MULTIMEDIA PROFILING

Creating communication profiles using videos, photos and the Internet

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Communication Resource Centre

scope

FOR PEOPLE WITH A DISABILITY

Scope's Communication Resource Centre (CRC)

We build the capacity of communities to include and support people with little or no speech

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Communication impairment is one of the most common disorders in our community
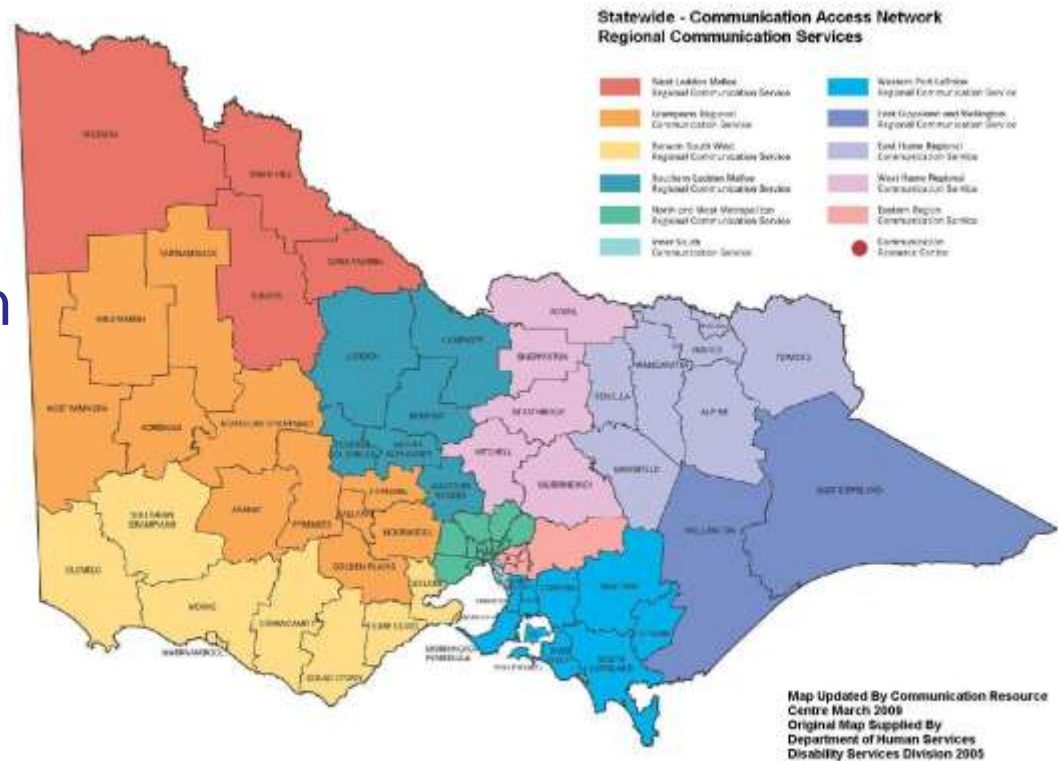
- Difficulties with speaking affects 1.3% of Australians

- In Victoria 1 in 500 people have complex communication needs (Perry, Reilly, Johnson & Bloomberg, 2002)

- Literacy - 47% of adult Australians do not have functional literacy skills (ABS, 2006)

Communication impairment limits people's ability to

- learn

- participate in paid/voluntary work

- be included and engaged in their local community

- speak up and influence decisions which effect them.

Communication Access Network

Communication Resource Centre

with

Regional Communication Services

=

Communication Access Network (CAN)

Statewide - Communication Access Network
Regional Communication Services

Map Updated By Communication Resource
Centre March 2009
Original Map Supplied By
Department of Human Services
Disability Services Division 2005

Vision - social inclusion for people with communication difficulties

- What is multimedia profiling?

- Why use multimedia profiling?

- Our project

- Consent

- How to make a multimedia profile

- Multi Me

- The way forward – mobile technology

Definition of multimedia profiling

Using a combination of photographs, video footage, voice-over, sound, graphics and text to document

- how a person communicates

- how a person likes to be treated

- their strengths

- their health needs

- their relationships

- their support needs

- their likes and dislikes

Reasons to do multimedia profiling

- A communication tool

- A story telling tool

- A planning tool

- Document support (e.g. proactive strategy for behaviour support)

- Social networking (safely)

- Support needs - coordinating

Introduction

- In 2010 Scope's Communication Resource Centre was awarded grants from the Telematics Trust and the Jack Brockhoff Foundation to work on an innovative and important project.

