

## Finding a Voice/Breaking the Silence for Children with Complex Communication Needs

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## Themes from the past three days

- It is a basic human right to communicate
- The inability to communicate is detrimental to physical, emotional, psychosocial and developmental health
- Tools, technology and strategies exist to support success
- Hong Kong has many remarkably dedicated, motivated and energized professionals who strive to address the needs of people with complex communication difficulties.



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## Finding a Voice/Breaking the Silence of Children with Complex Communication Needs

Community/School

Hospital



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## Additional theme: Barriers

- Practice
- Attitude
- Knowledge
- Resource
- Environmental



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## Practice barriers:

- It interrupts the way I teach my class if a child is using an augmentative communication system.
- I am not able to change the pace of my class or take the time to support a child to use augmentative communication in my classroom
- People in 'the real world' will not take the time to give my student a successful experience with augmentative communication
- A person is often in the hospital for life saving or life sustaining measures and patient communication has not been part of our practice
- "We do not welcome staff who are not part of our ICU/acute care unit"



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## Attitudinal barriers

- This child is not capable of REALLY communicating except to tell me his choices and needs
- Communication learning can only be done in formal therapy sessions
- medical thinking – nurse/doctor knows best
- 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:

- As a school clinician, I don't have the information available to me regarding best practices for how to assess and implement augmentative communication
- I don't know the tools and strategies that are available to meet my student's needs.
- In my hospital, information about resources (tools and professionals) is frequently not available to clinicians, doctors, nurses and others
- I don't know WHO in my facility is the best resource to help my patient communicate



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## Resource barriers:

- We do not have the tools available to make those communication boards and materials for my students
- We do not have the resources to let students actually have their own communication tools to use throughout the day.
- We don't have the needed assistance in the classroom to help a child who uses AAC to participate
- We do not have the physical tools and devices available in our school or hospital
- We do not have the clinicians (intellectual resources) available to support our students/patients
- We do not have enough pre-service professional training opportunities to know how to do this well.



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## Environmental Barriers

- Even if my student had his own communication device, it would be hard for him to use it in all the places he needs to communicate
- Our hospital rooms do not have the right connections for nurse call button modifications
- There are too many tools and too much equipment in the hospital room to also add a communication device. It will get in the way of patient care.



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The GOAL of using  
Augmentative Communication



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Goals of AAC Intervention  
in the Schools and Community

- Equalize the Gap...
- Promote greater participation
- Enhance vocational opportunities
- Promote interpersonal interactions
- Reduce frustration associated w/ comm. failure
- Enhance language comprehension
- Facilitate speech development
- Serve as an organizer of language
- Enhance speech intelligibility or *perception*



From Shane, 1984

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Goal of AAC Intervention  
in the Hospital

- Allow the child to participate in own care
- Support medical staff to provide the highest quality care possible by insuring successful patient – provider communication
- Minimize stress and anxiety to enhance recovery
- Avoid medical error or other serious events due to communication breakdown
- Enhance patient and family satisfaction with care



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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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**Finding a voice?  
CREATING an OPPORTUNITY for a Voice**



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**There is an EXTRAORDINARY energy focused on making systems change in Hong Kong**

- Policy change
- Advocacy
- Assessment tools that address the whole child
- Professional preparedness
- ‘trail blazers’ willing to take risks and make mistakes
- Technology



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## Change in schools?

- International Classification of Functioning, Disability and Health –Child and Youth ICF-CY
- Social Networks



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## ICF-CY International Classification of Functioning, Disability and Health - -Child and Youth

### Why USE?



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## Why use the ICF-CY?

