

AAC Clinical Pathways for Neurodegenerative Disease

Chris Gibbons, Ph.D., CCC-SLP
Melanie Fried-Oken, Ph.D., CCC-Sp
Oregon Health & Science University
Portland, Oregon

Augmentative and Alternative Communication refers to any strategy, technique or tool that enhances, replaces, augments or supplements an individual's communication capabilities.

Who is an AAC user?

Anyone whose communication is adversely affected by an impairment in speech, language, cognition, and/or physical abilities.

Communication impairments leading to AAC use

- Physical impairments
 - ALS (Lou Gehrig's Disease)
 - Cerebral Palsy
 - Spinal Cord Injury
 - Parkinson's Disease
 - Multiple Sclerosis
- Cognitive impairments
 - Traumatic brain injury
 - Developmental Delay
 - FTD, AD

Communication impairments leading to AAC use

- Language Impairment
 - Aphasia from a stroke
 - PPA (eventual FTD)
 - Autism
- Sensory Impairment
 - Blindness
 - Deafness

Augmentative Communication Approaches

- Speech
- Vocalization
- Gestures
- Eye gaze
- Body language
- Sign language
- Paper and pencil
- Communication books
- Communication boards and cards
- Remnants
- For-purpose software
- Re-purposed software
- Voice output communication aids

AAC Across the Lifespan

- Cause and Effect
- Concrete Referents
- Communication Context
- Dyadic Exchange
- Play
- Cognitive Development
- Language Development

AAC Across the Lifespan

- Peer interaction
- Academic Participation
- Broader Social Access
- Workplace Readiness/Participation
- Language Remediation
- Alternative Language Access
- Cognitive Cuing

AAC Across the Lifespan

- Conversation Context Support
- Dyadic Support
- Symbolic Reference
- Visual/Physical Prompt
- Functional Memory Aid
- Direct Referent Cuing
- Basic Needs Choice Support

AAC Clinical Path

- Functional outcome drives goals and clinical path
- Function of AAC in various populations vastly different depending on
 - Developmental trajectory
 - Assumed course of condition/disease/disability/remediation/cognitive stability
 - Language knowledge/accessibility, etc.

Defining A Clinical Path Crucial for Success



Defining the Path

- We begin with a Participation Model of service delivery
- Participation, not Stimulation
- Participation model hinges on thinking differently about disability
- Focus on function, not disability per se

Defining the Path

- Stress functional outcome
- Neurodegenerative diseases warrant well-considered clinical paths
- Will use 3 specific DX to guide discussion
- Look for where the lines intersect
- Use those points to inform specific functional approaches with neurodegenerative intervention

Evaluation philosophy

- For patients with neurodegenerative disease, the purpose of AAC is to provide tools and strategies so that an individual can continue to participate in daily life.
- AAC treatment is not necessarily based on assumptions to regain skills, improve skills, or even maintain skills.

3 Focus DX

1. Amyotrophic Lateral Sclerosis
2. Primary Progressive Aphasia
3. Alzheimer's Disease

Group discussion of PD and MS to follow

Amyotrophic Lateral Sclerosis

Our Goals:

Evaluation philosophy:

Participation not stimulation

AAC for patients with:

ALS

- Language representation
- Output mode
- Motor access
- Microprocessor considerations
- Disease trajectory assumptions
- Probes for FTD

I Do Not Communicate, Where Am I?

- In the presence of ALS, the symphony of speech is problematic and vulnerable.
- 80% of pALS will lose their speech (Saunders, Walsh, & Smith, 1981).
- “Loss of Speech” most frequently associated symptom with “worst aspect of disease” (Hecht et al., 2002).
- Devastating breakdown in social interaction, control, independence, identity.

Communication and ALS What Happens

- Musculature enabling speech weakens. Most often the tongue first.
- Speech volume changes, softer, less able to modulate with emotion, prosody.
- Speech quality changes, rough, husky.
- Speech clarity changes, slurred sounding, hypernasal, reduced intelligibility, dysarthric.

Communication and ALS What Happens

- Limb onset – 75%
- Bulbar onset – 25%
- Concomitant FTD – 20% but may be higher – highly variable presentation
- Pseudobulbar effects highly variable
- About 10% familial
- 90% sporadic (Guam, Italian soccer players, U.S. Military service most popularized risk groups)

Communication and ALS: Perspective Taking

- Caregivers rate patients as having less energy and more suffering than patients rate themselves.
- Patients rate their caregivers as more burdened overall than caregivers rate themselves (Adelman et al. 2004).
- Even basic communication strategies can alleviate such misperception and help relieve emotional distress.

What Does the Communication Partner Typically Look Like?

- Dominant socially/conversationally (“big people”).
- Directive
- Unresponsive to AAC (avg. 7% response).
- Anticipatory
- Question after question after question.
- Poor communication opportunity creators.

How Should the Communication Partner Look?

- Ask questions appropriate to the communication system
- Respond
- Discuss the “rules” of communication openly and honestly
- Don’t be afraid to request complicated information, but be prepared to wait
- Let the AAC users be who they are first, reinforce their identity and independence

Communication and ALS:

- Given the appropriate systems, training and partner participation, pALS can continue to
 - communicate with their spouse and children about “mundane” household decisions
 - Manage their medical care
 - Make important financial arrangements
 - Be funny
 - Impart comforting words to their caregivers and family
 - Make new friends

“Communication competence and the control it brings insures that patients will maintain the ability to guide, direct, and influence the management of medical and personal aspects of their lives.”

Yorkston, Miller, Strand, 1996

What Does Communication for pALS Look Like?

- It is comprehensive, not always complicated, and always changing.
 - Verbal with amplification.
 - Non-verbal (facial expression, eye blink Y/N, gesture, pencil/paper, communication board, E-Tran, etc.).
 - Light Tech – multi-message speech playback.
 - High Tech – computer-based software driven communication systems, voice output.
- It accommodates increasing physical disability.
 - Alternative access (switch, head mouse, eye control, etc.)

