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

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

Contacts: John.costello@childrens.harvard.edu
https://www.facebook.com/ACPCHBoston

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Dear John, Amatya and Peggy,

I want to thank you for everything you did for my mother [redacted], and for our family. Although she passed before she was able to make full use of the message banking, I think our visits with you were an important part of her journey. As you know, ALS is a disease of continual loss, and all of our energies were focused on that loss until our first meeting at Children's with John. At that time, we were able to discuss the technological options available to my mom, but what we were really talking about was hope, an ability to be proactive rather than passive, and the opportunity to hold onto a piece of who she was. What a precious gift. At the risk of embarrassing John, after that visit I texted

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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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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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Types of ALS/MND

- Sporadic - the most common form of ALS in the United States - 90 to 95% of all cases.
- Familial - occurring more than once in a family lineage (genetic dominant inheritance) accounts for a very small number of cases in the United States - 5 to 10% of all cases.

resource: http://www.alsa.org

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Onset

- Bulbar
- Spinal
- Atypical
  - Example: Brachial amyotrophic diplegia (man in the barrel): severe muscle involvement was confined to the upper limbs, predominantly the proximal portion and shoulder girdle, sparing the face and the legs until late in the disease's course or until the terminal stage.

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Bulbar onset Resource: ALS/CA fact sheet 2016

- What is it?
  - Bulbar ALS destroys motor neurons in the corticobulbar area of the brainstem in the early stages of ALS.
  - The corticobulbar area controls muscles of the face, head and neck.
  - Bulbar ALS usually progresses faster than limb onset
- **How Common is Bulbar ALS?**
  - observed in 20-30 percent of people with ALS.
  - Almost all people with ALS display bulbar symptoms at later stages
- . **Symptoms Affecting Speech**
  - Changes in voice and speech. - Harsh, hoarse or strained voice.
  - Breathy speech pattern. - Poor articulation.
  - Decrease in range of pitch and loudness of voice.
- **Other Symptoms**
  - Spasms in muscles of the jaw, face, voice box, throat and tongue.
  - Inappropriate excessive laughing and crying. - Brisk jaw jerks.
  - Involuntary twitching in the muscles of the tongue. - Dysphagia
  - Vocal cord spasms causing the sensation that air cannot be moved in or out.

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Spinal onset

- initial symptoms may affect only one leg or arm. Individuals may have awkwardness and stumbling when walking or running. They may have difficulty lifting objects or performing tasks that require manual dexterity (e.g., buttoning a shirt, tying a shoe, turning a key). Eventually, the individual will not be able to stand or walk, get in and out of bed without help, or use hands and arms to perform activities of daily living, such as washing and dressing.
- 70-80% of patients, symptoms begin with limb involvement
- Eventually develop bulbar symptoms

Resource: *Orphanet Journal of Rare Diseases*20094:3
DOI: 10.1186/1750-1172-4-3

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Spinal onset (cont'd)

- Upper motor neuron involvement include spasticity and exaggerated reflexes
- Patients with upper limb onset have twice the likelihood for onset in the dominant arm, compared with the nondominant arm
- Symptoms of lower motor neuron degeneration include muscle weakness and atrophy, muscle cramps, and fasciculations

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What to expect when coming to our ALS Augmentative Communication Program

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As appropriate, Speech-Language Pathology will:

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

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Based on assessment of current voluntary motor abilities, Occupational Therapist/AT specialist:

- **identify adaptations and tools to facilitate continued physical access to daily activities.** A wide spectrum of options exist, ranging from minor modifications to one's computer keyboard and mouse to hands free control of a computer, tablet and smartphone.
- In addition to supporting hand function as much as possible**, voluntary movements of one's eyes, head and feet are explored to minimize the overuse** of any one muscle group.
- Accommodations to minimize fatigue and facilitate function often include a combination of:
  - **positioning mounting adaptations,**
  - **low and high tech adaptive pointers,**
  - **alternative computer mice and switches**
- In addition to facilitating one's access to written and spoken communication, **email, the Internet and social media, options for independent access to reading, television operation and other leisure time activities can also be addressed.**

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Also provide:

- Home-based services may be available when patient can no longer travel to the center.
- Tele-support
- Web based training modules (late 2016)
- Web based downloadable templates (late 2016)

