Introducing AAC and AT to Adults with Acquired Disabilities

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Special acknowledgments: David R. Beukelman, Sarah Yong, Laura Ball, Melanie Fried Oken

Some resources

- University of Nebraska website - http://aac.unl.edu
  - Books, aphasia resources, visual scene display resources, demographics, Speech Intelligibility test
- *Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions* Book with CD Rom
- AAC-RERC website - www.aac-rerc.com and webcasts
  - Medicare assessment protocol

Overview

- Unique characteristics of adults with acquired disabilities
- What we know/don't know about different populations
- What we do…assessment and treatment considerations
- Case examples
- What's in the pipeline

UNIQUE CHARACTERISTICS

- The shock!
- Capacities and preferences
- Variability across disability groups (ALS, TBI, aphasia, brainstem stroke, multiple sclerosis, *etc*.)
- Ongoing desire to use residual speech
- Acceptance and use of AAC and AT
- Changing living situations, activities and supports

Challenges

- Functional limitations
- Reactions to becoming disabled
  - Acquired conditions
  - Degenerative conditions
    - End of life issues
- Building capacity and maintaining supports
- Integrating AAC/AT into daily life

Medical issues and management of care

- Planning for today
- Preparing for the future
- Decision-making processes
  - Preferences, priorities & capacities of individual and family
  - Living situation (stable/changing)
  - Resources
  - Access issues: not only to equipment but also to community

Across the Continuum of Health Care

- Acute Care/ICUs
- Inpatient Rehabilitation
- Outpatient Rehabilitation
- Extended care and Home health

Social Networks

- Well established, but often shrink after disability
- Condition also impact social networks of spouse/family members
- Influences AAC/AT decision-making process
  - Contexts within which communication occurs
  - Modes
  - Range of partners
  - Range of topics
  - Capacities and preferences of interactants

Continuum of AAC strategies from natural speech to aids

- Natural strategies:
  - Speech, gestures
  - Speaking in “breath groups”
  - Sign language, eye gaze, facial expressions

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- Nonelectronic aids and speech:
  - Relying on handwriting
  - Pointing to an alphabet board for first letters while speaking
- Nonelectronic aids:
  - Alphabet and phrase boards
  - Communication books, wallets, photo albums
- Electronic aids:
  - Adapted computers
  - Speech generating devices

Tips for Partners

- **Please be patient - it is hard work.**
- **Please pay attention - watch my eyes and lips. You will understand.**
- **Start up casual conversations.**
- **Speak in a regular tone of voice.**
- **Talk to me like any other conversant.**
- **Let me know if you don't understand - we can repair the conversation together.**

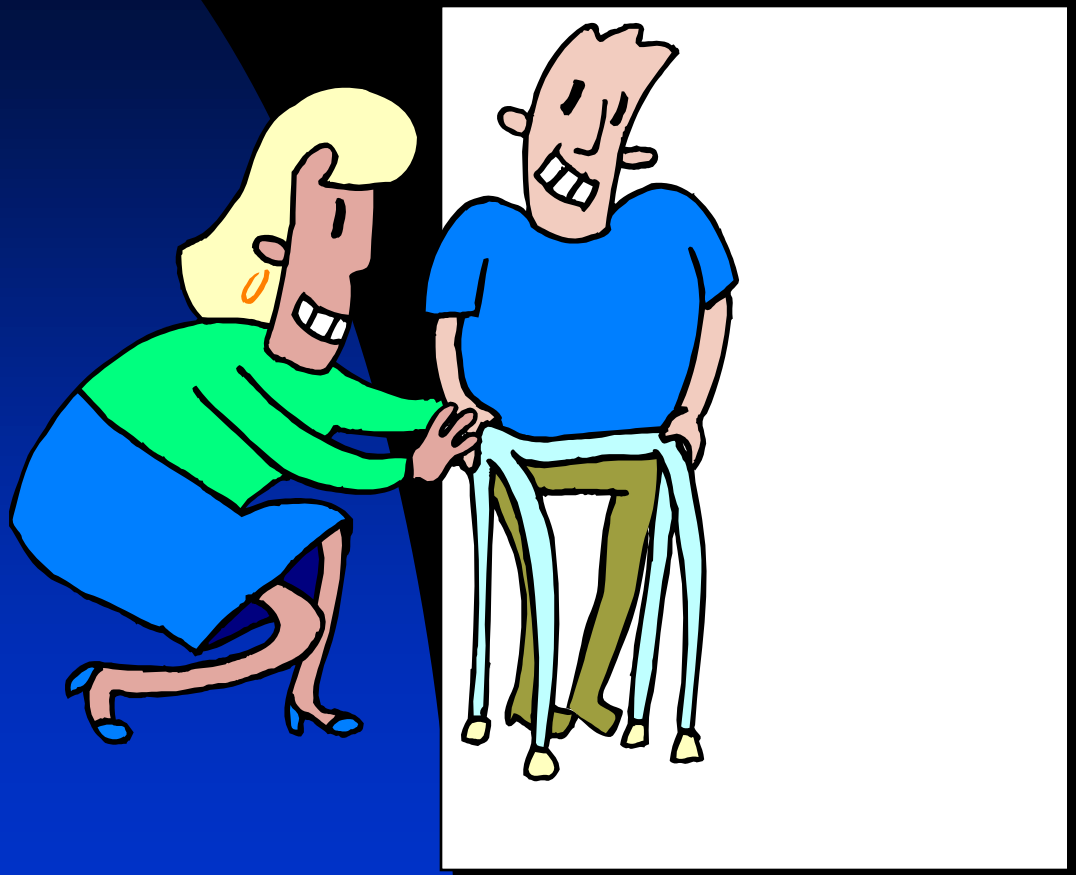
Desired features of AAC technologies

- Intelligible, natural sounding speech
- Designed with population characteristics and preferences in mind
- Link to mainstream technologies
- Phone and Internet access
- Account for BOTH partners characteristics (hearing, vision)
- Easy to learn

