Preserving Legacy: A Guide to Message Banking

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

www.childrenhospital.org/acp

Begin with THANK YOU to many extraordinary people with ALS

Patient video or Patient Photos
Notice the ‘term’
“Message Banking” not
“Voice Banking”

Patient video or
Patient Photos

Patient video or
Patient Photos
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 focuses on representing individual personality, personal interests, personal humor or phrases particular to the individual
- No message was ‘rejected’ by the clinician

Sometimes I was tempted to ‘reject’ but I learned a valuable lesson from an 11 year old!

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

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.

---

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

---

AssistiveWare Video July 2012
“I finally finished recording the inventory of phrases. There are about 1,600 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 these recorded phrases the Speech Research Laboratory at A.I. duPont Hospital for Children and the University of Delaware synthesized a voice based on my recorded phrases and committed it to a voice bank. It sounds a lot better than any other voice I have heard such as the one Stephen Hawking used - and best of all it sounds like ME.

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 urge all PALS to do this now before it is too late.”

http://www.modeltalker.com/registration/

---

“DANGERS OF MODEL TALKER:
Don't get me wrong – I love Modeltaker as one of the most amazing programs out there. It is such a comfort knowing that even after I've lost the ability to speak I will still be able to talk using a synthetic version of my voice. All for free. I owe the developers of Modeltaker a huge debt of gratitude.

As it becomes more and more difficult for me to speak, I've started practicing with the program – and I've uncovered an insidious side to Modeltaker.

Now every time I have a disagreement with my wife, she takes the computer, types in the response she wants to hear, presses “speak” – and with a “click” I agree with her.

“Of course dear, I'd much rather watch taped episodes of Oprah instead of the Superbowl”

“By all means, go right ahead and re-decorate the house in pink”

“You're quite right dear. Angelina Jolie is looking haggard”

And the problem is I'm usually swayed by such an eloquent and knowledgeable sounding voice.

But I have to find some way to password protect the program after I caught my nephew typing in: “I look like a monkey and smell like one too.”

Accessed 11.6.11 @ http://www.alsforums.com/forum/comedy-humour-jokes/24494-dangers-modeltaker.html

---

Custom voice created by Scottish company ‘Cereproc’
http://www.cereproc.com/en/home

---

Costello, J.M. ATIA © 2013 Boston Children's Hospital
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.mdltalker.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 these words to create unique messages,
although the output will sound more staccato than your natural speaking.

Message Banking by proxy is the selection 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
Outcomes?
- Patients report it "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, 2011
Friday @ 7:10 PM

“John, I want to send a patient to you next week for voice banking - he is a 56 y.o. heading into surgery 3.22 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: John 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’

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.
Charlie, age 42
Diagnosed with ALS at age 41

My voice Messages that reflect ‘you’

Patient video or Patient Photos

July, 2011, having a little fun with messages

May 2011

Patient video or Patient Photos

Need to bank more, body is changing

Has been banking messages in many formats for children

Patient video or Patient Photos
Vocabulary

• Vocal play with children
• Many loving messages to children
• Many messages to wife
• Vacation/quality family time messages
• Anger
• Defending self dignity anticipating severe disability
• Directives to anticipated staff
• Changes in physical state
• Refusal of medical treatment

Strategies/categories identified by patients

- pillows
- drinks
- personal care list
- messages related to special events over the next two years
- not what I meant

Patient video or Patient Photos

Costello, J.M.  ATIA © 2013 Boston Children's Hospital
Strategies/categories identified by patients

- Bedroom
- Other

Drinks

Patient video or Patient Photos

Not what I meant.
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 bankers (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
Kim’s husband commencing on hearing his wife’s recordings.

Patient video or Patient Photos

Beta My Talk page 1

Beta My Talk page 2
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

Paul, age 52
diagnosis: ALS
ten months prior to first visit
June, 2011

Patient video or Patient Photos
Introductio to Message Banking: the process

Patient video or Patient Photos

Note: comment on supersCCon of some Patient video or Patient Photos
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)

Patient video or Patient Photos

What Platform??

There are MANY but here are a few possibilities
Embedding audio files on SGD

Loading audio files in MyTalk app
Predictable (with integration of synthetic speech with word prediction AND stored .wav files for banked messages) *** pending new release

Handout available at:

www.childrenshospital.org/acp