

# Augmentative Communication to Meet the Needs of Children with Severe Communication Difficulties in the Hospital and Community

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John M. Costello, MA-CCC/SLP  
Director, Augmentative Communication Program  
Boston Children's Hospital



## Boston Children's Hospital

Programs and History





# Children's Hospital Boston at Waltham





## Augmentative Communication Program

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





## Inpatient Augmentative Communication Closet



## Augmentative Communication Program



Holly Fadie, SLP



Alycia Berg, SLP



Jenny Abramson, SLP



Rachel Moritz, SLP



Jennifer Buxton, OTR, ATP



Jessica Gosnell, SLP



Emily Laubscher, CFY



Susanne Russell,  
OTR



John Costello, SLP



Rebecca Theriault, SLP

Needs of children with severe  
communication difficulties in the  
hospital and community

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



“If all my possessions were taken  
from me with one exception,  
I would choose to keep the power of  
communication, for by it I would  
soon regain all the rest.”

Daniel Webster



The silence of speechlessness is never golden. We all need to communicate and connect with each other – *not just in one way but in as many ways possible*. It is a basic human need, a basic human right. And much more than this, it is a basic human power.

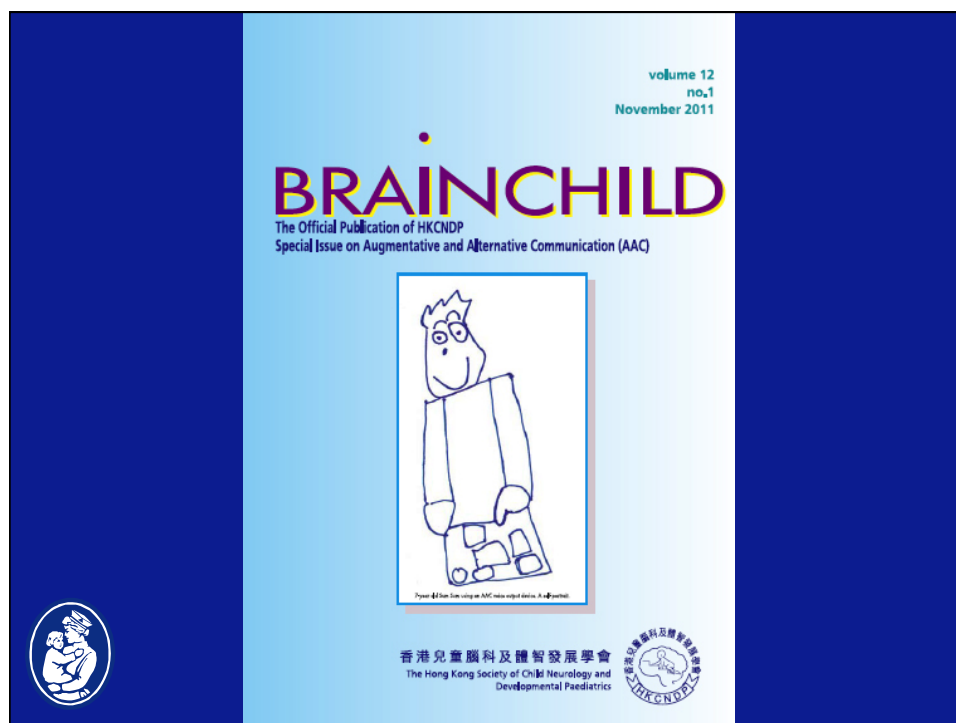


(Bob Williams in Beukelman and Mirenda, 2012)

**“As long as people consider my brain useless and my facial expressions and sounds meaningless, I was doomed to remain voiceless”**



Ruth Sienkiewicz-Mercer



## The United Nations Convention on the Rights of Persons with Disabilities (CRPD)

### Article 1 - Purpose

*“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.*







## United Nations Convention on the Rights of Persons with Disabilities

Preamble (a-y) states:

