


**AAC Assessment and Intervention in the Intensive Care/Acute Care Settings: From Referral Through Continuum of Care**

ISAAC Biennial Conference  
Lisboa, Portugal  
Full day - July 1, 2014

John M. Costello, MA, CCC-SLP  
Rachel Santiago, MS, CCC-SLP  
Boston Children's Hospital  
Boston, Massachusetts USA

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**Augmentative Communication Program at Boston Children's**

Expert care meets creative solutions

Join us on facebook at:  
<https://www.facebook.com/ACPCHBoston>

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Programs and History



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## Augmentative Communication Program

- Outpatient (Waltham campus)
- Inpatient (Longwood campus)



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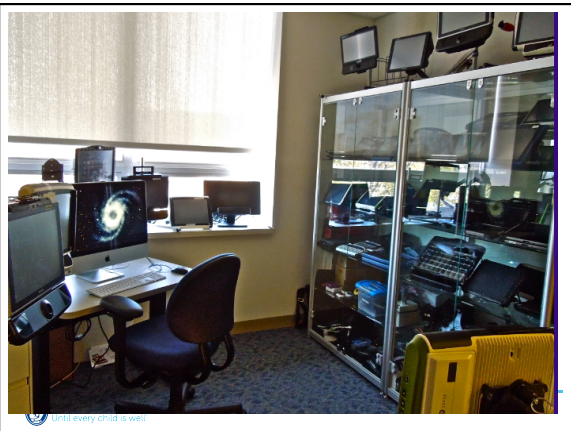
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### Inpatient Augmentative Communication Closet



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### Augmentative Communication Program

 Holly Fadie, SLP	 Alysa Berg, SLP	 Jenny Abramson, SLP	 Rachel Moritz, SLP	 Jennifer Buxton, OTR, ATP
 Katie O'Neill, SLP	 Emily Laubacher, SLP	 Susanne Russell, OTR	 John Costello, SLP	 Rebecca Theriault, SLP

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It is not possible to pay too much attention to communication vulnerability in the hospital setting



what i think

what i say

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# Communication Vulnerability: What is it?

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## What is communication vulnerability?

- Vision so poor that the patient is unable to read/see, even with corrective lenses\*
- Inability to understand loud speech, even with hearing aids\*
- Inability to produce speech that is intelligible to the team\*
- Altered mental status\*
- Inability to speak or understand the language of the medical team

\*Serious communication disabilities in hospitalized patients.  
Ebert, D. N Engl J Med. 1998

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## COMMUNICATION VULNERABLE PATIENTS

**Individuals with:**

1. **Pre-existing hearing, speech, cognitive disabilities** who may (may not) have access to communication tools supports
2. **Recent communication difficulties** occurring as a result of their disease/illness/accident/event
3. Communication difficulties that occur **as a result of medical treatment** (e.g., intubation, sedation)
4. **Linguistic** differences
5. **Limited health literacy**
6. Limited ability **to read/write**
7. **Cultural differences/mismatch**

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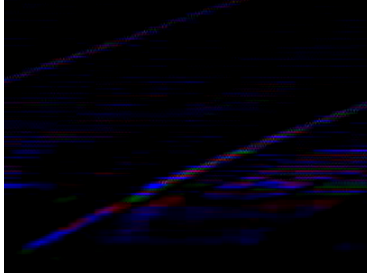
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Jeff Burns, M.D., Anesthesiology and Director of Multidisciplinary Intensive Care Unit and Andrew (16 y.o. with Duchenne Muscular Dystrophy) October 1996



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### Profile of Patients with communication vulnerability

- Congenital conditions
- Acquired conditions
- Degenerative conditions
- Condition related to medical intervention (surgery)
- Condition related to medical treatment

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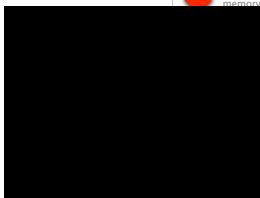
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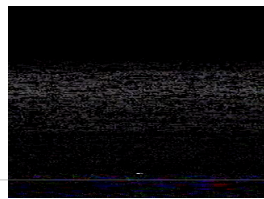
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### Jeff – Nager Syndrome Congenital non-speaking condition



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Congenital

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Fracture of third and fourth cervical vertebrae,  
leaving him paralyzed

FM  
consideration:  
Meds

**Acquired and Linguistic m  
match**

**Acquired**



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Andrew  
Duschenne Muscular Dystrophy



**Degenerative**



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**Related to medical intervention/surgery**



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Reassuring to parents *and* links  
pre and post op



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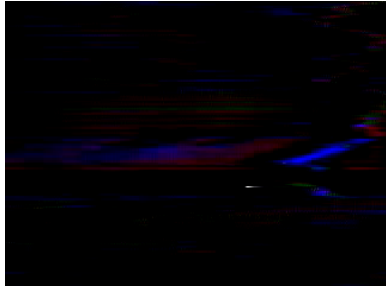
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Prepare in advance (you can do  
this at school or at home)



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How did our Inpatient AAC  
program begin?



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I don't work in a hospital

What role can I play to help someone who is communication vulnerable?

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Advanced planning!!!

Learning is easier in familiar and low stress environments.

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Benefits of Advanced Planning:

- The hospital admission is stressful enough
- Postoperative status → misunderstanding, confusion, changed mental status, impact of medications and pain management
- Patients can participate in selection of tools and messages during a lower stress time
- Message Banking may be an option
- Time to familiarize → easier and more functional use
- Sense of control in own care and preservation of personality

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**Remember:**

**SPONTANEOUS  
COMBUSTION  
OF SKILL**



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**WHY PREPARE IN ADVANCE?**

“Those who participate in generating goals are more likely to pursue them”

- Nicki Nelson (AAC by the Bay, 2014)



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**HOSPITAL NARRATIVES**

- Social Stories™ - Carol Gray
- Design varies based on language skill and use of visuals
  - Photographs
  - Picture-communication symbols
  - Symbol supported text
  - No visuals
- Outline expected details of the hospital admission, procedures, bedside cares, and more.
- **Call the RN, Child Life Specialist, or Social Worker** to gather information related to admission for inclusion in narrative.



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## Social stories/visual schedules

### Rachel Santiago, MS, SLP

**BEFORE SURGERY**

**AFTER SURGERY**

**Ambulance Ride**

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## Social Story Example: Trach and Gtube

Tomorrow, I will get a new trach. A trach is a small tube in my neck that helps me breathe. It might look like this.

The trach tube might make my throat feel different. After my trach surgery, I might have a sore throat. I will not be able to talk right away. Instead, I can use my picture boards. Later I will be able to use my voice.

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### HOW I COMMUNICATE

I can understand everything you say!  
Please speak directly to ME

I...

1. Talk
2. Spell
3. Use an eye gaze spelling board
4. Use a QWERTY spelling board with partner assisted scanning
5. Use a communication book with partner assisted scanning

Also...  
I pucker my bottom lip when I'm mad!!

### HOW I COMMUNICATE

My sayings:

<b>When I say:</b>	<b>I may mean:</b>
Dah dah	food/hungry
Manda	medicine
Mah mah	milk
Ah ah	poop-poo
Ah I yuh	I love you

**My eye gaze letter board**

My eye tracking device

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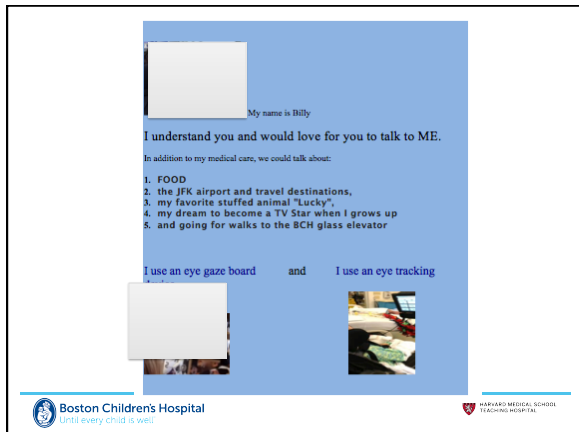
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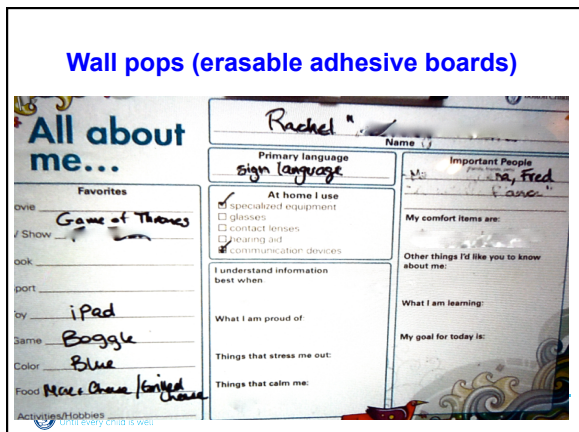
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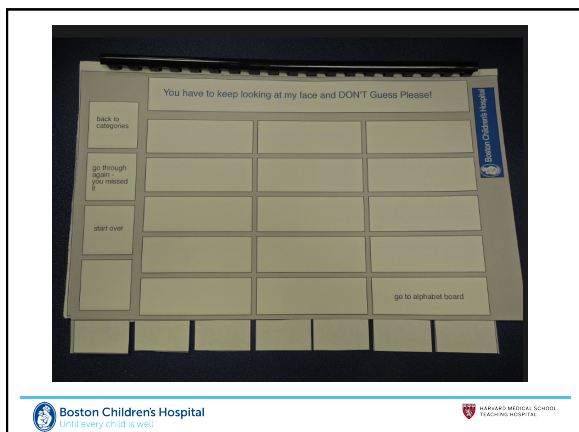
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You have to keep looking at my face and DON'T Guess Please!

BACK TO EMPLOYEE	BED	BIOPAP	URGENT	OTHER
START OVER	RAISE/LOWER HEAD	TAKE OFF MASK	CAN'T BREATHE CHANGE POSITION	HEALTHY DRY - WASH TY WASHERS OUT
TAKE ARM OUT OF COVER	TAKE ARM OUT OF COVER	TURN ON BIPAP	END	COMFORT
GET ALPHANET BOARD	RAISE/LOWER FOOT OF BED	ADJUST MASK	BECK	FEED
CALL JOAN	COLD/HOT	RESTART BIPAP	SMALL TOWEL STAYING WARM	NOSE - SALINE
			FOLLOW TOO HIGH TOO LOW	NOSE - O2
IN BED	COMFORT	TRANSFER AND POSITION	WHEELCHAIR	COMPUTER
				BATHROOM

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**Customization – can at least be STARTED before entering the hospital!**

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**Use an 'authoring' approach to help child highlight important themes and content**

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**Communication about who I am and what I like  
(it's not all about medical care!)**

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**Continuing Education in Anaesthesia, Critical Care & Pain | 2013**

Continuing Education in Anaesthesia, Critical Care & Pain Advance Access published January 20, 2013

**Anaesthesia for children with special needs, including autistic spectrum disorder**

Justin Allison Short B Med Sc FRCA FRCA  
Alison Calder BSc MRCP FRCA

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**Barriers/challenges**

Discussion: *What are the barriers to the use of AAC in the hospital setting?*

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**Barriers to communicative success according to The Participation Model**  
(Beukelman and Mirenda 1988)

- Access Barriers
  - Physical/motor
  - Cognitive
  - Literacy
  - Visual/auditory
- Opportunity Barriers
  - Policy
  - Practice
  - Knowledge
  - Skill
  - Attitude

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**What are some of the current barriers in many hospital settings?**

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### Practice barriers

- A person is often in the hospital for life saving or life sustaining measures.
- The clinical priorities of the medical team focus on the urgent medical needs of the patient before communication.
- It is only in rare instances that poor patient communication and the ensuing stress and fear related to that communication vulnerability is recognized as a direct factor in a patient's medical state and recovery.\*
- "We do not welcome staff who are not part of our unit"



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### Attitudinal barriers

- medical thinking – nurse/doctor knows best
- the medical environment is too scary, new and complicated to expect a novice to be a partner in the process
- It is easier to provide medical care if the patient does not interfere by asking questions, negotiating or challenging decisions.



