



Preserving Legacy: A Guide to Message Banking a Patient's Voice

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Conflict of Interest Statement

John Costello has no financial relationship with any companies, manufacturers or tools discussed in this presentation.
John is a full-time employee of Boston Children's Hospital

Kaytie Dimery has no financial relationship with any companies or manufacturers or tools discussed today. Kaytie is a graduate student at Emerson College.





Expert care meets creative solutions



BEST
CHILDREN'S HOSPITALS
USNEWS

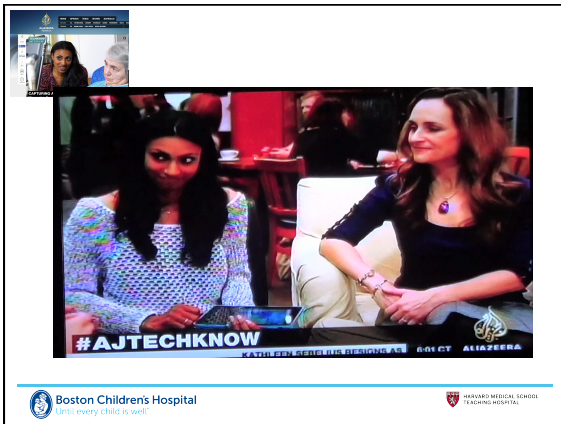
HARVARD MEDICAL SCHOOL
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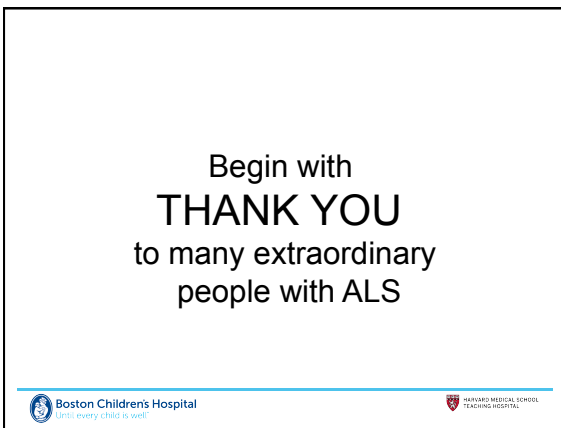
Augmentative Communication Program at Boston Children's

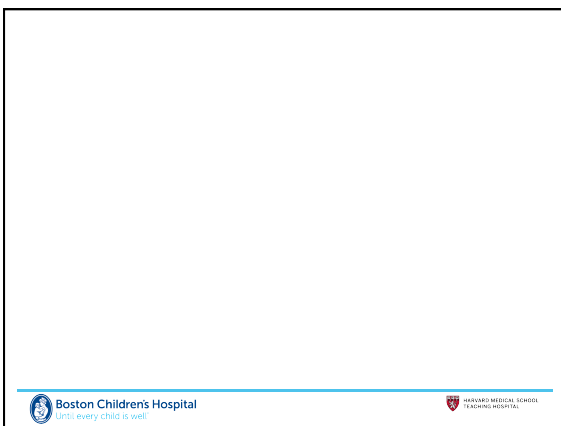
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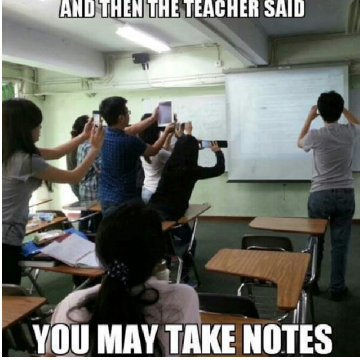










AND THEN THE TEACHER SAID




**DO NOT
Video record or
Photograph my
videos**


YOU MAY TAKE NOTES

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what i think



what i say

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 Mohamed Ghoneim
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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 partners!


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 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 bring the way you talk with me now unless we have recently developed a more intimate relationship.
6. Don't touch me (press 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.