(e) Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,

(j) Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support

(r) Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child



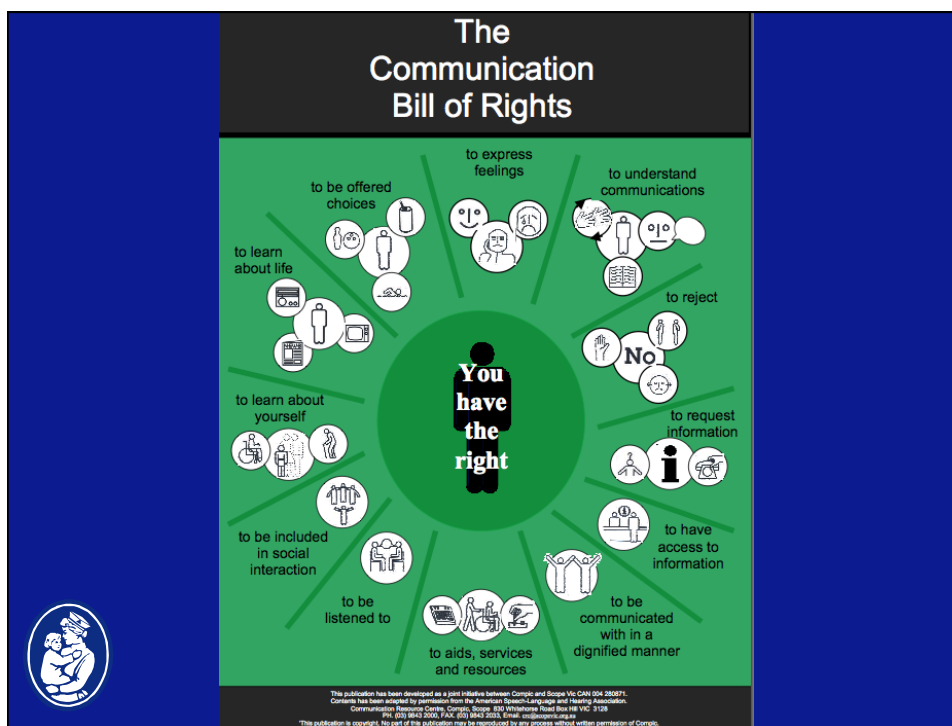
### National Joint Committee for the Communication Needs of Persons with Severe Disabilities

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions. These rights are summarized from the Communication Bill of Rights put forth in 1992 by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities.

Each person has the right to

- request desired objects, actions, events and people
- refuse undesired objects, actions, or events
- express personal preferences and feelings
- be offered choices and alternatives
- reject offered choices
- request and receive another person's attention and interaction
- ask for and receive information about changes in routine and environment
- receive intervention to improve communication skills
- receive a response to any communication, whether or not the responder can fulfill the request
- have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
- have AAC and other AT devices that function properly at all times
- be in environments that promote one's communication as a full partner with other people, including peers
- be spoken to with respect and courtesy
- be spoken to directly and not be spoken for or talked about in the third person while present
- have clear, meaningful and culturally and linguistically appropriate communications

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communication needs of persons with severe disabilities. Asha, 34(Suppl. 7), 2-3.



## Needs of children with severe communication difficulties in the hospital and community

- #2 All stakeholders recognize what barriers to successful communication exist and must develop a plan to overcome these barriers.

## Barriers to communicative success according to The Participation Model

(Beukelman and Mirenda 1988)

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



## What are a few barriers for children in the community with congenital non- speaking conditions?

- Limited ***opportunity*** and exposure
- Few opportunities to ***develop communicative competence***
- Minimal modeling through ***aided language stimulation***
- A focus on 'success' with a tool without proper focus on ***the foundations of success***