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Begin with
THANK YOU
to many extraordinary
people with ALS

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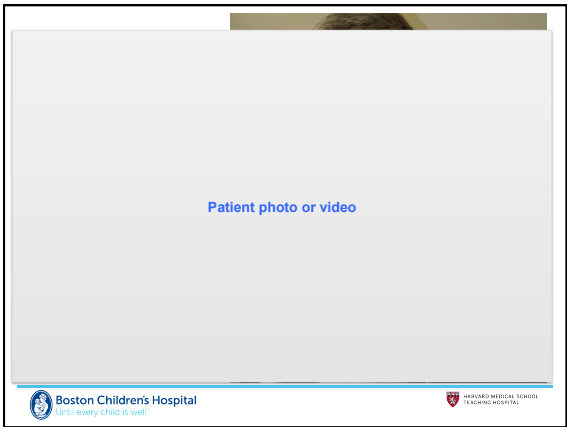

Opening statement:

"My goal is to waste your time"

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

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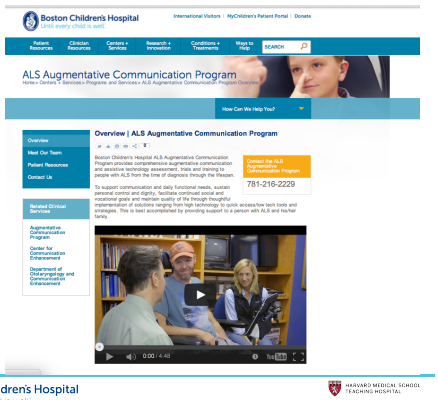

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Speech strategies

- Pacing/segmenting with breath control
- Breathing awareness (diaphragmatic vs. clavicular)
- Reduce gravel with quieter voice (in concert with amplifier)
- Over articulation (without strain)
- Economizing
- Stretching – 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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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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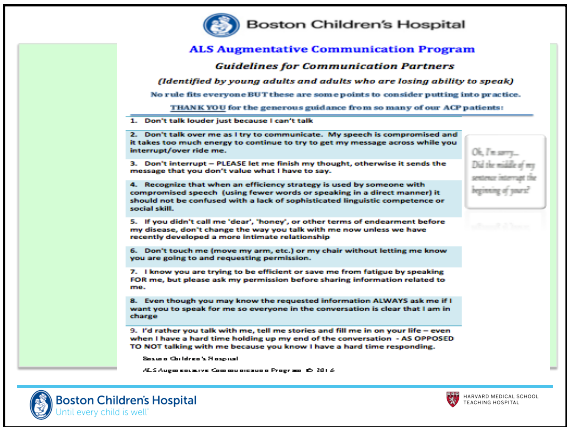

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Guidelines for Communication Partners

(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 fewer words or speaking in a direct manner) it should not be confused with a lack of sophisticated linguistic competence or social skill.
5. If you didn't call me 'dear', 'honey', or other terms of endearment before my disease, don't change the way you talk with me now unless we have recently developed a more intimate relationship
6. Don't touch me (move my arm, etc.) or my chair without letting me know you are going to 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 so everyone in the conversation is clear 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 holding up my end of the conversation - AS OPPOSED TO NOT talking with me because you know I have a hard time responding.

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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

Often will be told:

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

Speech production requires:

- Articulation
- Phonation
- Resonation
- Respiration

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Amplification while using bi-pap

Assessment of transdermal microphone options

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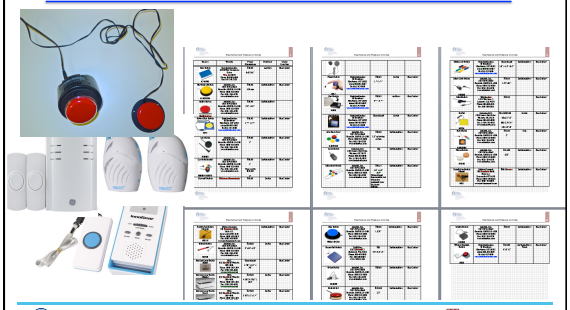
Call system(s)/switch control



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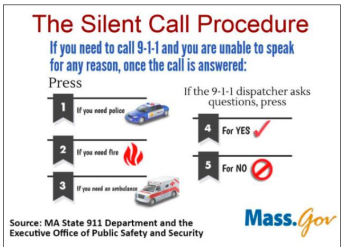
Home alone and calling 911 when speech is difficult