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Argumentative Communication Program © 2013


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Opening statement at each eval:


“My goal is to waste your time”


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Knowledge is power


- Message banking
- Non-electronic strategies
 - Independent
 - Partner assist
 - Context specific
- Voice supplementation
- Emergency call
- High tech SGD/integrated system

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MESSAGE BANKING
A BRIEF HISTORY



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1994: CHB founded a model of AAC service delivery in the ICU including preoperative 'voice banking'.



Parent perspective on hearing daughter's voice



Programmed devices awaiting patient admission



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

M		mom	friends	ADD	TOILET	bathroom	WIP UP AT END	WIP UP AT END	WIP UP AT END	WIP UP AT END	WIP UP AT END	WIP UP AT END	WIP UP AT END
D		Dad	here?	NO	NO	NO	NO	NO	NO	NO	NO	NO	NO
A		Nana	NO	NO	NO	NO	NO	NO	NO	NO	NO	NO	NO
S	12.23.1997	Annie	thank you	SUCKS!	?	NO	NO	NO	NO	NO	NO	NO	NO
E		YES	NO	OK	NO	NO	NO	NO	NO	NO	NO	NO	NO

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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.

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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.

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Sidebar:


Let's examine terminology

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

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

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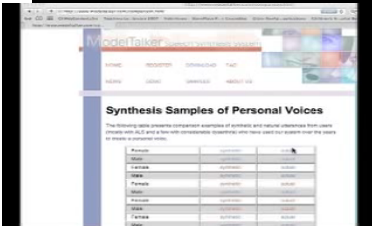
- Model talker
- Cereproc (Edinburgh Scotland)
- OKI Electronic Industry Co Japan
- Edinburgh Voice Banking and Reconstruction project



 

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



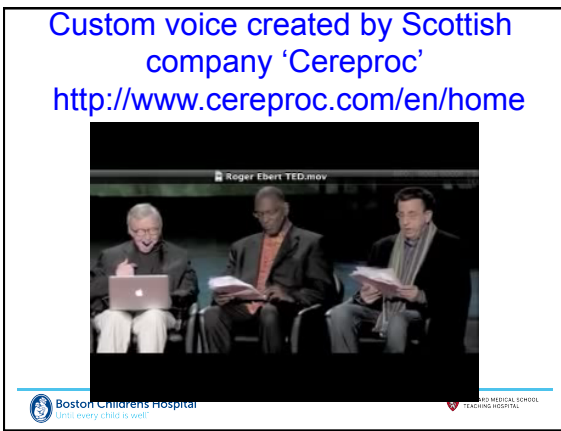
  <http://www.modeltalker.com/comparison.html>

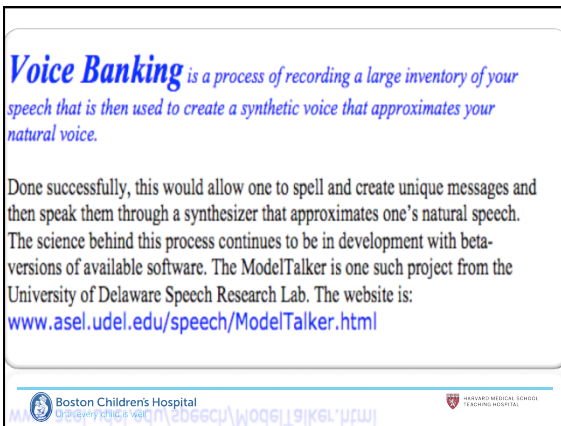
AssistiveWare Video July 2012














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.





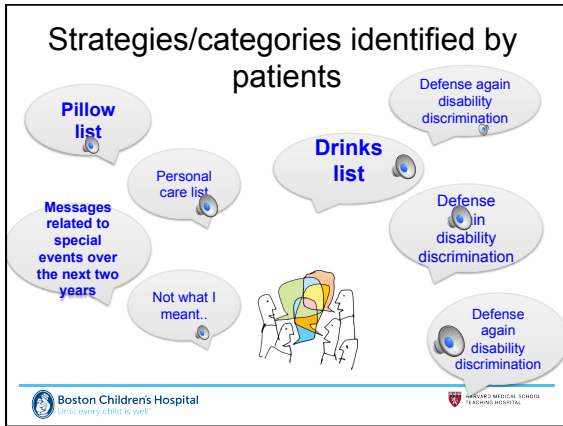
- set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for best quality
- Practice timing of push - speak – push