Speech recognition

- Dragon-Naturally Speaking
- Must have consistent speech production
- Mild-moderate dysarthria is adequate for controlling computer with speech input.

Voice Amplification Options

ChatterVox voice amplifier

JustAMP or JusTalk
JustMED, Inc.
503-524-4223

Microphone attachments

Voicette and Mini-Vox from Luminaud

Attention Getting Devices

- Bicycle horns



- Cow Bells



- Battery Powered Doorbell



DrumBum.com

Telephone Options



Ameriphone XL25s Amplified Telephone with Outgoing Amplification

product #: 76563.000
 The XL25s™ amplified corded phone, by Clarity®, features Clarity® Power™ technology to make words not only louder, but also clearer and easier to understand. The XL25s™ provides up to 18 decibels of outgoing voice amplification, making it an ideal solution for those with low speech or a mild-to-moderate hearing loss. \$99.00

Available through

PUC TDAP:
Telecommunication

Device Access

Program

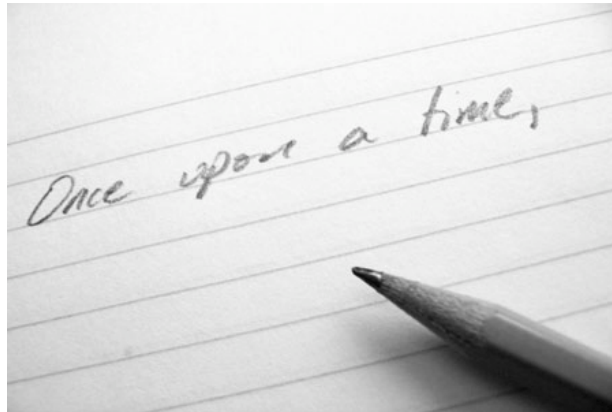
www.tdap@state.or.us



TTY and
Oregon Relay System



Speakerphone with SGD (available through PUC TDAP)



<http://gracemagazine.files.wordpress.com/2007/03/writing450.jpg>



E-Tran Board

The "MegaBee" E-tran Device



FRONT OF BOARD

I AM

- Short of breath
- Frustrated
- Nauseous
- Anxious
- Disappointed
- Tired
- Drowsy
- Better
- Thirsty
- Hot
- Unsure or don't respond

I WANT

- Grogginess
- In pain
- Light-headed
- Lonely
- Angry
- Wet
- Worse
- Hungry
- Cold
- Stuck/med
- To sit up
- To lie down
- Water
- Ice
- Bath
- Shampoo
- Lotions
- Eyeglasses
- Hairbrush
- Massage
- Socks
- Urinal
- Bedpan
- Call light, TV
- Pillow
- To Turn Right
- To Turn Left
- Lights On
- Lights Off
- Lights Dim
- Blasted
- To sleep
- To Rest

I WANT TO SEE

- Doctor
- Nurse
- Assistant
- Respiratory Therapist
- Physical Therapist
- Mouth
- Teeth
- Face
- Nose
- Hands
- Hair
- Chaplain
- Social Worker
- My Family

BACK OF BOARD

PAIN CHART

LEVEL OF PAIN

- 10 worst
- 9 severe
- 7 moderate
- 4 slight
- 2 none

THIS PART

- My head
- Neck
- Stings
- Hurts
- Cramps
- Can't move
- is numb
- Aches
- Burns
- is tender

THE PAIN IS

- Constant
- Intermittent
- Radiating
- Throbbing
- Dull/Aching
- Sharp

PLAN OF CARE: YES NO Please Explain Need Reassurance

Where When What How Why What Stop What is the plan? When can I try When What What How am I doing? How am I doing? How am I doing?

<http://www.bindependent.com/hompg/bi/bindep/store/aistes/s-needs/communication/communic.htm>

Hard copy print out

1. Wash my face
2. Brush my teeth
3. Put on my nightgown.



Mayer-Johnson Writing with Symbols

"Talking Typewriters"

DynaWrite



Lightwriter SL35



Proloquo2go





Dynamic Display



Headmouse Adapted Laptop



Eye Control Adapted Laptop



Cyber Link



Tobii C12 Integrated Eye Control

Single/dual switch access



Working while locked in

Brain-computer interface



Cyber link



AAC staging for pALS and their families

www.dukespeechandhearing.com

- STAGE 1. Normal Speech Processes
- STAGE 2. Detectable Speech Disturbance
- STAGE 3. Behavioral Modifications
- STAGE 4. Augmentative Communication Use
- STAGE 5. Loss of Useful Speech

Stage 1 Normal Speech: Initial Consult, Education, Counseling

- Listen
- Begin to build trust and rapport
- Explain your general resources, why you are part of their intervention team
- Depending on person, may or may not bring up likelihood of speech loss at first visit
- Assure that resources exist to accommodate loss of communication if conversation goes there
- Baseline speech/lang eval, cognitive screen and speech sample if possible

Stage 2 Detectable Disturbance: Education

- Listen
- Explain what is happening
- Attempt to determine rate of speech change
- Speech/lang eval, cognitive screen and speech sample
- Augmentative resource education based on symptoms (dysarthria vs. low volume)
- Begin to sketch intervention plan to comprehensively address needs and maximize resources

Stage 3 Behavior Modification: Basic Implementation

- Listen
- Explain what is happening
- Attempt to determine rate of speech change
- Speech/lang eval, cognitive screen and speech sample
- Augmentative resource education and application of light strategies based on symptoms (dysarthria vs. low volume = TX or amplification, etc.)
- Continue to formulate intervention plan to comprehensively address needs and maximize resources

Stage 4: Augmentative Communication

- Listen
- Explain what is happening
- Attempt to determine rate of speech change
- Speech/lang eval, cognitive screen and speech sample
- AAC serves as a means to *augment* residual speech and writing.
- Speech rate: rapid deterioration of intelligibility often occurs when speaking rate reaches 45-60% of habitual rate or 85-125 wpm.