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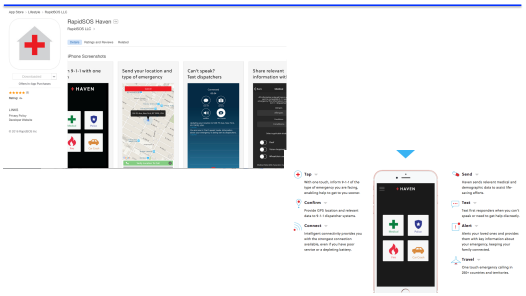
Phone app for emergency requiring no speech



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Message Banking

- Introduce concept/definitions and idea of *'technology agnostic'*
- Practice recording with a hand held recorder to support high quality recordings 'in the moment'.
- Share clinical stories and outcomes and provide concrete examples
- Provide full handout with definitions and thousands of examples from people with ALS
- Download, playback, label and store audio files, providing guidance for improving quality if needed.
- Review potential technologies that could accommodate message banking across varied platforms.
- Provide person with ALS with their own recorder to take home and use to functionally record.

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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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Message Banking with your own voice *digitally*

record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.

These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or sound storage files. This will allow you to 'retrieve' a message and speak it in your own voice but does not allow you to create novel messages by spelling. If you have recorded individual words, you may combine those words to create unique messages, although the output will sound more staccato than your natural speaking.

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TERMINOLOGY:

Legacy Messages are those messages, often delivered with unique intonation and prosody that are unique or particular to you. 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 unique and personal meaning to only you and a loved one. Further, a legacy message does not need to be real words to be meaningful. It may be the way you clear your throat in a sarcastic manner to communicate "*I told you so*" or it might be the invented pet name you have for a loved one delivered with your unique voice, intonation and prosody. Similarly, legacy message may be that stereotypical thing you say after your favorite sports team scores or it may be a unique greeting you deliver to friends. Those close to you may be helpful with identifying these *Legacy Messages* because sometimes they are so naturally part of socially relating with others, you may not even be aware you are 'known' for them.

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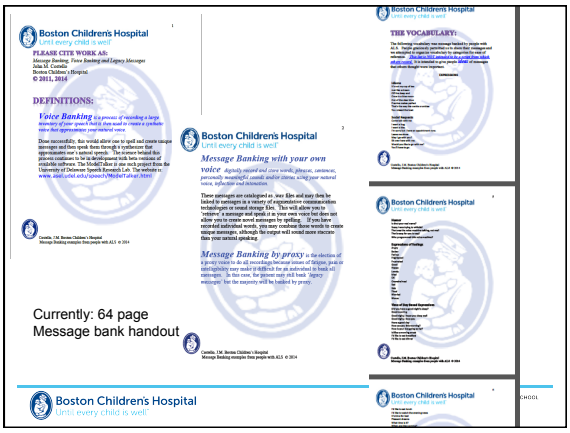

64 page handout will be on new ALS website but can be found now at:

- http://www.childrenshospital.org/~/media/messagebankdefinitionsandvocab201613.ashx?la=en

