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The Challenge of the Ethical Provision of Assistive Technology

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The Challenge of the Ethical Provision of Assistive Technology

Introduction – What is Assistive Technology?

Some Practical Examples

A Holistic Model for Provision

Challenges

Reflections/Conclusion

Introduction

What is Assistive Technology?

Assistive Technology - devices or equipment for people with disabilities.

Goal is to enhance quality of life by;

- assisting, improving or restoring the physical, mental and social function and well being of the user;
- promoting greater independence by enabling people to perform tasks that they were formerly unable to accomplish.

If electronic, then Electronic Assistive Technology [EAT].

Two examples:

Assistive Technology "Communication"

From a "low tech" Communication book

to a "high tech" computer with a voice output.

Assistive Technology "Mobility"

- walker

- to a powered wheelchair

The Challenge of the Ethical Provision of Assistive Technology

Some Practical Examples

- Reflect on experience in England of providing an Assistive Technology Service.

- Consider Examples from three interdependent areas of Assistive Technology

  - Posture Management

  - Powered Mobility

  - Communication Aids

- Consider some ethical issues.

Posture Management
"Custom Made Seating"

- Who is it for?
- Why is this vital?
  - Function & Development
    - Cognitive load
    - Access for daily living
  - Comfort
  - Correction or containment of deformity
  - Key requirement for accessing assistive technology

Independent Powered Mobility "Specialised Controls"

Switch Scanning

Joystick with Computer and Environmental Control

Mini Joystick

Sip & Puff

Specialised Powered Chair Controls "Posture and Access"

Communication "Low Tech"

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Two Message Switch

Switch Control of
Windows Media Player

Single Message Switch

Communication "Mid-Tech"

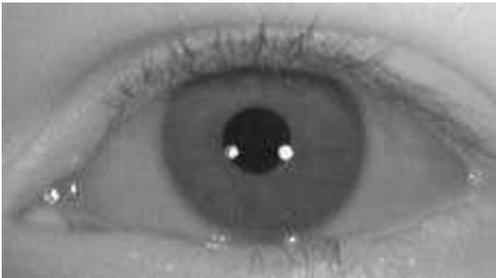iPad
with
Communication Software
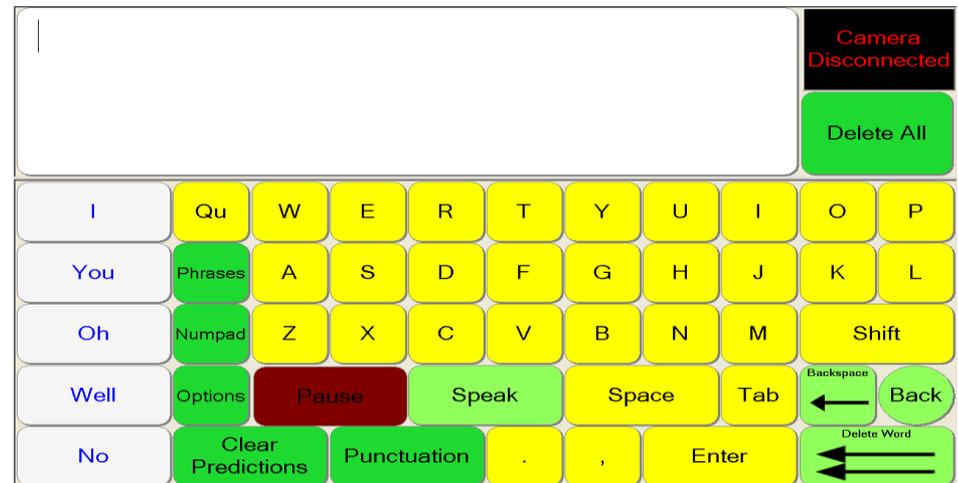
Communication "High Tech"

Communication Access
"Switches"