(Ball L, Willis M, Beukelman D, Pattee G. A protocol for identification of early bulbar signs in ALS. J Neuro Sci, 191, Oct 2001, 43-53.)

Stage 5: Alternative Communication

- A person no longer has any use of functional speech; AAC is an *alternative* for their verbal communication.
- Include many techniques from no tech (vocalizations) to low tech (alphabet board) to high tech (SGDs and ECUs).
- Our role: integrate AAC into their daily lives at a pace suitable to their functional needs, environmental support and emotional capacity.

Why do we intervene?

4 purposes of social interaction (Light, 1988)
Basic Needs and Wants
Share New Information
Social Closeness
Social Etiquette

Fried-Oken M, Fox L, et al. Purposes of pALS communicating with technology. *Augmentative and Alternative Communication*. 2006.

4 Social Purposes of Communication

1. Expression of needs/wants.
 - Regulates behavior of listener, content important, accuracy important, often rated as more critical by AAC practitioner and communication partners than users
2. Information transmission.
 - Share information, content important, tend to be more novel messages – more difficult for AAC user
3. Social Closeness
 - Develop social bond, content less important, interaction quality important – good use of voice banking
4. Social Etiquette
 - Fulfill conventions, predictable content (e.g. please and thank you) – many systems pre-loaded with this, or voice banking

Competencies Supporting AAC

- Linguistic: What code used? What is knowledge of code? How will it be represented? How will it be learned?
- Operational: How does the technology work? Who will support it?
- Social: What are the rules of social intercourse? How does the AAC user characterize those rules?
- Strategic: How well does the AAC user comprehend the limitations of the system? How are those limitations dealt with?

How successful is AAC? Acceptance of AAC by pALS

- In a sample of 50 pALS,
 - 90% accepted AAC technology immediately (no sig. diff by gender, spinal vs. bulbar ALS, or age.)
 - 6% accepted AAC technology after some delay
 - 4% rejected AAC technology (due to lack of support from family or recommendation from physician)

Ball L, Beukelman D, Pattee, G Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*. 2004. 20(2), 113-122.

Clinical impressions

- AAC use puts pALS (and other neurodegenerative Dx groups) in a “bilingual speaking situation”
- Most pALS are capable of learning to use AAC multi-modal system, adapt to motor access changes as needed
- But not without significant counseling and support using a participation-based approach
- No “one best way” to intervene – “optimal” a moving target

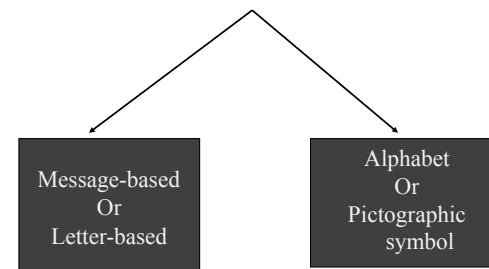
Employment and AAC

- Do pALS use AAC at work?
 - pALS who can adapt jobs for text-generation remain employed longer
 - pALS express satisfaction with employment and motivation to continue contributing in the workplace

Fried-Oken M. AAC and employment for individuals with neurodegenerative disease. Pittsburgh Employment Conference for Persons who Use AAC. 1988.

What is current AAC technology intervention?

Language Representation



Rate Enhancement Techniques

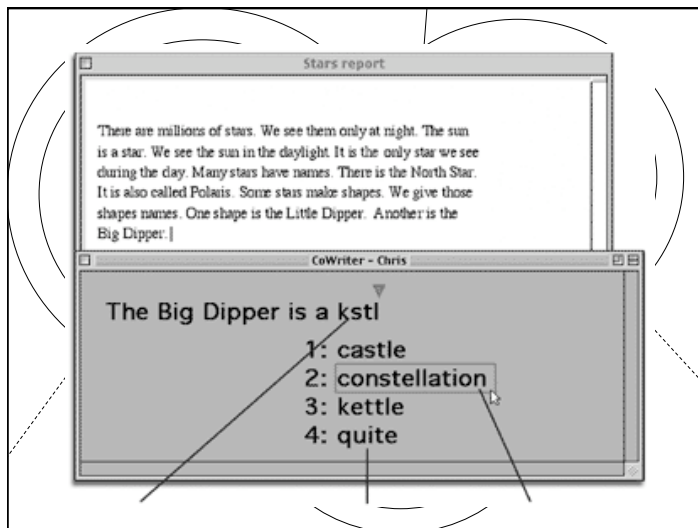
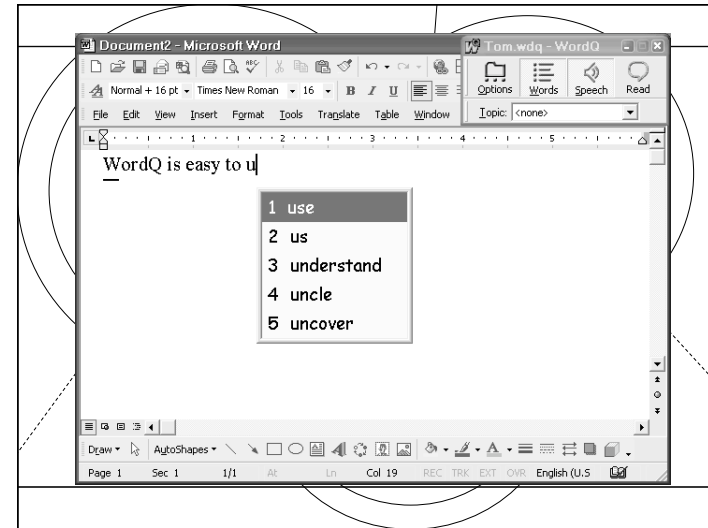
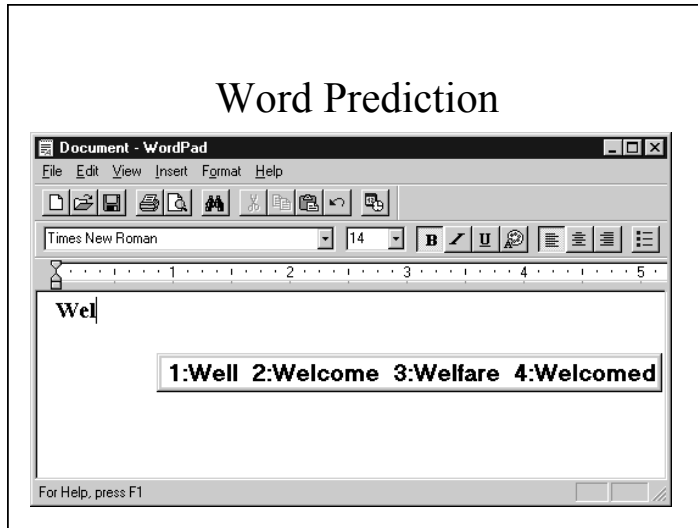
- Quickfires by Dynavox
- Word and phrase prediction
- Visual Scene Displays
- Natural Language Processing with closed vocabulary sets
- RFID or some facsimile thereof, server-based vocabulary?