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### Knowledge barriers

- Nursing has identified communication as an area of need for more than 20 years.
- Information about resources (tools and professionals) is frequently not available to nurses.
- The practice of AAC for patients who are nonspeaking, is not familiar to nurses as this is not part of nurse training and minimal information in the nursing literature addresses the issue of communication vulnerability.
- The lack of knowledge regarding the assessment process, identification of appropriate tools and strategies and implementation expertise is a significant barrier to patient care (*What can they do for him? They work with speech?*)



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### Resource barriers

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- Resources may be described both in terms of clinical tools and access to clinical experts.
- Tools: While it is not uncommon for an ICU to use marker and paper, a letter board or a dry erase board, even generic communication boards or simple voice output aids are typically not available.
- Clinical expertise in the assessment and implementation process may not be available to the institution
- \*Even within field of speech pathology, professional preparedness has not kept up with the growing interest in augmentative communication services especially as it relates to hospital services

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### Environmental Barriers

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- The hospital environment is dense with medical equipment and supply carts.
- Patient bedspace may have limited room for additional equipment/material
- Due to storage limitations, communication tools and equipment may not be readily available (at a bedspace OR even on the unit).
- Electromagnetic Interference (EMI) considerations may be barrier for some technology
- We can't so that because you can't clean the communication equipment.

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### Why is this topic timely in the United States and in a growing number of nations?

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- Changes to hospital standards for accreditation that address "communication vulnerability" in 2011
- (measured as of 2012 July).
- Increased focus nationally and internationally on the impact of communication vulnerability on patient care.
- Increased focus on the Joint Commission International Standards of Care

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**Importance of communication and potential impact on patient outcomes is recognized by:**

- American Association of Critical Care Nurses
- Society for Critical Care Medicine
- National Institute of Health
- The Joint Commission




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**Bartlett, G. et al.  
CMAJ 2008;178:1555-1562**

•“The presence of physical communication problems was significantly associated with an increased risk of experiencing a preventable adverse event”

•“We found that patients with communication problems were three times more likely to experience preventable adverse events than patients without such problems”




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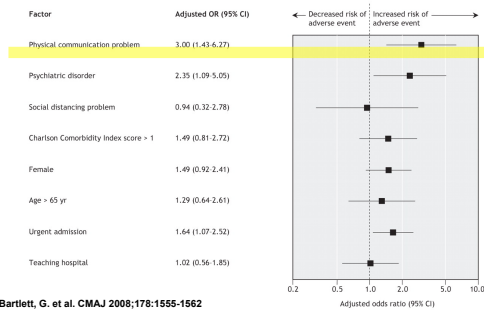
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**Figure 3: Odds ratios (ORs) and 95% confidence intervals (CIs) for factors associated with preventable adverse events, adjusted for age, sex, Charlson Comorbidity Index score, admission status and type of hospital**



Bartlett, G. et al. CMAJ 2008;178:1555-1562




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## Research Data

- Happ (2004) and Patak et al. (2006)
- Patients with access to communication:
  - Receive less sedation
  - Are transitioned quicker
  - Have increased satisfaction with health care
  - Feel more in control...and generally do better...
- Available simple tools and strategies to improve communication usually go unused and ignored.



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## Poor Communication Impacts Patient Safety

- Communication vulnerable patients are at increased risk for:
  - Serious medical events (Cohen et al., 2005)
  - Sentinel events (The Joint Commission, 2007)
  - Poor medication compliance/ adherence (Andrulis et al., 2002; Flores et al., 2003)



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Communication  
Saturday, November 14, 2009  
www.patientprovidercommunication.org

### About PPC

#### About Patient Provider Communication

The Patient Provider Communication Forum is a national and international effort to promote information sharing, cooperation and collaboration among individuals who are committed to seeking improvements in patient-provider communication across the entire health care continuum—from a doctor's office, emergency room, clinic, ICU, acute care and rehabilitation hospital, home health service and hospice.

Members of the group bring together a range of perspectives and experience in the area of patient-provider communication. The group works to share knowledge and resources and to raise awareness at both the practice and policy levels of the need to overcome existing communication barriers and to increase communication access across health care settings.

The Patient Provider Communication Forum seeks to achieve shared learning about patient-provider communication through:

- monthly conference calls among participants.
- an interactive website to share resources and tools and to seek feedback and opinions from the field.
- collaborative projects such as white papers, presentations and research studies that intersect the areas of interest and experience of group members.
- Special interest conversations about topics, such as (e.g., emergency preparedness, intensive care units (ICUs), The Joint Commission's Proposed Standards related to effective communication, cultural competence and patient-centered care and information about specific populations and/or healthcare settings.)

Supported By:  
ACI  
AMERICAN COLLEGE OF AMBULATORY CARE

<http://www.patientprovidercommunication.org/>

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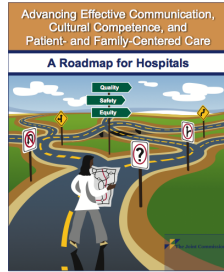
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## Roadmap 'Guide' to help facilities implement standards

**p. 10 Recommended issues and related practice examples to address during Admission:**  
Identify whether the patient has a sensory or communication need ... *"it may be necessary for the hospital to provide auxiliary aids and services or augmentative and alternative communication (AAC) resources to facilitate communication."*

Identify if the patient uses any assistive devices... *"make sure that any needed assistive device are available to the patient throughout the continuum of care."*



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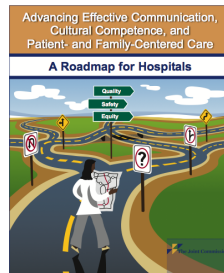
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## Roadmap 'Guide' to help facilities implement standards

**p. 18 Monitor changes in the patient's communication status ...** *"Determine if the patient has developed new or more severe communication impairments during the course of care and contact the Speech Language Pathology Department, if available. Provide AAC resources, as needed, to help during treatment"*



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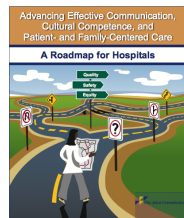
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## p. 59 **New Standard** PC.02.01.21 The hospital effectively communicates with patients when providing care, treatment, and services:

*"Patients may have hearing or visual needs... or be unable to speak due to their medical condition or treatment. Additionally, some communication needs may change during the course of care. Once the patient's communication needs are identified, the hospital can determine the best way to promote two-way communication between the patient and his or her providers in a manner that meets the patient's needs"*



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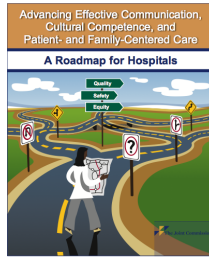
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**New Standard** PC.02.01.21  
(cont'd)

*“Examples of communication needs include the need for personal devices such as hearing aids or glasses, language interpreters, communication boards and devices...”*



Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care  
**A Roadmap for Hospitals**  
Quality  
Safety  
Equity

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**WHAT IS “EFFECTIVE COMMUNICATION”?**

- “the successful joint establishment of meaning wherein patients and healthcare providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood”
- (The Joint Commission, 2010b, p. 91 ).

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**Guidelines for admission to Pediatric ICU**

AMERICAN ACADEMY OF PEDIATRICS AND THE SOCIETY OF CRITICAL CARE MEDICINE  
PEDIATRICS, V 103, NO. 4 APRIL 1999

- **Severe or potentially life threatening Pulmonary or airway disease requiring:**
  - Endotracheal intubation and potential mechanical ventilation
  - Rapid progressing pulmonary disease with risk of respiratory failure
  - High supplement of oxygen

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**Guidelines for admission to Pediatric ICU**


American Academy of Pediatrics and the Society of Critical Care Medicine  
*Pediatrics*, V 103, No. 4 April 1999.

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- **Children with severe, life threatening or unstable cardiovascular conditions**
  - Includes Children with high risk cardio vascular procedures

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**Guidelines for admission to Pediatric ICU**


American Academy of Pediatrics and the Society of Critical Care Medicine  
*Pediatrics*, V 103, No. 4 April 1999.

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- **Neurological conditions or seizures**
  - spinal cord compressions
  - Head trauma
  - Progressive neuromuscular dysfunction

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**Guidelines for admission to Pediatric ICU**


American Academy of Pediatrics and the Society of Critical Care Medicine  
*Pediatrics*, V 103, No. 4 April 1999.

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- **Hematology/oncology disease: tumors or masses compressing (or threatening to compress):**
  - - vital vessels
  - - airway
  - - nerves of the face

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**Guidelines for admission to Pediatric ICU**


American Academy of Pediatrics and the Society of Critical Care Medicine  
*Pediatrics*, V 103, No. 4 April 1999

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- **Endocrine/metabolic disease**
  - inborn error of metabolism and acute deterioration requiring respiratory support
  - acute dialysis management of intracranial hypertension

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**In general, these conditions include**


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issues of :

- Airway patency/management of blood gasses
- Muscle function, strength and coordination
- Neuro-cognitive/neuro-linguistic impairment

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Communication vulnerability may be related to one or all of these

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Communication Vulnerability  
Can Impact All Patients

**BUT** our treatment is not the  
same for all patients

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Children are NOT small Adults

Why is pediatric acute and  
intensive care different from  
adult services?

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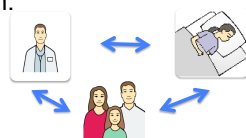
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- The bedside assessment and intervention involves a triad of interaction including the child who may be developmentally quite young, the parent(s) and siblings and the clinician.



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**We propose basic tenets (A-B-C-D-E-F) for successfully engaging a child at bedside.**

- Assure
- Bring
- Control
- Direct
- Emotion and Personality
- Fun

Costello and Santiago, manuscript in review

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**A-B-C-D-E-F**

- **Assure** – In a hospital setting, a child is constantly on guard for the clinician who will invade their personal space and introduce an unwanted procedure
- **Bring materials and tools** with you to the first visit. For many children, 'seeing is understanding'
- **Control.** Children need to feel a sense of control in the hospital.

Costello and Santiago, manuscript in review

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**A-B-C-D-E-F**

- **Direct attention to the child.** While your behavior will ultimately be directed by the child's behavior, your attention should always be to the child first
- **Emotion and personality** - hospitalization is a very emotional experience. Loneliness, isolation, separation, anxiety, sorrow, etc. The reflection of personality is essential and is key to successful development and implementation of communication strategies.
- **Fun.** Children understand their world and cope through play. Despite potentially life threatening medical circumstances, you must be ready to focus on fun

- Costello and Santiago, manuscript in review

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### The business of being a child is play.