Acute Care/ICUs

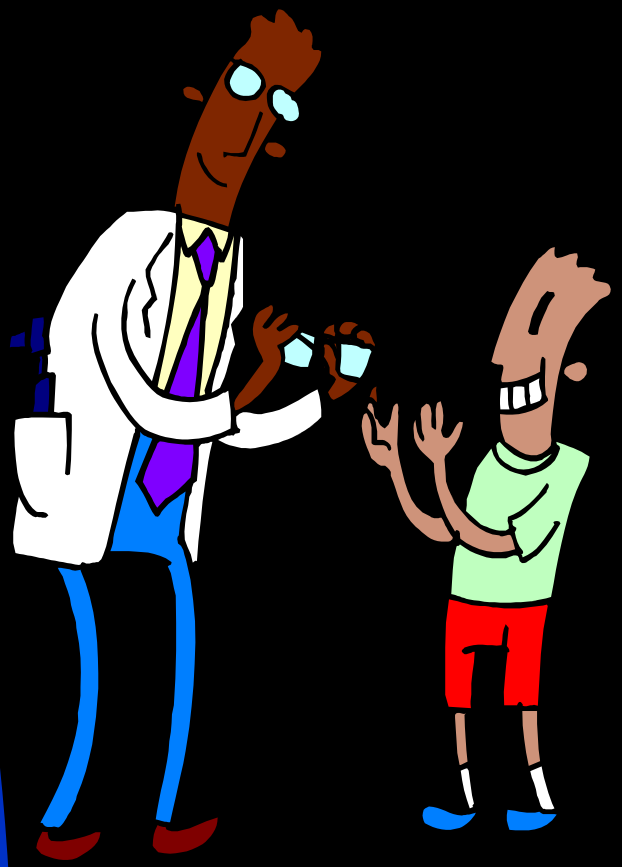
- Providing communication access
- Introduction of AAC
- Information
- Referral

Inpatient Rehabilitation



- Educate patient about strategies and tools for AAC
- Introduce strategies and tools to patient
- Begin partner training

Outpatient Rehabilitation

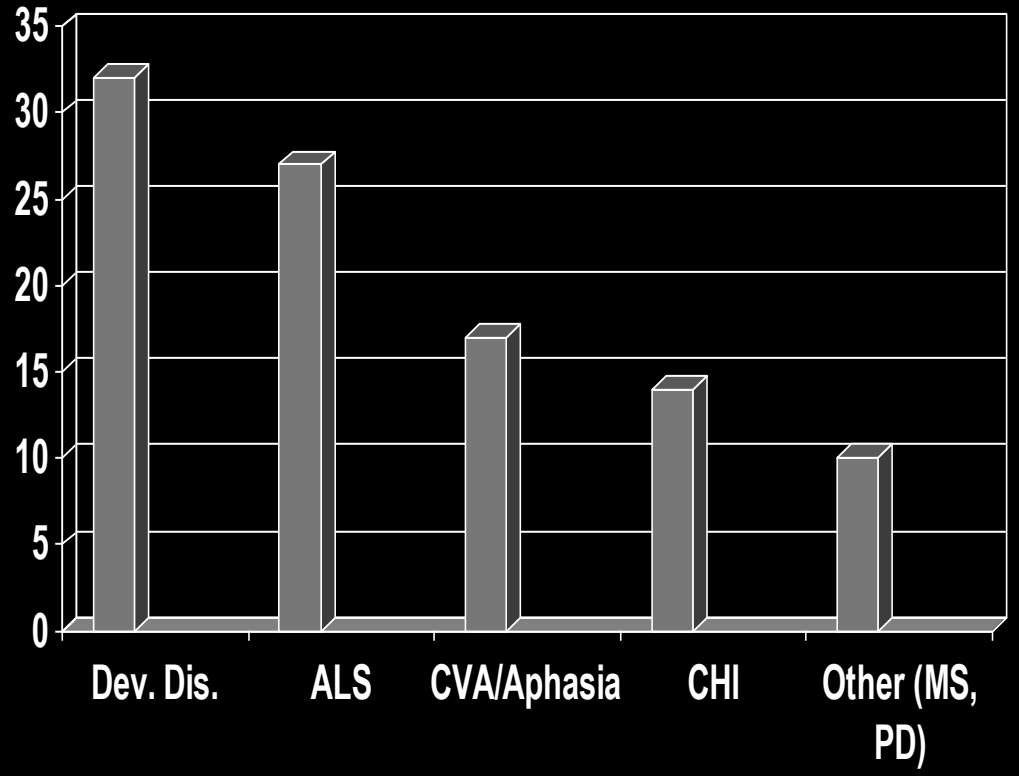


- Get to work!
- Complete environmental inventories
- Establish functional strategies and tools
- Partner training and supports

Extended Care and Home Health

- This is where the work can make a difference!
- Adjust functional use and tools to meet environmental needs
- Generalize strategies
- New partner training
- Getting on with life

Outpatient diagnoses for one quarter, adult AAC clinic



- The man with aphasia at home with his elderly wife.
- The young man with a closed head injury at a skilled nursing facility
- The daughter with a fast growing glioblastoma.
- The preacher with olivo-ponto-cerebellar degeneration (OPCD).

MOTOR NEURON DISEASE (ALS)

- Case example
  - Tom and Linda

Information in this section comes from David R. Beukelman & Laura Ball and their colleagues at the University of Nebraska

Augmentative Communication News v. 17 #2

- Maintaining their social network
- Making others feel comfortable
- Living life
- The key role of low and high tech AAC technologies

- **Before Tom's diagnosis with ALS, you and Tom had a very active social life. Did that change?**
- **When did Tom begin to use his AAC technology?**
- **How did Tom communicate his basic needs?**
- **How did his use of the AAC device impact your family life?**

Tablet XL Impact[2] speech generating device (SGD)
• enabled him to store a large amount of novel information
• relatively easy to program
• allowed him to easily retrieve messages.

