

# ALS and Augmentative Communication: Seeking Improved Outcomes Through Early Engagement in Assessment, System Design, and Implementation

John M. Costello, MA CCC-SLP  
Director, Augmentative Communication Program and  
ALS Augmentative Communication Program  
Boston Children's Hospital



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For more information, handouts and Video links go to:

<http://www.childrenshospital.org/ALSaugcomm>



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For lots of related resources, Join us on Facebook at:

<https://www.facebook.com/ACPCHBoston>



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ALS Augmentative Communication Program

John Costello, SLP    Meghan O'Brien, SLP    Amanda Smith, SLP    Peggy Dallas, CTR

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### Objectives

Participants will be able to:

1. List no-tech, low-tech and high-tech augmentative communication strategies
2. Detail the steps for pro-active message banking
3. Describe the feature matching process for assessment and evidence based trials

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what i think      what i say

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**Being Proactive**



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**Program Mission:**

The mission of the ALS Augmentative Communication Program is to provide comprehensive augmentative communication/assistive technology assessment, trials and training to people with ALS from the time of diagnosis through the lifespan.

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**Program Goal:**

“Our goal is to support communication and daily functional needs, sustain personal control and dignity, facilitate continued social and vocational goals and maintain quality of life through thoughtful implementation of solutions ranging from high technology to quick access/low tech tools and strategies. This is best accomplished by ACP-ALS clinicians constantly communicating and collaborating on how best to support patient-centered functional outcomes in the presence of changing physical abilities while providing support to a person with ALS and his/her family.”

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**What to expect:**

Our team hopes to meet people as early as possible after diagnosis but remains eager to support people with ALS at any time during their journey.



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Our assessment and intervention protocol has developed and evolved based on guidance and direction from people with ALS, their family and their care providers.

Our affiliation with many proactive neurologists and team members, initially through the MGH ALS Clinic, has given us the opportunity *and honor* to learn from many people with ALS who choose to meet with us early in the disease process.

This continues to inform our practice and evolve our protocol.



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Dear ALS Clinic provider,

Thank you for allowing us to care for your patients by making referrals to the ALS Augmentative Communication Program.

When introducing the idea of an augmentative Communication assessment to a person with ALS it may be most useful to offer the following information:

"Communication is a pretty broad word. It obviously includes speaking with people one-on-one and in groups, but it also includes writing, talking on the telephone, using a keyboard/computer, using the internet, social media or texting – even if you are having problems with your hands. We all use multiple methods of communication other than speech; we all use augmentative communication strategies.

This program will partner with you to monitor your communication success across all methods of communication. The goal is to be proactive and provide as much information as possible and have you drive all the decisions. If something is becoming more challenging, they will collaborate with you to increase your success by introducing and assessing tools and strategies to support you."



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### Since January 2016

- 240 new referrals for AAC evaluation and treatment
- 610 completed appointments




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### AAC as part of best practice in ALS patient Care

*Recommendation of Bulbar committee of NEALS*

- .....These survey findings highlighted the need to develop a standardized set of best practice guidelines, for the clinical assessment and monitoring of bulbar function throughout the disease course. Therefore, the aim of this symposium was to develop a practical consensus based bulbar assessment protocol feasible for implementation in all ALS multi-disciplinary clinics for speech, swallowing, and augmentative communication.




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### AAC as part of best practice in ALS patient Care

*Recommendation of Bulbar committee of NEALS*

- .....The Augmentative communication assessment should focus on assessment of success for communication participation across a variety of communication functions, proactive introduction of voice and message banking, early consideration of low tech/quick access strategies and exploring strategies to maintain functional use of telephone, texting, keyboarding, internet access as well as standard methods of face to face and distance communication.




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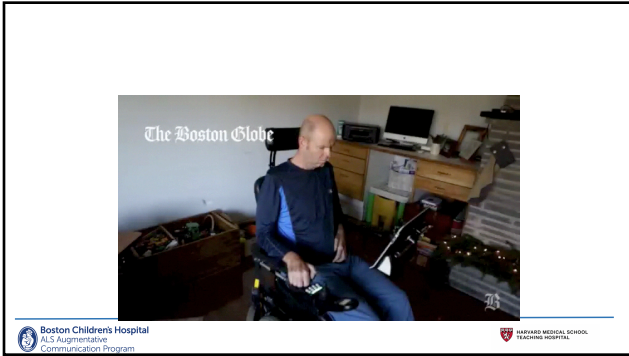
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Begin with  
**THANK YOU**  
to so many extraordinary  
people with ALS

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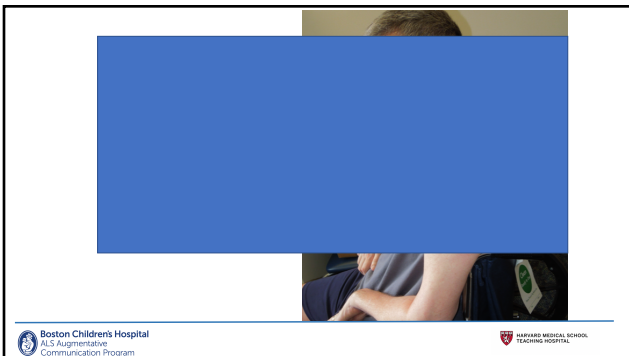
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Opening statement:

***“My goal is to waste your time”***

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Second statement:

***“You are stuck with us”***

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*For our purposes today:*

**Defining Communication**

**The ability to express oneself face to face, in group settings, via telephone, writing, email or text.**

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*In addition: QUALITY OF LIFE indicators identified by people*

- Maintain social connectedness
- Avoid or minimize changes to communication partners
- Continue to perform activities of interest/importance, even through modified means (including work)




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### Service delivery

- introduce strategies to minimize fatigue associated with speech including: strategies to enhance intelligibility or preserve energy, and may introduce varied voice amplifiers.
- partner with patient and family to create – over time – custom quick access communication tools
- May introduce our model of Message Banking and/or options for Voice Banking




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### Service delivery

- Introduce and assess various communication technologies to support face to face communication as well as communication through internet/telephone.
- Establish and coordinate evidence based trials
- assess and provide call systems to meet individual needs.