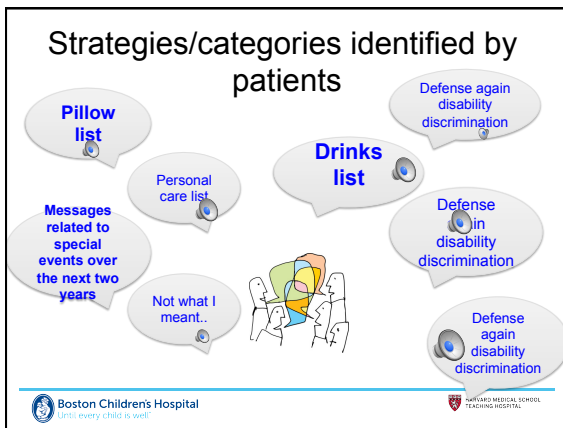
 

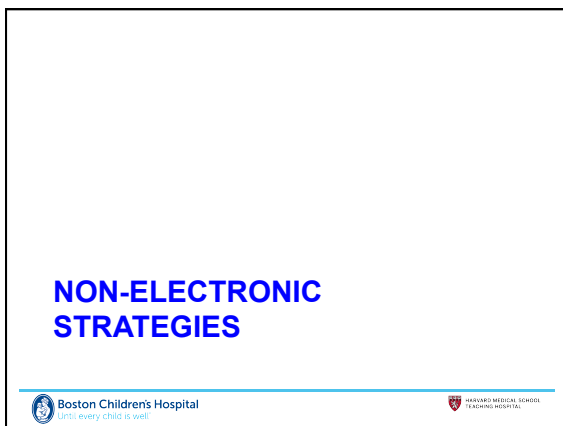
Vocabulary

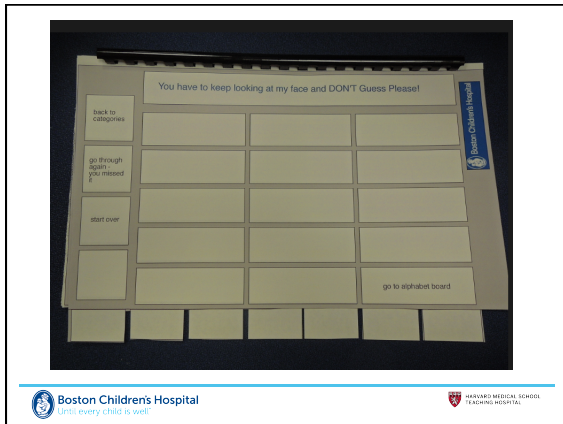
- Vocal play with children
- Many loving messages to children
- Many messages to wife
- Vacation/quality family time messages
- Anger
- Defending self dignity anticipating severe disability
- Directives to anticipated staff
- Changes in physical state
- Refusal of medical treatment