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

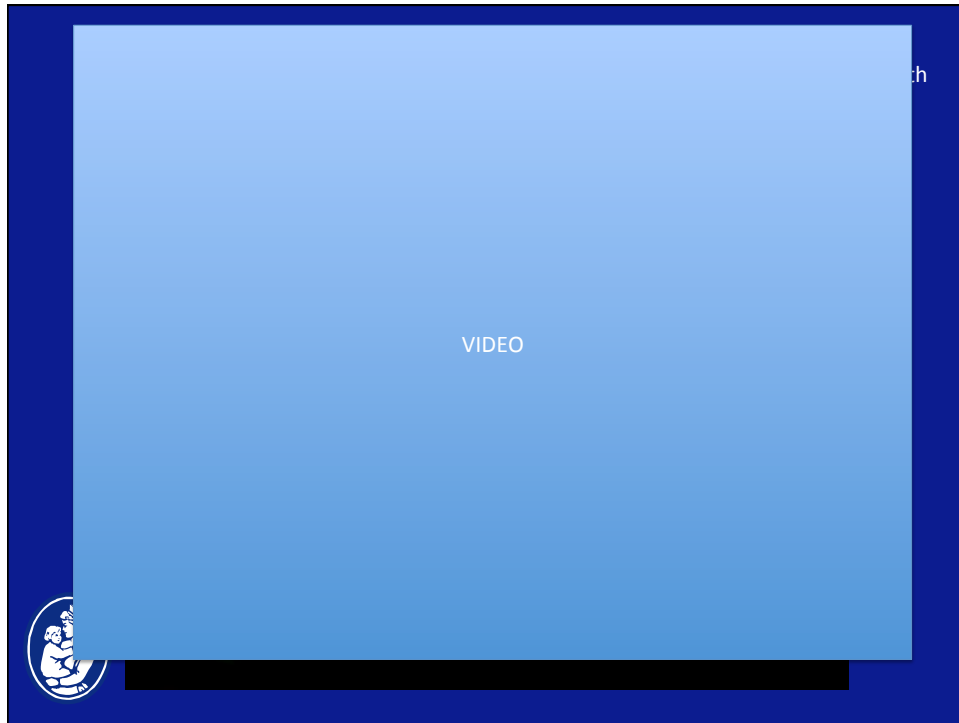


## Practice barriers:

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- 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"





## Attitudinal barriers

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- 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.



## 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?*)



## Resource barriers:

- 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