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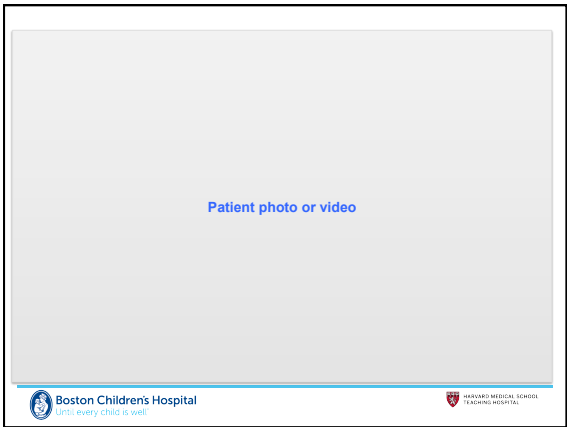
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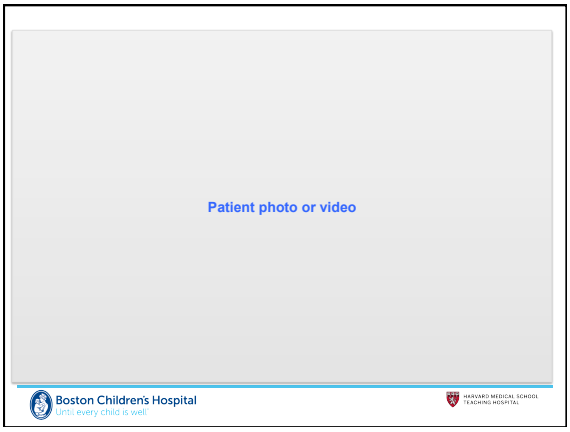
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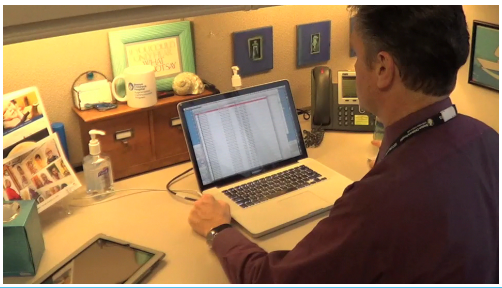
Until recently…



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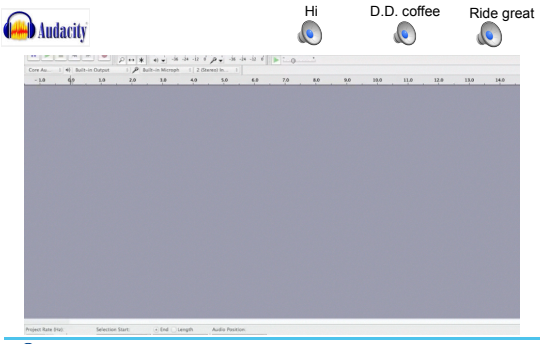
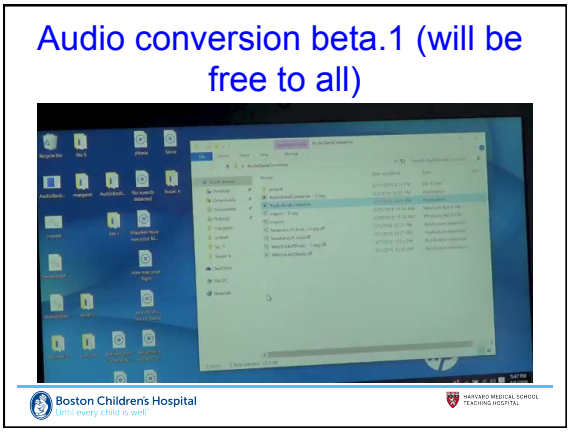
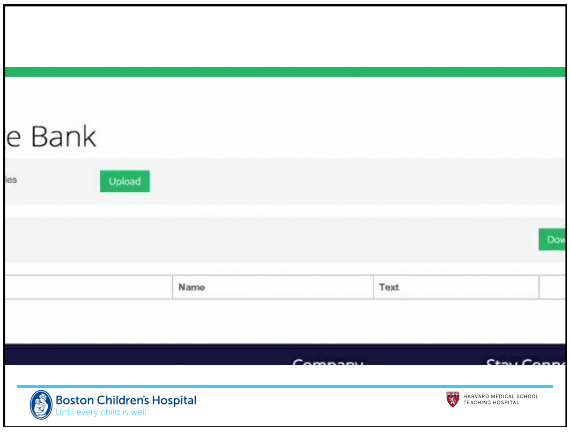
Edit one audio file into multiples



Audio conversion beta.1 (will be free to all)





Voice Banking

- Provide definition and description of process
- Provide examples of voices created

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Voice Banking *is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.*

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one's natural speech. The science behind this process continues to be in development with beta-versions of available software. The ModelTalker is one such project from the University of Delaware Speech Research Lab. The website is: www.asel.udel.edu/speech/ModelTalker.html

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- Model Talker
- Cereproc (Edinburgh Scotland)
- OKI Electronic Industry Co Japan
- Edinburgh Voice Banking and Reconstruction project
- Acapella project
- VOCALiD