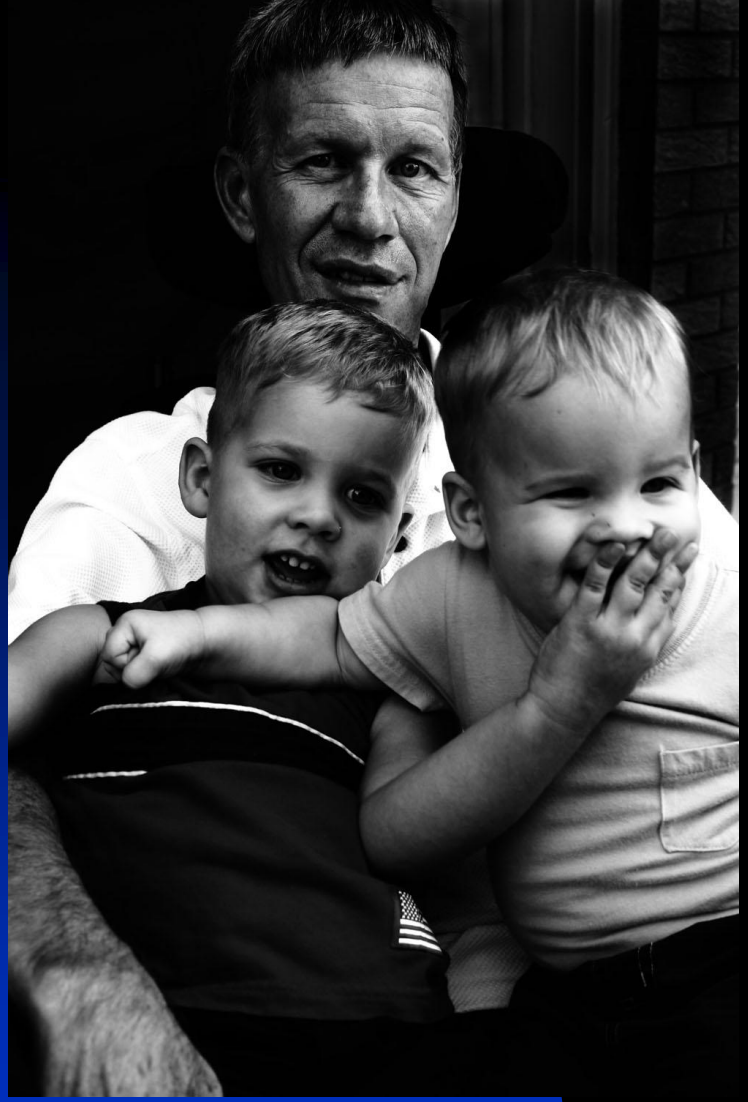
Accessed the device using HeadMouse® technology.

Table I. Configuration of Tom's AAC device

Pages	Content	Links
Main Page	Alphabet and word prediction page for spelling. The message window.	Quick Talk/Master Table of Contents (MTOC)
Quick Talk/Master Table of Contents (MTOC)	Quick Talk; Greetings/phrases that get people to talk. MTOC: Navigation page to stored messages.	Main Page, Jokes TOC, Thought for the Day TOC, News, Phone, AAC Device Description, Care
Jokes	Six to eight jokes per page. 25 pages of jokes. Organized with a Jokes TOC page.	Main Page, News
Thought for the Day	Six to ten thoughts per page. Organized with a Thought for the Day TOC page.	Main Page, News
News	Brief descriptions of news items organized by week. Retained for one month	Main Page, Jokes TOC
Phone	Messages for phone conversations.	Main Page, News
AAC Device Description	Messages that describe the device.	Main Page
Care	Messages about basic needs, medical issues and care.	Main Page

Outpatient Profiles

- The father with ALS who chooses to use a ventilator and be part of his family as his girls grow up.
- The person with ALS who chooses to work from home.
- The woman with Parkinson's Disease in a nursing home near her grandkids.



I know in advance approximately when I will die. So I have been able to make a personal videotape for each member of my family. I have been able to say all of the things that are difficult to say or go unsaid many times. And each week at Time Out with Tom, I am able to see and share my thoughts with many of my friends. If there is one by-product of this disease, it is the time to say goodbye.

Tom Rutz, August 2004

What we know

- Progressive neuromuscular disease
- Spinal MND survive 5 x longer than bulbar MND.
- Ventilation extends life.
- Artificial nutrition (PEG) improves quality of life.

Decision – making

- Best predictor for the AAC referral

When speaking rate reaches 125 wpm on Speech Intelligibility Test
(Beukelman, Yorkston and Tice, 1998)

Acceptance and use

- 95% with ALS become unable to speak prior to death
- 96% accepted and used AAC. Male=female
- Those rejecting had medical conditions (cancer) or dementia
- Use between 23.1 and 25.9 months

(Ball, Beukelman, Pattee, 2004)

What we do

- Phase I. Monitor Speech
- Phase II. Assess, recommend and implement
  - Body-based, low- and high-tech options
- Phase III. Adapt and Accommodate
  - Changing communication needs and living situations
  - Use of mechanical ventilation

Caregivers and facilitators

- Typically not professionals. Mostly family members (female) with non-technical backgrounds
- Implications for treatment
  - Prefer hands-on detailed, step-by-step instruction. Continuing need for “just in time instruction.”
  - Mentor, coach unfamiliar partners, program messages, trouble shoot and care for equipment.
  - Those with greater technology skills report greater rewards associated with caregiving and increased perception of closeness to person, less difficulty providing care

AAC use in everyday conversation

Key features

- The function of AAC in conversation
- Multi-modality – ecology of resources
- Ongoing interaction within AAC message construction
- Co-construction of AAC utterances

‘Heather and Cecil… you can eat upstairs if…’

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Key features

- **AAC function** – repair then telling news
- **Multi-modality** – speech, eye gaze, gesture and AAC, attempts at verbal spelling (initiated by B)
- **Ongoing interaction** - C&B engage in Q&A sequences *within* AAC utterance construction
- **Co-construction** – B completes C's utterances in progress

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Clinical issues?

- Understanding **HOW** people manage conversation (incl. AAC use) – what strategies do they employ?
- Appreciating the range of modalities – AAC as part of an ecology of resources
- Recognising the alignment between participants
- Less interest in AAC as an isolated event?