## Environmental Barriers

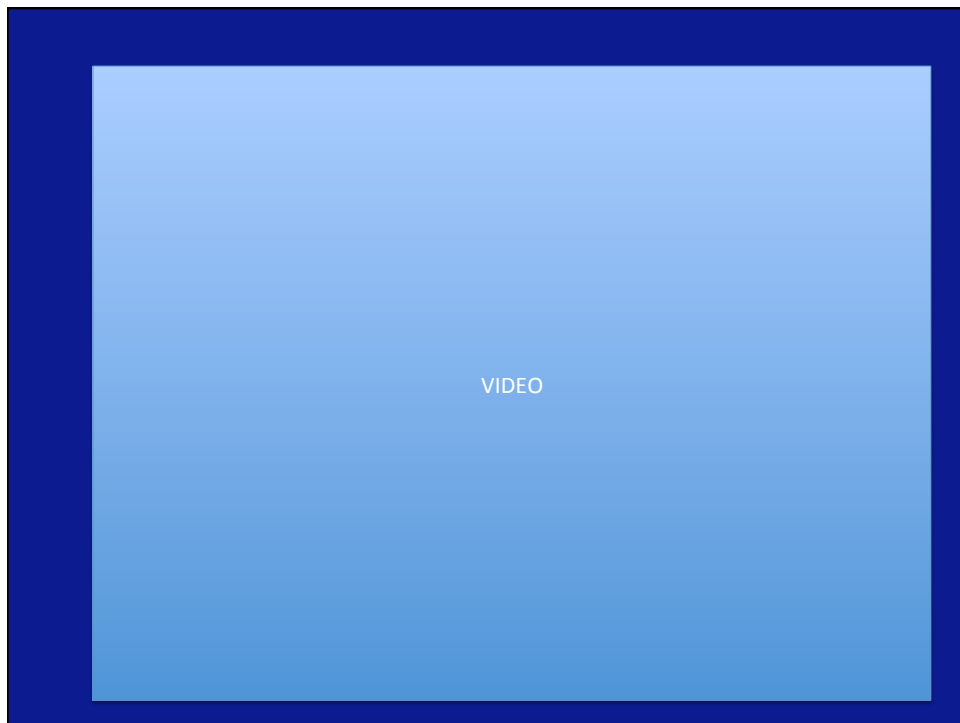
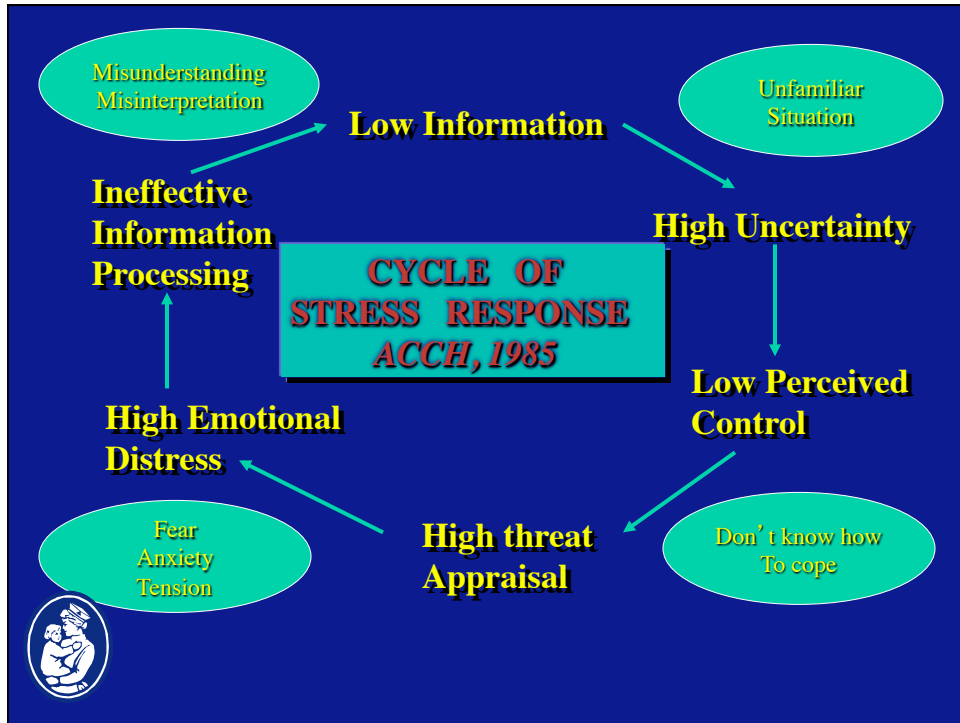
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- The hospital environment is dense with medical equipment and supply carts.
- Patient bedspace may have limited room for additional equipment/material
- Due to storage limitations, communication tools and equipment may not be readily available (at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