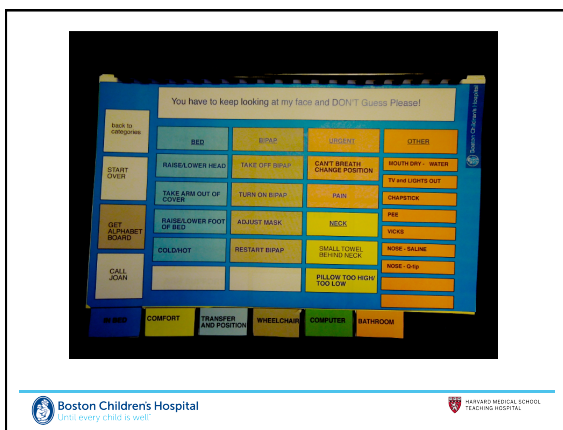
 

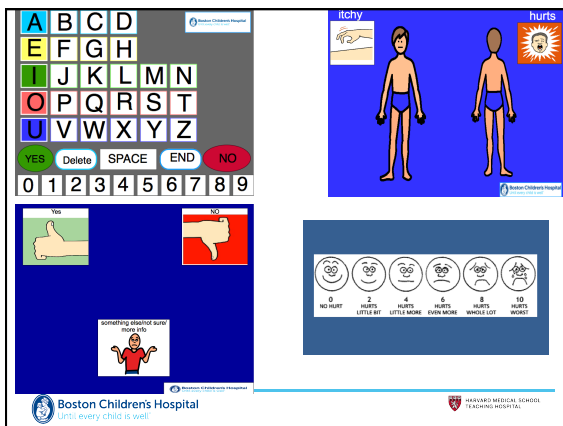
















**VOICE ASSIST/
AMPLIFICATION**

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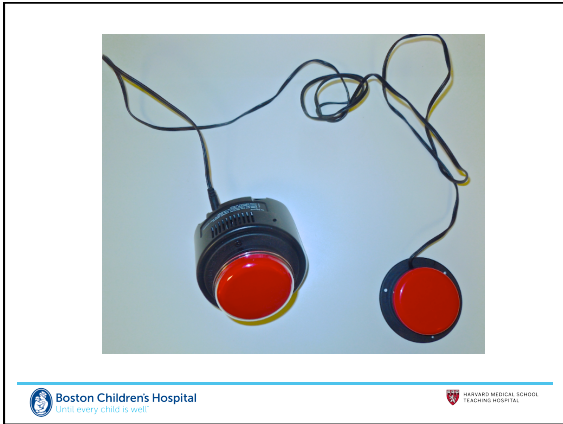
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EMERGENCY CALL

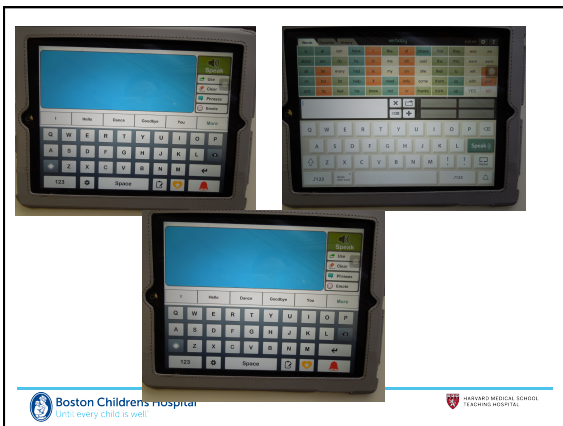
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ISAAC 2014 Costello and Dimery










Early referral of PALS


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

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


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Charlie, age 42
Diagnosed with ALS at age 41

Messages that reflect 'you'


My voice


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May 2011


July, 2011, having a little fun with messages


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Need to bank more, body is changing


Has been banking messages in many formats for children


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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


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Susan

Heard of voice banking on web


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Strategies that change with you

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27 days
later


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Considering vocabulary lists

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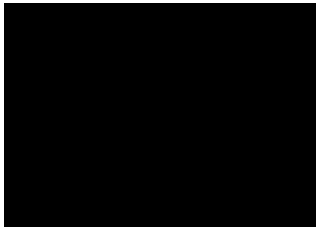
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Kim's husband commenting on hearing his wife's recordings


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MP
Age 68
First (and only) Message Bank Session




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July 2013



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September 2013





Not losing self (Oct 2013)



Rubber Ducky Oct 2013





Intro tech early October 2013





November 2013




January 9, 2014





Susan





Richard



**Our Experience Integrating
Message Banking Model
with Current Technologies**


**Practical OPERATIONAL
Considerations**


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GOALS:


- 1. Configure programming** so that recorded (digital) messages play *in combination with* synthesized speech from the message window
- 2. Organize messages** in a personally intuitive structure that promotes easy use in spontaneous conversation
- 3. Load messages and programming** onto users' devices, integrating with their current page sets
- 4. Receive feedback** from users on organization and function