Future considerations

- Communication access
  - AAC Technologies – eye gaze; brain research?
  - Supports – maintaining social roles, networks, health, communication access
  - Policy and funding issues
  - Medical management decisions
  - Other complications (dementia)

BRAIN STEIM STROKE: LOCKED IN SYNDROME

- Case Example
  - Merle – late 50s/early 60s
  - Acute Rehab at Madonna
  - Only vertical eye movement intially
  - Safe laser under development at the time…wanted to have it turned on when he was resting!
  - Used prototype for about 4 years in nursing home near family

Video

- Merle learning to access communication using head control
  - Yes/No
  - Head pointing with safe laser and other access methods

Characteristics

- Quadriplegia
- Eye movement – limited to vertical
- Dysarthric speech
- Limited head control
- Most often cognitive abilities are intact
- Emotional lability

What we know

- Clinical profiles: continuum
  - From complete locked in to functional speech
- Nearly all require AAC interventions
- Successful outcomes dependent on carers to learn current AC approaches and indentify unmet needs

Phases of treatment

PHASES	GOALS
Initial Assessment	Functional Yes/NO. Call system
Early Intervention	Low-tech strategies Functional communication
Formal Assessment	Long-range communication planning; Communication advocate
Ongoing assessment	Guidelines for carers and communication partners

Mr H

- 37 years old – “locked in Syndrome” following a brain stem stroke, 5 years ago
- Initially very reluctant to use any AAC techniques – rejected scanning – partner facilitated, Lightwriter, computer software
- Found own solution – using Blackberry to type with thumb
- Requested assessment for My Tobii eye gaze computer
- Very efficient at using My Tobii (eye gaze and switch selection) – is about to start a web design distance learning course

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Mr L

- Aged 33 years – rare brain disease 15 months ago resulting in very “locked in” picture
- After 3 months of not doing much, he began to use his eye to communicate – looking at people, objects etc
- Started using Frenchay colour coded ETRAN frame – now dreams using this method of communication!
- Tried Grid 2: computer access/communication – scanning access – found difficult/frustrating
- Tried a My Tobii in Nov 07. Talked for 2 hours non-stop

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Mr L contd.

- Mr L now has his own My Tobii
- But there are still delays and frustrations:
  - Has waited for many months for a suitable powered chair, following assessment – now has it
  - Now waiting for mounting system for My Tobii
  - Problems with internet access in his nursing home

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AVI

David

- 50 + year old shipping executive
- Brain stem stroke in Papua New Guinea, Jan 2004
- After short time in Caines, Australia, transferred back to Singapore for treatment

David's communication milestones

- Jan 2004, Brain stem stroke
- Rehab centre – Family developed low tech AAC
- End of 2004, REACH interface software using sensor switch
- March 2005, tried Dynawrite
- Feb 2006 ……..

David and Dynawrite…

- ATF Application written for Dynawrite
- Mounting system trialed
- In the process of obtaining new wheelchair, so that system can be mounted

Lesson learned from David

- Integrate high tech and low tech
- Communication occurs everywhere
- Look at the person, not the disability

APHASIA (severe, chronic)

- Case example. Mr. R.
- Dynamic and ongoing assessment and intervention processes

Mr. R

Juli Trautman Pearson in *Augmentative Communication News, 2004.*

- 67 year old man with aphasia (6 years post)
- Not interested in using technology
- Dependent on wife as interpreter
- Wanted ways to increase participation in enjoyable activities
- Wife wanted more freedom to do what she enjoyed

Assessment and intervention process

- Traditional therapy not addressing needs of Mr. R or his wife
- Initial solution (AAC device) not used
- Use of *Social Networks* identified circles, modes, preferences, supports and intervention plan to address needs
- Reviewed outcomes after one year

Communication goals

1. Use adapted camera to take pictures and interact with people in 2nd & 3rd circles.

   Baseline: No use of camera. Minimal use of photos in aphasia group. Difficulty interacting in group.

2. Develop and use gesture dictionary with three additional caregivers.

   Baseline: Only wife and primary nurse understood Mr. R's gestures.

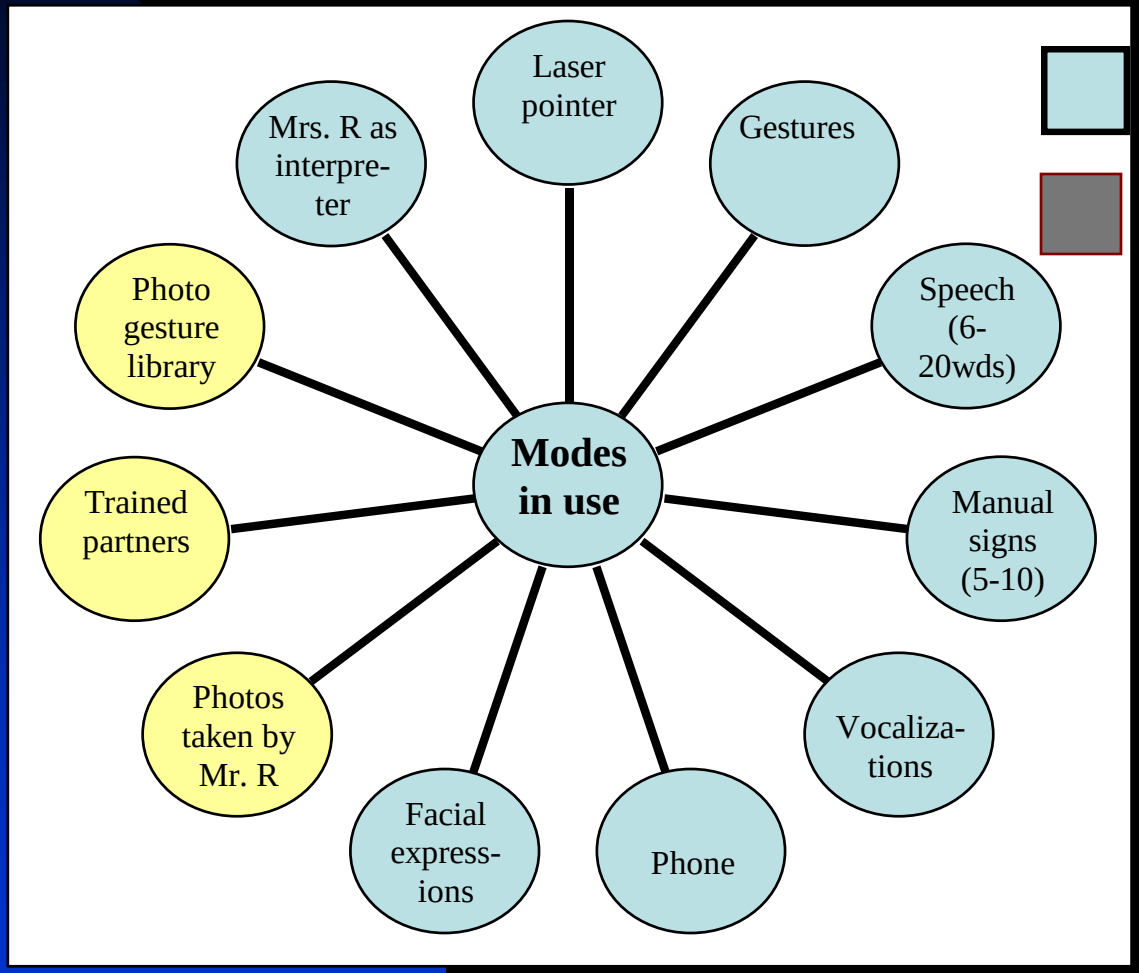
3. Train partners to support Mr. R's interactions at church and at his local model train group.