## Communication Vulnerability







## 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

## 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



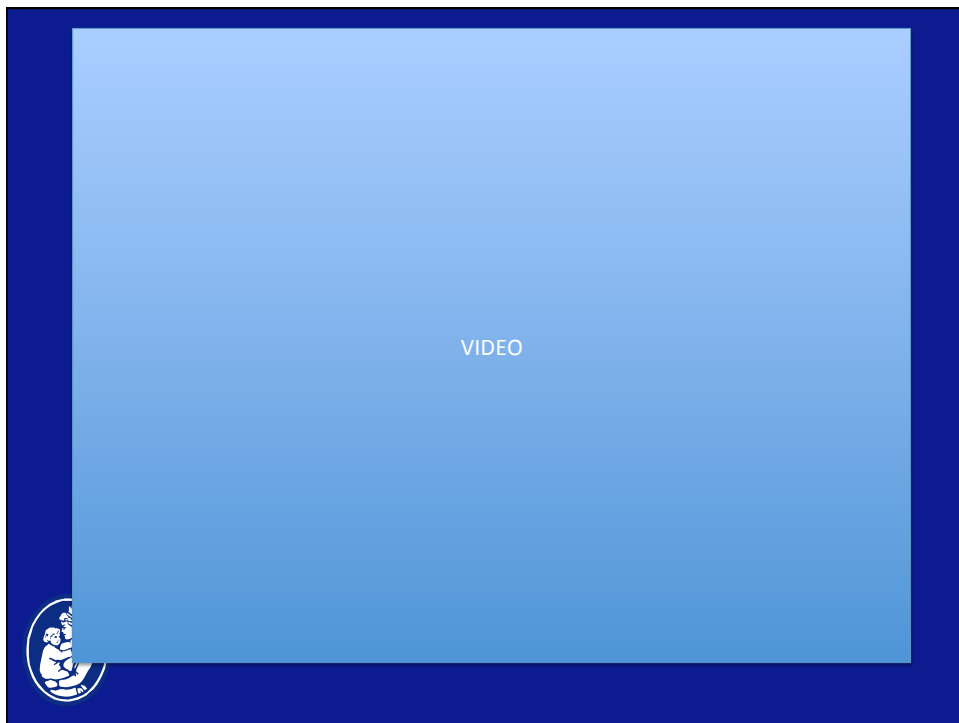
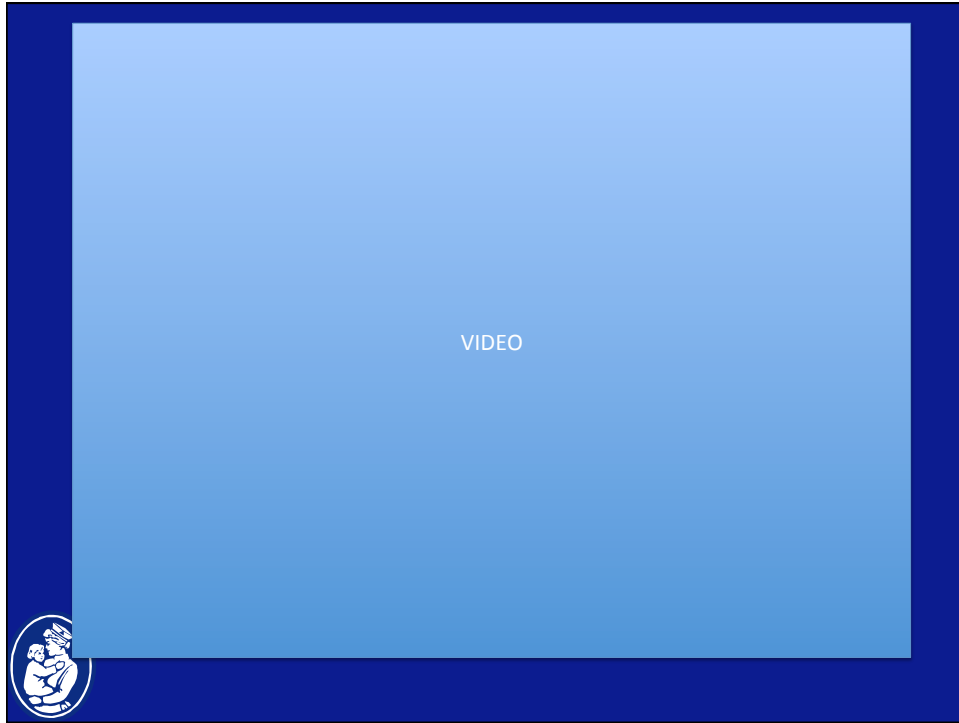
## Profile of Patients with communication vulnerability