- To describe children and their intervention needs with a systematic scheme that can be used across education, medical and social services.
- To focus on function, instead of etiology or diagnosis.
- To understand a child with more than ICD-10 codes



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## How would ICF-CY help

- The ICF-CY organization assists with better understanding the child
- Separate codes for speech and communication
- Can help distinguish strengths and challenges of children beyond diagnostic code



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## The ICF-CY for AAC assesses the Environment to identify supports (facilitators) or barrier

- Physical environment
- People in the environment
- Presence or absence of assistive tech
- Services and policy of school



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## **PROBLEM with other measures: Knowledge of health condition does not predict child's functional communication**

- Children may have difficulty speaking/writing related to a variety of different health conditions
- Identifying the health condition only may not suggest the appropriate intervention
- The child's functional capacity in different environments + knowledge of the health condition suggests appropriate interventions



M. Fried-Oken, C. Rowland, D. Lollar, SAM Steiner, ASHA 2010

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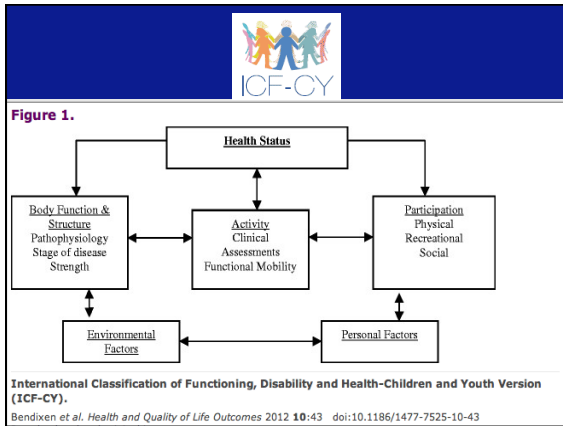
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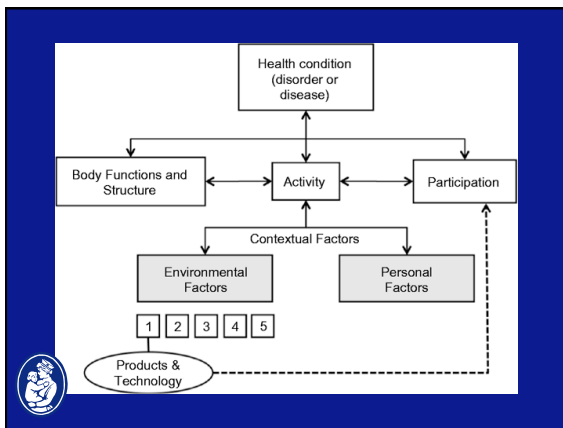
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**Participation is a key construct of the ICF-CY**

- The construct is described as children's involvement in life situations (WHO, 2007)
- Eriksson and Granlund (2004) defined as "a feeling of belonging and engagement, experienced by the individual in relation to being active in a certain con-text".
- The ICF highlights the importance of considering how children experience a life situation, not only how they perform tasks (Jette, Haley, & Kooyoomjian, 2003; King et al., 2007; King et al., 2010)

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M. Fried-Oken, C. Rowland, D. Lollar, SAM Steiner, ASHA 2010  
<http://icfcy.org/aac>



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### Current Version of the ICF-CY for AAC Profile

<http://icfcy.org/aac>

Four sections:

- 1. Communication Limitations
- 2. Functional Impairments that affect communication
- 3. Participation Restrictions caused by communication limitations
- 4. Environmental Barriers and Facilitators that affect participation



M. Fried-Oken, C. Rowland, D. Lollar, SAM Steiner, ASHA 2010

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A social-relational understanding of disability is prevalent, meaning that a person's functioning is related to the impact of a broad variety of physical, human-built, socio-cultural, attitudinal, and political factors (Danermark, 2005; Grönvik, 2007).



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Understanding Communication Partners in order to Understand How to Support Augmentative Communication

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Social Networks



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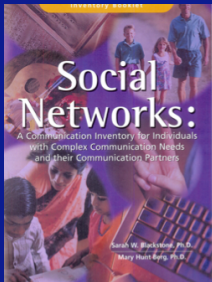
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Social Network



Blackstone & Hunt-Berg

1. Life Long Partners
2. Close Friends and relatives
3. Acquaintances
4. Paid workers
5. Unfamiliar people

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**Social Networks:**  
A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners

Authors: M. B. ...  
Mary Heath Burns, Ph.D.