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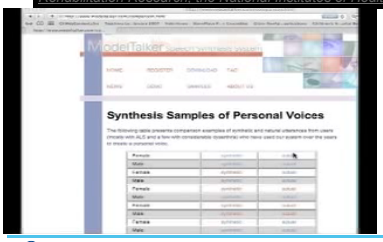
ModelTalker
http://www.modeltalker.com

The ModelTalker System was developed by the Nemours Speech Research Laboratory located at the Alfred I. duPont Hospital for Children with funding from the National Institute for Disability and Rehabilitation Research, the National Institutes of Health, and Nemours



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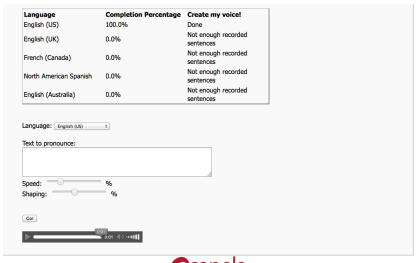
http://www.modeltalker.com/comparison.html



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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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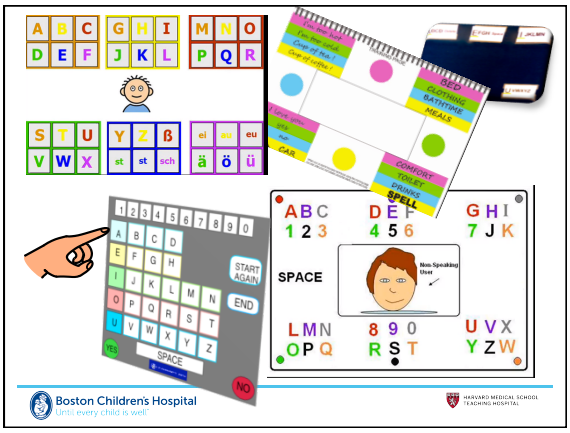
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DRINK
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EAR
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END
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NO
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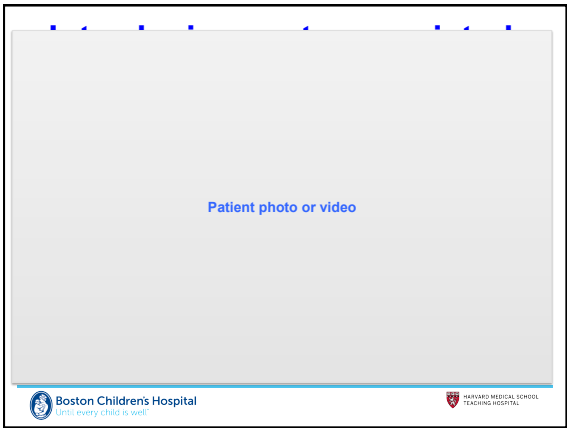
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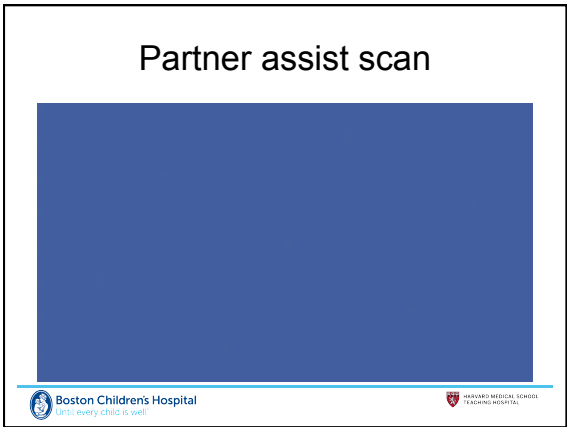
Partner assist scan
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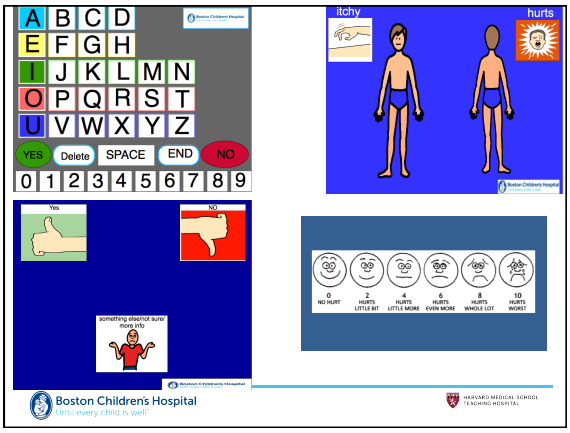
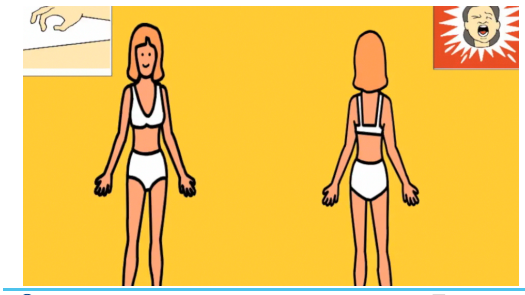