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### Service delivery

- Provide partner training
- Home-based services may be available when patient can no longer travel to the center.
- Tele-support
- Web based training modules on select topics (to launch Summer 2017)
- Web based downloadable templates (launched and growing)

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### AAC/Speech Pathology Protocol of Assessment Considerations

Speech strategies	
Amplification considerations	
Amplification while using BIPAP	
Partner training	
Call system for emergency and attention	
Quick access encoding strategies (non-electronic)	
Electronic encoding	
Quick access encoding strategies (non-encoding)	
Writing strategies	
Message Banking	
Voice Banking	
Speech Generating Device assessment	
Speech Generating Device trial for Practice Based Evidence	
Training, implementation/integration	

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### Occupational therapy/Assistive Technology Protocol of Assessment Considerations (wait for Peggy Dellea!)

- Positioning/support
- Access to mobile technology
- Phone access
- Call system/attention signal access
- Environmental control
- Access to books (hardcopy or digital)
- Computer access: keyboard
- Computer Access: mouse
- Computer Access: speech/voice
- Speech Generating Device Access
- Training

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**Speech Strategies**

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**Environmental strategies:**

a. Speaking with competing noise in the environment is difficult under any circumstance. For people with ALS, trying to speak when there is lots of noise can be extremely difficult. While you should consider using a voice amplifier throughout the day ([link to voice amplifier page](#)) here are some other considerations:

- a. Make sure you have your partner's attention
- b. Mute the television, radio or other sound source when speaking

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**Environmental strategies:**

- c. Make sure your communication partner can SEE your face and hear you (in the event partner has hearing loss) as you are speaking. Not only can seeing you speak make it easier to understand words or sounds that are not clear but also gestures, facial expressions and your eyes add a great deal of information to the message.
- d. When going to restaurants, consider choosing a table that is away that is in a quieter section of the restaurant.

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Environmental strategies:

- e. When in **noisy environments** such as grocery store, shopping plaza, sports events OR when in the car (even in a well insulated car, traffic and road noise can be significant), use a **voice amplifier**.
- f. **Avoid speaking while eating** (when food is in your mouth) or drinking

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Speech Production strategies:

By making some modifications to the way you speak, you can enhance the intelligibility of your speech. These modifications include:

- a. **Pace your speaking rate.** Providing a brief stop after each word you speak can slow the pace of your speech and improve intelligibility. As one man with ALS recently stated to us: "When I think of all of my partners as non-English speakers, I naturally pause between each word and speak at a clearer pace". Providing this pause after each word will also eliminate the merging/slurring of the last sound of a word and the first sound of the next word!

**NOTE:**  
Pacing does *not* mean speak slowly! Speaking slowly will often require more energy and will likely be less intelligible! ALSO – Resist trying to talk louder! Speaking louder will only use more energy and does not impact your intelligibility.

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Speech Production strategies:

- b. **Produce each syllable of a word:** If it is difficult to speak clearly and sometimes parts of words are not intelligible. While the most important advice is to preserve your energy, consider producing multi-syllabic words in a deliberate and paced manner. This way, every part of the word is clear.

- c. **Consider producing sounds that are sometimes 'glossed over'** in words: In American English, some words the 't' sound is normally 'softened' when followed by a vowel, but with typical speech production they are understood. An example of this is the word 'water', which is most often produced 'wader' with the 't' being distorted. For people with ALS, it may be helpful to produce some sounds more deliberately so, in this case, one may speak in a paced manner 'wa – ter'. Examples of other words include: button, kitten, waiter, theater, etc.

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Speech Production strategies:

d. Economize/phrase words per breath: Many people try to speak as many words per breath as possible. For the natural speaker, this often results in some words being softer or less clear. A person with ALS should 'economize' words per breath so each word has strong breath support. When pacing one's speech, it can be easier to also speak fewer words per breath so, if you feel out of breath while speaking, consider pausing and taking a new breath.

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Your positioning while speaking:

Growing up, many of us were told 'sit up straight' or 'don't slouch'. When it comes to clarity of speech and ALS, positioning is really key! To maximize breath support for speech production, be sure you are comfortably positioned. If you are sitting, be sure you are not leaning forward, you are not too reclined or leaning to the side as it will be harder to speak loud enough or clearly.

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Additional speech related strategies:

•Stretching/limbering – NOT oral motor exercise/repetitive motion. \*\*\*Discuss issues of muscle recovery.

•Letter cueing

•Topic cueing

•Counsel on positioning/support

•Counsel on speech fatigue/over-use and difficulty with recovery



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What to do: If your communication partner asks you understand a word, use an alternative letter to spell for the first letter of the target word for you can substitute the word.

Letter cueing devices can be organized in many different ways. Below are a few:

**WORDY Format**

**WORDY Format with color-coded letters**

**Alphabetical organization**

**Topic Cueing**

Below is an example of a generic topic cueing board. A topic cueing board should represent the topic of the current activity. The board should be highly visible to you and the topic of the board should be the current topic of the activity.

NO	YES
SHUT	DOWN
R	S
X	Y
8	9
0	1

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### Letter Cue board

THE WORD BEGINS WITH.....