   Baseline: Interactions minimal at church. No longer attended the model train group.

	Circle 1 Family	Circle 2 Friends	Circle 3 Acquaintances	Circle 4 Paid Workers	Circle 5 Strangers
Initial number of partners (January 2003)	17	2	8	4	2
Current number of Partners (January 2004)	18	6	15	5	6
Change in number of Partners (January 2004)	+1	+4	+7	+1	+4

Increased # and balance of partners across circles

Increase modes he used



Initial Modes (January 2003)

Additional Modes (January 2003)

Topics

Strategies for interaction

Quality of life

Outcomes

- Exceeded all communication goals.
- Relies on wider range of modes to communicate
- Uses photos to interact with friends and acquaintances. Circles – more balanced.
- Has partners who can support his communication efforts.
- Is more independent and has more successful communication exchanges.
- Wife can spend more time with her friends.

What we know

- Up to 40% of people with aphasia have chronic severe language impairment.
- Life expectancy following stoke varies widely
- Traditional aphasia intervention focuses on impairment level "restoration"

- AAC strategies:
  Drawing, low-tech books and boards, remnant materials, gestures, writing, AAC technology

Key language issues

- Difficulty with symbols (representation) of printed messages and icons
- Difficulty formulating messages (spelling, combining words into messages)
- Difficulty with navigation (locating information in a book or electronic device)

AAC acceptance and use

- Low Tech
  - Limited contexts
  - Limited topics/ personalization
  - Tendency to provide commercially available boards (medical settings)
- High Tech
  - Task oriented (phone use, ordering, giving speech, saying prayers, other scripted interactions)
  - Speech output

AAC strategies to consider

- Speech clarification
- First letter pointing to an alphabet board
- Interactant support strategies
- Phrase boards:
  - conversational control
  - medical needs
  - frequent messages
- Attention getting techniques
- Co-construction

Mrs B

CVA following road traffic accident 4 years ago at age 48

- Non-fluent dysphasia, expression much more impaired than comprehension (OK for everyday conversations), difficulty with spelling beyond the 1st letter of a word
- Very communicative, using gesture, facial expression, vocalisation and some words
- “personal dictionary”
- Clicker 4 with word banks for writing
- Say-it-Sam as a portable VOCA – also used for diary functions etc
- Now using Grid2 on laptop for email and writing

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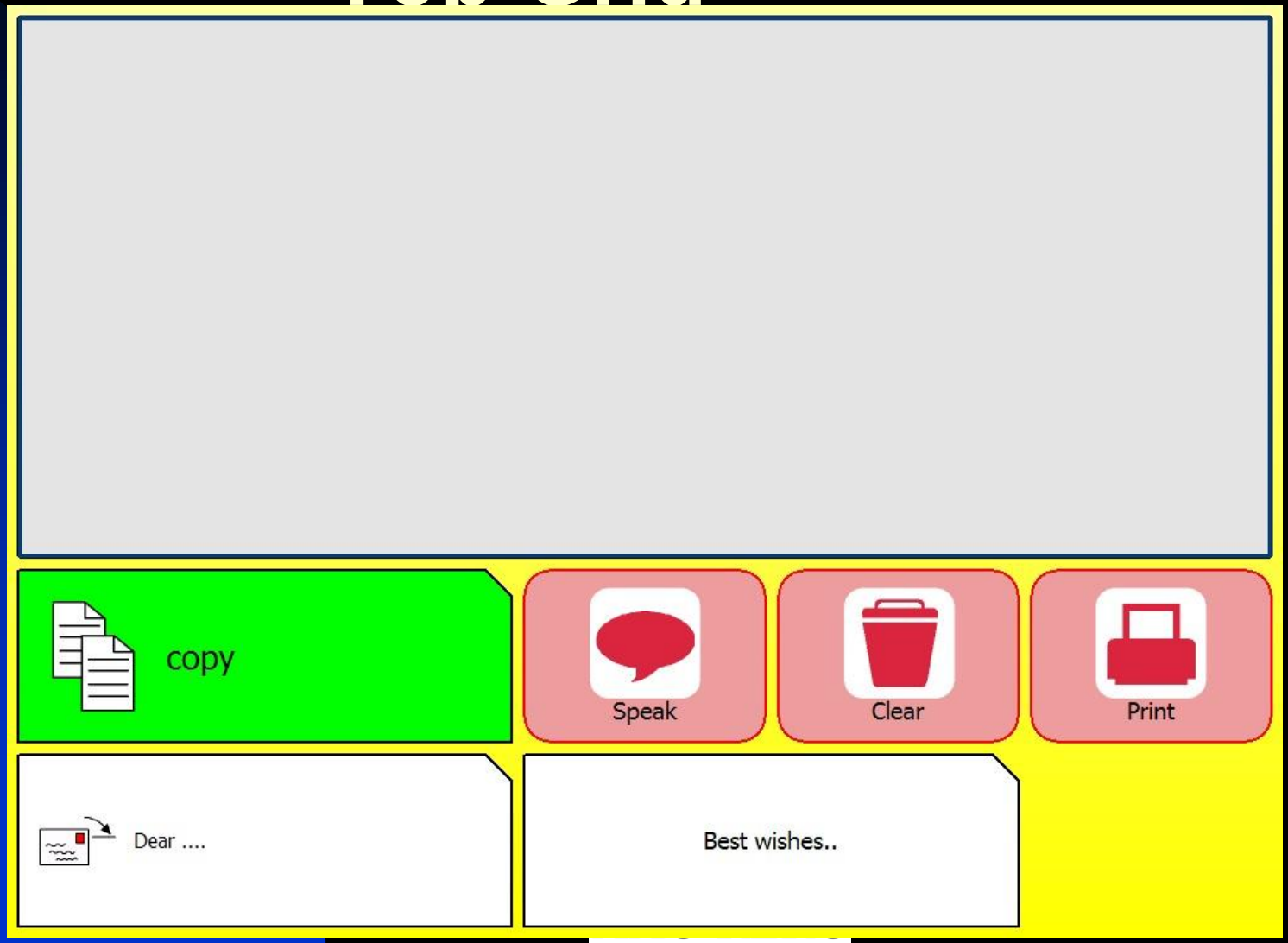
Email/writing configuration