Review of 'body board'



Quick Access (non-electronic)

- Personal tabbed flip chart
- AlphaCore displays or others with direct selection by:
  - Hand
  - Stylus
  - Safe laser

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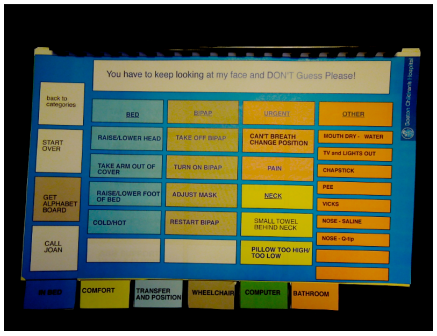

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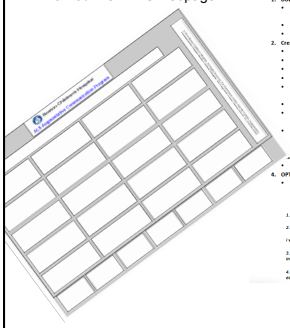
On our new ALS webpage



Creating a customized flip chart for PARTNER ASSISTED SCANNING

(a partner reads through categories, turns pages and reads through messages on selected page for the communicator)

1. **Download and save template**
   - Verify your computer is running the most recent version of Adobe Acrobat Reader (free download from https://get.adobe.com/reader/)
   - Download flip book template from website (ADD LINK)
   - Save template to a convenient location on your computer
2. **Create topic-specific pages:**
   - Open saved template in Adobe Acrobat Reader
   - RENAME template to prevent loss of saved information (File →Save as → NEWNAMEFORFILE)
   - Click 'Fill and Sign' (on right of the screen)
   - Click on an empty 'TAB' at bottom and type desired topic category
   - Rename the page for the TAB name (you will ultimately have multiple pages saved, each for the tab/category name (example: food page, positioning page, bed page, personal care page, etc.)
   - Repeat this process to create as many pages as needed, staggering the TAB labels from left to right
   - You may then fill each page with appropriate messages (you may have to drag the text and center it after you type it)
   - Print each page
     Cut the excess paper and the blank tabs on each page so ONLY the labeled tab remains.
     Line up all pages to be certain ALL tabs are visible.
   - **…emble flip chart:**
     - Place topic-specific pages with tabs staggered from left to right
4. **OPTIONAL DIRECTIONS PAGE**
   - Because many people have multiple communication partners, some of whom may not be familiar with how to use this customized flip chart, you may wish to add a 'directions' cover sheet. The following directions have been developed by and successfully used by many people with ALS and their partners:

1. When I signal a need, if the message is not immediately understood, ask "Is it on the flipbook?" If the answer is "YES", then:

2. Read through and point to each topic 'tab'.

I will select by (enter appropriate method…blink, nod, vocalize, etc.) indicating what I want to say is on that page.

3. Point to each row on that page. I will select the row by _____. To save energy, I WILL NOT indicate NO, I will only indicate 'yes'…so continue to go through each item until I respond.

4. Point to each item in selected row. To save energy, I WILL NOT indicate NO, I will only indicate 'yes'…so continue to go through each item until I respond.