Q	W	E	R	T	Y	U	I	O	P
A	S	D	F	G	H	J	K	L	
Z	X	C	V	B	N	M	<i>Start again</i>		
br	cr	fr	gr	tr	pl	str	<i>Next word</i>		
bl	cl	fl	gl	sw	dw	tw	<i>End</i>		
sl	sc	sk	sm	sn	sp				
sw	squ	spl	spr	ser					

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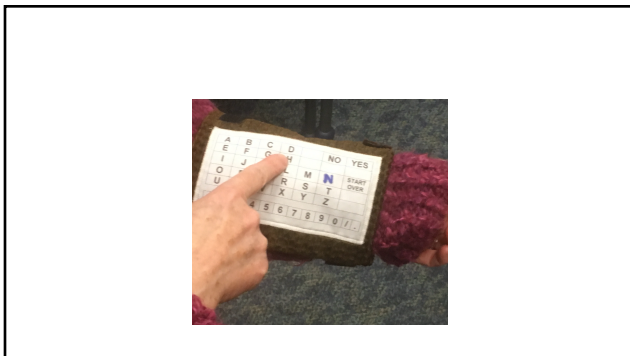
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**Amplification Strategies**

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Often will be told:

“I can talk loud enough, I just get worn out by 2 in the afternoon and am too fatigued”

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**Amplification considerations**

- Counsel regarding impact of speech efforts on fatigue
- Discuss pro-active approach (as appropriate) to preserving energy
- Introduce amplification options
- Identify microphone headset placement considerations with head movement

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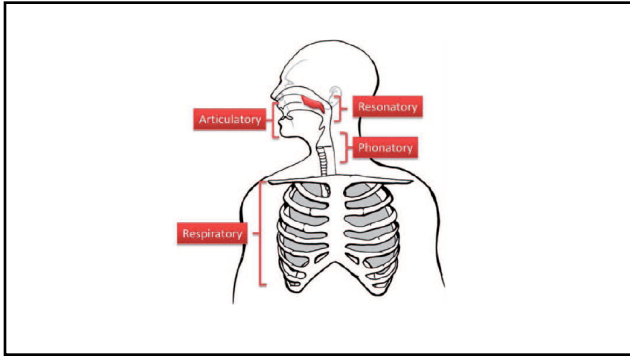
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### Articulation

Highly coordinated movement of lips, tongue and jaw

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### Respiration

An often noted symptom is patient taking more frequent and longer pauses between words or word clusters when speaking.

\*\*\* many people continue to try to speak as many words as possible on a breath and 'trail off'

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**Amplification with BiPAP**

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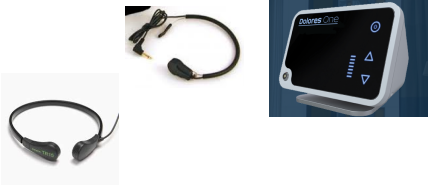
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Amplification while using bi-pap

Assessment of transdermal microphone options



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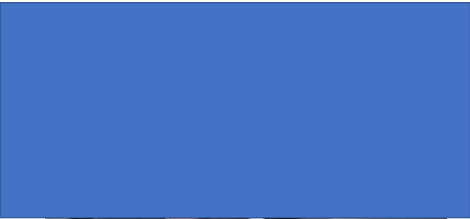
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Partner Training

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*"I've noticed that people are uncomfortable with silence and feel the need to fill it, even as I am putting together a message. Because I am slower, other conversations start or people ask me lots of yes/no questions and not only do I lose the opportunity to complete my message but I also lose the opportunity to be part of the conversations happening while I am putting my message together"* R.H., age 55

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### Partner training

- Identify communication partners/supports
- Share anecdotal feedback from people with ALS and families
- Share handout on "Guidelines to Communication Partners"
- Discuss strengths and major challenges with asking yes/no questions
- Discuss the pros and cons of prediction and permissions that should be in place.

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**Partner Training**

**Objectives**

- Identify communication partners/supports
- Share anecdotal feedback from people with ALS and families
- Share handout on "Guidelines to Communication Partners"
- Discuss strengths and major challenges with asking yes/no questions
- Discuss the pros and cons of prediction and permissions that should be in place.

**Introduction**

The following activities have been designed to help for several people with ALS, including that this...

**Activity 1: Identifying Communication Partners**

An communication partners, changing our behavior can really help reduce this fear...

**Activity 2: Anecdotal Feedback**

Share your experiences with communication partners...

**Activity 3: Guidelines to Communication Partners**

Share your experiences with communication partners...

**Activity 4: Strengths and Challenges**

Discuss the pros and cons of asking yes/no questions...

**Activity 5: Prediction and Permissions**

Discuss the pros and cons of prediction and permissions...

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*Guidelines for Communication Partners*  
*(Identified by young adults and adults who are losing ability to speak)*  
 No rule fits everyone BUT these are some points to consider putting into practice.  
**THANK YOU!** for the generous guidance from so many of our ACP patients:

1. Don't talk louder just because I can't talk
2. Don't talk over me as I try to communicate. My speech is compromised and it takes too much energy to continue to try to get my message across while you interrupt/over ride me.
3. Don't interrupt - PLEASE let me finish my thought, otherwise it sends the message that you don't value what I have to say.
4. Recognize that when an efficiency strategy is used by someone with compromised speech, using phrases or speaking in a direct manner is **SHOULD NOT** be confused with a lack of sophisticated linguistic competence or social skill.
5. If you didn't call me "deaf", "mute", or other terms of endearment before, **PLEASE** don't change the way you talk with me now unless we have mutually developed a new intimate relationship.
6. Don't touch me (move my arm, etc.) or my chair without letting me know you are doing so and requesting permission.
7. I know you are trying to be efficient or save me from fatigue by speaking FOR me, but please ask my permission before sharing information related to me.
8. Even though you may know the requested information ALWAYS ask me if I want you to speak for me or someone in the conversation to share that I am in charge.
9. I'd rather you talk with me, tell me stories and fill me in on your life - even when I have a hard time building up my end of the conversation - AS OPPOSED TO NOT talking with me because you know I have a hard time responding.

Revised October 2017 HCP  
 ALS Augmentative Communication Program © 2018

Oh, I'm sorry... Did the middle of my sentence interrupt the beginning of yours?