*"She did everything you asked her to do because you made it fun. She wasn't even seven years old and she loved the fact that she could continue to 'win' over an adult. She could always find the picture faster than you. She could always get the right answer before you. When you kept score, she always had more points. At a time when everything was designed to measure her losses, everything she did with you was a 'win'. In her last days, instead of being frustrated that her hand could not always get to the pictures quickly to tell us what she was thinking, she celebrated all the 'points' on the score board on the wall of her hospital room that highlighted the fact that she used her picture board to tell us things and all the adults kept forgetting to use theirs".*

Parents of Rebecca, a 6 year 7 month old girl with an Anaplastic astrocytoma of thalamus



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### Intensive Care Unit Experience: through the Eyes of a Child



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### Children's reaction to pain

Toddlers and preschoolers (2-5 yr):

- Experience pain but can not always identify the source or location
- **'Magical thinking'** may lead child to believe their pain is punishment for real or imagined misbehavior...they believe the pain is someone's fault.



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**Toddlers and preschoolers (2-5 yr)**


**•Communication needs:**

**•At this stage, children may view procedures as punishment for bad behavior**

**•This makes it particularly important to communicate: fear, anxiety and solicit parents and loved ones for comfort, explanation and protection**



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**Children's reaction to pain**


**School age (6 - 12 years)**

— Can tell the location of pain

— know that illness is caused by germs and believe that staff's response depends on how well they express pain

Brewster, Arlene B. Chronically Ill Hospitalized Children's Concepts of Their Illness  
PEDIATRICS Vol. 69 No. 3 March 1982, pp. 355-362

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**School age (6 - 12 years)**

**• Communication Needs:**

**• Children need to be able to effectively communicate matters of comfort and pain**



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## Children's reaction to pain Adolescents (13 and older)

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- begin to understand that there are multiple causes of illness, that the body may respond to many different factors and illness is caused by physical weakness or susceptibility.
- children understand that different interventions may be needed to address illness and that staff act with necessary intent and empathy.

Perrin, Ellen C., Gerrity P. Susan, There's a Demon in Your Belly: Children's Understanding of Illness PEDIATRICS Vol. 67 No. 6 June 1981, pp. 841-849

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## Adolescents (13 and older)

- Communication need:
- At this more mature stage, a child may be particularly anxious to be able to ask questions, interact with staff and understand the intent of intervention.



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### Thinking about pain scales....



Chambers and Craig (anchor affect):  
Scales that start with a smile produce higher pain scores than scales that start with a neutral face. For example, on the

Wong-Baker FACES Pain Rating Scale, the lowest scoring face that shows any expression of distress is rated 6/10. Older children readily discern the intent or the underlying dimensional nature of the scale; that is, they understand that the faces for scores 2 and 4 are intended to indicate low and moderate pain, respectively, although they show no distress.

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**CYCLE OF STRESS RESPONSE**  
*ACCH, 1985*

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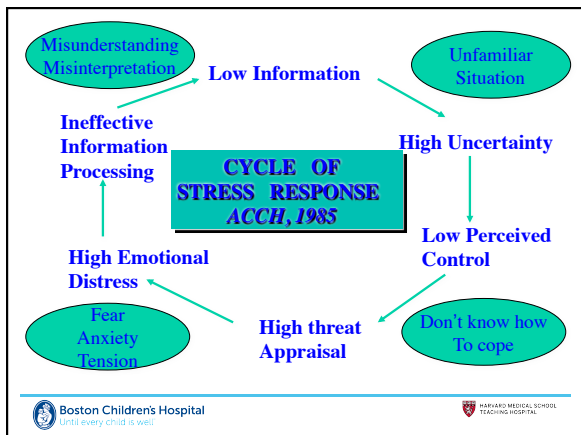
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**Communication Vulnerability:**  
Who does it impact?

- Patient**
- Family**
- Staff**
- Payer**

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**Communication Vulnerability:  
Who does it impact?**

**Patient**

- Loss of control of environment, sense of self, ability to participate in own care (Garrett et al., 2007)
- Inability to speak is closely linked to: insecurity, panic, worry, fear, anger, stress, and sleep disturbances (Happ et al., 2004)
- Feelings of low mood can lead to withdrawal from family and care givers. This impacts participation in care and recovery (Magnus and Turkington, 2005)

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**Impact of communication vulnerability:  
Impact on the patient**

- ❖ Powerlessness
- ❖ Loss of Control
- ❖ Disconnection from loved ones
- ❖ Inability to participate in own care
- ❖ Inability to ask questions, express needs, fears, PERSONALITY, etc.

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**Communication Vulnerability:  
Who does it impact?**

**Family**

- Afraid child/family member will not be able to communicate wants and needs
- Concern that communication vulnerable person will not be able to call out for them and may feel abandoned
- Distress over temporary loss of the patient's personality (Costello, 2000)

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## Communication vulnerability: Impact on Family

- Stress for parents (Costello, 2000), fear child will feel abandoned as can not solicit loved one and has not way of advocating for self
- (Hurtzig and Dowden 09) “ parents, although completely exhausted, refuse to leave or sleep due to their concern that their child will require assistance and no one will be there to interpret the child’s efforts to get help”

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## Best job as parents

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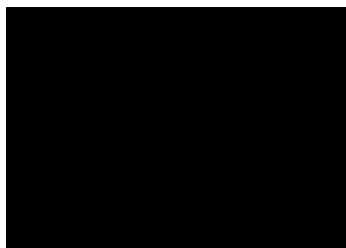
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*My son’s ability to communicate, allowed me to  
advocate for him*



Post heart-transplant,  
a mother’s perspective

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### Communication Vulnerability: Who does it impact?

**Staff**

- Nurses typically do not have time to “figure out” what patient is trying to communicate.
- Education regarding patient care and delivery of medical information can be compromised
- Challenge to support a patient from an emotional, psychological, and developmental perspective
- May lead to limiting communication attempts beyond what is essential (Costello, 2000 and Garrett et al., 2007)

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### Communication Vulnerability: Impact on staff

1. Quality of care issue “all patients who described good communication with their providers told us they were treated in a caring, concerned and respectful manner”  
-Duclos, et. Al. 2005 International Journal of Quality in Health Care v 17 # 6 page 483
2. Patients inability to communicate has a negative impact on the nurse/doctors tendency to communicate with them, (Ashworth, 84)

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### Rachel video (nurse) When there is a communication board

- Saves the frustration of both the nurse and the patient and instead of the patient getting madder and madder...
- patient gets what they want when they need it, instead of the nurse having to figure it out.

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### Communication Vulnerability: Who does it impact?

#### Payer

- Extended hospital stay
- Medical errors
- Unnecessary use of sedation and pain medication
- Poor compliance due to inability to engage with medical staff (questions, comment, etc.)



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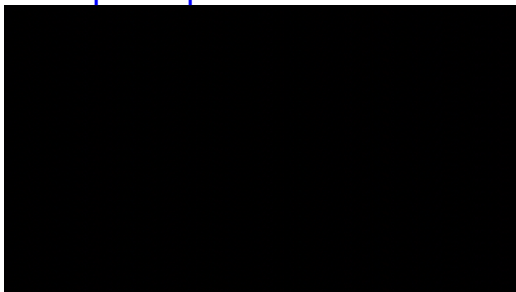
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### Mother on daughter's own participation in cares



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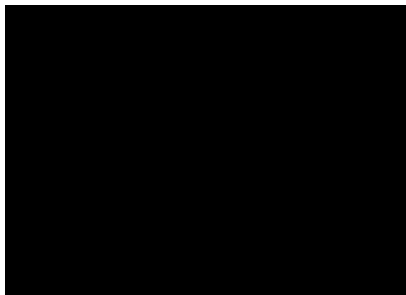
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### Kyle – 'suggestions'



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**What does this focus on patient provider communication and Communication Vulnerability mean for the Speech-Language Pathologist?**

- An increased demand for expertise in AAC with acute and intensive care patients
- This will require increased training to prepare SLPs to provide AAC services for patients who are communication vulnerable in the medical setting.
- There will be an increased need for AAC tools and strategies to be readily available for assessment and intervention.



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**What strategies (if any) are used when a patient can not speak?**

- Nurses rely on lip reading
- Have a familiar family member interpret
- Gestures
- Pen and paper
- Alphabet board
- Hand drawn pictures
- Medical staff ask yes/no questions\*



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**Profile/Phases of Communication Vulnerable Patient**

**Phase 1:** Emerging from Sedation

**Phase 2:** Increased wakefulness

**Phase 3:** Need for Broad and diverse communication access

(Costello, Patak, and Pritchard, 2010)



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## Phase 1 Emerging from Sedation

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- Yes - no - I don't know
- Call for nurse/modified nurse call
- Gain attention of loved ones/staff with simple voice output

Also – developmentally young/emergent communicators and 'control'



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## Phase 2 Increased wakefulness

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- Require all of phase 1 strategies
- Require more relevant vocabulary
- Picture boards – needs, body/comfort, personal interests
- Alphabet boards
  - ABC
  - QWERTY
- Multi-message voice output devices with digital or synthetic messages
- Voice amplification

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## Phase 3 Broad and Diverse Communication Access

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- All options from phase 1 and 2
- Generative communication with alphabet and sophisticated page sets
- Word and grammar prediction
- Encoding strategies
- Music and video files
- Internet access
- telephone

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**Key Components to Successful Intervention:**

- Getting the Referral
  - Recognizing when a patient is communication vulnerable or *at risk* for communication vulnerability
- Providing effective resources
  - Making sure provided resources and materials are feature match to the patient (including customized as needed) and available and accessible to the patient at all points of care.
- Follow through
  - Implementation of communication supports and modification as needed throughout admission

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**Phases of Communication Vulnerable Patient**

- Not so black-and-white
- Timing of recovery *and* ability to participate in communication varies greatly

Quick case review from Rachel Santiago, MS, CCC-SLP  
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**Potential Candidates for AAC**

- Communication Vulnerable at Baseline
- Acute Onset of Communication Vulnerability
- At Risk for Communication Vulnerability
- Palliative Care and End of Life

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**Communication Vulnerability At Baseline:**  
**Possible candidates**

- Baseline speech, language, and/or communication deficits
  - Congenital
  - Acquired prior to inpatient admission Intellectual disability
- Trach or other form of mechanical ventilation
- Language difference
- Baseline motor skills that impact use and access to nurse call system

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**Role of the SLP**  
**Baseline communication vulnerability: interventions**

- Assess use of current AAC system in hospital
- Adjust current system as appropriate for vocabulary, mounting, physical access
- Develop new system that is used only in hospital environment when current system can not be used.
- Adapted nurse call and tool for attention

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**Role of the SLP**  
**Baseline communication vulnerability: interventions (cont'd)**

- Baseline communication vulnerability
  - Assist with adding medical related vocabulary to patient's current communication system
  - Design and construct new communication supports
  - Explore optimal access options
  - Set up adapted call button
  - Identify patients who are appropriate for referral to our outpatient department
  - Disseminate information about how the patient communicates

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### Communication Vulnerability: Acute Onset Possible Candidates

- New trach
- Intubation or other form of mechanical ventilation
- Medical procedure, treatment, or device that impedes a patient's ability to effectively speak (e.g.. fixation, etc.)
- Brain injury, aphasia
- Aphonia or new onset vocal cord/fold paresis
- Dysarthria
- Altered mental status
- Psychiatric disorder
- Decreased motor skills needed to effective use and access the nurse call system