Is everything OK?
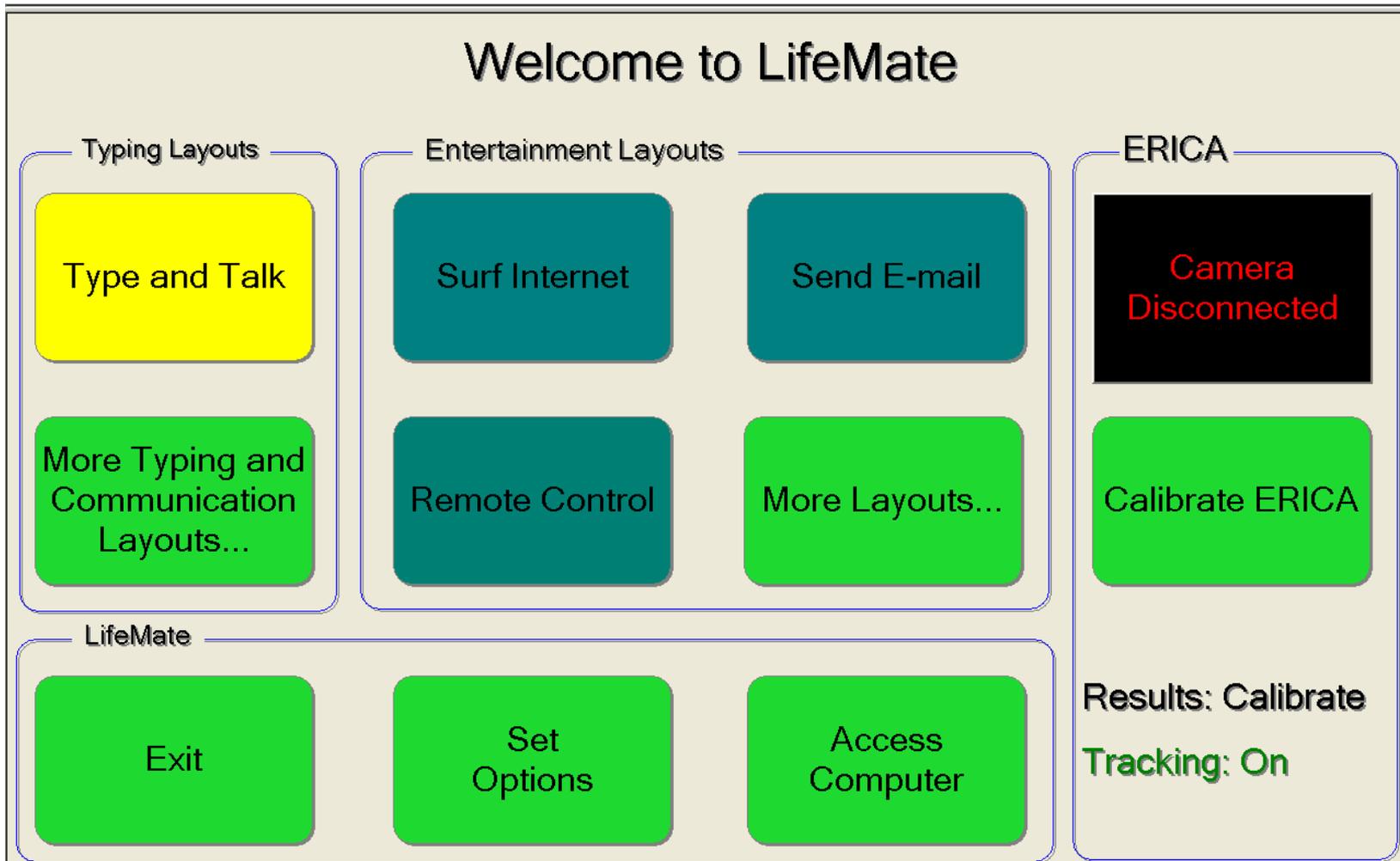
Communication Access
"Eye Gaze System"

Access by Eye Tracking
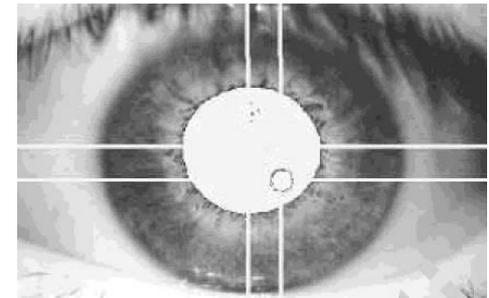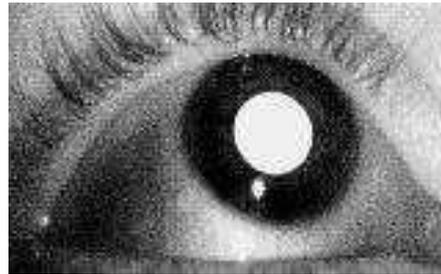
- Track Eye Position
- Control the on-screen cursor
- Select objects by:
    - Blinking
    - Remaining on the object

The Promise of Independence

The Reality?

- Specialised eye gaze hardware
  - Sunlight sensitive
- Specialised software to track eye movement
  - Sensitive to
    - Glasses
    - Eye colour
    - Eye shape
    - Position of the user's head

Also - Integrated with

- Specialised communication software

Also - Integrated with

- Windows operating system
- The likely outcome - reliability?

Communication Rate – 1 selection a second?

Support Required?

Be realistic in expectations?

Posture, Communication, Access and Mounting

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If one element is incorrect – What is the possible outcome?

A Holistic Model for Provision of Assistive Technology?

Assistive Technology is provided to:
- Improve the quality of life of
  - Users
  - Members of their care network
- Who are members of the Care Network?
  - User
  - Family
  - Carers
  - Local health care professionals
  - Expert health care professionals
  - Suppliers and manufacturers?

A Holistic Model for Provision?

So why include care network?