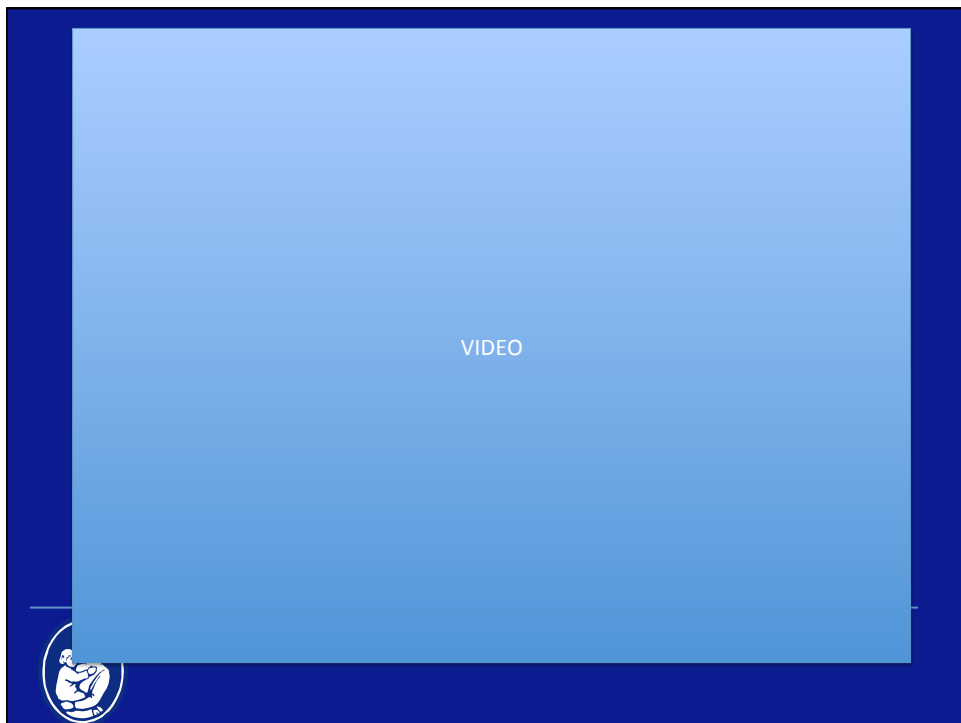
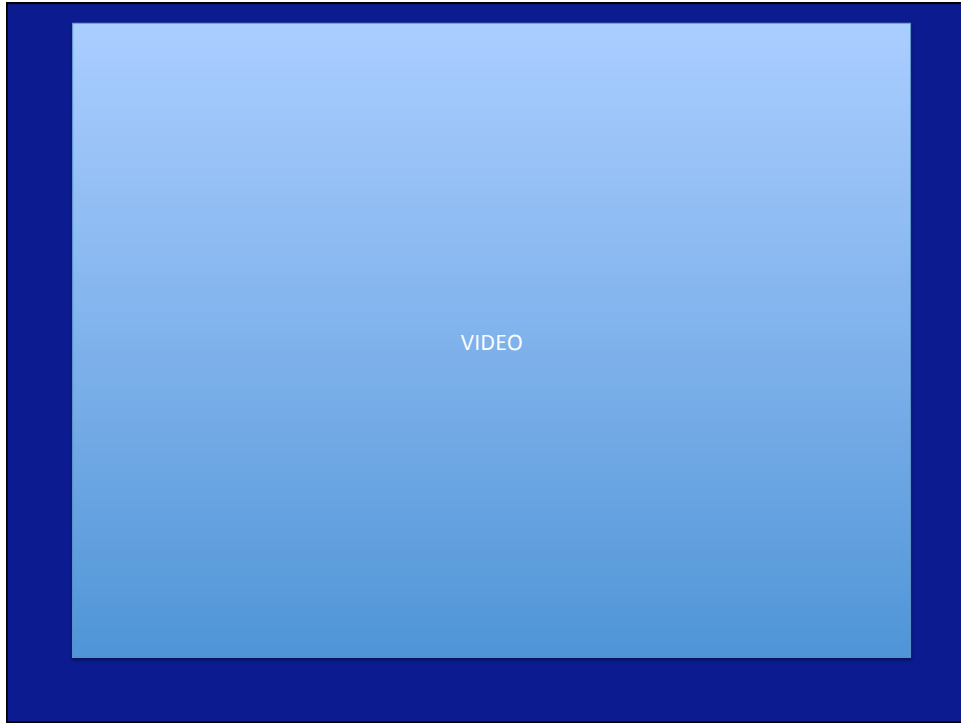
- **Congenital conditions**
- **Acquired conditions**
- **Degenerative conditions**
- **Condition related to medical intervention (surgery)**
- **Condition related to medical treatment**