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### Role of the SLP

#### Acute onset communication vulnerability: Interventions

- Evaluate current communication skills/bedside
- Design and construct supports to meet needs (refer to phases)
- Mount, train partners
- Periodic reevaluation and modification or enhancement of communication supports as needed
- Explore optimal access options
- Set up adapted call button
- Identify patients who are appropriate for referral to our outpatient department
- Disseminate information regarding how the patient communicates
- Provide education regarding communication supports and strategies to the family and medical team

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### Communication Vulnerability: At Risk Possible Candidates

- Risk for intubation or other form of mechanical ventilation
- Anticipated tracheostomy
- Changing neurological status
- Medical procedures or treatments
- Degenerative condition

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**Role of the SLP**  
**At risk for communication vulnerability**  
**Intervention**

- BCH Model of Preoperative AAC
  - Allows patient participation in selection of tools and messages during less acute and stressful situation
  - Allows for time to familiarize with communication supports, leading to more functional use
  - Sense of control in own care
  - Preservation of personality
- Message Bank when possible
- School based/community based instruction and pre-planning
  - Vocabulary selection
  - Message banking
  - Creating materials

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**Who might have a  
Temporary Nonspeaking  
condition?**

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**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

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**Potential conditions leading to nonspeaking condition:**

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

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**Airway Problems**

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- Congenital/acquired abnormalities
- Granulation tissue
- Hemangioma
- Laryngeal injury
- Laryngectomy
- Small mandible
- Venous malformation
- Tumors
- Vocal cord paralysis

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**Lung Problems**

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- Bronchopulmonary Dysplasia (BPD)
- Chronic pulmonary disease
- Chest wall injury
- Diaphragm dysfunction
- Cystic Fibrosis

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**Waiting for a Double Lung Transplant...**

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**Neuromuscular Diseases Affecting Respiration**

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- Arnold Chiari Malformation
- Cerebral palsy
- Muscular dystrophy
- Myasthenia gravis


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**Patients with or undergoing tracheostomy**

When to refer:

Patient Status:	Intervention:
<p><b>WILL undergo tracheostomy:</b></p> <ol style="list-style-type: none"> <li>1. Patient speaks at baseline</li> <li>2. Patient does not speak at baseline</li> </ol> <p><b>Trach at baseline</b></p> <ol style="list-style-type: none"> <li>3. Tolerates deflated cuff/speaking valve but requires mechanical ventilation</li> <li>4. Does not tolerate deflated cuff/speaking valve at baseline</li> </ol>	<p><b>WILL undergo tracheostomy:</b></p> <ol style="list-style-type: none"> <li>1. Preoperative message banking; set up communication system</li> <li>2. Identify supports/strategies to enhance patient-provider communication.</li> </ol> <p><b>Trach at baseline</b></p> <ol style="list-style-type: none"> <li>3. Identify supports/strategies to enhance patient-provider communication until able to tolerate deflated cuff/speaking valve.</li> <li>4. -Support use of existing augmentative and alternative communication (AAC) supports/strategies. -Identify new AAC supports/strategies</li> </ol>


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[www.tracheostomy.com](http://www.tracheostomy.com)



Welcome to Aaron's Tracheostomy Page. The Internet's leading tracheostomy resource since 1996.

This site is dedicated to my son Aaron who had a tracheostomy for the first 4 years of his life. I hope that Aaron's Page will be helpful to others caring for a child with a tracheostomy, or to anyone seeking to learn more about tracheostomies.

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**Communication Vulnerability:  
Palliative Care  
Possible Candidates**

People living with life threatening illness

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**Role of the SLP**  
**Palliative Care and End of Life**  
**Interventions**

Introduce broad range of AAC tools and strategies to support:

- √Expression of needs
- √social connectedness
- √comfort
- √nurse call

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### Goals for the SLP

- Support participation in daily care/decision making
- Enable patient to express emotional state
- Support patient to talk about illness or concrete experience related to illness
- Support expression of self
- Support opportunities for control
- Maintain social connectedness and emotional closeness
- Support reflection/contemplation of positive life events
- Support expression of legacy

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### Rachael

**May 02, 1992 - May 15, 1999**

•7 years of age

•**Diagnosis:**  
**Anaplastic astrocytoma of thalamus**

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**Rachael**

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## Clinical lessons

- **A simple message can create a powerful connection (for patient and family), especially in the last days or hours of life**

**Continued ability to communicate a simple message, even when intentionality is in question, can contribute to the legacy of emotional connection with loved ones**

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## Brian

- **12 years of age**
- **Advanced Juvenile Huntington's Disease**
- **Communication skill varies from moderate to severe Dysarthria to complete Aphonia.**
- **Communication interests have changed with advancement of disease process**

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












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**Initial speech output tool**

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stop 	home 	school 
Feeling 	dog 	books 
	people 	body 
pain 	uncomfortable 	stay with me 

**General topic display to give partners context from which to guess or cue him**

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
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When I am sad or afraid, I feel better if I have:

books 	Game Boy 
play station 	HUG 1..2..3 

**To solicit comfort... the things that bring Brian comfort**

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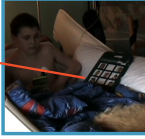





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 ANDREA		 ALYSSA	<p><b>Communication needs shift from physical and medical needs to <i>personal connections</i></b></p>  <b>GoTalk 9 Overlay</b>
 JAY	 JAY	 MARY	
 Nedda		 John	

**Some of Brian's hospital personal connections**

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### Clinical lessons

- Communication needs and goals change with disease progression
- Try to anticipate course of changing needs
  - Better to pre-plan and not need it, then have a lost opportunity
  - Voice banking
  - Tools with varied access options
- At each stage, make sure that maintaining 'the person' is foremost.
- **Always remember** that the person with a life threatening illness is not the only person affect by loss of communication skill.

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## Impact of AAC

Patients taught to use communication tools such as picture boards, word boards or simple communication devices, reported improved satisfaction and comfort when compared to care without communication support

(Patak et al 2007, Costello 2000, Stovsky, Rudy & Dragonete, 1988)

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## First: must get the referral

### KEY:

- √ staff recognizing communication vulnerability and then
- √ recognizing that it is NOT alright

\* Huge opportunity for nurse /staff training by SLP

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## Questions to ask/consider at admission

### questions to ask:

- Does the patient currently have difficulty communicating and participating in the admission process?
- Does the patient have an existing augmentative communication device or strategy that he/she employs for expressive and/or receptive language?
- Is a process or procedure during hospitalization expected to induce communication vulnerability?
- Will hospitalization make the use of current and needed vision or hearing aids not possible?

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**Patient Profile/Communication Information**

General Information

Individual Living with Patient

Primary Language

Interpreter needed

Specialties

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**Functional Health Patterns - Part 2**

Is the Patient A Newborn and Nerver Been Home?

Cognitive/Perceptual Pattern

Any Speech Issues?

Does Your Child Have Difficulty Hearing?

Does Your Child Have Any Visual Difficulty?

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**Hearing Admission Assessment - YEST, BETH**

Coping Stress Tolerance Details

Cognitive/Perceptual Pattern

Sexuality/Reproductive Pattern

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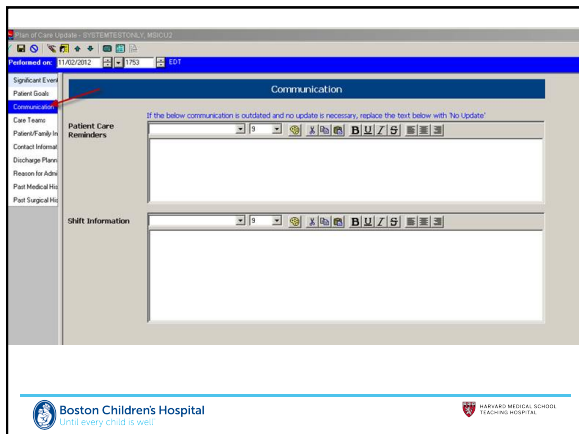
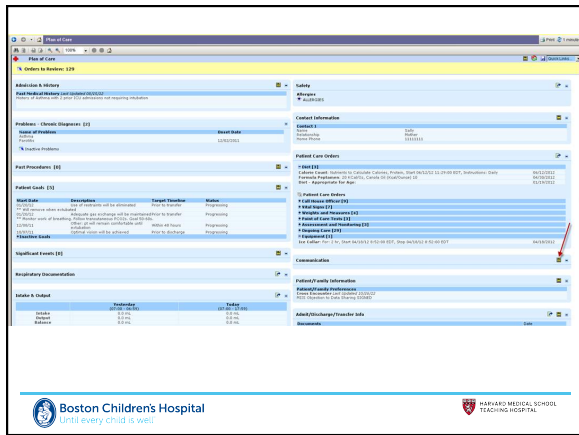
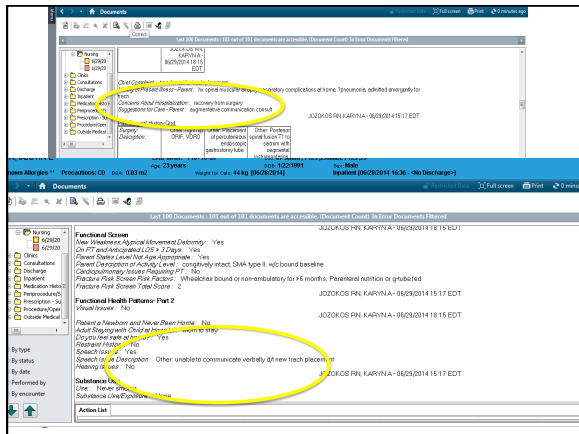
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**Addressing the needs of persons with communication vulnerability in the hospital ( or community) requires:**

Policy Makers, Physicians, clinicians, educators and family to recognize that not being able to communicate, *under ANY circumstance and even for a brief period of time*, is **unacceptable!**

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**Communication Needs: What to consider?**

- Communicate medical information (i.e. pain, positioning, comfort, etc.)
- Understand medical information
- Emotional needs and social interaction
- Control
- Personality
- Gain attention
- Regulate task (opt in/out)
- Ask questions
- Call for help or assistance
- Other

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**What do we know?**

**•We know that not being able to speak in the ICU/**

Stress to patient, family and medical staff

**•We know positive correlation has been suggested between a patient's ability to communicate and quality of communication in the hospital setting**

Correlation between ability to communicate and interaction with nurse


**•We know that positive**


Inability to communicate correlated with poorer recovery time

**•We know that some patients in the hospital setting have had a nonspeaking condition anticipated before getting to hospital**

Nonspeaking condition anticipated before getting to hospital

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

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**ICU stay in an inopportune  
time for new learning:**


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**RESULT:**

**Ineffective processing of new  
information**

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**Researchers have reported:**


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- Anxiety, fear, insecurity, anger all  
result from ineffective information  
processing and the inability to speak  
and, contribute to interference with  
sleep**

Mentzel, 1984

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**It is recognized that sleep patterns of persons in the ICU are highly irregular and disturbed - sometimes leading to ICU Psychosis.**

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**IT IS SUGGESTED THAT ALL OF THIS MAY HAVE AN INFLUENCE ON:**

- **MEDICAL RECOVERY**
- **PAIN MANAGEMENT**
- **LENGTH OF HOSPITAL STAY**

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**Christiano and Tarbell (1998)**

Children with the lowest pain scores were given relevant information in significantly more preoperative intervals than children with higher pain scores.