Quickfires: Formal						Hello.	Okay.	Goodbye.	
Delete Word		Help me, please!	Put it in my hand.	Put it in my wheelchair.	I need the pen.	I need my glasses.	Yes.	Maybe.	No.
Present	Who/What	I'm hungry.	I'm thirsty.	I'm in pain.	You can take it out of my bag.		Right.	Yeah.	Don't
Past	Where/When	Please slide my nose.	I need some soap.		Please move my arm.		Good.	Oh.	That's terrible!
Future	Why/How	Please wait.					Could you help me?	Thank you.	You're welcome.
Menu [My Care]	Keyboard	Go slow.					Pardon me.	Please wait.	I'm so sorry.
Clear	My Phrases	Opinion	More	Medicine & Equipment	Expand Quickfires Off	Formal	Oh dear!	You don't say?	For Pete's sake!

Expanded Quickfires: Hi.						Hi.	Okay.	Bye.	
Delete Word		Close	How are you?	My name is First Name.	Good to see you.	Remember me?	Yes.	Maybe.	No.
Present	Who/What	Good morning!	What's up?	I missed you.	Nice to meet you.	Have we met before?	Right.	Yeah.	Don't
Past	Where/When	Good afternoon!	How's it going?	Long time no see.	You look good today.		Good.	Oh.	That's awful!
Future	Why/How	Good evening!	How's it hanging?	I'm so glad I ran into you.			Please.	Thanks.	Fine.
Menu [My Care]	Keyboard	Hey you.	Hi guys.	Hello, sis.			Excuse me.	Hang on.	Sorry.
Clear	My Phrases	Opinion	More	Medicine & Equipment	Expand Quickfires Off	Normal	Uh oh!	Really?	Darn!

H									
Handy	Honest	Huge	Human	Hungry					
How are you doing?		How are you today?	How are you?	How big was it?					
q	w	e	r	t	y	u	i	o	p
Caps Lock	a	s	d	f	g	h	j	k	l
Shift	z	x	c	v	b	n	m	,	Backspace
Menu	Go Back	Delete Word	Space	.	?	Clear	Numbers and Punctuation	E-mail To...	Send Text to Next Application

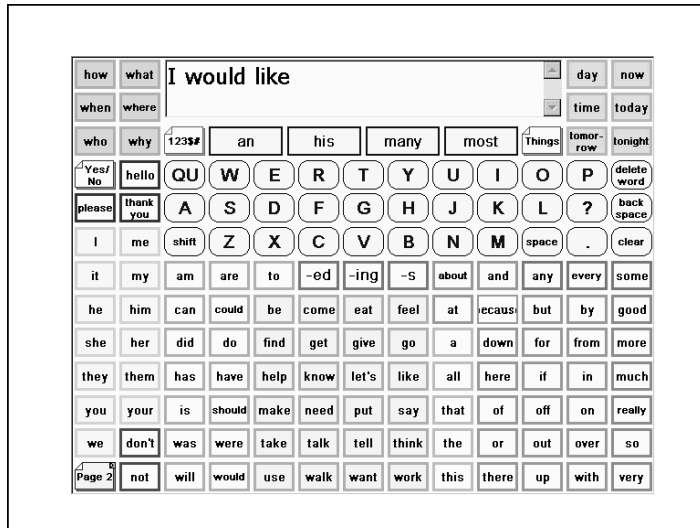
Word Prediction



abbreviated expansions (macros)

- AAC = Augmentative and Alternative Communication
- 3S = 3 spades
- 3C = 3 clubs
- 3H = 3 hearts
- 3D = 3 diamonds





Morse Code

- 2 switch option



Visual Scene Displays: Support for storytelling



Benefit of visual scene displays

- Highly naturalistic organization of communication vocabulary
- Decreased memory load
- Less need to re-work system with cognitive decline
- Establish a shared communication space
- Serve as a platform for co-constructing messages
- Allow for integration with other types of communication supports

Contextually-based NLP

- Access large vocabularies for specified topics
- Use in word or phrase prediction
- Use with location-specific or partner-specific messages (*e.g. messages related to preschool when talking with 3 y.o. grandson*)

Output Mode

- Voice banking
- Off-the-shelf speech synthesis
- Personalized speech synthesizer

Voice Banking

- Allows communication in pALS' voice and intonation patterns to retain personality during nonspeaking condition "*Yeah, right!*"
- Reduces depersonalization of AAC
- Reduces feelings of loss of control, helplessness;
- Reduces anxiety and fear
- pALS takes active role in care
- Gives family a concrete way of assisting in care by choosing messages

Source: Costello, John. (2000). AAC Intervention in the Intensive Care Unit: The Children's Hospital Boston Model. *AAC*, 14: 144-153.