  This Multimedia Profiling Project resourced and coordinated an approach to multimedia profiling/advocacy technique for people with severe to profound intellectual disabilities.

Aims

- Train and mentor key people within Scope to lead the pilot;

- Purchase dedicated hardware and software designed specifically for the purpose of developing multimedia information;

- Purchase digital video cameras;

- Develop 10-15 multimedia communication profiles for people with severe to profound intellectual disabilities (children and adults);

- Implement and evaluate two approaches to multimedia profiling;

- Develop a booklet to accompany each multimedia profile;

- Develop an educational resource for multimedia profiling.

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- Focus on people with profound and multiple learning disabilities

  "It's nice to have a project focused on someone who doesn't have behaviours of concern, someone who usually misses out ."

Project overview

- Advisory group

- Mentoring from UK

- Consent process

- Equipment purchased

- Participants recruited (circles of support)

- 2 approaches

- Resources & training

- Self-advocacy approach

- Sharing information about MMP

- Technology

- Adaptions to the project

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Consent

How can we make sure that the rights of people with an intellectual disability are respected when we collect, use and show their images?

- – Involve the person at every step

- – Show the person what you are doing, don't just talk about it

- – Involve people who know the person well. This may include family, friends, support workers and/or advocate

- – Make sure that the person is comfortable through observations and by checking with people who know the person well

- Stop if the person shows they are unhappy, distressed or uncomfortable

- The person owns the material. We need permission from the person and people who know them well to show any of the material to other people

- If images are shown to the general pubic, they should always portray the person in a positive and respectful way. All images will be approved by people who know the person well

- All media needs to be kept securely

Reference: Mencap. Consent for videos and photos of people with a learning disability. www.mencap.org.uk

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Participants

- 7 male

- 1 female

- 5 metro

- 3 regional

- 2 people passed away

- 5 people withdrew

Some of the resources / proformas developed

- Information session pack

- Consent process (before and after)

- Communication Skills Profile (and its adaptation over time)

- Tip sheets

- Communication Behaviours Profile

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Before you start multimedia profiling

- Plan and plan again!

  - Assessment of communication

  - Assessment of behaviour

  - Observation

  - Discussion with support network

  - Pre-video

  THIS WILL SAVE YOU TIME AND EFFORT!

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Where to find information

- Personal Communication Dictionary

- About Me Book / All About Me

- Personal History

- Health Information

- Individual Support Plan
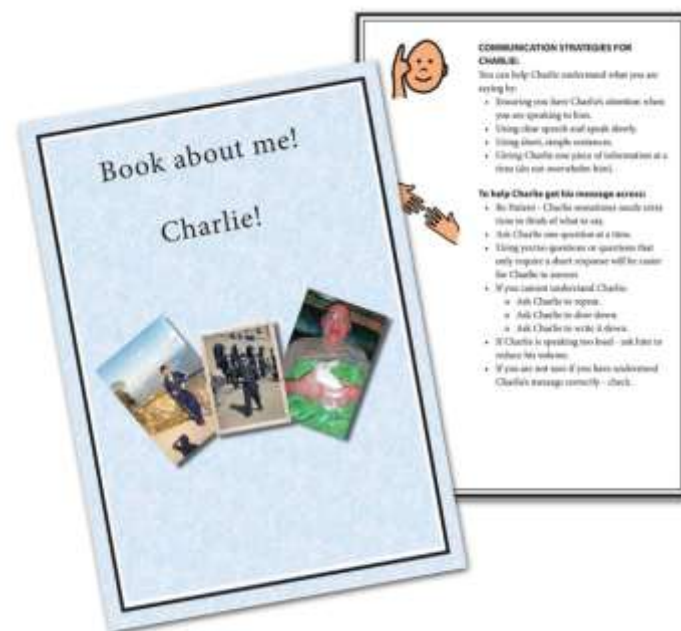
Preparation

- Observe

- Video

- Discuss the video with family and support people

Instructions - Affective Communication Assessment

- Choose optimum conditions

- Video

- Video at rest (provide a baseline)

- Allow time between stimuli

- Present stimuli more than once

- Allow time for a response

- Identify the strongest response and interpret it

- Look for

  – Head turn, lift/lower, rotate, other

  – Facial expression

  – Mouth movement, open/close, tongue movement

  – Eye movement, open/close, gaze, search, look

  – Vocalisation – sounds, laugh, cry

  – Hand movement, finger movement

  – Arm movement, reach

  – Body parts movement

And combinations!