This suggests that preoperative training may assist patients to cope with pain management issues better than those without preoperative training.

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The Children's Hospital Boston Model of AAC Intervention in the ICU

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- Preoperative Intervention
- Postoperative Intervention
- Discharge Intervention

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Historically, primary communication interventions include:

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- Alphabet board
- Picture boards
- Small typing systems
- Paper and pen
- Magic slate
- Electrolarynx
- Eye gaze systems

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**Preoperative Intervention**

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- Patient expectations/education
- Initial introduction to communication tool
- Vocabulary selection
- Brief review of sensory/motor and literacy skills.
- Introduction to symbols
- Review of mounting and positioning options
- Voice and message banking\*\*\*\*

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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](http://www.asel.udel.edu/speech/ModelTalker.html)

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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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- 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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### Vocabulary

'Legacy' messages  
Core vocabulary  
Fringe vocabulary

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### 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.

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### September 2013

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# Not losing self (Oct 2013)



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# Rubber Ducky Oct 2013



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AAC in ICU Use 153

**APPENDIX B**  
Examples of Patient-Selected AAC Messages for the ICU

<b>Personal Needs</b> I'm hungry I'm thirsty I'm cold I'm hot I'm tired I'm uncomfortable I need to go to the bathroom I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist I need to see a psychologist I need to see a psychiatrist	<b>Interactions/Procedures</b> I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist	<b>Medicines</b> I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist
<b>Basic</b> I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist	<b>Advanced/Settings</b> I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist	<b>Complex/End-of-life</b> I need to see a doctor I need to see a nurse I need to see a pharmacist I need to see a dietitian I need to see a physical therapist I need to see an occupational therapist I need to see a speech therapist I need to see a social worker I need to see a chaplain I need to see a religious leader I need to see a counselor I need to see a psychologist I need to see a psychiatrist

AAC in the ICU: Children's Hospital Boston Model  
AAC, V. 16, Sept 2000

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## Vocabulary Selection part I

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

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## Vocabulary Selection part II

- Clinician guidance
- Encourage to select approximately 30 messages
- Encourage vocabulary that focuses on representing individual personality, personal interests, personal humor or phrases particular to the individual

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## Gries and Firmsler (1988)

Confirmed need for person-specific vocabulary as patients who had previously been nonspeaking in the ICU expressed significant stress related to the inability to express their personality.

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## Introduction to symbols

- Mayer-Johnson symbols
  - Digital photos
  - Custom symbols
- \*\* Even people with established literacy skills have chosen symbols in anticipation of challenge with visual focus

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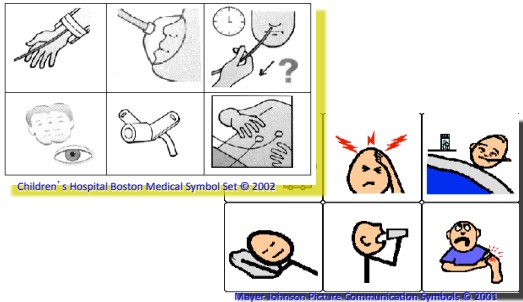
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## Symbols/Representations



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## Our Strength at CHB

- History of innovative service delivery to meet patient needs
- Culture of patient centered care and recognizing inter-disciplinary collaboration
- Leadership with commitment to embracing strategies that support exceptional patient care, exceptional service, and high patient-family satisfaction.

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### Areas to focus:

- Consistency in provider awareness for identifying and addressing patient communication needs.
- Addressing communication vulnerability at all points of care
  - Inability to speak
  - Inability to see/hear
  - Understand the language
  - Inability to physically access the nurse call

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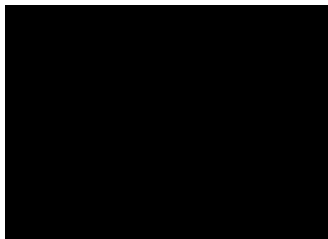
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### The Importance of AAC Inpatient: “That’s not what I’m saying!”



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### Overview: What we believe to be best Practices

- All providers recognize “Communication Vulnerability”
- Administrative support for services to address
- Communication Access: Preadmission through discharge/follow up
- Equipment : availability, storage and dispensing
- Treating the whole person through multi-disciplinary collaboration

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### Case Example

- Child, age 10 years 9 months
- Native of Iraq
- Arabic only spoken by patient
- Reason for hospitalization: surgery for spinal compression related to multiple congenital anomalies; newly introduced tracheostomy with no air leak, minimal joint strength and ability to push switches with hands or use standard keyboard

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### Communication Needs

- To have parents and child understand information from the medical staff
- To communicate medical needs to staff
- To enable the child to communicate emotional needs and social phrases (including jokes) to family
- For parents to ask questions about diagnosis, treatment, prognosis, care



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#### • General Accommodations

- Arabic (hospital service). All teaching and information sharing/feedback sessions with family (*general hospital provision*)
- English/Arabic communication board provided to family (*SLP and general hospital provision*)
- Picture communication board developed with English-Arabic text to support child, English speakers AND foster provider-to-patient communication. (*SLP collaboration with family and interpreter*)
- Basic nurse to patient/family messages also paired on cards. Nurse could point to message and family could read or speak to patient if appropriate.
- Modified nurse call/attention calling system for patient due to inability to access standard hospital system.

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## Pre-op Technology Supports

- Simple voice output aid (Message Mate 40)
  - Digital recordings with symbol overlay\* and messages recorded in both Arabic and English (SLP provision in coordination with interpreter services and parents. Arabic recordings by father)
  - Single switch row-column scanning planned



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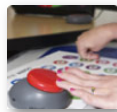
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## Post-op intervention

- Preplanned
  - All pre-op tools available.
- Due to Reduced mobility → modified nurse call system with large switch placed near child's right elbow.
- Simple voice output tool - Step-by-Step Communicator (Ablenet ®) with messages in Arabic to call parents. Located by child's right elbow (based upon access assessment)



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## Unexpected post-op needs

- Minimal movement->
  - Partner assisted scanning for parents and child
  - Demonstration/reminder with single switch scanning with Message Mate 40.
- Interpreter present to translate instructions.
- Parents demonstrated competence using 'teach back' demonstration

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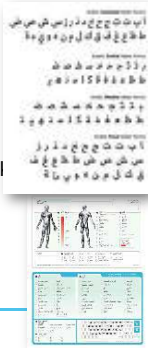
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## Added support for family

- Parents wrote down all 'day to day' communications they wanted to communicate without summoning the interpreter.
  - 40 messages generated, e.g., "I will be in the laundry", "I will be in the parent sleep space", "I need to speak with the interpreter"
- Messages translated /cards created with the Arabic and English correlates.



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## Domains of Assessment and Feature Matching in *Bedside Assessment*

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**Bedside assessment considerations**  
By domain

Assessment domain	Assessment considerations	System selection/Feature matching considerations
<b>Cognition</b> *Alertness/awareness *Premorbid status	<ul style="list-style-type: none"> <li>o Report of nursing staff</li> <li>o Ability to remain awake</li> <li>o Patient's ability to follow commands</li> </ul>	<ul style="list-style-type: none"> <li>o Will determine if assessment should occur over several sessions, be postponed or continue.</li> <li>o Will determine complexity of instructional language and strategies introduced</li> </ul>
<b>Sensory</b>	<ul style="list-style-type: none"> <li>o Pre-morbid vision status</li> <li>o Current vision status</li> <li>o Availability of vision aids</li> <li>o Hearing</li> <li>o Pre-morbid hearing status</li> <li>o Ability to use hearing aids if needed</li> </ul>	<ul style="list-style-type: none"> <li>o Symbol set/representation selection including characteristics of text, symbols and overall layout</li> <li>o Use of voice output technology</li> <li>o Feedback loop of speech generating device.</li> <li>o Use of FM system</li> <li>o Use of auditory scan component</li> </ul>
<b>Language comprehension and literacy screening</b>	<ul style="list-style-type: none"> <li>o Comprehension</li> <li>o Ability to answer yes/no questions</li> </ul>	<ul style="list-style-type: none"> <li>o Match vocabulary and representation to current level of comprehension</li> <li>o Consider initial use of single message system for soliciting attention/assistance</li> <li>o Use of yes/no/maybe system or strategy</li> </ul>

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**Bedside assessment considerations by Doman**

Assessment domain	Assessment considerations	System selection/Feature matching considerations
Language comprehension and literacy screening (cont'd)	<ul style="list-style-type: none"> <li>○ Non-English speaking:</li> </ul>	<ul style="list-style-type: none"> <li>○ Native language based communication board to address immediate needs (bilingual format)</li> <li>○ Picture board</li> <li>○ Use of digital voice recording for patient to nurse/nurse to patient communication of basic messages</li> </ul>
	<ul style="list-style-type: none"> <li>○ Literacy screening:</li> </ul>	<ul style="list-style-type: none"> <li>○ Use of written words</li> <li>○ Use of alphabet to generate novel utterances</li> <li>○ Consideration for picture based system</li> <li>○ Consideration for sophisticated speech generating device that incorporates generative literacy based encoding</li> </ul>
Motor access assessment * in different positions	<ul style="list-style-type: none"> <li>○ Gestures/pantomime</li> </ul>	<ul style="list-style-type: none"> <li>○ Natural gestures</li> <li>○ Gestural codes</li> <li>○ Yes/no signals</li> </ul>
	<ul style="list-style-type: none"> <li>○ Control/access</li> <li>○ Direct selection including hand/eyes/other</li> </ul>	<ul style="list-style-type: none"> <li>○ Signal of yes/no</li> <li>○ Target layout on word/picture board</li> <li>○ Use of keyboard</li> <li>○ Use of dynamic display</li> <li>○ Need for keyguard</li> <li>○ Use of non-electronic eye gaze strategies or eye gaze encoding strategies</li> <li>○ Considerations of electronic eye tracking technology</li> </ul>
	<ul style="list-style-type: none"> <li>○ Indirect selection</li> </ul>	<ul style="list-style-type: none"> <li>○ Technology based scanning</li> <li>○ Partner assisted scanning</li> </ul>
	<ul style="list-style-type: none"> <li>○ Ability to write/draw</li> </ul>	<ul style="list-style-type: none"> <li>○ Use of alphabet/word communication board</li> <li>○ Pen/paper</li> <li>○ White board and marker</li> </ul>

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**Bedside assessment considerations By domain**