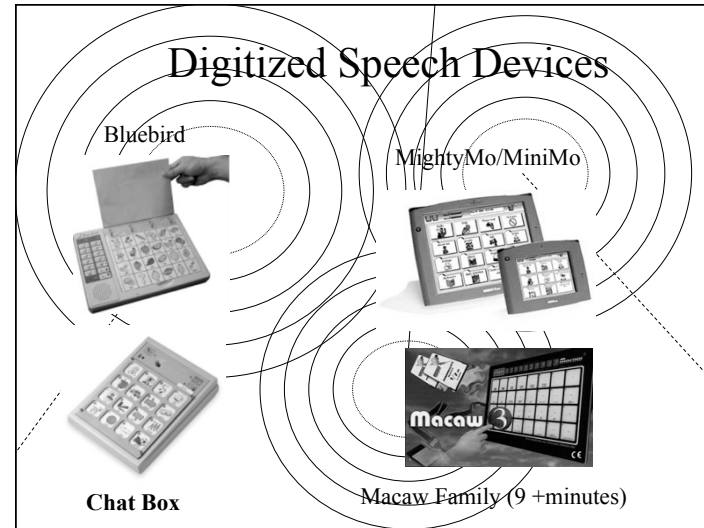
Voice Banking Procedure

- Before starting remind yourself to be sensitive to psychological demands of voice banking
- Be prepared to stop if too emotional
- Determine messages to be saved for later use
- Consider
 - Personal, idiosyncratic messages
 - Question words
 - Purposes of communication
- Digital recording best option (<http://audacity.sourceforge.net/>)
- Transfer to speech generating device later

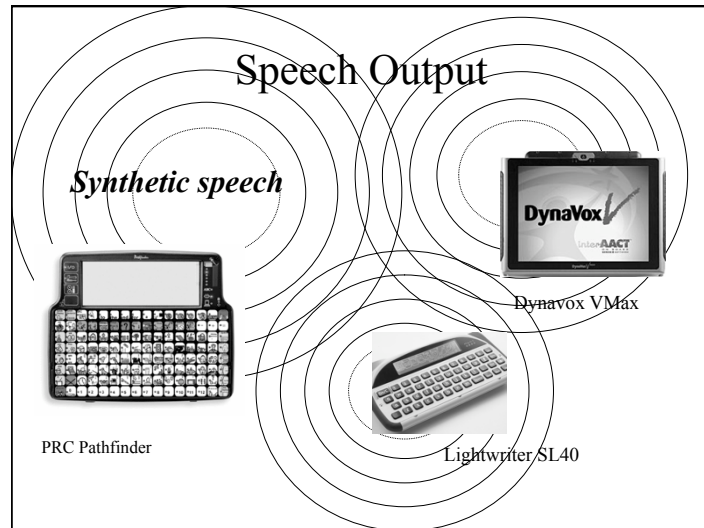
Speech Synthesis

- Quality of synthetic speech:
 - Multilingual options for same SGDs
 - As speech science advances, so does the quality of speech output.
 - Synthetic vs. Concatenative
- Customized synthetic speech:
 - The concept: Synthesize a voice based on the parameters of an individual user.
 - Record samples of user's voice and use as data for speech synthesis.
 - <http://www.modeltalker.com/>

Digitized Speech Devices



Speech Output



Software Example



Motor Access

- Alternative access options
- Switches
- Eyegaze options
- BCI (brain-computer interfaces) options
- Always consult an OT/PT with ALS experience

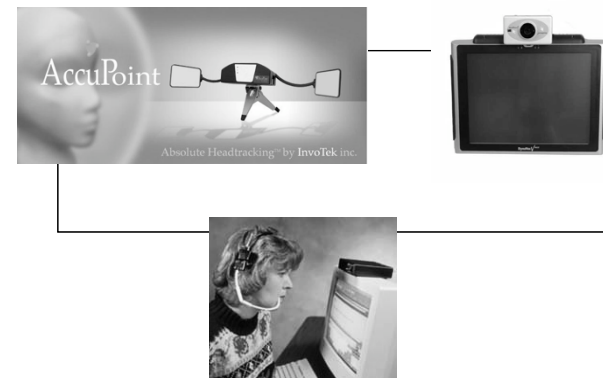
Positioning

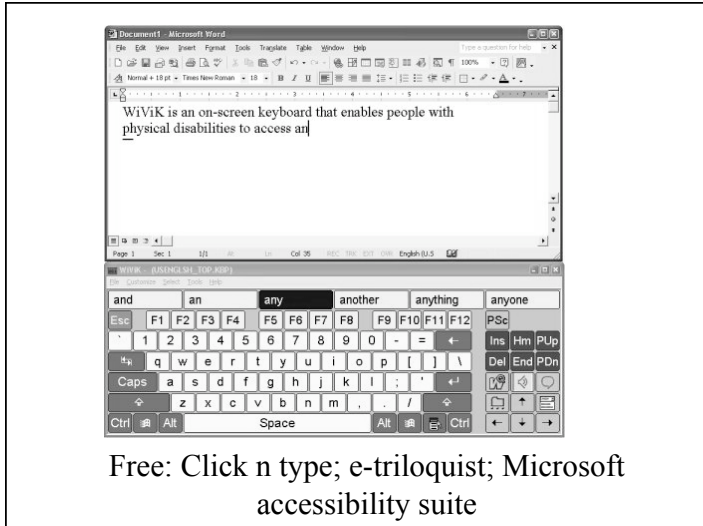
- Majority of time in power chair = huge potential for chronic pain, injury, terrible support for access, high fatigue, gross underestimation of potential.
- Variations in tone throughout body (high in some regions, low in others) requires extensive assessment and support.
- Reflex patterns can be controlled to a degree via positioning/support.

Positioning

- Attempt to achieve symmetry
- While placing a switch imagine what it would be like to use it.
- Stabilize trunk and extremities. Don't ask someone to extend their arm into space or crane their neck.
- Minimize residual movement (usually by providing good support).
- Allow resting position.

