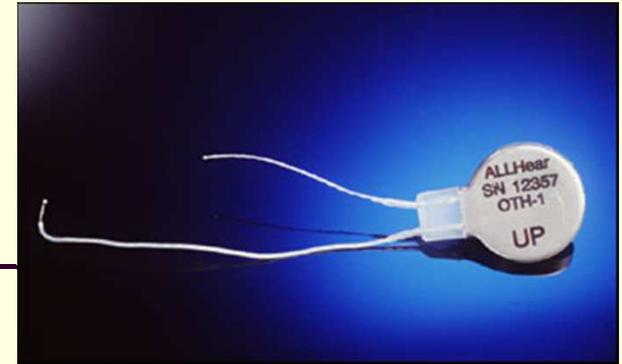
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- Prosthetics can provide functionality for a lost limb.
- However, it is imperfect technology.
- Are there alternatives?
  - Yes, children, in particular, can learn to compensate for a lost limb.
  - They may not realize they are “missing” anything.
- When are the alternatives appropriate?
- When is a prosthetic device appropriate?

# Cochlear implants

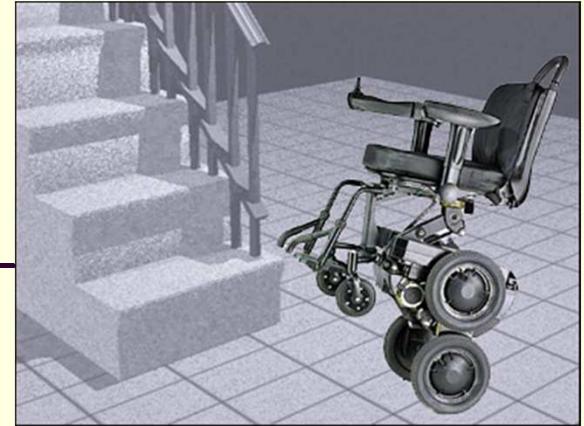
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- The cochlear implant technology is still relatively new.
  - The cochlea (inner ear) is very complex.
  - Cochlear implants do not nearly match the performance of the human cochlea.
- Are there alternatives?
  - Yes, children and adults can learn to communicate using sign language.
- When are the alternatives appropriate?
- When is a cochlear implant appropriate?

# Climbing Wheelchair

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- Wheelchairs, that can climb stairs, have been developed .
  - With this wheelchair, people with disabilities can access more places.
  - But – will this work on any type of stairs? What if it malfunctions?
- Are there alternatives?
  - Modify the environment instead.
- When are the alternatives appropriate?
- When is a climbing wheelchair appropriate?

# Assisted ventilation

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- Invasive ventilation via tracheostoma.
  - Enhances both the person's quality of life and life expectancy.
  - However, it places a great deal of strain on the care giving relatives, especially in situations where an interruption of ventilation would immediately lead to death.
- Are there alternatives?
  - To live or to die.
- Who should decide to ventilate a person or not?
- Who may judge about the quality of life of a ventilated person?

# Conclusions

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- Useful AT which have been proven to be effective, should definitely be made accessible within the public health care system.
- Collection of data should be strictly restricted to data that is necessary for the activity supported by the system.
- Special arrangements must be made in respect of the technology-assisted monitoring of individuals who are incapable of giving consent and those who are vulnerable.

*(Austrian Bioethics Commission, 2009)*

# To be successful...

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- Insure that the device will help the user and his/her family achieve their goals.
- Work as a team with the user, family, therapists, teachers, supervisors, etc.
  - **Communication is crucial!**