Grid 2

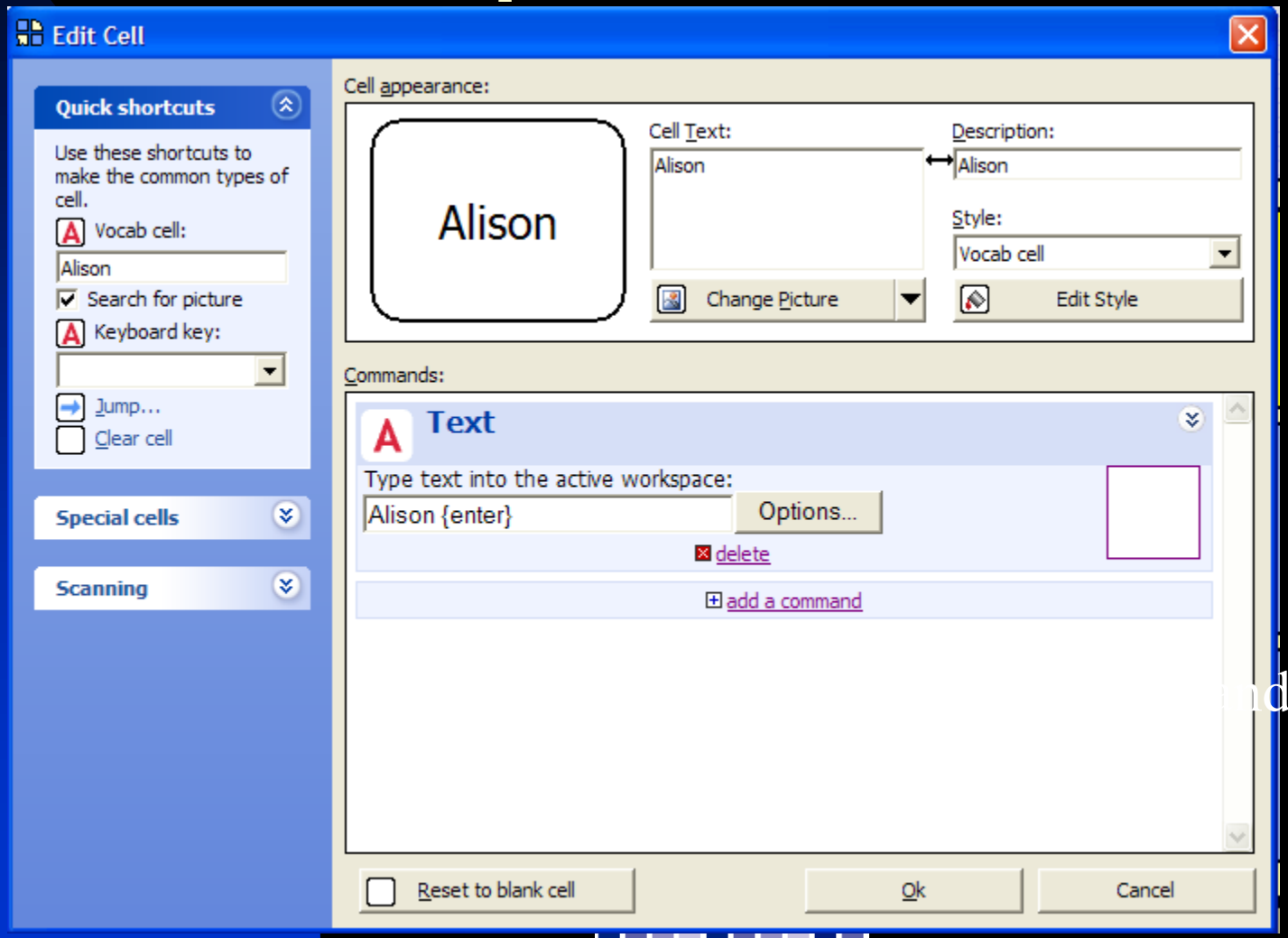
Top Grid



Message recipients

Dear	Alison			Home page
Hello				write more
Hi				More people
and				

Setting up a message recipient



Writing topics

Home Page	I am sending you this	Thank you for	the weather	questions
people	places	what I think	health	
what I've been doing	music	TV	reading	gardening
time	days, months etc	special events	art	