Head Mouse Access





Eye gaze as input www.cogain.org

Catalogue of currently available eye trackers for interactive applications within AAC

- [Alta Technologies GmbH](#)
Intelligaze IG-30
- [DynaVox Technologies](#)
EyeMax System
- [Eye Response Technologies](#)
ERICA
- [EyeTech Digital Systems](#)
EyeTech TMS
- [H.K. EyeCam](#)
VisionKey (5+, 6V/H, 7)
- [HumanElektronik GmbH](#)
SeeTech
- [LC Technologies](#)
The Eyegaze Communication System, Eyegaze Edge and Eyegaze Edge Tablet
- [Metrowision](#)
VISIONBOARD
- [Opportunity Foundation of America](#)
EagleEyes
- [PRC \(Prentke Romich Company\)](#)
EOPoint
- [TechnoWorks CO. LTD.](#)
TE-9100 Nursing System for Enhancing Patients' Self-support
- [Tobii Technology](#)
Tobii C8, C12, CEye, MyTobii P10, D10



Clinical Application...

- AAC Paths will vary due to:
- Rough ALS type
 - Bulbar onset
 - Limb onset
 - Presence of FTD
- Patient specific variables
- Environmental support
- Access to external support (clinic, reps, etc.)

Primary Progressive Aphasia

What is PPA?

1. A degenerative language disorder.
2. A language disorder that does not easily fit into the classical aphasia typology.
3. A syndrome, often followed by cognitive decline, that has been described with 3 variants.

Diagnostic Criteria for PPA

Mesulam, M. *Annals of Neurology*, 49 (4), April, 2001

- | | |
|--|--|
| <ol style="list-style-type: none"> 1. Insidious onset and gradual loss of word finding, object-naming or word-comprehension skills in spontaneous conversation; 3. Intact premorbid language skills; | <ol style="list-style-type: none"> 2. ADL limitations attributable to language impairment, for at least 2 yrs after onset; 4. Absence of significant apathy, disinhibition, forgetfulness for recent events, visuospatial impairment, visual recognition deficits or sensory-motor dysfunction within initial 2 yrs of L impairment; |
|--|--|

Diagnostic Criteria for PPA

Mesulam, M. *Annals of Neurology*, 49 (4), April, 2001

5. Acalculia & ideomotor apraxia may be present in first 2 yrs.
6. Other domains possibly affected during 2 yrs, but language most impaired function.
7. Absence of specific causes (i.e., stroke, tumor, infection, metabolic disorder) on neuroimaging.

Diagnostic Characteristics

- Age of onset 40-75 years old, mean onset age of 60 years.
- Preponderance of male patients – 2:1 ratio
- Roughly 50% with genetic component

PPA is a clinical syndrome which may overlap with

- Alzheimer's disease
- Frontotemporal dementia
- Corticobasal degeneration
- Dementia-lacking-distinctive-histology (DLDH)
- CJD
- ALS
- ACD (Asymmetric cortical degeneration; Caselli, 1995)
- Pick's disease

Kertesz & Munoz, *Amer. J. of Alzheimer's Disease*. (2002), 17(1).

3 variants of PPA

- Nonfluent progressive aphasia (NFPA)
 - *PPA with agrammatism*
- Semantic dementia (SD)
 - *Fluent progressive aphasia*
- Logopenic progressive aphasia (LPA)
 - *PPA with comprehension deficits*

NFPA: nonfluent progressive aphasia

(most common type of PPA in an AAC clinic)

- *Anomia* or “trouble thinking of or remembering specific words when talking or writing”.
- Initial “empty” speech with preserved prosody and fluency but little information.
- Slow, hesitant and labored speech frequently punctuated by long pauses and filler words, early symptoms of agrammatism.
 - Simplification (generic words for specific concept)
 - Circumlocutions
 - Substitution by fillers (“thing,” “Whachamacallit”)
 - Phonemic paraphasias
- Marked increase in speech errors, early symptoms of a progressive apraxia of speech.
- Relatively preserved single-word comprehension with later difficulty comprehending complex syntactic structures.
- Stronger oral reading than generative language skills.

Progression of disease varies

- Yes/No confusion for responses
- Apraxia of Speech
- Agrammatism → Mutism
- Written language generation often mimics spoken language generation

Case Example

“Jay”

[video clip]

Semantic Dementia (SD)

- Fluent, grammatical speech;
- Confrontation naming deficits (often word knowledge can be accessed through visuo-perceptual route)
- Surface dyslexia (written word does not cue lexicon, auditory does)
- Deficits in word comprehension (2-way naming problems) *“In time, even the most common words fail to be decoded and the comprehension of conversation becomes impossible, although visual recognition of objects and faces remains relatively preserved” (Mesulam, 2001)*
- Later connected speech includes neologisms and semantic paraphasias

Case Example

- “Deb”
- Excellent Comprehension
- Word Salad
- Marginally aware that she is serving up as large a helping of word salad as she is
- Confusions increasing, no longer able to handle phone calls and independent shopping, etc.

Logopenic progressive aphasia (LPA)

- Repetition and comprehension impaired for sentences but preserved for single words
- Naming moderately affected
- Severely impaired in digit, letter, and word span tasks
- Pointing does not improve performance
- No influence of word length and do not show the normal phonological similarity effects
- Atrophy or decreased blood flow consistently found in the posterior portion of the left superior and middle temporal gyri and inferior parietal lobule (Gorno-Tempini, M.L., et al., *Neurology*, 2008)

Case Example

- “Doug”
- Virtually no verbalizations beyond 3-4 perseverative phrases (“I’m okay” or “I love you”)
- Decent naming ability, picture presentation
- Terrible performance when picture board presented – semantic linking only

Stages of Intervention during the Neurodegenerative Language Process: NFPA

- I. No noticeable interference with generative language but some word finding problems;
- II. Detectable language lapses with hesitations and dysfluencies;
- III. Reduction in language use leading to behavioral strategies and introduction of low tech AAC (circumlocutions; paraphasias; simplification; agrammatism)
- IV. Use of AAC tools and other techniques;
- V. No functional language.

