



**Preserving Legacy: A Guide to
Message Banking**


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



www.childrenshospital.org/acp

Begin with
THANK YOU
to many extraordinary
people with ALS






Patient Video








**Notice the term
'Message banking'
NOT
'Voice Banking'**



**Children's Hospital Boston
History of 'Voice' Banking**



Some non-speaking conditions may be anticipated before surgery

- Maxillofacial/Orofacial surgery
- Organ transplantation (lung, heart)
- Disorders of the airway requiring tracheolaryngeal or tracheoesophageal reconstruction
- Oncology related interventions
- Scheduled ventilation supports
- Tracheostomy

Potential conditions leading to nonspeaking condition:

- Airway problems
- Lung problems
- Other
 - Respiratory disorders
 - Neuromuscular diseases
 - Head injuries
 - Spinal cord injuries



Patient Video

Neuromuscular Diseases Affecting Respiration

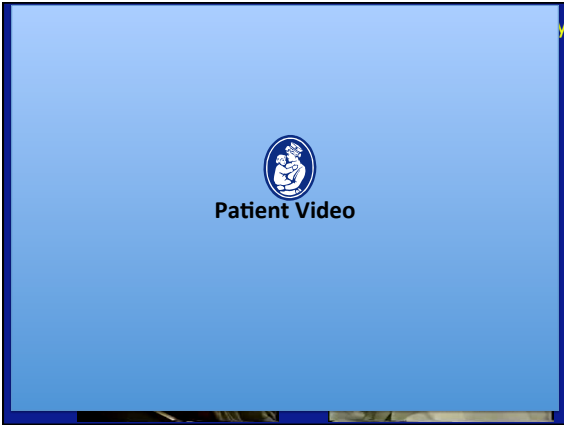
- Arnold Chiari Malformation
- Cerebral palsy
- Muscular dystrophy
- Myasthenia gravis
- Spinal muscular atrophy



**The Temporary Nonspeaking Condition
in the ICU = High Emotional Distress
Coupled with a Sense of Loss**

ICU stay in an inopportune time for
new learning:

RESULT:
**Ineffective processing of new
information**







Postoperative Intervention

- Bedside screening of awareness, sensory and motor skills
- Mounting of AAC device
- Assessment of functional use of communication tools
- Family and staff inservicing

Studies reveal that nurse communication with patient is positively correlated with the patient's ability to give feedback.

Ashworth (1984)

Ashworth (1978) reported a study from five established ICUs


- 32% of verbal communication was short term info (I'm going to suction you)
- 38% were commands or requests (lift your arm)
- 21% were questions (most related to physical care)
- 7% longer information such as teaching or orienting

Tracked interaction between nurses and patients with endotracheal tubes




General model for 'voice banking'

- Patient directed focus
- Patients are asked to imagine nonspeaking condition or reflect on previous experience
***many had previous experience
- Patient and family members 'free flow' selection



Vocabulary Selection part II

- Encourage vocabulary that that focuses on representing individual personality, personal interests, personal humor or phrases particular to the individual
- No message was 'rejected' by the clinician





Categories of banked messages
(analysis of messages banked by 50 patients age 4 – 27 years)

- Personal needs
- Social
- Control
- Positioning
- Statements/directives
- Questions
- Emotions/Feelings
- Leisure/entertainment
- Sarcasm
- Clarifications
- Comfort
- Medical

Reference: Costello, J. AAC Intervention in the ICU: Children's Hospital Boston Model. AAC, Sept 2000.




2006

CHB Augmentative Communication Program asked by local ALS provider to see PALS.

2009

- Pilot program launched under grant for fast-forwarding SGD assessments
- Through fast-forward, Initial PALS referrals for high-tech SGD candidates seen by J. Gosnell
- Referrals diversified to head/neck cancer patients post-op
- Suggested our pediatric pre-op model could be applied.



Sidebar:
Let's examine terminology



**The term 'voice banking' has continued to be used since we introduced it in the early 90's
BUT
technology has changed!**

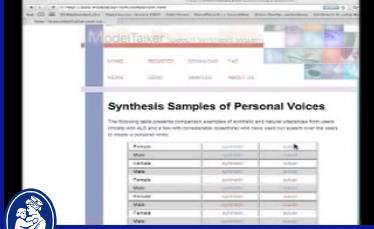
With research and advanced technology, the term Voice Banking is now used to define a more sophisticated strategy.