Assigning meaning

- get your attention/interrupt

- choose

- ask for help

- ask for more

- say stop

- reject something or someone

- accept something or someone

- show dislike

- show like

- Joking/sharing a story

- hanging out

- I am happy/content/comfortable/excited

- I am unhappy/worried/upset/angry/bored/ frustrated/scared

- I am unwell/in pain/uncomfortable

- I need help with personal care, e.g. hungry/thirsty/ to move out of my chair

Also - How do you support me?

- get my attention first

- make sure I can see your face

- remove any distractions

- use clear simple language

- use positive and specific language (e.g. tell me what to do as opposed to what not to do)

- use gestures / simple signs

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- make sure your body language and facial expressions don't send conflicting messages (e.g. having a grumpy face when your message is not grumpy)

- point or hold onto the object that you are talking about

- use visual cues such as gesture/sign, objects, or pictures to help me understand what is about to happen
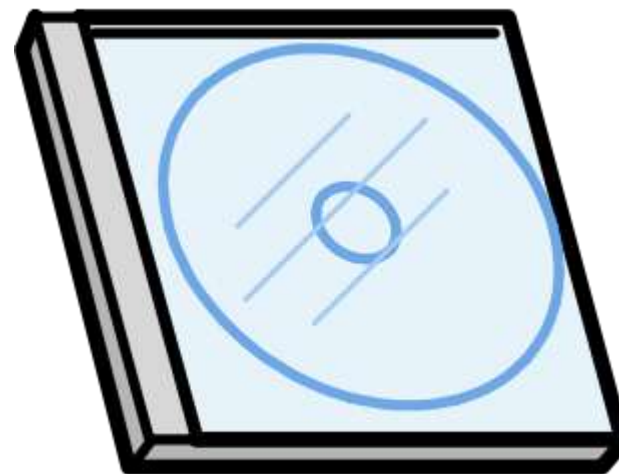
- use description to help me understand times of the day (e.g. lunch now rather than 12.00)

- you are aware I am less likely to understand what you are saying to me when I am sick, stressed, tired or upset

- break down complex instructions into parts

- demonstrate what you are talking about

Outcomes

8 completed profiles

multi me ®

5 Multi Me

3 DVDs

- **Multi Me - demonstration**

  – Interactive

  – collaborative

  – readily updated

  – the profile is separated into individual stories so it is not possible to watch the profile as a whole.

http://www.multime.com/prices/

Findings

- Health of participants / complexity of family life

- Our Vision - capacity building

- An important approach/option for individuals their DSW, family members, therapists

- Equipment (generic ok)

- Circles of support (varied commitment by each participant's COS, family involvement)

- CRC support required (implications of this for funding a service)

- DHS

- Technology – DVD, USB (encrypted), internet access, download software (file converter/movie viewer/player), storage of video

- Cost per participant – approx. $2000 - $5000 (future: ISP, NDIS)

Project evaluation

- **The majority (75%) of respondents stated time was a significant barrier** to working with a new approach such as multimedia profiling, learning the technology and then implementing it with other staff. There was only one family who were able to commit time to (independently) film and edit.

- **Fear of technology was also a barrier**.

   For example,

   "Not enough time and also: what do we do with all the footage and what happens if only a few staff members are interested in using it? Many staff are scared to use it and they would never turn the laptop on and look at it. So the few people who are using the camcorder or the digital camera should try and teach their colleagues. That would be great."

- **In 90% of responses there was an increase in satisfaction** with the way information is currently shared.

- In one case there was a marked decrease in the satisfaction with the **consistency** of sharing information

- **The respondents' descriptions of the participant's communication in post-evaluation was much more detailed and informative**. For example,

  What are the most important things you want a multimedia profile to convey to others about the person?

  Pre-project - Needs, likes and dislikes.

  Post-project - what he is trying to tell us by his non-verbal communication methods - gesturing, vocalizations, using real objects, reading his body language

- **The following response highlights how the approach could be utilized for self-advocacy**. For example, Describe your experience of participating in this Multimedia Profiling Project

  "It has been very interesting and I have discovered that you can help a person to get their story across with very limited communication methods. I really think it is a great project for staff to be involved in to learn about clients needs and wants to communication methods and how to interpret them with little or no language".

- **It appeared that some Circles of Support did not feel they had reached completion**.

  For example, "This is still an ongoing project and all has not been completed yet. We have tried to show likes, dislikes, happy, sad…."

- **The project prompted new thinking and ideas.**

  For example,

  "Through the filming we could see what the person likes to do or not want to do. We got ideas of what activities we should plan for him. Multi Me will help to focus on activities he really enjoys.