Communication Treatment Goals

- **#1: To compensate for progression of language loss (NOT stimulate the language system to regain skills).**
- **#2: To begin compensatory treatment as soon as possible. Be proactive so patient can learn to use communication strategies and tools.**
- **#3: To include primary communication partners in all aspects of training, with outreach to multiple partners.**

The Treatment Challenges:

1. To put the patient's residual lexicon **visually in front** so that the patient can participate in daily activities as language skills decline.
2. To begin soon enough to allow learning of this approach.
3. To engineer the environment to support successful communication.
4. To teach the communication partner that functional communication will be partner driven – this often upside down for many couples.

Low tech tools


- Customized communication boards
- Customized brag books
- Remnant bags/boxes
- Single message devices
- Talking photo albums
- Dry erase board

High tech tools

- Dynamic display devices with customized messages:
- Dynavox V or M3, or Express
- Words+ Say It Sam Tablet SM1



- Digitized devices with hard copy pages (Saltillo Bluebird II or VocaFlex)
- Talking Photo Album (Augmentative Communication, Inc.)



Messaging

- What messages to include in tools?
- Messages that cannot be expressed by other means
- Story telling: 87% of adult conversation is reminiscence and chatting

Partner training is an essential component of AAC for persons with PPA.

- To tailor intervention and compensatory techniques to specific functional needs (PPA type)
- To identify vocabulary for external lexicon.
- To support use of tools in familiar communication settings.
- To identify new opportunities for communication with tools.
- To offer or confirm choices.
- To initiate conversation during late stages of PPA.

Rogers, MA & Alarcon, NB. (1998). Dissolution of spoken language in primary progressive aphasia. *Aphasiology*.

Impairment 1993 -> 1997	Intervention Unassisted -> Assisted
Increased frequency of speech errors Increased severity of apraxia of speech Difficulty accessing phonologic form Decline in appropriate syntax use Difficulty accessing semantic information Decreased access to orthography Auditory comprehension declines Reading declines Amnesiac	Develop long term Probes Pacing, syllable segmentation Decrease fillers, word retrieval Identify topics and key words Gestures, writing, drawing Involve communication partners Communication book AAC device Partner-focused guided communication

Early Stage Intervention

- Learn about the patient and their primary communication partners (Hx, interests, family, ADLs, travel, etc.)
- Integrally involve the patient in constructing “memory” booklets, word lists, hierarchy of difficult situations – always evolving
- All practice should occur with the primary communication partner for future success
- More now = more later

Mid-Stage Intervention

- Capitalize on early learning and practice with communication partner to bulk up communication books
- Be mindful of text vs. pictures, combination, visual scene display, etc.
- Be mindful of comprehension difficulties (auditory, visual, orthographic)
- Use other output modes when possible (e.g. drawing, writing)

Late Stage Intervention

- Will likely scale back longer, more complex communication books, lists, etc.
- Stress daily routines, procedural memory for enjoyable activities
- Constantly monitor communication partner’s ability to facilitate use of tools
- Watch for further changes in comprehension, ability to use other modes of output, etc.

www.brain.northwestern.edu/PPA*

- PPA Newsletters from 1996 (on line)
- Join mailing lists
- Connect to PPA databases
 - Clinician search and database
 - PPA literature database
- Question and answer archive
- PPA Family Support Group
- *maintained by The Cognitive Neurology & Alzheimer’s Disease Center at Northwestern University, Dr. M. Mesulam

Alzheimer's Disease

*Individuals with dementia
have NOT traditionally
been listed as a clinical
group that has benefited
from AAC.*

Alzheimer's Disease

- Most common form of dementia
- >65years old = 10%
- >85 years old = 50%
- 4x more likely if first order relative affected

Alzheimer's Disease

- Episodic memory (events) sig impaired
- Semantic memory (facts) mod → sig impaired
- Procedural memory (doing stuff) lightly impaired
- Recognition better than recall
- Very little evidence for how AAC works best for people with Alzheimer's dementia

Premise of pairing AAC and dementia

- Pairing the external aid with familiar and spared skills (such as page turning, reading aloud) should maximize a person's opportunity for success
- These skills are based on intact procedural memory
- The stimuli are relevant to a person's ADLs
- It helps "chunk" information, provides external stimulation

So, what AAC strategies and aids should we consider for adults with dementia?

Electronic Devices

- Speech generating devices
 - Synthesized speech output
 - Digitized speech output
- Computers (Handheld, wearable, or desktop)
 - Dedicated versus integrated devices
 - Software purposes:
 - Schedules
 - Reminders
 - Augmented input or output



AbleLink Web Trak



AbleLink Handheld Visual Compass



ERI Picture Planner

CIRCA

A hypermedia reminiscence program designed and marketed in Scotland, then the UK

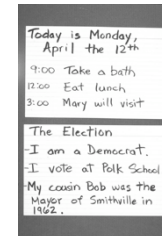
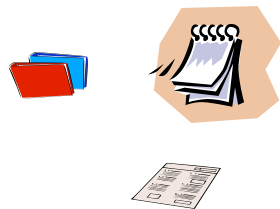


• “Foto Dialer”



External memory aids:

- Notebooks
- cards
- communication boards
- calendars
- signs
- timers
- labels
- color codes
- tangible visual symbols





Bourgeois research (1991-1994)

- Made individualized memory wallets or cards
- Persons with mild AD
- Measured outcomes of conversations between trained caregivers (spouse, adult child, day staff)
- Wallets: Pictures and words for 3 topics:
 - Family names
 - Biographical information
 - Daily schedules

Results

- Increased the frequency of factual information
- Decreased the rate of ambiguous, perseverative, erroneous, or unintelligible utterances
- Increased the conversational responsibility (turn taking) of person with dementia
- Increased the number of on-topic statements during a conversation

*So, we have some evidence
that straightforward electronic
and non-electronic AAC
options can work.*

*How can we make them work
better?*

3 things to consider for each aid:

1. The messages or language in the aid
2. How those messages are presented
3. The output, or result, of selecting a message from the aid

What messages should be chosen?