**Circle of Communication Partners Orientation Forms**

Use this blank form and the example form to introduce the concept of Circle of Communication Partners (CCP) to the individual being interviewed. You may wish to copy and laminate this form. See page 8 of inventory booklet and page 26 of manual.

**LEGEND**

- 1. You only (self-partner)
- 2. Family (parent/siblings)
- 3. Significant others (spouse/partner)
- 4. All other people with whom you interact
- 5. The entire community of potential partners

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- facial expression/body language
- gestures
- vocalizations
- manual signs/sign language
- speech
- writing/drawing
- nonelectronic communication board/book
- simple communication device
- complex communication device
- special communication software used on a computer
- phone
- email
- other modes of communication \_\_\_\_\_

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**Social networks and the development of competence**

- Individuals learn competencies relevant to life's circumstances through social networks (culturally based) (Tietzjen, 1989)
- Competence is NOT fixed attribute of person
- Competence emerges in social practice and opportunity

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## Change in Hospitals?

- Changes to hospital standards for accreditation that address communication vulnerability (measured as of 2012 July).
- Increased focus nationally and internationally on the impact of communication vulnerability on patient care. Particular precedence in US, UK, Australia, Italy, France, Sweden
- 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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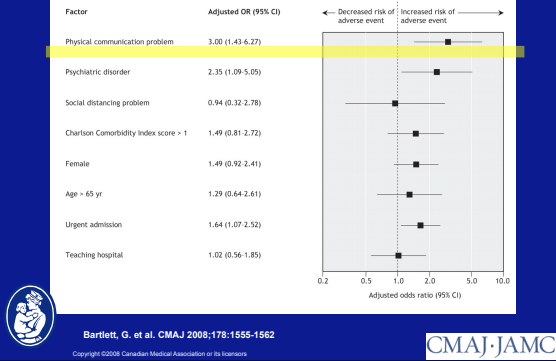
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Figure 3: Odds ratios (ORs) and 95% confidence intervals (CIs) for factors associated with preventable adverse events, adjusted for age, sex, Charlson Comorbidity Index score, admission status and type of hospital




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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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### WHAT IS “EFFECTIVE COMMUNICATION”?

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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."



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

### A Roadmap for Hospitals



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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."



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

### A Roadmap for Hospitals



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## 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



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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



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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:

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

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## Technology – new innovations

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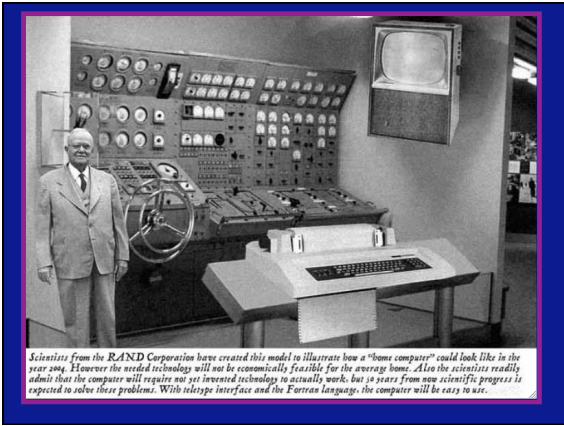
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### Personal Comment: Michael Williams

“I will say that I'm mightily concerned about these gesture-based OSs that are coming into prominence as well as the increasing use of voice recognition in everything, including television sets. These factors have serious implications for people with complex communication needs and other disabilities that aren't being addressed or even identified by folks in our field...”





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### Michael Williams (continued)

- ...Computer technology used to be thought of as "the great equalizer;" now I feel people with disabilities are in danger of being shut out by these added "features" that can be utilized by the public at large, but are frustrating useless to people with significant disabilities. This is what I'm concerned about.




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