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

ModelTalker
<http://www.modeltalker.com/>

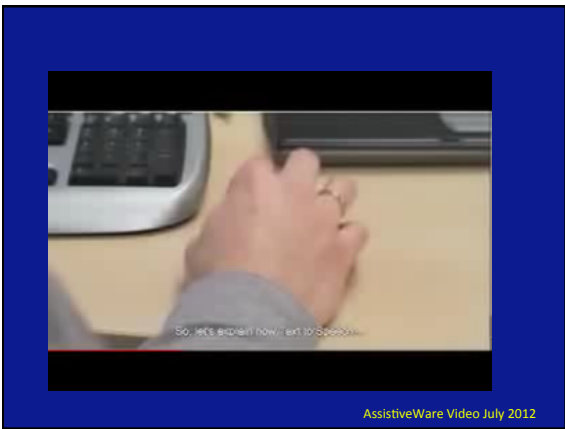
The ModelTalker System was developed by the Nemours Speech Research Laboratory located at the Alfred I. duPont Hospital for Children with funding from the National Institute for Disability and Rehabilitation Research, the National Institutes of Health, and Nemours Biomedical Research.



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

ALS forum: post dated 10.06 retrieved: Nov 6, 2011
 "So I finally finished recording the inventory of phrases.
 There are about 1600 phrases and I would think you would need to dedicate a good 2 weeks of 1 or 2 hours a day.
 But it is worth it. From those recorded phrases the Speech Research Laboratory A.I. DuPont Hospital for Children and the University of Delaware synthesized a voice based on my recorded phrases - and it sounds amazing. Far better than I expected. It still sounds a bit electronic - but it sounds better than any other voice synthesizer I've heard such as the one Stephen Heywood had - and best of all it sounds like ME!
 So now I can write anything (even if the words were not in my recorded vocabulary) - and it will be converted into speech using my voice.
 I was almost in tears when I first heard it and I can't express what it means to know that, whatever happens to me, I will be able to communicate with my own voice.
 The whole process and software are FREE and just requires some time commitment on your part.
 I am forever indebted to everyone at the Speech Research Laboratory A.I. duPont Hospital for Children and the University of Delaware
 I would urge all PALS to do this now before it is too late."
<http://www.modeltalker.com/registration>








Custom voice created by Scottish company 'Cereproc'
<http://www.cereproc.com/en/home>



Proposed Definitions:


Voice Banking

Message Banking



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



The science behind this process continues to be in development. The ModelTalker is one such project from the University of Delaware Speech Research Lab and their business partner AgoraNet.

The website is:

<http://www.modeltalker.com/>

(AgoraNet is the business partner for the speech research lab ModelTalker project)



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.



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.


Message Banking by proxy is the election of a proxy voice

to do all recordings because issues of fatigue, pain or intelligibility may make it difficult for an individual to bank all messages. In this case, the patient may still bank 'legacy messages' but the majority will be banked by proxy.



**Message Banking:
historically, typical strategy used**

- Acquire high quality microphone
- Create a list of appropriate message
- Use a recording software on your computer such as sound recorder
- Try to record message that sound as natural as possible






Patient Video

Outcomes?

- Patients report is 'hard' to know what to record
- "I can't figure out what I am going to want to say"
- Some prioritize and record specific messages to loved ones (terms of endearment, appreciation to loved ones)
- Is tedious and artificial so is a 'chore' to accomplish
- Informal survey of colleagues nationally reveals banking of 10 – 20 messages on average with some instances of about 100



Message Banking:

We can do better!

My dilemma



Email referral: March 04, 2010
Friday @ 7:10 PM

“John, I want to send a patient to you next week for voice banking - he is a 46 y.o. heading into surgery April 3 for a likely total glossectomy/total laryngectomy. Surgeon does not know if he needs to take the whole tongue but he likely will. The patient is calling Monday to schedule this. His name is: Bob XX. Let me know what you need - The MD is faxing a referral to you”.



What would make this process easier and more functional?

- Record any time and on the spot
- Have each recording be a .wav file
 - Highest quality so we have flexibility of all platforms at highest quality
- Easily download to a computer and determine communication platform later



On-line search for 'handheld .wav file audio recorder'

- Kept finding 'zoom' products
- Wanted to be certain so called the US distributor:
Samson Technologies Corp.
45 Gilpin Avenue, Hauppauge, NY 11788
- Described my exact mission and was directed to Zoom H1 which I purchased from Amazon and received next day delivery

On-line search of 'handheld .wav file audio recorder'



Zoom H1 Pak Portable Digital Recorder With Accessories Bundle and Headphones
by Zoom
(24 customer reviews) | (3)

List Price: ~~\$249.99~~
Price: **\$128.20** ✓Prime
You Save: \$121.79 (49%)
Special Offers Available