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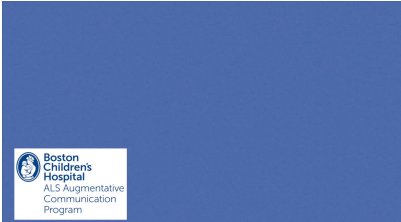
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Bob on predicting



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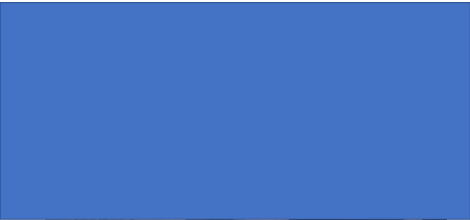
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Holly on predicting (or being inpatient)



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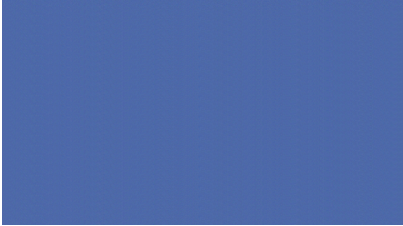
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Bob (assessing dwell-less keyboard)  
discussing people reading over his shoulder



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**Calling/attention systems**

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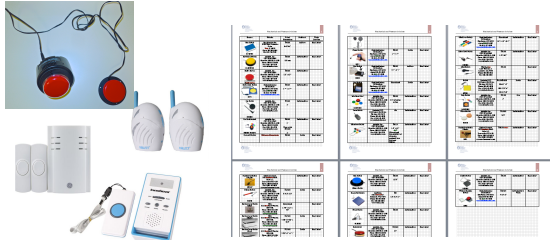
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### Call system(s)/switch control



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When using in the same house...



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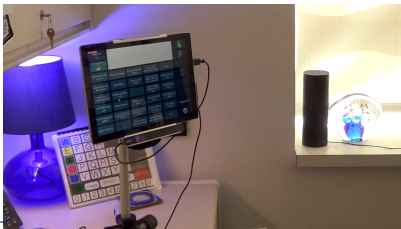
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### Alexa Voice Call



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### Quick Access Encoding

- Standard Etran two-step encoding
- eye gaze and partner assist combination (AEIOU)
- Alpha – color encoding
- EyeSpeak board

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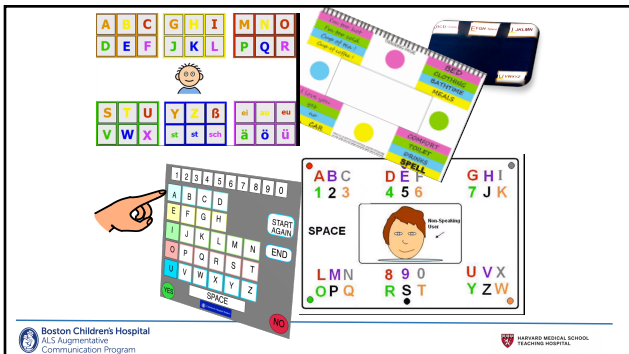
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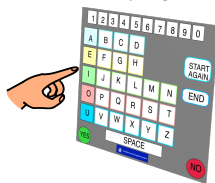
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### Partner Assisted Scan spelling

- Establish patient's "yes/no" response
- Scan by row/column to identify target




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**Training video**

**Partner – Assisted Spelling using an AEIOU configuration**

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**Partner assisted scan spelling**

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**A-E-I-O-U COMMUNICATION BOOK**

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**Etran**  
 Video courtesy of ALS association  
 (Iowa Chapter YouTube)



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**Electronic encoding**

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**Electronic encoding**

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- Minimize working memory demands for communicator and partner
- Provide a visual script/reminder of message progress

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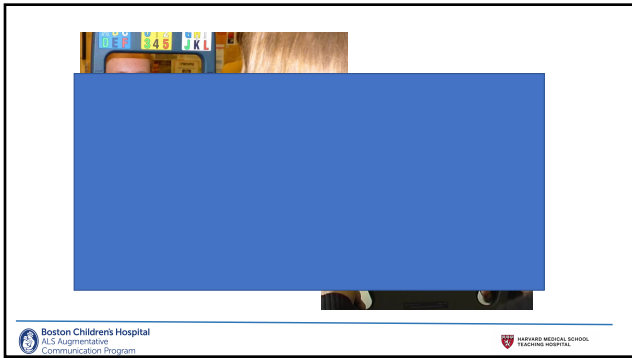
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**Efficiency strategy when using encoding**  
 \* With electronic encoding it auto expands  
 \*\* With non-electronic encoding you need a 'cheat sheet'

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- A logical relationship exists between the key words of the phrase or sentence and the code selected
- O D = Please open the door
- J C = My name is John Costello

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**Quick access: NOT encoding**

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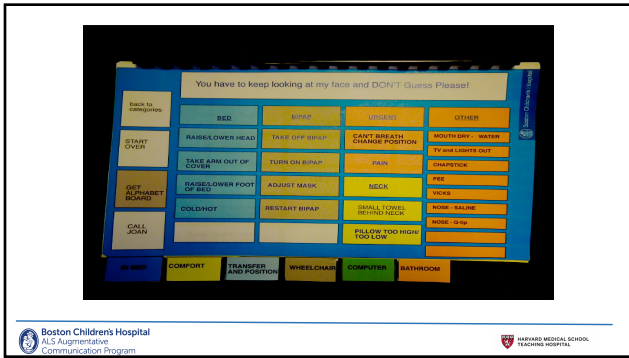
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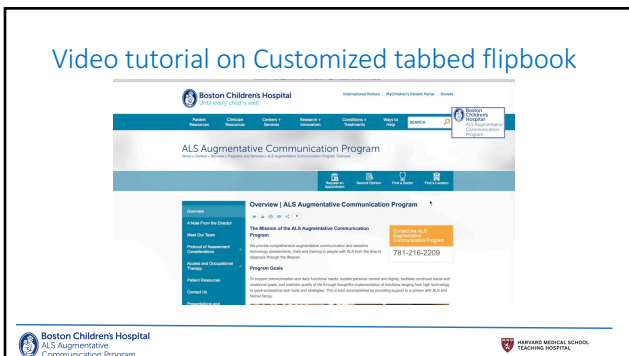
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Could Do Don't Feel For From Get Go Had Has Have He  
 Help Her Him His How I I am If In Is It Know  
 Like Maybe Me More My Need No Not Of Okay On Only  
 Or Our Please Put She So Thanks That The Their Them Then  
 There These They Think This To  
 Up Us Want Was We Were  
 What When Where Which Who Why  
 Will With Would Yes You Your