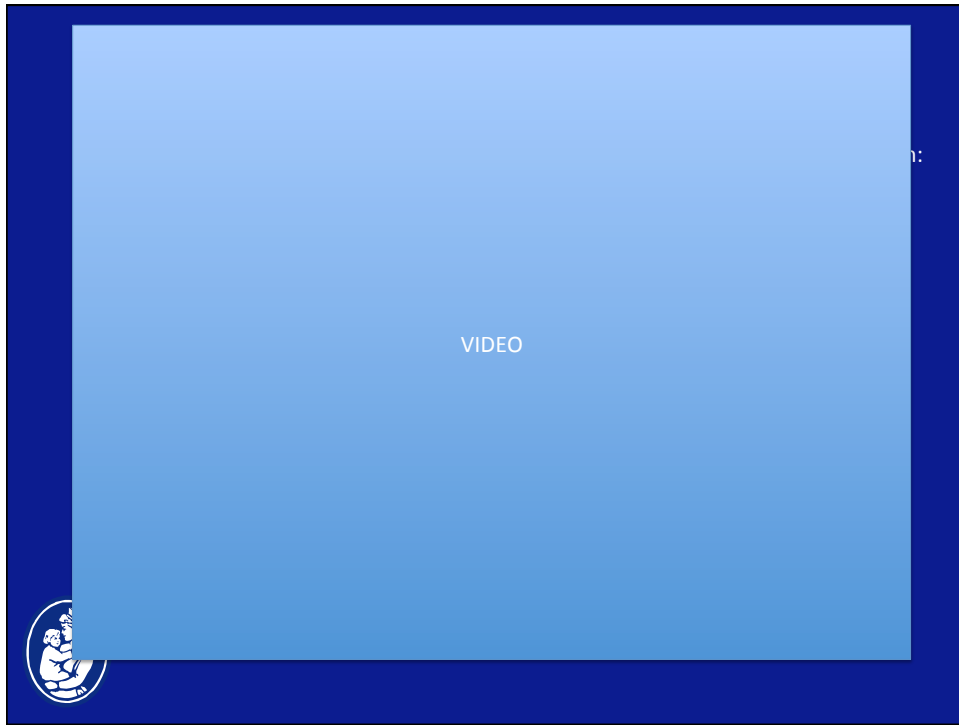


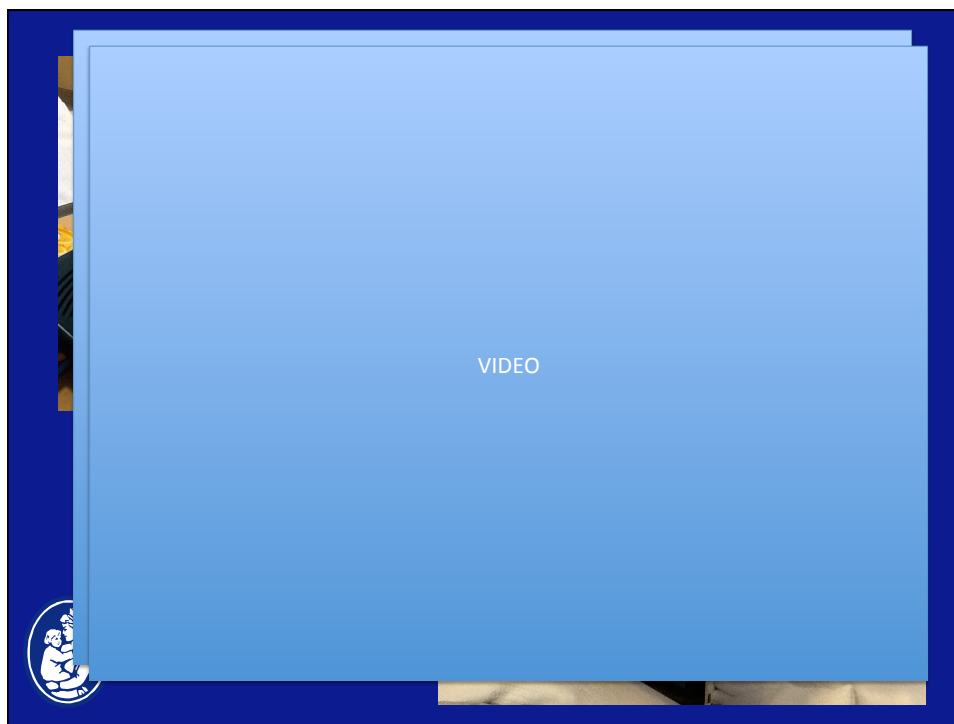
VIDEO











## Guidelines for admission to Pediatric ICU

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

- A. **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



## Guidelines for admission to Pediatric ICU

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

- **B. Children with severe, life threatening or unstable cardiovascular conditions**