Sample topic grid

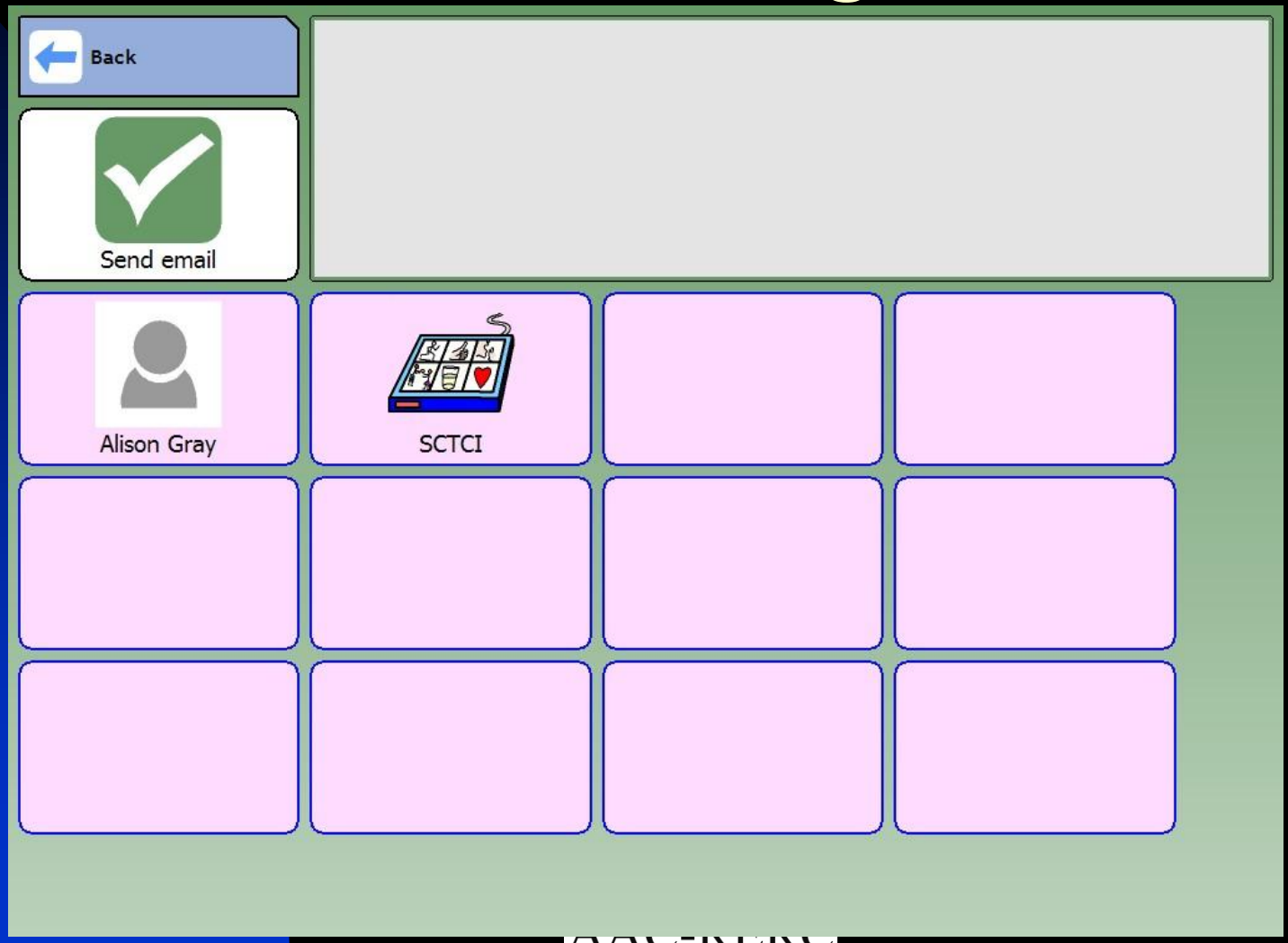
back	I have been to	people	gardening
I've been listening to	I had a trip to	places	travel
I've been watching	I have started	music	art
I've been to see	I have joined	TV	
I visited		reading	

Finishing off a message

Home page			Ken
Hope to see you soon,	Get back to me soon,	Take care,	
Bye for now,	Get in touch,	Love,	
Speak to you soon,	Best wishes,		

Copying workspace to either email or print

Email send grid



Sample message to be printed or sent as an email

- This is an example of what could b created by th user without them having type anything extra in.

Dear Alison

I am sending you this just for a chat.
How are you? What have you been up to?

I've been watching Antiques Roadshow.
I have started Art in Hospital.
I've been working with oils.
I like that.
I've been planning the garden.

Bye for now,

Ken

copy

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Mr M

- CVA at 49 years
- Significant dysphasic and dyspraxic difficulties
- Keen to look at technology
- Had tried Lightwriter – but this had not offered sufficient literacy support
- Used the SM1 – in spelling with word/phrase prediction and with a personalised word based page set

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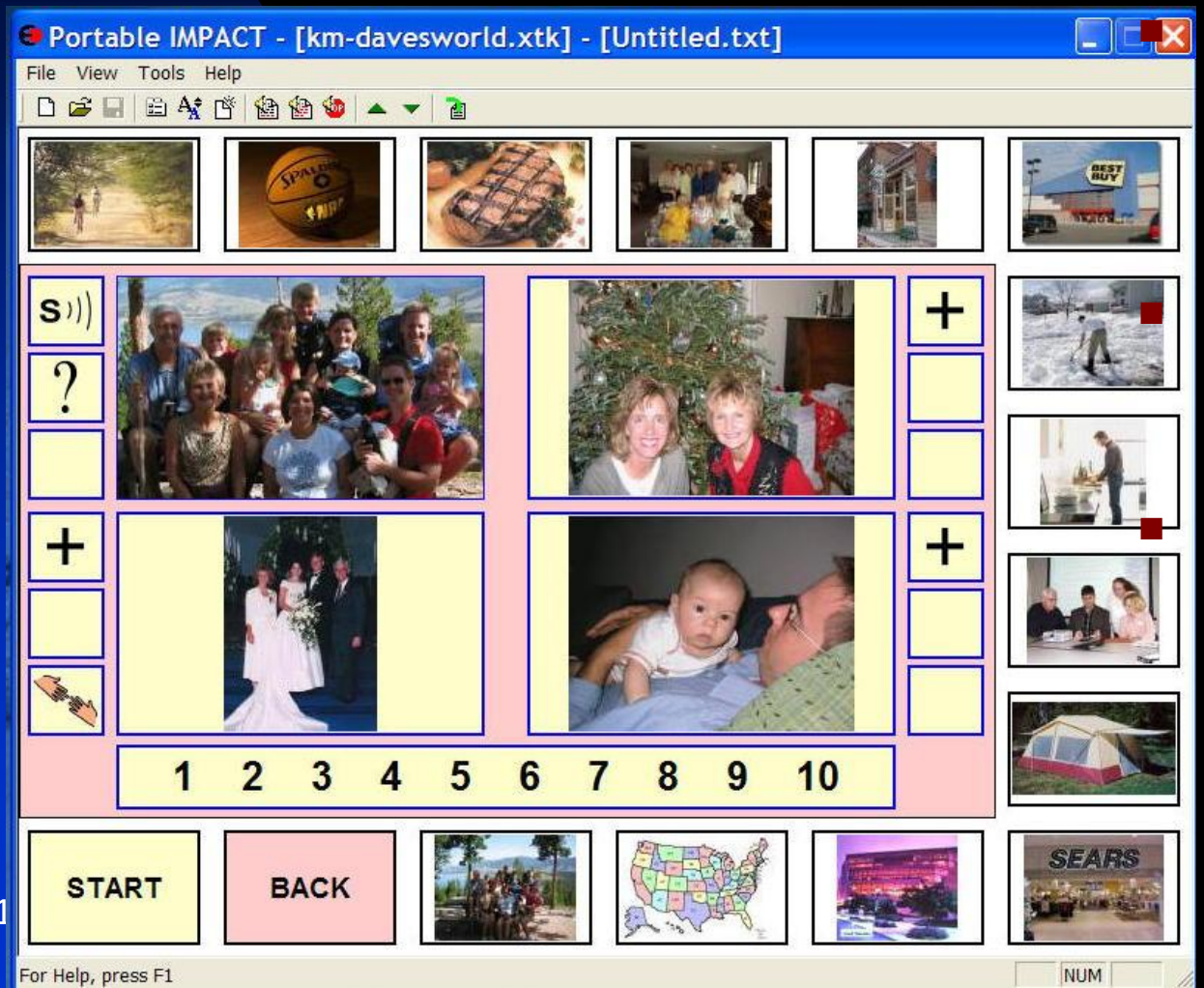
Creating a shared conversational space