<http://lowtechsolutions.org>

Amy Roman's boards  
 Sold by Margaret Cotts

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Nancy, core board and laser pointer

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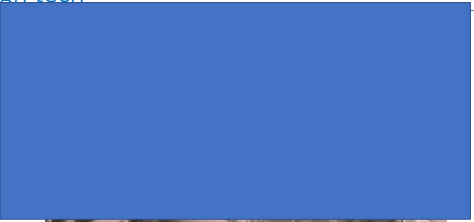
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Holly - need all the tools quick access AND high tech



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**Writing**

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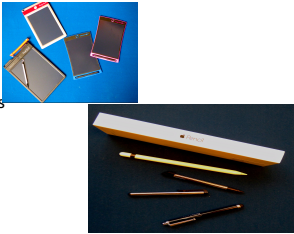
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Writing strategies

- Notepad
- Notebook
- Boogie board
- iPad/android – note apps
  - Finger
  - Rubber tipped stylus
  - Jot stylus
  - Apple pen



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We prefer the Jot version as the erase button is easier to press



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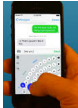
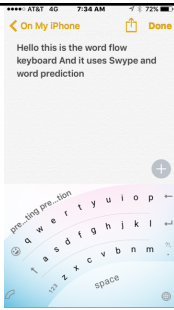
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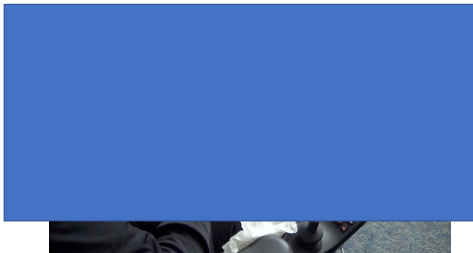
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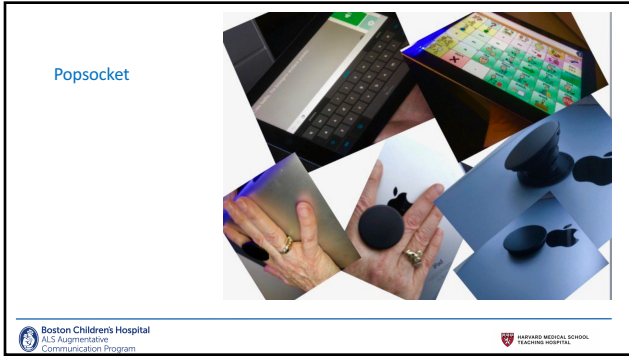
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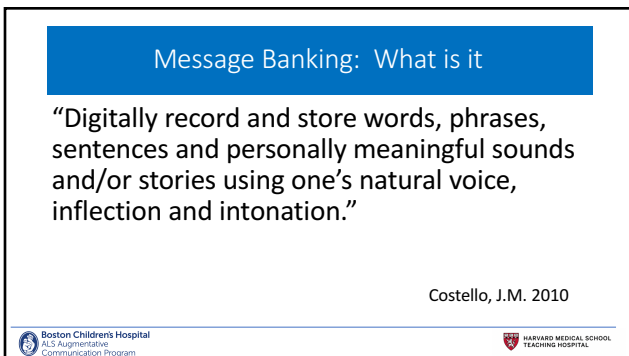
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### Legacy Messages™ : What is it

“Legacy messages are those messages, often delivered with unique intonation and prosody that are unique or particular to you. They are your ‘isms’. It may be a ‘trademark’ message you say or it may be a trademark delivery of a message that many people say. A legacy message does not need to be meaningful to the general population. Instead, it may have a unique and personal meaning to only you and a loved one. A legacy message does not have to be real words to be meaningful.”

Costello, J.M. 2010



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“Our voice is our ACOUSTICAL fingerprint”



Costello, J.M. 2010



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### History of Message Banking™

- Premiered Boston Children’s Hospital Model for Augmentative Communication in the Intensive Care Unit in 1994.
- Consulted with Cystic Fibrosis Team, Heart Transplant Team, Pulmonology, Craniofacial Team and ORL and Tracheostomy Team to identify and pre-op refer patients who will likely be unable to speak post-operatively
- Referral sources grew to the teams throughout the medical center within twelve-months of initiating services
- A cornerstone of the model, based on proactive education, engagement and system selection and training became ‘Message Banking’.



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### History (cont'd)

- 2000, Published first paper on voice/message banking highlighting outcomes from over 100 patients seen at Boston Children's Hospital  
(Costello, J.M. *AAC*, Sept 2000)
- Initially used the term *voice banking* but transitioned to term '*message banking*' as technologies such as Model Talker were unveiled in 2003/2004 focused on creating synthetic voices that approximate one's biological voice or 'voice banking'
- In 2009, applied the BCH model of Message Banking for short term loss of speech to people with motor neuron disease and other conditions such as oral/orofacial cancers, who are at risk of permanent loss of speech




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### Our Message Banking Model




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### Our Message Banking Model




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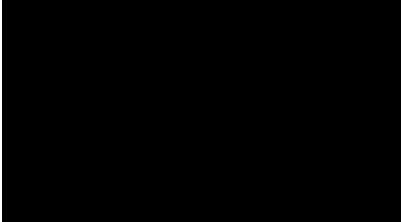
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**Our Message Banking Model**



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**Our Message Banking Model**

- Technology/platform agnostic
- Bank with as much or as little structure/'hand holding' as you would like
- Continue over time for as long as you would like. As life and the disease progress, new messages become evident.
- You are never 'finished' but also you have no quota. Focus on what is important to you.