Assessment domain	Assessment considerations	System selection/Feature matching considerations
Speech production	<ul style="list-style-type: none"> <li>○ Reduced volume</li> <li>○ Moderately compromised intelligibility</li> <li>○ Severely compromised speech production</li> </ul>	<ul style="list-style-type: none"> <li>○ Electrolarynx</li> <li>○ Amplification</li> <li>○ Display based letter cueing/topic cueing</li> <li>○ Writing/typing</li> <li>○ Word or symbol based communication board</li> <li>○ Speech generating device</li> <li>○ Consideration for voice and message banking</li> <li>○ Alphabet board</li> <li>○ Word/symbol communication board</li> <li>○ Speech generating device</li> </ul>
	<ul style="list-style-type: none"> <li>○ Patient needs</li> <li>○ Patient personality</li> <li>○ Patient interests</li> <li>○ Address medical, personal and psychosocial needs</li> </ul>	<ul style="list-style-type: none"> <li>○ Pre-made commercial boards</li> <li>○ Custom boards</li> <li>○ Alphabet encoding</li> <li>○ Speech generating device ranging from simple message display to complex storage and encoding strategies.</li> </ul>
Environmental assessment	<ul style="list-style-type: none"> <li>○ Lighting</li> <li>○ Noise</li> <li>○ Mounting</li> </ul>	<ul style="list-style-type: none"> <li>○ Impacts features of system(s)</li> <li>○ Impacts availability of system(s)</li> </ul>
Communication partners	<ul style="list-style-type: none"> <li>○ Native language</li> <li>○ Literacy level</li> </ul>	<ul style="list-style-type: none"> <li>○ May require communication system/ interpreter that meets the needs of diverse partners with varied linguistic and literacy skills.</li> </ul>
Documentation/team teaching	<ul style="list-style-type: none"> <li>○ Team members</li> </ul>	<ul style="list-style-type: none"> <li>○ Diversity of team members and limited time will require a tool that is functionally supported with minimal training.</li> </ul>

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**Bedside assessment considerations by Doman**

Assessment domain	Assessment considerations	System selection/Feature matching considerations
Language comprehension and literacy screening (cont'd)	<ul style="list-style-type: none"> <li>○ Non-English speaking:</li> </ul>	<ul style="list-style-type: none"> <li>○ Native language based communication board to address immediate needs (bilingual format)</li> <li>○ Picture board</li> <li>○ Use of digital voice recording for patient to nurse/nurse to patient communication of basic messages</li> </ul>
	<ul style="list-style-type: none"> <li>○ Literacy screening:</li> </ul>	<ul style="list-style-type: none"> <li>○ Use of written words</li> <li>○ Use of alphabet to generate novel utterances</li> <li>○ Consideration for picture based system</li> <li>○ Consideration for sophisticated speech generating device that incorporates generative literacy based encoding</li> </ul>
Motor access assessment * in different positions	<ul style="list-style-type: none"> <li>○ Gestures/pantomime</li> </ul>	<ul style="list-style-type: none"> <li>○ Natural gestures</li> <li>○ Gestural codes</li> <li>○ Yes/no signals</li> </ul>
	<ul style="list-style-type: none"> <li>○ Control/access</li> <li>○ Direct selection including hand/eyes/other</li> </ul>	<ul style="list-style-type: none"> <li>○ Signal of yes/no</li> <li>○ Target layout on word/picture board</li> <li>○ Use of keyboard</li> <li>○ Use of dynamic display</li> <li>○ Need for keyguard</li> <li>○ Use of non-electronic eye gaze strategies or eye gaze encoding strategies</li> <li>○ Considerations of electronic eye tracking technology</li> </ul>
	<ul style="list-style-type: none"> <li>○ Indirect selection</li> </ul>	<ul style="list-style-type: none"> <li>○ Technology based scanning</li> <li>○ Partner assisted scanning</li> </ul>
	<ul style="list-style-type: none"> <li>○ Ability to write/draw</li> </ul>	<ul style="list-style-type: none"> <li>○ Use of alphabet/word communication board</li> <li>○ Pen/paper</li> <li>○ White board and marker</li> </ul>

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## You do NOT need fancy tools

You DO need a dedicated focus on problem solving communication supports and providing intervention

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## Sample Bedside Signs

- “I can understand what you are saying. Please speak directly to me.”
- “I blink *once* for YES and *twice* for NO”
- Please write when speaking with me. Use the dry erase board or typewriter”

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## Communication Boards

- General comfort
- Body board
- Body positioning
- ABC
- QWERTY
- Customized



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### Customized Communication Boards

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### Carly's dad – custom boards

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### Partner Assisted Scanning

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

\*\*\* will discuss partner assist scan considerations later

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## Dry Erase Board

- Used to write messages
- Receptive and expressive language
- No training required



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## Boogie Board

- Used to write messages
- Can use fingernail
- Lightweight
- Often motivating



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## Simple voice output aid such as Step-by-Step

- Allows for recording and playback of a series of messages
- Used for:
  - Gaining attention
  - Social scripts
  - Participation in motivating activities
  - Cause-effect
  - more



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## Jellybean Switch

- Used for access to communication tools, computer, and switch toys
- Can be mounted securely for optimal access
- Used with adapted nurse call system



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## Powerlink Timer

- Timer for switch operated toys and appliances
- Environmental control unit
- Variety of control options
- Good for toys with plugs, switch toys, music players, etc.



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## Digital recording tool such as MessageMate 40

- Speech generating device
- Digitized voice
- Up to 40 messages
- Access: direct selection or switch scanning
- Can be mounted securely for optimal access



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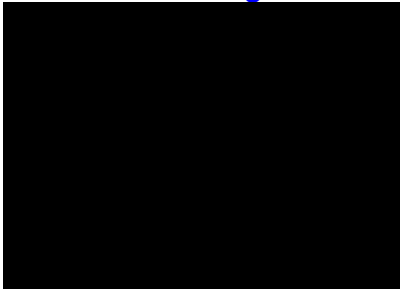
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### Kyle and MessageMate w/ Scanning



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### GoTalk

- Speech generating device
- Digitized voice
- Multiple levels and storage for overlays
- Core vocabulary
- Lightweight and portable



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### Rita – GoTalk 4

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### More Speech-Generating Devices



Nova Chat 7

Dynavox Maestro

Quick Talker

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### Lightwriter

- "Speaks" aloud typed messages
- Synthesized voice (multiple options)
- Dual screen
- Ability to store frequently used messages
- New Lightwriters = word prediction



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### Lightwriter & Personality

Carly's dad

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## Voice Amplifier

- Amplifies a weak voice
- Helpful for patients with vocal fold dysfunction and prolonged intubation
- Able to add headphones to amplify others speech for patient in need of auditory amplification



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## C Eye

- Requires calibration
- Over-the-bed mount



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## iPad

- Example Apps:
  - Assistive Chat
  - Predictable
  - Talk Assist
  - Touch Chat
  - Sounding Board
  - Proloquo2Go
  - SonoFlex
  - GoTalk Now



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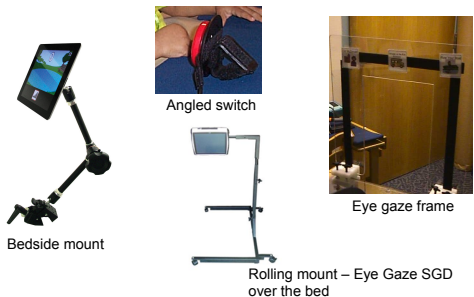
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### Physical Access



Bedside mount

Angled switch

Eye gaze frame

Rolling mount – Eye Gaze SGD over the bed

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What are some of the AAC assessment considerations when a patient is “Communication Vulnerable”?

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*ALL THE TIME* I am told:  
“I don't know how to do inpatient assessments and I don't have a full equipment library; so I will wait to start”

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### Introduce tools and strategies, and learn.....

- Can learn much about motor skill and access, neuro-cognition and overall communication skills.

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### And remember....

- It is NOT all about technology
  
- Often the best intervention is NO technology

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### ALSO remember that for some children:

- PLAY gets you acceptance
- Understanding of pain/sickness is different than adults
- Magical thinking
- May need 'permission' to advocate for self
- The FAMILY is integral in all steps of the process

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## Whirlwind review:



- Assessment Domain
- CORE Assessment considerations
- Impact on system selection and feature matching.

*This is a VERY dynamic process often with status changing regularly*

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## Cognitive status:

- Alertness
- Awareness
- Orientation
- Pre-morbid status

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## Cognitive Assessment considerations:

- Often status is first reported by bedside care providers
- Observe patient's wakefulness and fatigue (impact participation and length of assessment)
- Patient's ability to follow simple directions
- Patient's ability to respond to simple questions (yes/ no / don't know response)



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**Cognitive Assessment considerations:**

- Potential presence of delirium
- Impact of medications (example Versed)
- Quality and quantity of sleep
- Potential presence of dementia



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**Feature match/intervention considerations**

- Will determine if assessment happens over time, postponed or continued.
- May need to re-assess often and adjust recommendations frequently
- May require range of supports to be used at different times of day
- Will impact complexity of instructional language and strategies introduced
- May suggest selection of memory book or orientation strategies through visuals, visual schedule
- Consider use of symbols vs.. text

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**Sensory domain:**

- Vision
- Hearing
- Comparison to pre-morbid status?

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### Sensory Assessment considerations

- Does s/he wear glasses? If yes, are they here?
- Does s/he have hearing aids? If yes, are they here?
- If physical status will not support glasses or hearing aids (swelling, incision site, etc.), what accommodations can be made
- Have C.I.? Available?

I have NO sight in my right eye OR in the outside half of my left eye



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### Sensory Assessment considerations

- If using ventilation mask, what type of mask (impact on vision/binocularity and positioning of materials)



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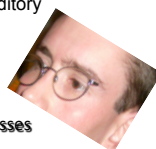
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### Feature match/intervention Considerations (sensory)


F.M. trainer to provide focused auditory input



Remove one or both arms of the glasses



**Ubi Duo for wireless patient-provider text based communication**



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**Feature match/intervention**  
**Considerations (sensory)**

- Consideration for communication with family/friends via phone:
- <http://ip-relay.com> OR TTY
- Use of web cam/Skype video for sign communication with family/friends

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**Feature match/intervention**  
**Considerations (sensory)**

- Use of voice output technology if minimal/no hearing
- Feedback loop of speech generating device
- Use of auditory scan component
- Use of tactile markers and keyguards\*



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**Feature match/intervention**  
**Considerations (sensory)**

- Symbol set/representation selection
- characteristics of text
- Size of targets
- Color contrasts
- Complexity of layout
- Use of symbols versus text
- System that supports keyguard
- System that supports tactile markers

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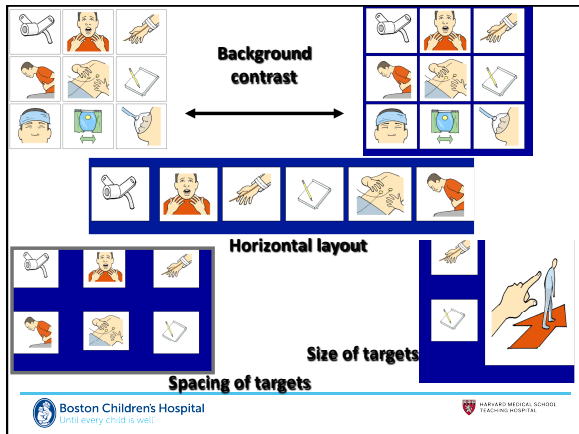
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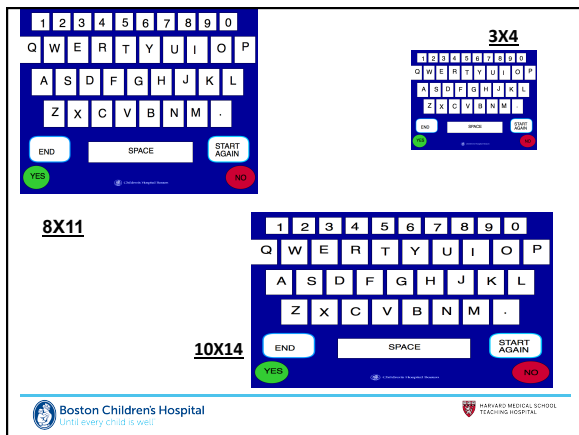
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## Motor Domain

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- Use of gestures/pantomime
- Control/access
- Physical positioning
- Direct selection (hand, eyes, other?)
- Ability to write/draw

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Logos for Boston Children's Hospital and Harvard Medical School Teaching Hospital are at the bottom.