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Safe laser and core vocabulary

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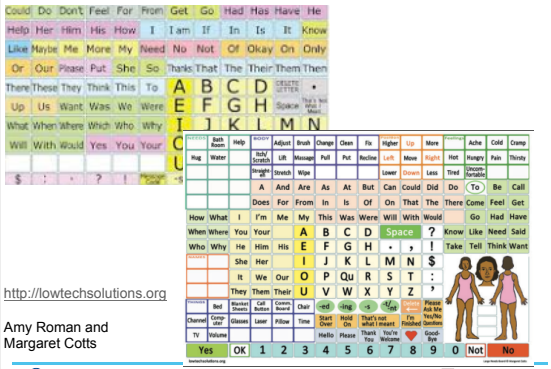

http://lowtechsolutions.org

Amy Roman and
Margaret Cotts

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Wearable eye speak technology

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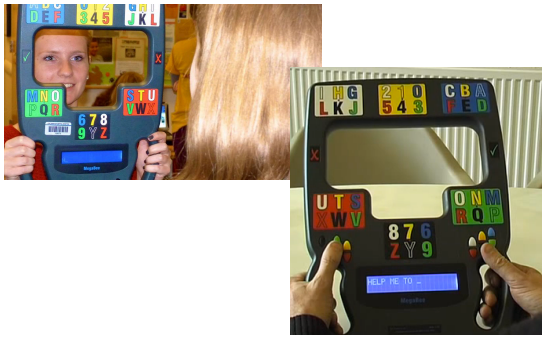
Electronic encoding

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



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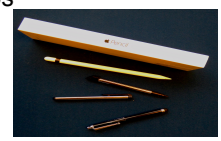
Writing strategies

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



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Speech Generating Device Assessment and trial(s)

Language Features:
- core vocabulary • phrase
- single words • Alphabet
- message organization (grid, list, taxonomic, contextual, etc.)

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
- *Scanning*
  - Single switch
  - Two switch
  - Use of switch interface for technologies
  - Software vs. tech access options within tech (accessibility features)

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Speech Generating Device Assessment and trial(s) continued

Integration features:
- Internet
- Telephone
- television
- text
- custom software
- system mirroring (Splashtop, Team Viewer, etc.)

Other:
- Language
- Text
- Symbols
- Synthesizer (and integration with environment such as 'Alexa')

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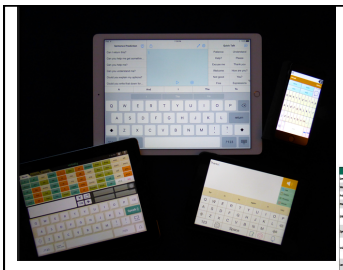

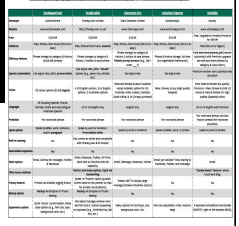

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Predictable (Therapy Box):

Import audio in Predictable

NOTE: You will not be able to hear the recorded voice until the end of the process

1. open itunes
2. click on the idevice
3. select the 'app' tab
4. then scroll to the bottom where you can see the 'file sharing' section
5. click on 'the predictable'
6. then select 'add to'
7. find and select the audio you with to import into Predictable
8. you can select a group of recordings
9. format can be .wav or others
10. from the app go to phrases
11. select the pencil icon
12. then select the phrase you wish to pair with the recording OR add new phrase
13. scroll through until 'choose from library'
14. the recordings will be listed alphabetically
15. select and it will pair with the text
16. exit edit mode to hear the recording

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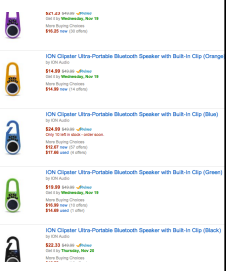
Ion Clipster
blue tooth speaker



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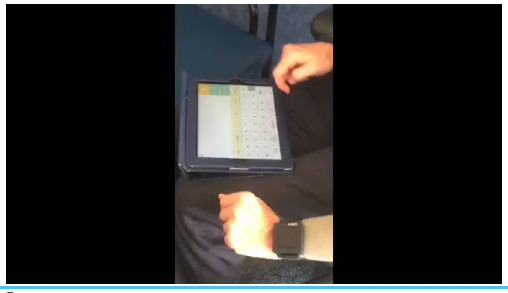
Wearable amplifier