- Includes Children with high risk cardio vascular procedures



## Guidelines for admission to Pediatric ICU

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

- **C. Neurological conditions or seizures**

- spinal cord compressions
- Head trauma
- Progressive neuromuscular dysfunction



## Guidelines for admission to Pediatric ICU

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

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



## Guidelines for admission to Pediatric ICU

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

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





## In general, these conditions include

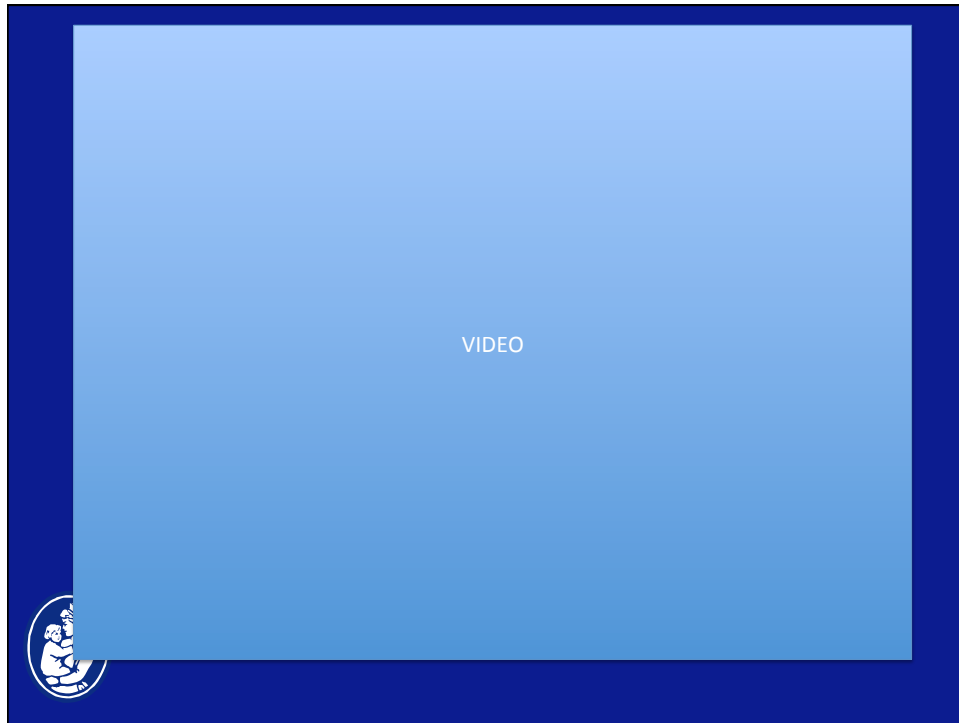
issues of :

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



Communication vulnerability may be related to one or all of these





## Why is this topic timely in the United States?

- 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



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

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



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

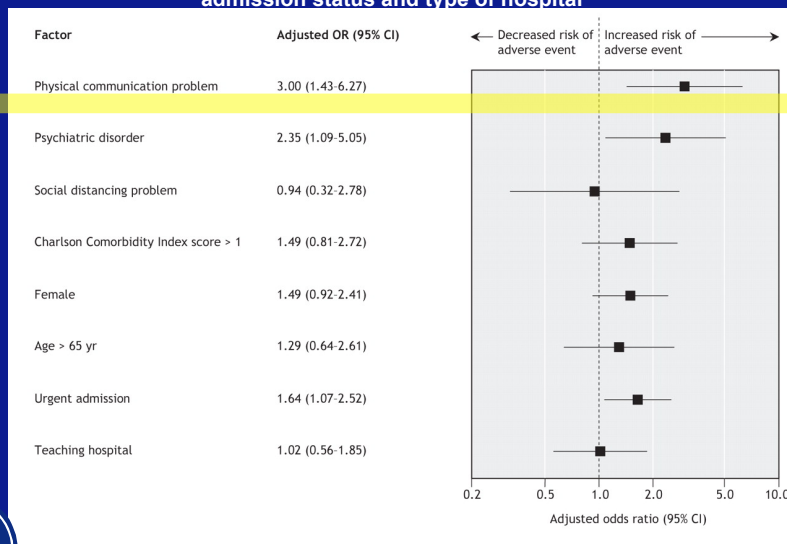
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•“The presence of physical communication problems was significantly associated with an increased risk of experiencing a preventable adverse event”

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



**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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CMAJ·JAMC

## 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)



## 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 ).



## 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.”



Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care

### A Roadmap for Hospitals



## 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."

Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care

### A Roadmap for Hospitals



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"*

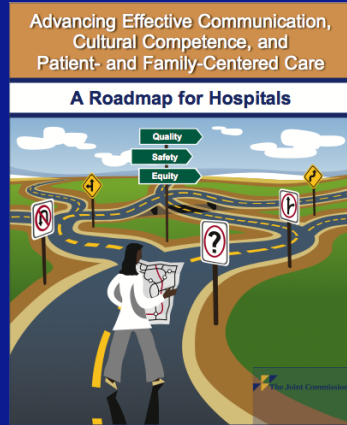
Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care

### A Roadmap for Hospitals



# 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...”*





*Is The Joint Establishment Of Meaning*

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Saturday, November 14, 2009 [www.patientprovidercommunication.org](http://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 Provide 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.)

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