  Also through Multi Me we focused more on the person and we found out more about him.

  How good would it be if he could share these activities with his friend. This is something to focus on."

- **People had fun on the journey!**

  For example, "The MMP project has been a wonderful experience. I have learned new ways of supporting people with CCN and built upon my current knowledge. I have loved supporting the person to develop his skills and his independence though the multi-me profile. ….the staff have been a wonderful support in assisting the person and I to get his profile up and running with any issues we have had. Overall it has been a great, fun learning experience."

Recommendations

- **When pictures speak a thousand words, video can say even more.**
  Video can be efficient and effective in conveying information about how someone communicates, particularly when their communication may be subtle, quick and idiosyncratic.

- Individuals with a severe to profound intellectual disability their first opportunity to "singled out" for an opportunity that was appropriate and meaningful

Don't do what we did!

Adapt or Die: 3 Challenges To Going Digital

DO YOU REMEMBER WHERE YOU WERE WHEN YOU REALISED THE WORLD CHANGED?

http://paulbromford.wordpress.com/2013/03/08/adapt-or-die-3-challenges-to-going-digital/

- unprecedented period of change with the focus on self directed support and personal budgets

- substantial budget cuts and increased expectations from service users for more personal and improved care services

- Urgent need to find new and more effective means of supporting people to live more independently in their communities.

- Innovation is simply the process of doing things better or differently.

- The care sector has been slow to embrace innovation.

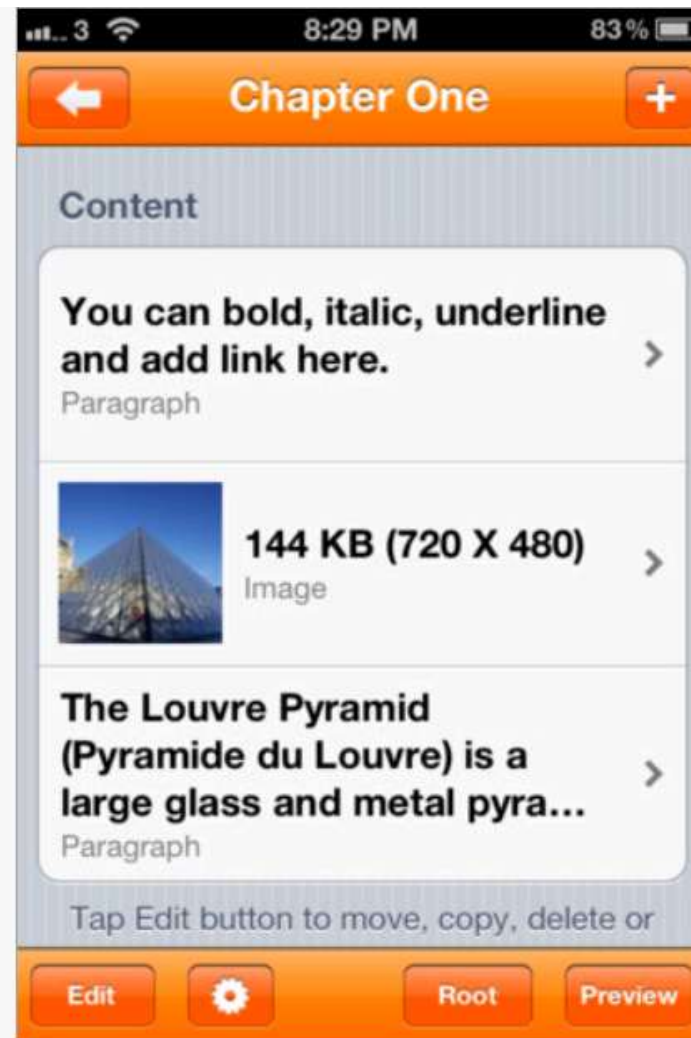http://www.nominettrust.org.uk/node/1143
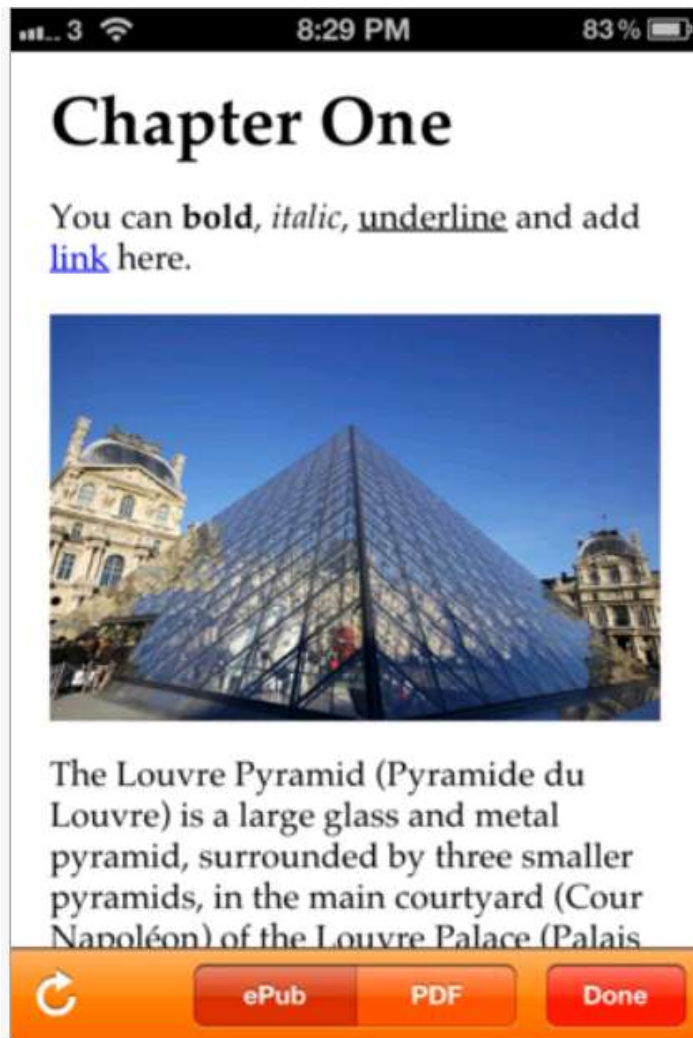
The way forward - considerations