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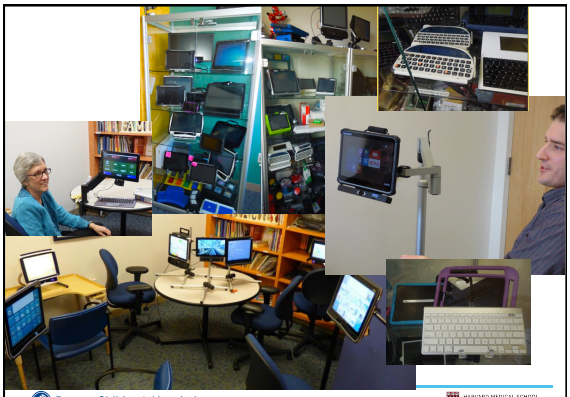

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Occupational therapy/Assistive Technology Protocol of Assessment Considerations	
Physical Access Control Site assessment	
Positioning/support	
Access to mobile technology	
Phone access	
Call system/attention signal access	
Environmental control	
Access to books (hardcopy or digital)	
Computer access: keyboard	
Computer Access: mouse	
Computer Access: speech/voice	
Speech Generating Device Access	
Training	

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Physical Access Control Site assessment

- Direct selection
- Non-direct selection
- Best control site (s) * don't over fatigue one control site:
  - Head, eyes, mouth, tongue, respiratory (sip/ puff), voice, chin, shoulder, trunk, arm/hand, leg, knee, foot.
  - Pressure, excursion, range
- Neural access (neural switch), BCI

General considerations for access selection:

(1)the range and control of movement

(2) the amount of training and practice required to use and

(3) the short and long-term costs/benefits of using access method

Access to iPad/Android tablets

- Position of device
- Use of finger and/or stylus
- Voice typing
- Siri
- Mounting options

Phone Access

- Landline options
- Speaker phone options
- Smartphone use
- Hands-free cell phone use
- Switch scanning on iPhone
- Siri
- Mounting options

Call system/attention signal

- Commercial wireless doorbell
- Switch-adapted attendant alarm
- Baby monitor
- Portable speech output device with or without switch

Environmental control

- Enlarged TV remote controllers
- Switch access to TV functions, lights, fan
- Voice control for TV functions, lights, fan
- Control through SGD

Access to books (hardcopy or digital)

- Kindle/Nook/iBooks
- Hardcopy books/ book holders
- Page turners
- Audio books

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Computer access: *keyboard*

- Built in accessibility features
- Keyboard/key size
- Ergonomic keyboards
- Forearm supports
- Typing aids
- Word prediction software
- Onscreen keyboard software

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Computer Access: *mouse*

- Customizing computer mouse settings
- Adaptive/alternative cursor control options
- Hand –based
- Head-based
- Foot-based
- Eye-based
- Auto click software
- Switch click options

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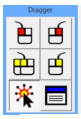

Example: Origin Head Mouse

Quha Zono Gyroscopic Air Mouse

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Computer Access: *speech*

- Speech recognition software
- Dictation strategies to improve software recognition
- Built in commands
- Custom commands
- Voice mouse controls

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Speech Generating Device Access

- Touch screen
- Stylus and stylus holders
- Keyboard
- Different computer mice
- And/or trackball
- Mouse
- Headtracking access (head mouse, gyro mouse, etc.)
- Adapted mouse
- Switch scanning
- Eyetracking access

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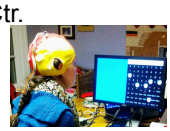
Brain Computer interface

- Projects with which we are currently affiliated:
- Oregon Health Science Project RSVP
- National Ctr for Adapted Neuro Technologies Wadsworth Ctr.



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Mounting/positioning

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Tele-treatment

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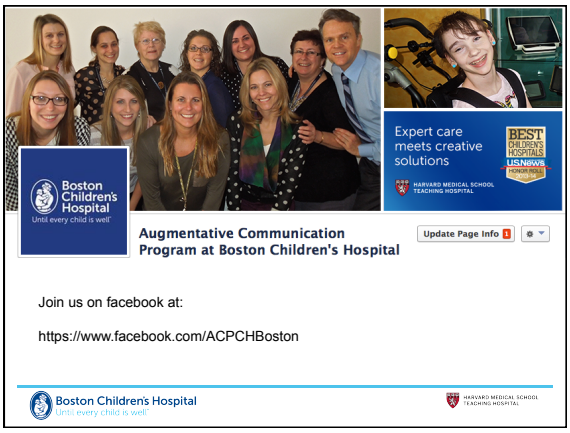
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