- If appropriate AT is supplied without taking into account the needs of all the members of the care network then may decrease Quality of Life of
    - User
    - Members of their care network.
- If this is not done then is the provision appropriate or ethical?

- What might be involved in a holistic model?

A Holistic Model for Provision?

So far have identified seven interrelated areas
- Needs of User
- Needs of members of the care network
- Development process for new AT
- Process for provision of AT
- Training and Support
- Relationships and empathy within the Care Network
- National and Regional Health Care Models and Resources

user and carer centred

- How might this work out in practice?

- What are some of the challenges

- Think generally about the User and the members of their care network

The Challenge of Provision

Users and Members of their Care Network

Firstly we note that Technology can = frustration

- How well do we manage our Digital camera?

The Challenge of Provision

Users and Members of their Care Network

- How well do we manage our Smartphone?

The Challenge of Provision

Users and Members of their Care Network

- How well do we manage our TV Recorder?

The Challenge of Provision

Users and Members of their Care Network

• How well do we manage our Computer?

The Challenge of Provision

Users and Members of their Care Network

Therefore as a starting point we note:

- Inappropriate Provision of Technology can result in
  - Frustration
  - Feelings of failure
  - Disappointment
  - Abandonment
- What is the Impact of abandonment of AT on
  - User?
  - Members of the care network?

Now consider some of the factors involved in provision of technology

The Challenge of Provision

Development Process for New AT

When developing Assistive Technology :

- Remember the total care pathway – what is it?
- Remember the user, care givers and all those involved
  - Identify what is expected of the technology– who can do this?
  - Who are they?
  - What is their capacity to use technology?
- ??

The Challenge of Provision

Identification and Supply of AT

- A multidisciplinary team and inclusive assessment process is vital
- Assessment process
- Identification of AT
- Will it meet the real needs of User?
  - Improve Quality of Life of
    - User?
    - Members of the Care Network?
- Impact of incorrect provision
  - Decrease Quality of Life of
    - User
    - Members of Care Network
- Other AT in the life of the User – Integration?
  - Telehealth/care
  - Powered Wheelchair
  - Environmental Control
  - Communication Devices

The Challenge of Provision

Support and Training

Appropriate provision without adequate support=

- Decrease of Quality of Life for:
  - User
  - Members of the care network
  - Waste of scarce resource
  - Unempathetic?
  - Unethical?

= inappropriate provision?

So how can we maximise the probability of effective provision?

The Challenge of Provision
Support and Training

At assessment:

- Recognise needs and abilities of
  - User
  - Members of Care Network
- The needs of user and care network may depend on
  - User Diagnosis
    - Rapidly changing conditions e.g. MND
    - Stable Condition e.g CP
    - Recovery from TBI
  - Technological ability of User and Members of Care Network.
- Start at delivery
- Long Term

The Challenge of Provision

Support and Training

- Can changes in needs be identified and adjusted for?

- Can support be flexible to meet the differing needs of the user and care network?

- Can training be planned to meet these needs?

- Resources?

- What is "good" support?

- If "good" support is not provided is provision ethical?

The Challenge of Provision Empathy

Do we understand:

- The importance of the function of the technology to the
  - User
  - Members of the care network
- What is it like when
  - AT fails or does not meet expectations?
  - We struggle with the AT?
- How the user's condition and changes in that condition affects the
  - User
  - Members of the family
  - Members of the wider care team
- The importance of developing empathy between all members of the care team?
  - User to members of team
  - Members of team to user
  - Member of team to members of team

The Challenge of the Ethical Provision of Assistive Technology

Health Care Models and Resource

We know that there are:

- Differences in Health Care Models Across EU Member States

- Regional differences within a Member State for delivery of;

  - Services
  - Funding models
  - Training and Support

How can an EU wide model for the provision of assistive technology be developed?

Conclusion

Ethical Provision is more than assessing for and placing Assistive Technology into the lives of the user and their care network.

Involves facilitating the integration of at least the following seven interrelated areas

- Needs of User
- Needs of members of the care network
- Development process for new AT
- Process for the provision of AT
- Training and Support – long term
- Relationships and empathy within the Care Network
- National and Regional Health Care Models and Resources

user and carer centred

What is the way forward?

Bedankt voor het luisteren
Merci pour votre écoute
Thank you for listening

The Team

The effective provision of Assistive Technology depends on the creation of multidisciplinary team which includes the;

- User
- Family
- Carers
- Therapists
- Engineers
- Suppliers
- ----------

Reflections

- Multidisciplinary Assessment Important

- User, family and Care Network are vital part of the team

- Can the User cope with the technology demands?

- Can the Care/Support Network cope?

- The extra demands for users with rapidly progressing conditions

Reflections:
The Challenge of Effective Provision of Assistive Technology - Increasing or decreasing quality of life?

- Training of "Expert" and Health Care Professionals   as well as users and care network
- High quality suppliers with expert "help desk"
- Keep it simple
- Understand and learn from the reasons for rejection
- Keep users and carers in the centre