- Autobiographical memories might be accessible
- Messages that affect the environment might be more meaningful
- Documented message topics from the language of elders

Some elder speak topics

Svoboda, E. (2001). Autobiographical interview: Age-related differences in episodic retrieval. *Department of Psychology*. Toronto, University of Toronto: 107.

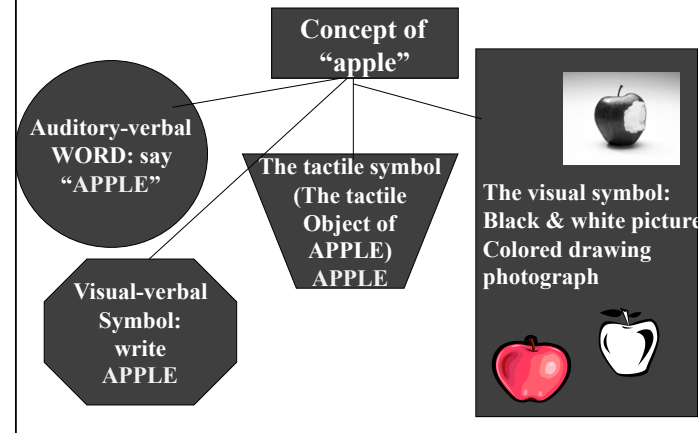
Emotional

- Losing something important
- Being embarrassed
- An argument
- Pet dying
- Being discipline at school
- Being lost
- Meeting a special friend
- Being chosen
- Wearing a special piece of clothing
- Holiday

Family Events

- Birth of sibling
- Someone's death
- Child's first day of school
- First house
- Moving to new home
- Moving to new school
- First love
- Wedding
- Engage
- First dance
- First child

Levels of representation



Symbol: visual or auditory representation for a referent

- Color
- Size
- Level of representation
 - Iconicity: Ease of symbol recognition
 - Transparent symbols- visually resemble their referents.
 - Opaque symbols- visual relationship to referent is not obvious. **DUCK**



What will be the result of symbol selection?

- Communication partner validates message
- Electronic voice output (if used) labels the symbol

AD AAC research question:

- Do AAC tools improve the quantity or quality of conversation by individuals with moderate Alzheimer's disease?

Specific Aims

- 1. To compare the effects of different input modes in an AAC device on conversational skills of persons with moderate AD.
 - Print alone
 - Print + photographs
 - Print + 3-dimensional miniature objects
 - Photographs alone
 - 3-dimensional miniature objects alone
 - Control condition (no board).

- 2. To compare the effects of output mode in an AAC device on the conversational skills of persons with moderate AD.
 - Digitized speech output
 - No speech output

Lena's cooking board (2-D only)



Lena's cooking board (3-D only)



Board with 2-D symbols + print



Method

1. Identify participant and randomly assign to condition for symbol type & voice output
2. Determine participant's preferred topic and vocabulary
3. Develop communication device for condition
4. Conduct videotaped conversations with participant for various conditions in their homes

Participant randomization to symbol type & voice output conditions

Output Mode	Input Mode		
	Print only	2-D +Print symbols	3-D + Print symbols
Voice output	5	6	3
No voice output	8	11	8
Total	13	17	11

Results for Voice Output

- Fewer utterances with Voice Output ($p < .007$)
- More Minimal Speech with Voice Output, especially one word utterances ($p < .018$)
- Anecdotal evidence suggests participants are distracted by Voice Output

IMPORTANT FINDING!



AAC supports simply placed in front of people with modAD does not affect conversation

No specific symbol type was beneficial
Attention to board or physical reference to board was minimal or nonexistent for many subjects

*Clinical message:
AAC WITHOUT TRAINING IS
NO AAC AT ALL!*



Add
training
component:



What is spaced retrieval?



•“A memory intervention that gives individuals practice at successfully recalling information over progressively longer intervals of time.” (Jennifer Brush & Cameron Camp, 1998)

•Relies on classical conditioning and repetitive priming.

•Used with elders with dementia to help remember compensatory strategies such as using a schedule, swallowing safely, using a daily calendar, and using adaptive equipment.

Adjusted study design

- Conditions varied within participants:
 - 1 primed experimental condition
 - 2 control conditions (no AAC device):
 - Standard control
 - Primed control
- 99 total conversations:
 - 3 conversations/condition
 - 9 conversations/participant

Add new dependent variables closely tied to semantic primes

- Number of primed words used during conversation
- Number of utterances
- Percent 1-word utterances
- MLU in words
- Type-token ratio
- Number of references to AAC device

*Used SALT software for transcription and analysis
(Systematic Analysis of Language Transcripts, Miller & Chapman, 1986-2000)*

Results: Subjects used the AAC device more when conversations were primed.



(References to AAC device during conversations quadrupled, as compared to untrained conversations)

AAC combined with spaced retrieval exercise improved access to topical vocabulary.

In AAC-supported conversations, subjects used significantly more primed words, as compared to control conditions.

Priming Wins with AD!

- AAC improves conversation of adults with modAD
- when training for semantic priming is added
- to account for attentional, perceptual, or memory impairments that interfere with performance.



Early Stage Intervention

- Learn about the patient and their primary communication partners (Hx, interests, family, ADLs, travel, etc.)
- Integrally involve the patient in constructing “memory” booklets, word lists, hierarchy of difficult situations – always evolving
- All practice should occur with the primary communication partner for future success
- Teach/practice priming method

Mid-Stage Intervention

- Continue to teach/model priming techniques to communication partners.
- Capitalize on early learning and practice with communication partner to bulk up communication books
- Be mindful of text vs. pictures, drawings, visual scene display, array size, etc.
- Be mindful of comprehension difficulties (auditory, visual, orthographic)

Late Stage Intervention

- Scale back communication books, boards to stress function, ADLs, basic choices, etc.
- Stress daily routines
- Constantly monitor communication partner’s ability to facilitate use of tools
- Monitor use and success of priming

*Assistive Technology
without training is not
assistive.*

- Rick Creech, A.T. user and advocate

Thanks for listening!

Chris Gibbons
gibbons@ohsu.edu
503-494-0378