- Shared context: sit next to person
- Digital images
  - Represent meaning and content
  - Support navigation

- Increase conversational turns
- Highly personalized

Visual scene displays for interaction: Adults with aphasia

David R. Beukelman, U of Nebraska



Hi, how you doing? "You've got quite a family." pointing to picture.

What are we doing here?…are these your children?

Person with aphasia can point to pictures, navigate through pictures, go deeper, ask questions, use lists, maps, etc.

John video

- Fluent aphasia with severe word retrieval
- Content comes from VSD
- Video shows using prototype. Note help he gets with navigation
- Currently prefers using low-tech version to support residual speech. Recently has had significant health issues

Pat video

- Severe expressive aphasia with undoubtedly apraxia for good measure. Only says paa paa paa
- After stroke social networks had collapsed. She refused to attend events/church activities
- Had a communication book…did a “linear search”…hoping to hit right page

Using visual scenes

- Don’t instruct.
- Sit side by side while conversing…sharing the space.
- Partner has access to pictorial information and gets general feeling for what topics might be…
- Technology enables co-constructed interactions to evolve as conversation

Resources for assessment and treatment approaches

- http://aac.unl.edu

Quotes…

- Great things are done not by impulse but by a series of small things brought together

Vincent Van Gogh

Adults with TBI

Jason:
30+ year old man
Photographer
Brain Injury
5 years post

Jason's communication milestones

- May 2005, refered to Specialised ATC
- Trialed switch access
- Power point slides, MTV with switch
- Established Y/N system
- Feb 2006….

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Lessons learned from Jason

- Everyone has the right to communicate
- Everyone can communicate if given the opportunity
- The ability to communicate alters the way a person is perceived
- It changes social networks

Demographic Data

- 6 females, 19 males
- Age range 21-44 (*M* = 3; *SD* = 6.55)
- Time post onset 3-28 years (*M* = 8; *SD* = 6.79)
- Rancho Levels VI-VIII

High Levels of Acceptance and Use

- High Tech
  - 17 had **high** tech AAC recommended
  - **16 accepted (94.22%)**
  - 15 received devices
  - 13 continued to use devices
- Low Tech
  - 8 had low tech AAC recommended
  - **8 accepted (100%)**
  - 5 continued to use AAC systems

AAC Non-Use

- High Tech (n = 17)
  - 1 rejection
  - 1 did not receive device due to funding issues
  - 2 discontinued use due to lack of ongoing facilitator support
- Low Tech (n = 8)
  - 3 discontinued use due to regaining natural speech to a functional level

Access, Message Formulation and Encoding Strategies

- High Tech (n = 15)
  - 13 used direct selection, 2 used switch-scanning
  - 11 used letter-by-letter spelling
  - 2 relied on symbols or line drawings
- Low Tech (n = 5)
  - 3 used direct selection, 1 used eye-gaze, 1 used partner-dependent scanning
  - 4 used letter-by-letter spelling
  - 1 relied on symbols or line drawings

Communicative Functions
Individuals who relied on High Tech AAC

Participants	1	2	3	4	5	6	7	8	9	10	11	12	13
Stories	X	X	X	X		X		X	X		X	X	X
Writing		X	X			X		X	X			X	X
In-Depth Information	X	X	X	X		X		X				X	X
Telephone	X	X	X	X	X	X		X					X
Quick Needs	X	X	X	X	X	X	X	X	X	X	X	X	X
Detailed Needs	X	X	X		X	X	X	X		X	X	X	X
Conversation	X	X	X	X	X	X	X	X	X	X	X	X	X

Communicative Functions
Individuals who relied on Low Tech AAC

Partcipants	1	2	3	4	5
Stories		X			X
Written Info	X	X			
In-Depth Info	X	X			X
Telephone		X			
Quick Needs	X	X	X	X	X
Detailed Needs	X	X			X
Conversation	X	X	X		X

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Characteristics

- High level of acceptance and use
  - advances in technology
  - increased exposure to AAC
- Reliance on letter-by-letter spelling
  - cognitive deficits impact ability to encode and utilize other message formulation strategies (i.e. abbreviation expansion)

…continued

- Communicative functions more varied for persons who relied on high tech rather than low tech AAC
- Non-use or discontinuation of AAC
  - recovery of natural speech
  - funding
  - loss of support

Quotes…

- Great things are done not by impulse but by a series of small things brought together

Vincent Van Gogh