In Stock.
Ships from and sold by Amazon.com. Gift-wrap available.
3 new from \$125.95

Demonstration of .wav file creation




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



Note:
Going to stay focused on today's topic

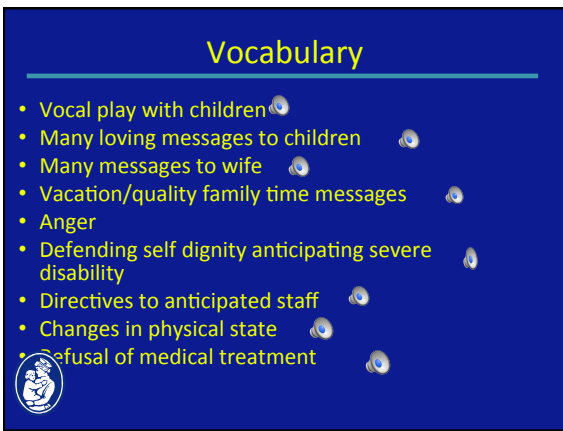
Clearly, the broader topic of AAC,
alternative access strategies and
Feature Matching must be addressed
with each patient as early as possible

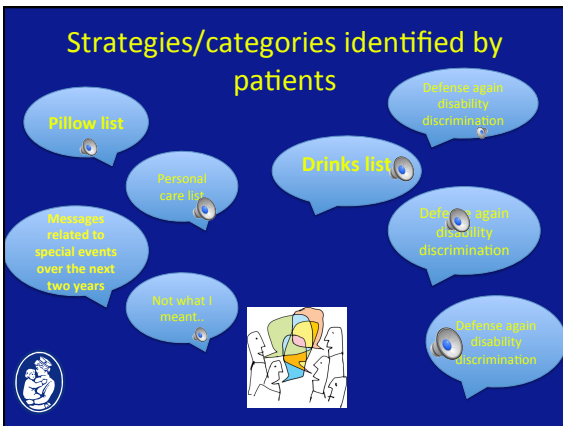








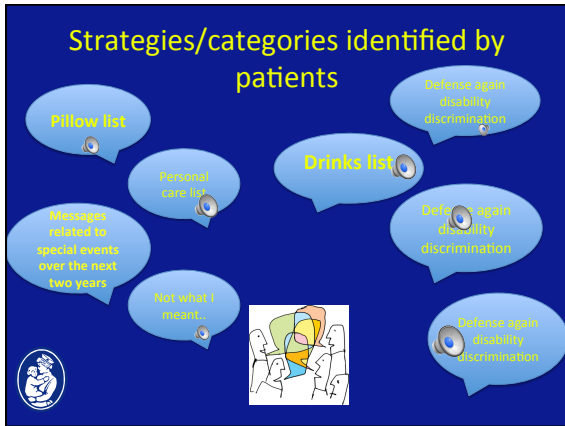





















Home			
daily needs	personal	food or drink	social
medical	medical appointments	emotions	need help
sarcasm	endearment	personal need	Untitled12

food or drink		
 a glass of juice	 glass of water	 can you help me with my breakfast
 could you help me with my lunch	 how about Vietnamese	 I'd like a black russian, please
 I'd like some potato chips	 list of cocktails	 I'd like a Klondike bar, please

Without patient involvement, having meaningful vocabulary is as likely as finding a...



Legacy Messages:

...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.



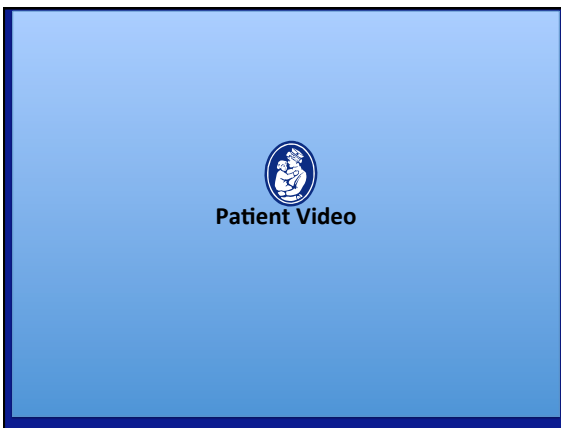
- **Core Vocabulary** refers to messages and words that are frequently used by many individuals across many contexts. This vocabulary typically consists of "functor" words such as "is, was, he, she" and common nouns and primary verbs (e.g. person, like, want). (Beukelman & Mirenda, 1992).
- **Fringe Vocabulary** is vocabulary specific or unique to a person or to one activity or topic (Beukelman & Mirenda, 1998).