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1. Configure Programming

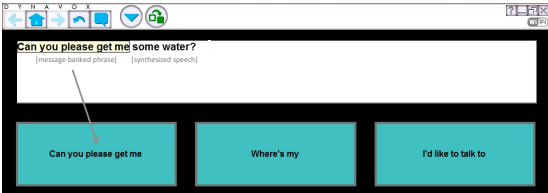
- We want the user to be able to play recorded (digital) messages both alone and *combined with* synthesized speech
- In essence, when the whole text is spoken from the message window, the programming should dictate:
 - which word(s) were intended to be produced via message banked sound file
 - which word(s) to generate with synthesized speech

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Current Technologies We Have Successfully Used

- DynaVox Series 5 Software

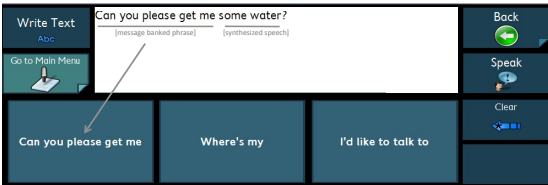


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Current Technologies We Have Successfully Used

- Tobii Communicator
 - Integration with Sono Key package



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2. Organize Messages

- Best when user is intimately involved in organization and categorization process
- Many considerations regarding organization structure and function, e.g.,:
 - Multi-level categorization and ease of message access
 - Verbatim transcription vs. shorthand label on the button
 - Speaking messages on button selection vs. sending to the message window, then selecting 'Speak'
 - Access to keyboard from each page for combination of message banked phrases with synthesized speech output

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3. Load Messages and Programming

- Integrate custom message banking pages within user's existing page set
 - Save message banking pages to device
 - Customize access for integration of banked messages into communication pages
- Save sound files to user's hard drive and direct the software to seamlessly locate and play those files when message selected



4. Receive Feedback

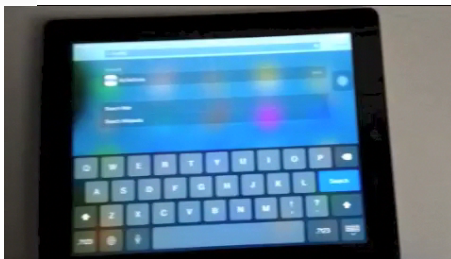
- Deliver page sets to users as quickly as possible for them to explore, use, and provide feedback

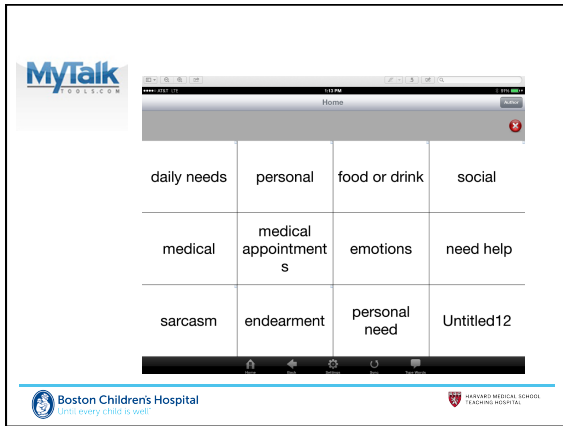
holly October 30, 2013 3:41 PM
To: Katherine Dimery
Grid size

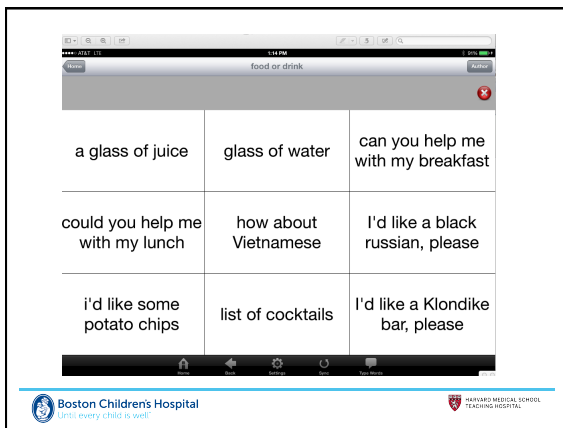
Katey,
while the small grid with individual phrases looked workable, in practice it is too tight to navigate quickly.
Options?




Message Banking with Apps







 **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 wish 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

At the bottom, there are logos for Boston Children's Hospital and Harvard Medical School.