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**Our Message Banking Model**

- Provide a 64 page handout with examples and categories of messages banked by people with ALS \*\*\*\*\*
- Discuss legacy messages with many examples
- Review 'relationship vocabulary'
- Sounds
- Laughter
- Same word or phrase/different intonation
- 'Isms'

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### Message Banking .wav technology given to people with ALS



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- set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for best quality
- Practice timing of push - speak - push

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### Typical message banking introduction session:

- 90-120 minutes
- Introduce concept of voice and message banking
- Discuss process of authentic message banking throughout day
- Intro portable .wav recorder and why .wav
- Describe and demonstrate use and integration into different platforms
- Compare voice and message bank (web video)
- Download, playback, label and store audio files, providing guidance for improving quality if needed.
- Demonstrate the edit process and highlight we will manage
- Demonstrate the Message Banking site as option for self management

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**Message Banking**

Message Banking is a secure place to share, receive, and store your messages. You can use Message Banking to share your messages with your family and friends, or to share them with your healthcare providers. Message Banking is a secure and private way to share your messages with your family and friends, or to share them with your healthcare providers. Message Banking is a secure and private way to share your messages with your family and friends, or to share them with your healthcare providers.

[Bostonchildrens.org/ALSMessaging](http://Bostonchildrens.org/ALSMessaging)

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**Web-based video tutorials**

[Bostonchildrens.org/ALSMessaging](http://Bostonchildrens.org/ALSMessaging)

**Why use a .WAV recording format?**

**Introducing the Zoom H1 recorder**

**Using headset microphone with Zoom H1**

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**Our Message Banking Model**

mytobidynavox Store | Pageset Central | Support

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This service is a joint project between Boston Children's Hospital, Department of Otolaryngology, and Tobii Dynavox with a goal of providing a free and open message bank for people at risk of losing their voice.

**Message Bank**

Message Bank | My Messages | Download All | Upload

Support | My Messages

Search

No messages found.

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**MESSAGE BANKING™ FOR EVERYONE**

**"After all, communication is the thread that connects us all."**

- John Costello, MA, CCC-SLP  
Director at Boston Children's Hospital and Creator of Message Banking

Message Banking is a joint beta project between Boston Children's Hospital Department of Otolaryngology and Tobii Dynavox with a goal of providing a free and open message bank for people at risk of losing their voice.

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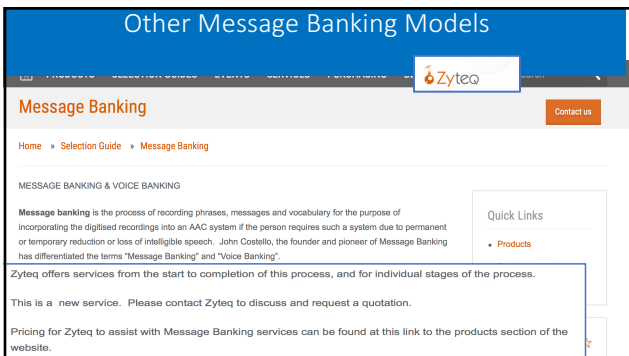
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**Other Message Banking Models**

**Message Banking** [Contact us](#)

Home » Selection Guide » Message Banking

**MESSAGE BANKING & VOICE BANKING**

Message banking is the process of recording phrases, messages and vocabulary for the purpose of incorporating the digitised recordings into an AAC system if the person requires such a system due to permanent or temporary reduction or loss of intelligible speech. John Costello, the founder and pioneer of Message Banking has differentiated the terms "Message Banking" and "Voice Banking".

Zyteq offers services from the start to completion of this process, and for individual stages of the process.

This is a new service. Please contact Zyteq to discuss and request a quotation.

Pricing for Zyteq to assist with Message Banking services can be found at this link to the products section of the website.

**Quick Links**

- Products

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**Other Message Banking Models**

A major project, which aims to help people with motor neurone disease (MND) to maintain a sense of identity after they lose their ability to speak, is being highlighted as part of a research event in Trinity College Dublin (TCD) this week.

The way we speak and our unique turn of phrase helps us to connect with friends and family in a more personalised way. Losing this ability can therefore have a devastating impact.

MND is the name given to a group of diseases in which there is progressive degeneration of the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells that control muscles, and their degeneration leads to weakness and wasting of the muscles.

This causes an increasing loss of mobility in the limbs and difficulties with speech, swallowing and breathing. There is currently no cure for the disease and around 110 people are newly diagnosed in Ireland every year. Over 300 people and their families are currently living with the disease.

A project led by assistant professor in clinical speech and language studies at TCD, Caroline Jago, and senior speech and language therapist in Beaumont Hospital, Lorraine Doyle, is focussing on the concept of message banking.

**Beaumont Hospital**

**Caroline Jago** @CarolineJago · 18 Oct 2017  
Irish message banking project funded by Research Motor Neurone, cohab. b4 #MND, #SL and SLP #Researcher, #Duke, @ASLPeople

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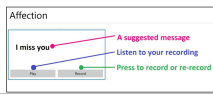
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## Other Message Banking Models

These recordings can be made easily using **Message Banking**, a free app available at the Windows Store. This app provides suggested messages, push button recording, and a single press to download all of your labeled, MP3 recordings into a folder on your computer. The MP3 format works on all speech generating devices or Text-to-Speech (TTS) apps that play audio files.




**Affection**

I miss you

A suggested message



Listen to your recording

Press to record or re-record



Amy & pALS

The "Message Banking" App can be used on any desktop, laptop or tablet that runs Windows 8 or above. This app is designed to help people with message banking by suggesting messages, making it easy to add your own unique messages (by using the "+" symbol at the bottom of the page) and making certain you are recording in the right format. If your father does not have any Windows based systems, he can use a recording app on his iPhone or iPad that records .wav files. For further suggestions, refer to the Message and Voice Banking handout under the "SLP Resources" tab on AmyandpALS.com. Please let me know if you have any other questions.