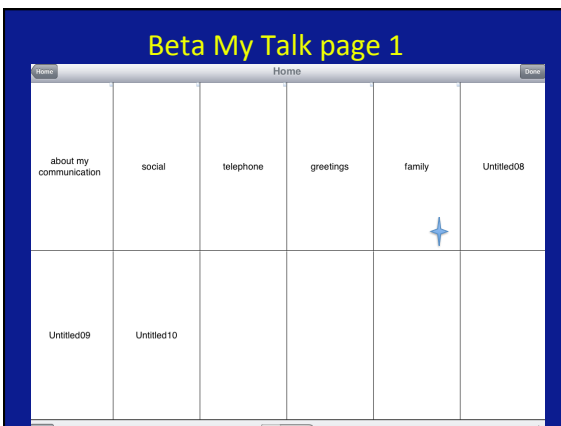


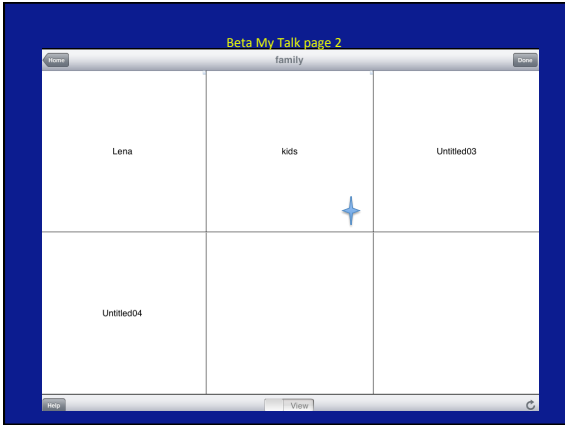
Categories of messages banked (initial analysis)

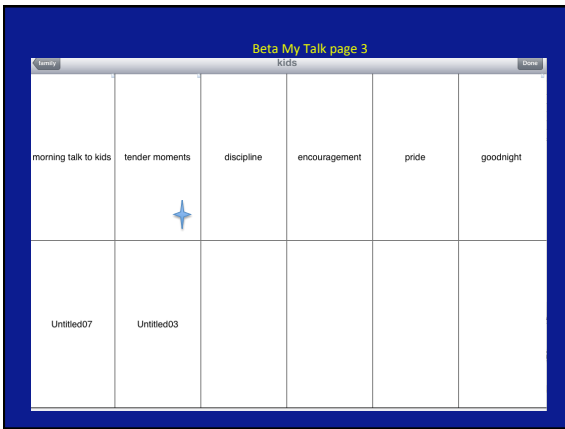
- Personal messages/noises/sounds that are uniquely meaningful
- Appreciation
- Conversational modifiers
- Family routines
- Initiation of social activity
- Explanation of condition
- Expletives
- Personally relevant locations
- Social – time of day related

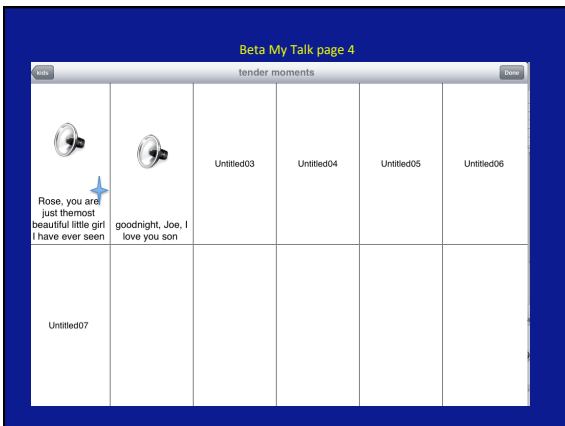














Vocabulary selection

- ### Categories of messages banked (initial analysis)
- Sports/cheers
 - Conversational starters
 - Conversational enders
 - Compassion toward others
 - Complaints
 - Personal info (biographical)
 - Personal state
- 

- ### Categories of messages banked (initial analysis)
- Messages to children
 - Daily routine
 - Pride
 - Tender moments
 - Discipline
 - future
 - Requesting assistance
 - Phone conversation
 - References to future
 - Humor and Sarcasm
 - Social questions
- 

Early referral of PALS

- Determining goals and motivations
- Voice vs Message banking
- Bank now, select platform later
- Vocabulary and counseling



- Tools and options to consider (based on patient's interest)
 - Simple/low tech
 - iDevice options
 - Dedicated/integrated SGD