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## Assessment considerations

- Ability to point with hand
- Ability to point with eyes
- Ability to point with head light
- Use of splints to support pointing
- Indirect access through scanning
- Indirect access through partner assist\*
- Access changed by positioning?

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## Feature match/intervention Considerations (motor)

- Inventory of natural gestures
- Basic sign language
- Adapted nurse call system
- Keyboard
- Paper and pen
- Use of keyguard
- Single switch access to technology
- Partner assisted scanning
- Eye gaze/Etran - Eye Linking
- Eye tracking



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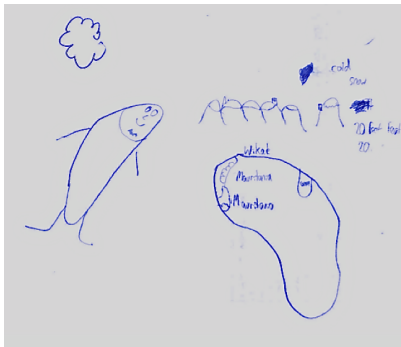
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**Message Mate from Words +, Inc.**



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**Physical Access**




**Bedside mount**



**Angled switch**



**Eye gaze frame**



**Rolling mount – Eye Gaze SGD over the bed**

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**Eye tracking**

**\* Feature matching consideration: Meds (ex: Baclofen)**

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**FM CONSIDERATION:  
MEDS**

Fracture of third and fourth cervical vertebrae, leaving him paralyzed

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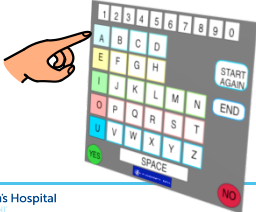
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### Partner Assisted Scanning

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



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### Key rule for partner assisted scanning...offer an 'out'

**Potential scenario:**

- Patient appears distressed
- Partner offers options that seem reasonable to the context
- Patient may become more upset or frustrated
- Heart rate increases and/or patient becomes emotional
- Medical management of distress/anxiety is considered



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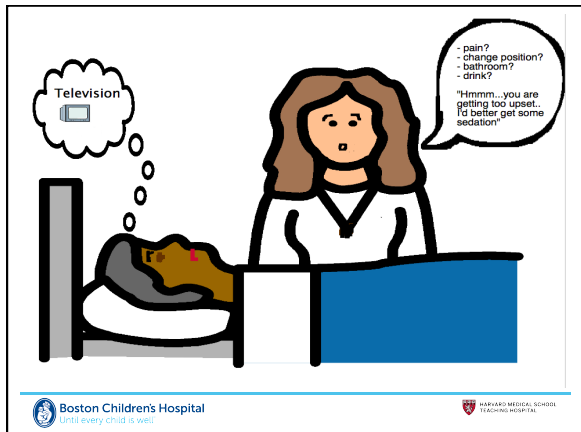
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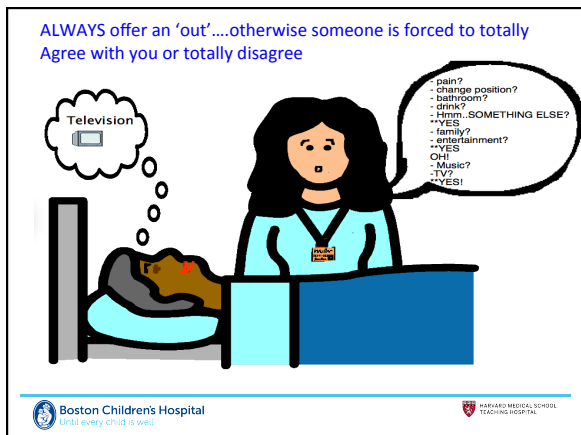
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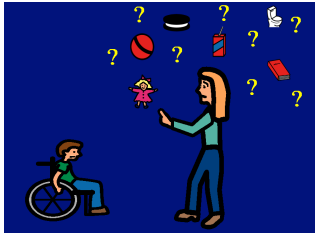
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For all users of AAC, we often ask many questions based on what the partners 'thinks' is important



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SAMPLE PARTNER ASSIST AUDITORY-VISUAL SCAN

Across categories	pain	move	people	comfort	needs	entertain	feelings	none
THEN	back	down	mom	back rub	suction	read	afraid	
Down Selected category	legs	bed up	father	cloth	medicine	music	sleepy	
	Head	turn	nurse	swab	toilet	tv	bored	
	none	none	none	none	none	none	none	

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1	2	3	4	5	6	7	8	9	0
A	B	C	D	START AGAIN					
E	F	G	H	END					
I	J	K	L	M	N				
O	P	Q	R	S	T				
U	V	W	X	Y	Z				
YES	SPACE	NO							

Partner assisted scanning spelling board

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### Megabee



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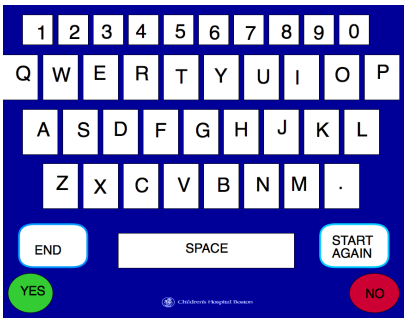
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**Direct selection spelling board**

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**Step by Step**  
From Ablenet, Inc.

**Hannah,**  
communicating with nurse call

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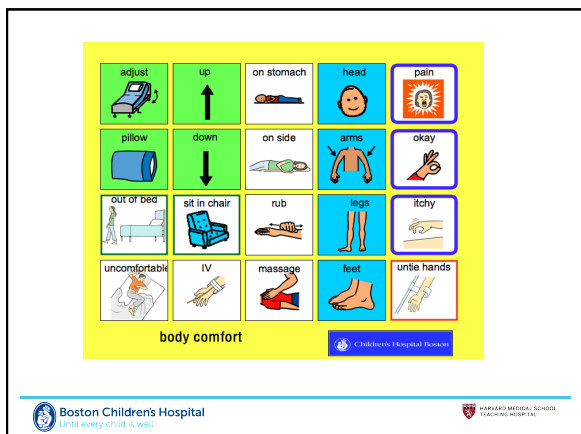
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**● I AM**

- short of breath
- in pain
- choking
- feeling sick
- to be suctioned
- lip moistened
- water
- to be comforted
- to sleep
- hungry/thirsty
- cold/hot
- tired
- dizzy
- tv/video/dvd
- call light remote
- it quiet
- lights off/on
- to go home
- angry
- afraid
- frustrated
- sad
- to sit up
- to lie down
- to turn left/right
- head of bed up/down
- get out of bed

**● I WANT TO SEE**

- doctor
- nurse
- family
- chaplain

**Keyboard:** A B C D E F G H I 1 2 3 Thank You  
 J K L M N O P Q R 4 5 6  
 S T U V W X Y Z . 7 8 9  
 + 0 -

For selection control purposes, please do not reuse this board between patients.

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

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**PAIN CHART**

LEVELS OF PAIN: 10, 9, 8, 7, 6, 5, 4, 3, 2, 1

**I WANT PAIN MEDICINE**

- shot
- one pill
- two pills

**Icons include:** Itches, slings, hurts/lashes, dull, sharp, radiating, burn, bathroom, cool cloth, pillow, glasses, wash face, shampoo, comb/brush, teeth brushed, how am I coping?, what day/time?, what is happening?, when is tube coming out?, remove restraints, exercise, massage, leave me alone, don't leave, come back later, prayer, can't move things, I WANT PAIN MEDICINE.

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

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**● I AM**

- Short Of Breath
- Fluorinated
- Nauseous
- Chagging
- Ch Pain
- Light Headed
- Disappointed
- Tired
- Drowsy
- Better
- Thirsty
- Tired
- Unsure if tube is working

**● I WANT**

- Bursters
- To Sit Up
- Blanket
- Blanket
- Blind
- Books
- Change A Call
- To Turn Right
- Lights Off
- Call Quiet
- More Control
- To Lie Down
- Ice
- Shampoo
- Handwash
- Massage
- Bedpan
- Phone
- To Turn Left
- Lights On
- Blanket
- To Sleep
- To Rest
- To Be Comforted
- Prayer
- Exercise
- Lotion
- Message
- Combs/Brush
- Toilets
- Teeth Brushed

**● I WANT TO SEE**

- Doctor
- Nurse
- Respiratory Therapist
- Assistant
- Social Worker
- My Family
- Physical Therapist

**● I WANT TO CLEAN**

- Wash
- Teeth
- Face
- Head
- Clothes
- Other

**Keyboard:** A B C D E F G H I 1 2 3  
 J K L M N O P Q R 4 5 6  
 S T U V W X Y Z . 7 8 9  
 + 0 -

**PAIN CHART**

LEVEL OF PAIN: 10 (Worst), 9, 8, 7, 6, 5 (Moderate), 4, 3 (Slight), 2, 1 (None)

**THIS PART**

- Itches
- Slings
- Hurts
- Changes
- Can't Move
- Is Numb
- Aches
- Burns
- Is Tender

**THE PAIN IS**

- Constant
- Intermittent
- Chasing
- Throbbing
- Stabbing
- Sharp

**I WANT PAIN MEDICINE**

- shot
- one pill
- two pills

**PLAN OF CARE:** YES/NO, Please Explain, Need Reassurance, When, Why, How, What, Stop, What Is The Plan?, When Can I Have, How, Why, Continue, How Am I Doing?, How Often?

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

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**Eye gaze displays to participate  
In decision making**


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come back later	uncomfortable	fix pillow	swab mouth	lips dry
hold hand	stay with me	light on	washcloth on head	suction mouth
I love you	cold	hot	open curtain	bathroom
When tube out mouth	television	listen to music	read book	leave me alone


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mom	I love you	swab mouth	suction mouth	pray
dad	hold hand	medicine	happy	mad
stay with me	bathroom	okay	sad	hurt
TV	watch video	music	sit in chair	want go home


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**I'm bored, I want to....**

car	car	draw color	playroom
watch video	watch TV	paint	read book
watch DVD	change channel TV	game	out of bed

**Play/playroom**

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**itchy**

**hurts**

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**itchy**

**hurts**

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### Eye Linking

**Partner**                      **User**

Resource: <http://www.cini.org>

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### mounting

**Loc line**

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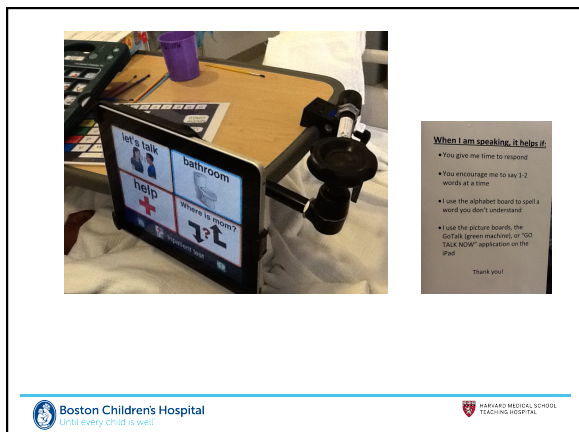
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**When I am speaking, it helps if:**

- You give me time to respond
- You encourage me to say 1-2 words at a time
- I use the alphabet board to spell a word you don't understand
- Use the picture boards, the GO-TALK system machines, or "GO TALK NOW" application on the iPad.