- Staff time

- Technology

- Hardware and software

- Multimedia profiling approach – too detailed, too much support needed

Mobile technology

- Tablets and iPads

  - not trialed in this project

  - Now Multi Me works on iPads

  - More apps with video capability coming onto the market
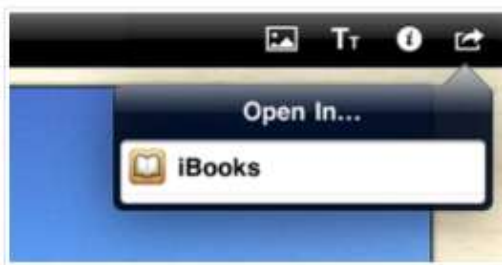
App –Creative Book Builder

App – Book Creator

Making books is fun

Simple arrange pictures and words using your fingers, and tap to edit. Book Creator is simple to use, leaving you to get on with making great books.

Read in iBooks

A quick tap and you're reading your book in iBooks. Book Creator has full support for iBooks' fixed layout format, including double page images.

Share your books

Your books are not tied to your iPad. Send your books to your friends over email, to iTunes on your computer, over Dropbox, or to a WebDav server.

Beautiful books

With your own pictures, all of the iPad's fonts and powerful layout tools such as snap to grid you have

Publish to the world

Submit your book for publication in the iBookstore, safe in the knowledge that your book will meet

Standards compliant

With your books created using the international ePub standard you know they will be readable now and in

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- **Creative Book Builder**. Cost $5

http://itunes.apple.com/us/app/creative-book-builder/id451041428?mt=8.

Also available on Android

- **Book Creator**. Cost $7

http://www.redjumper.net/bookcreator/ - $7

- "We've been doing PCPs on Book Creator. They have turned out really well. We can use video and sound grabs that bring the PCP alive for the individual and the staff seemed to have enjoyed putting them together."

John Blaze`, Communication Coordinator, Araluen, Victoria

Where could/should this happen

- Trial with existing communication coordinator networks in Victoria

- DHS – part of the referral process to therapists

Other ideas for use

- Emergency services – cloud storage of personal information

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- Training to the disability sector on multimedia profiling and online social networks

- Investigate a multimedia profiling service in Victoria to support people with little or no speech and their families and staff to develop their own multimedia profiles in various formats, i.e. DVD/USB, Multi Me

Other applications/ideas

- My People and Places -

  http://www.mypeopleandplaces.co.uk

- Tyze - http://www.tyze.com

- Rally-Round - https://www.rallyroundme.com/welcome

- Jointly - http://www.sidekickstudios.net/projects/jointly-

- Grouple - http://www.grouple.cc

- Here's a Hand https://heresahand.org.uk

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