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## Other Message Banking Models

### Personify™ Voice Recording System

**Create your vocal legacy**

Think of a friend or loved one. When you do, you can probably imagine them saying certain things a certain way — expressions that only they say. These are known as legacy messages that uniquely express an individual's personality.

Many people with progressive disorders such as Amyotrophic Lateral Sclerosis (ALS) lose their voice as their condition progresses. When that time comes, they use speech-generating devices to communicate their wants and needs. While synthesized voices do a great job of creating speech, they cannot recreate the unique sounds and intonations of the individual.

With the Personify Voice Recording System, people with progressive disorders are able to record their legacy messages while they are still verbal and later use them with their speech-generating device. Voice recordings are saved, trimmed, labeled and organized into folders on the Personify Recorder, where they are also backed up to a cloud server. When needed, our experts will integrate the recordings into a Forbis AAC speech-generating device for access via touch screens, switch scanning, head mouse or eye tracking.



PERSONIFY™

Personify™ Product Information




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## Other Message Banking Models

**LaVerità**

**► SALUTE E SOLIDARIETÀ**

**C'è una banca che dona parole ai malati di Sla**

Per offrire una voce umana a chi l'ha perduta a causa delle malattie neurodegenerative, il centro **Studio Nemo** lancia una campagna. Grazie a un'app, chiunque può registrare un vocabolo proprio e salvarlo nella possibilità di registrarsi a €1000 in un'attività di raccolta fondi.

La vita nervosa viene meno, si fa inerte. Uno delle gambe, delle braccia e delle mani. Tutto diventa difficile soprattutto nella parola. Ne basta una, quella che ci rimanti alle prime difficoltà caratteristiche che ha più o meno parole, il percorso valore per noi. Per farne parte progressivamente a costo? Per restituire la voce immaginare una persona a coloro a cui una malattia nel silenzio. A questo punto si chiede la possibilità di esprimersi articolando dispendio, un atteggiamento vocale. L'imitazione del di produrre il suono associato alla parola o alla frase muscolare omnicentrico di preconstituita che il paziente. Milano, può per esempio: la parità con lo sguardo in re in modo specifico e alla un video. Il timbro però è mente, specializzato alle elettronico, fido e piano, necessità di coloro che non hanno un'attività di lavoro. hanno una malattia neurodegenerativa, come la Sla, che non possono registrare la loro

**Studio Nemo** lancia una campagna di raccolta fondi per offrire una voce umana a chi l'ha perduta a causa delle malattie neurodegenerative. Grazie a un'app, chiunque può registrare un vocabolo proprio e salvarlo nella possibilità di registrarsi a €1000 in un'attività di raccolta fondi.

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### Other Message Banking Models

- Record directly to augmentative communication software on a device
- Record directly to an augmentative communication software on app

*\*\*\* We have concerns and have seen some difficult situations when someone has been advised to acquire a device or software and message bank prior to knowing it is the right match to their authentic needs*




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### AAC Feature Match

*Some of the technology in our ALS AAC Clinic for assessment and/or evidence based trial/loans*




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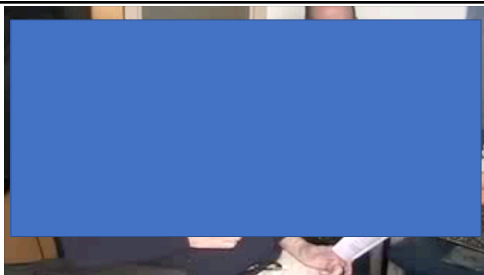
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Considering vocabulary lists




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Nancy



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July 2013



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March 2016



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Gene and banked messages May 2017



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Voice vs message banking

Text to pronounce:  
yell

Speed: \_\_\_\_\_ %  
Shaping: \_\_\_\_\_ %

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Voice Banking: What is it?

Voice banking is a process of recording a large inventory of your speech following a pre-determined script designed to capture a sampling of all co-articulated sounds in the language. The completed collection of recordings is then used to create a synthetic voice that approximates your natural voice.

Costello, 2011

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- ModelTalker
- Cereproc (Edinburgh Scotland)
- Edinburgh Voice Banking and Reconstruction project
- Acapela
- VOCALiD

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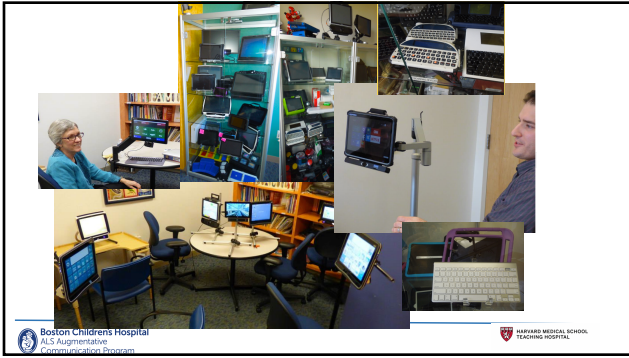
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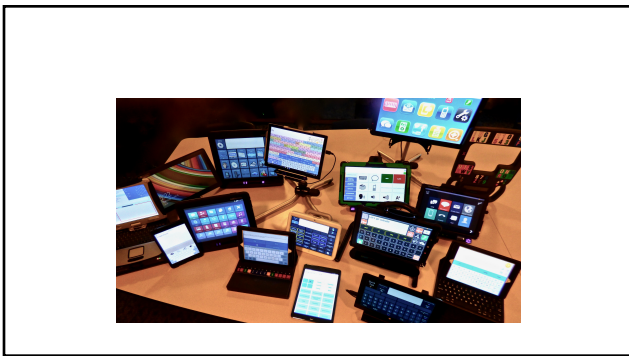
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“The feature matching process focuses on identifying the strengths, skills and needs (current and future) of a person who is a candidate for augmentative communication and matching the features of available (or potentially available) augmentative communication tools, devices and strategies to that person”