Thank you!

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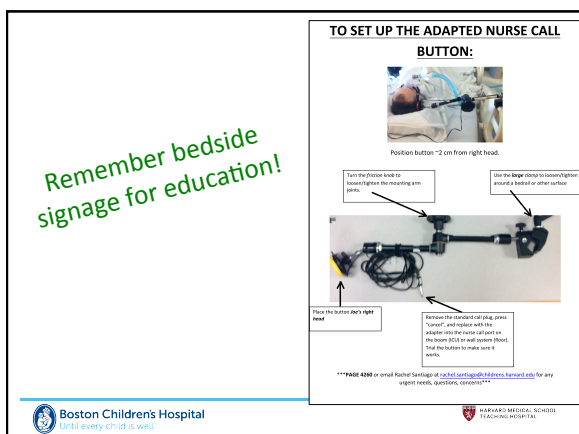
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• Example Apps: iPad

- Assistive Chat
- Predictable
- Talk Assist
- Touch Chat
- Sounding Board
- Proloquo2Go
- SonoFlex
- GoTalk Now



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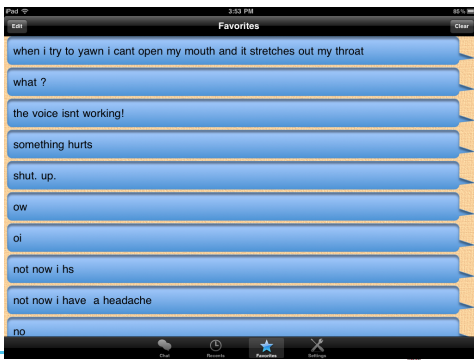
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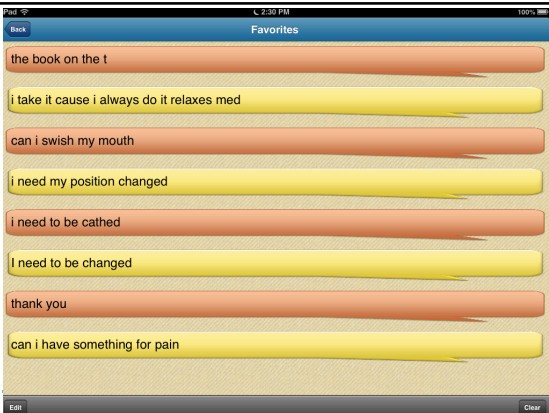
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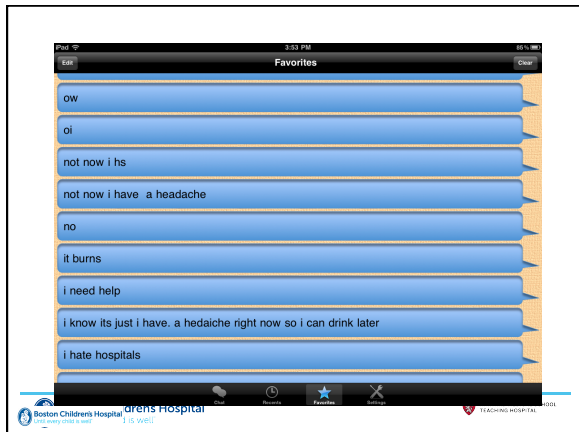
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### Communication Applications

- Picture Symbols

Answers HD-  
YesNo

SoundingBoard

GoTalk NOW

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### Communication applications

- Full featured symbol based apps:  
– Picture symbols and text-to-speech

Proloquo2Go

TouchChat

SonoFlex

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
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## Positioning



- Cuff inflation may vary by positioning and impact need for AAC vs.. ability to use speech.
- Access skill may change with physical positioning (in bed/in chair) and require different strategies or mounts
- Medical procedure may impact positioning which will impact feature match
  - Example: spinal fusion/rod insertion
  - reconstruction surgery with tissue graphing



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## Language Comprehension Domain

- Native language?
- Comprehension
- Ability to follow directions
- Able to answer yes/no questions

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### Feature match/intervention Considerations (language)

- Post how patient indicates yes/no in obvious space in room
  - Examples: thumbs up/down
  - Squeeze eyes or blink eyes
  - Squeeze hand once or twice

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**Feature match/intervention**  
**Considerations (language)**

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- Use of visuals (symbols, photos, text)
- Intervention may focus on simple single message output devices
- May focus on strategies to support control and impact on environment

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**Feature match/intervention**  
**Considerations (language)**

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- ALWAYS use QUALIFIED MEDICAL INTERPRETER services when patient does not speak English/uses ASL
- Use of digitally recorded communication aids for communication in native language and English (approved by qualified medical interpreter)

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**Andrew**  
**MVA in Shanghai**

**English and Chinese recorded**

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Collaboration with Interpreter services

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## Communication Boards with Language Translation

**Vietnamese**

**Spanish**

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## Interpretation on the spot

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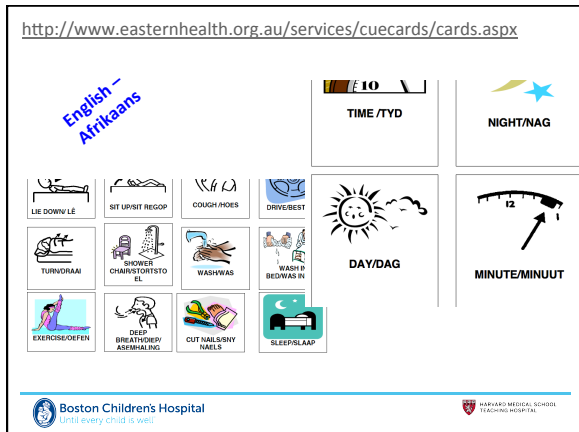
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### Feature match/intervention Considerations (language)

- Selection of tools/strategies with transparent organization versus requiring meta understanding of navigation/organization \*
  - \* may change rapidly with medical status change
- Selection of sophisticated tools and integrated features for environmental control, web access, etc.

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### Literacy Domain Feature Match considerations

- Use of written words
- Use of alphabet for generative communication
- Encoding strategies
- Use of keyboard based systems
- Keep pen and paper at bedside along with easily accessible strategy to request (simple voice output tool)

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### Literacy Domain Feature Match considerations

- Use of cell phone/text messaging for communication
- Use of letter cues/topic cues
- \*\*\*Note: good decoding skills and reading comprehension does not mean patient has good encoding skills
  - May be able to use canned text but not generate novel text.

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### Executive functioning may be highly impaired

- Planning
- Working memory
- Attention
- Problem solving
- Verbal reasoning
- Inhibition
- Mental flexibility
- Task switching

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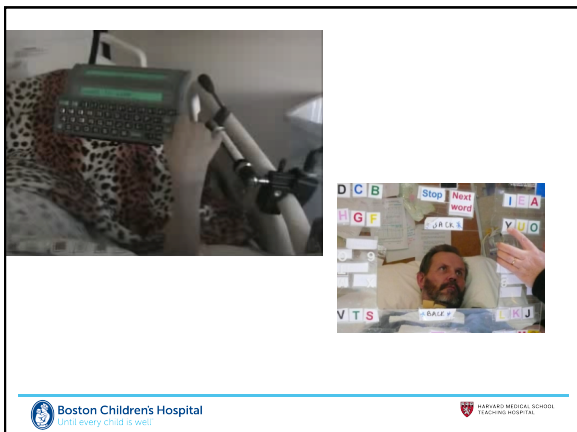
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The image is a composite of two photographs. The left photograph shows a close-up of a hand typing on a laptop keyboard. The right photograph shows a man sitting at a table with a board of letter cards. The board has various letters and words on it, including 'D C B', 'Stop Next word', 'G F', 'A L K S', 'V U O', 'V T S', 'E R A K Y', and 'L K J'. The man is looking at the board and has his hand near it.

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**Feature Match: QWERTY vs. Alphabetical**

The image shows two keyboard layouts side-by-side. On the left is the standard QWERTY layout with a blue background. On the right is an alphabetical layout with a grey background. Both layouts include a numeric row, a row of letters, a second row of letters, and a bottom row with 'END', 'SPACE', and 'START AGAIN' buttons. The alphabetical layout has letters arranged in order: A, B, C, D, E, F, G, H, I, J, K, L, M, N, O, P, Q, R, S, T, U, V, W, X, Y, Z.

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**For Patient who Can write...**

The image shows a Boogie Board, which is a tablet that can be used as a chalkboard or a whiteboard. It is shown in its closed position and in its open position, displaying handwritten text and drawings.

**Boogie Board**

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**Use of Boogie Board**

The image contains two photographs. The top photo shows a person using a Boogie Board as a writing surface. The bottom photo shows a person using a Boogie Board as a tablet device, displaying a video or image.

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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 *Start again*

br er fr gr tr pl str *Next word*

bl cl fl gl sw dw tw *End*

sl sc sk sm sn sp

sw squ spl spr scr

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### Topic Cue board

<b>People</b>	<b>Food</b>	<b>Emotions</b>
<b>Places</b>	<b>Colors</b>	<b>Questions</b>
<b>Animals</b>	<b>Entertainment</b>	<b>Body</b>
<b>School</b>	<b>Home</b>	<b>Community</b>

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## Speech Production



- Reduced volume?
- Tracheostomy
  - Why?
  - Type (cuffed/cuffless)?
  - Airleak?
  - Changes with positioning?
  - Candidate for speaking valve?
  - Tolerance of valve?
- Vent?



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### Speech Production

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- Moderately compromised intelligibility?
- Severely compromised intelligibility?
- Type of intubation/ cannula ?
- Impacted by cpap/bipap mask and type of mask?
- Impacted by fixation or other hardware?



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### Voice Amplification or use of Electrolarynx



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### Vocabulary Selection

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- Patient needs
- Patient personality
- Patient's developmental status
- Patient interest
- Address medical, personal and psychosocial needs

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**Comparison of MessageMate  
Overlays: Twin Brothers**

K Y L E	Mom	MOM	NURSE	you're	food	drink	high chair	bed	clock	
	Patrick	DAD	PATRICK	mean drink	hudson	had	toilet	urinal	glasses	television
	Dad	scared	play	bring you	open	point	hip	teja	arms	
	HI	BYE	hold my leg	call my leg	hang up	my leg	break bed	board bed	move my leg	switch sides
P A T R I C K		help	nurse	come here		MOSTISM	I love you	job my hood	hold hand	can't wait
		thirsty	cough	falling	Machine Off	Bed up	bed down			
		bathroom	Walmart on	disaster call	legs	Chuck	glasses		what is that?	
		TV	newspaper	ipod						

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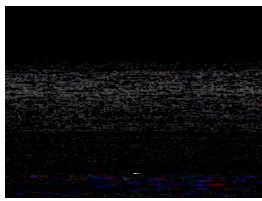
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**Vocabulary selection and  
multiple strategies**



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**Domain of Assessment:  
Environmental**

- Lighting
- Noise (including noise from vent and other medical equipment)
- Available real estate/furniture for Mounting/ access
- Nurse route of access maintained
- Open room or isolation/precautions

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