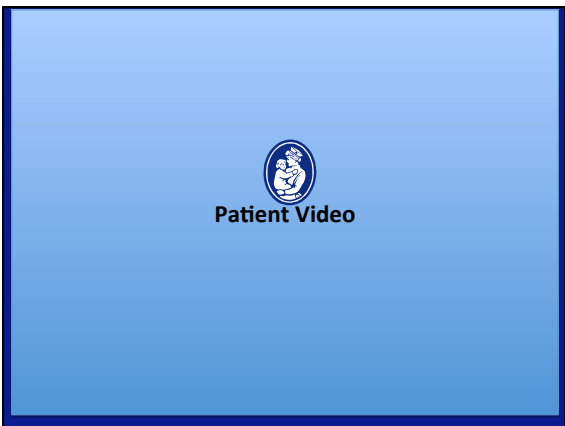




Patient Video









Categories

- Greetings
- Need 'food/drink'
- Need 'medical'
- Need 'personal'
- Advice to boys
- Apologies
- Appointments
- Communication with doctors
- Phone calls to friends
- Car related messages
- Change of location/position in the house
- Social initiation 'do you wanna..'
- Environmental needs/control
- Encouragement to others
- General social
- Gratitude
- To family 'be there for each other'
- Silly intonations
- Statements about medical status
- Special occasions
- Sports
- Thanks and love to others
- Thanks (general)



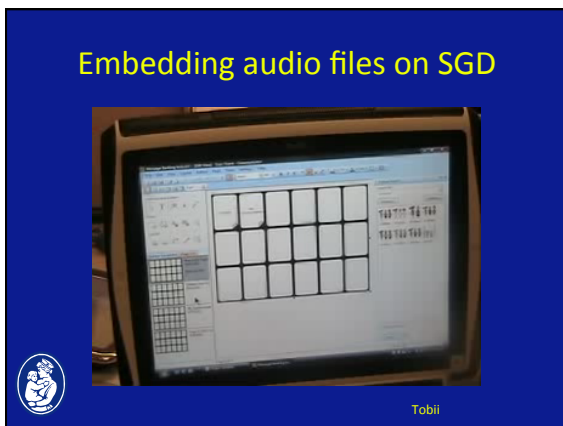


What Platform??

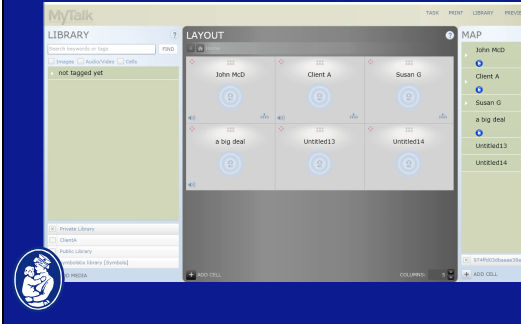
There are MANY but here are a few possibilities

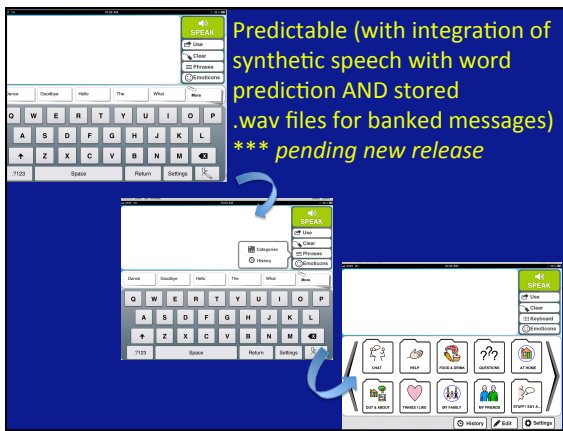


Embedding audio files on SGD



Loading audio files in MyTalk app





Today:
www.childrenshospital.org/acp
In mid-August:
<http://www.patientprovidercommunication.org>

From the ALS on-line forum

There are a few key phrases that I want to make sure I record with my own voice - such as:

- "Take a picture - it will last longer"
- "I've got ALS - what's your excuse?" I should make this into a T-Shirt
- "You're barking on thin ice" my father's favourite mixed metaphor
- "Oops - sorry for the drool - I'm just happy to see you"
- "I know you are but what am I?" the ultimate come back
- "Do you want some fries with that shake"



Next steps

- Continue to work with current patients to have full access to Messages
- Learn from categories created how to better inform new patients
- Explore additional organizational strategies including Amy Roman's 'WordCore'
- Explore hybrid approaches of banked and synthetic for generative communication
- Complete the [CHB Message Banking Guide](#) (preliminary is on website)
 - <http://www.childrenshospital.org>
 - <https://www.facebook.com/ACPCHBoston>