- Shane and Costello, 1994

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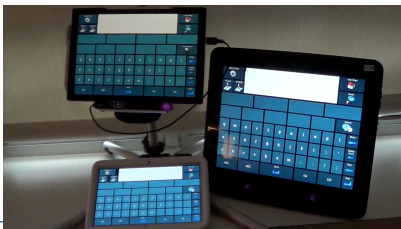
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### Feature match to minimize need for new learning



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### Assessment Domains: Preparing for today and tomorrow

- Historic
- Patient centered
- Family centered/partner centered
- Medical
- Sensory
- Motor (access and seating/positioning)
- Speech
- Language(s)
- Environmental
- Cognitive
- Social/cultural
- Financial

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SOME considerations for Speech Generating Device Assessment and trial(s)

Language Features:

- primary/secondary language
- core vocabulary • phrase
- single words • Alphabet
- message organization (grid, list, taxonomic, contextual, etc.). • text/symbol/both

Encoding strategies

- Abbreviation expansion
- prediction (word, grammar, morphology) • letter stream prediction (Dasher)

Access features (in concert with OT)

- Direct selection (unaided)
- Direct selection (aided)
  - headmouse
  - eye tracking
    - dwell, switch, blink, release
- Scanning
  - Single switch
  - Two switch
  - Use of switch interface for technologies
  - Software vs. tech access options within tech (accessibility features)




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SOME considerations for Speech Generating Device Assessment and trial(s)

Sensory Features:

- vision status • one eye or binocularity
- glasses • ocular conditions

Auditory Features:

- Voice output • volume
- auditory cue/prompt
- auditory scan

Voice Features:

- Synthetic options • voice bank integration
- Message bank integration • hybrid voice integration
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Alert Features:

- Auditory preview (different voice from communication voice)
- Click
- Highlight (adjustable highlight color/size/etc.
- expand/zoom




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Integration features:

- transition from communication to web to email to other functions




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SOME considerations for Speech Generating Device Assessment and trial(s)

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|---|---|---|
| <b>Integration features:</b>  | <b>Other:</b>   | <b>Other:</b>   |
| <ul style="list-style-type: none"> <li>• Internet</li> <li>• Telephone</li> <li>• television</li> <li>• text</li> <li>• custom software</li> <li>• system mirroring (Splashtop, Team Viewer, etc.)</li> </ul> | <ul style="list-style-type: none"> <li>•Language</li> <li>•Text</li> <li>•Symbols</li> <li>•Synthesizer (and integration with environment such as 'Alexa')</li> <li>•Warranty/tech support</li> <li>•Funding options</li> </ul> | <ul style="list-style-type: none"> <li>• Size</li> <li>• Weight</li> <li>• Portability</li> <li>• Mounting/stand</li> <li>• Use in varied environments</li> </ul> |



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Data collection during assessment and trial

- **Linguistic:** Receptive and expressive language skills, as well as the ability to use the symbolic system (text, symbols, etc.) of a communication system to create messages with complex meanings
- **Operational:** Technical Skills to operate AAC systems, which includes the organizational system and hardware and access method(s)
- **Social:** Skills in the social rules of interaction, knowledge and judgment needed to initiate, maintain, and terminate interactions, engage with familiar and less familiar partners
- **Strategic:** Compensatory strategies that users of AAC require to overcome communication breakdowns including encoding strategies, rate of communication, use of prediction or other endemic efficiency strategies.



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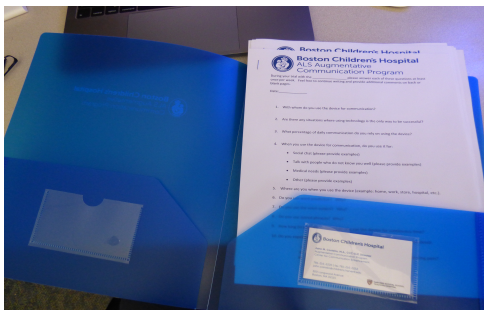
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### A few outcomes of trials that have led us to DIFFERENT technology that was successful:

- Throughout trial, continuous difficulty with setting up/positioning/charging and having authentic use
- Home lighting/windows interfere with camera for eye tracking
- Success is fleeting (possibly due to medication schedule)
- Communication partners can not hear the speech output
- FATIGUE (hand, foot, eyes or other access site; neck, shoulder, trunk, etc.) sets in after 30 minutes of use
- Care providers do not understand the language of the communication system (requiring bilingual options to address all partners needs).

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During your trial with the \_\_\_\_\_, please answer each of these questions at least once per week. Feel free to continue writing and provide additional comments on back or blank pages.

Date: \_\_\_\_\_

1. With whom do you use the device for communication?
2. Are there any situations where using technology is the only way to be successful?
3. What percentage of daily communication do you rely on using the device?
4. When you use the device for communication, do you use it for:
  - Social chat (please provide examples)
  - Talk with people who do not know you well (please provide examples)
  - Medical needs (please provide examples)
  - Other (please provide examples)
5. Where are you when you use the device (at home, work, store, hospital, etc.)?
6. Do you use word prediction? Why?
7. Do you use the voice output? Why?
8. Do you use word prediction? Why?
9. How long (in minutes or hours) do you use the device for continuous time?
10. Do you experience fatigue or pain when using the device? If so, please detail:
  - i. How much time before fatigue is evident?
  - ii. If you experience pain, how long does it last before experiencing pain?
  - iii. If you experience pain, where do you feel the pain?

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### Integrating SGD's with commercial voice controls

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**Language organization for Environmental Control**

Amazon Alexa activated by synthetic speech and responding appropriately

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**Alexa and Hue Lighting**

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Boston Children's Hospital

ALS Augmentative Communication Program

For more information, handouts and Video links go to:

<http://www.childrenshospital.org/ALSaugcomm>

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Contact information:

John M. Costello, MA, CCC-SLP  
Director, ALS Augmentative Communication Program  
Boston Children's Hospital  
[John.costello@childrens.harvard.edu](mailto:John.costello@childrens.harvard.edu)  
[www.Bostonchildrens.org/ALSAugComm](http://www.Bostonchildrens.org/ALSAugComm)  
O. 781 216 2220

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