AAC as a Critical Component to Patient Care throughout the Hospital:
ISAAC Pre-conference Highlights

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Boston, MA

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Disclosures

- Rachel Santiago is employed full time by Boston Children's Hospital

- John M. Costello is employed full time by Boston Children's Hospital

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For handouts, videos and other related resources:

- https://www.facebook.com/**ACPCHBoston**

- INPATIENT: https://www.childrenshospital.org/centers-and-services/programs/f-_-n/inpatient-augmentative-communication-program#

- OUTPATIENT: https://www.childrenshospital.org/centers-and-services/programs/a-_-e/augmentative-communication-program

- ALS PROGRAM: http://www.childrenshospital.org/centers-and-services/programs/a-_-e/als-augmentative-communication-program

- AUTISM LANGUAGE PROGRAM: https://www.childrenshospital.org/centers-and-services/programs/a-_-e/autism-language-program

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- Twitter: @costello_j

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Augmentative Communication /Autism Language Programs

Outpatient Augmentative Communication Program

Outpatient ALS Augmentative Communication Program

Outpatient Autism Language Program

Inpatient Augmentative Communication Program
- Intensive Care Units
  - Cardiac
  - Medical
  - Medical/Surgical
  - Neonatal
- Acute Care Units

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AGENDA

- Discuss the evidence base and current practices in AAC implementation in hospital settings

- Describe patient profiles and phases of communication needs

- Identify assessment and intervention strategies

<u>Inpatient:</u>

- Common barriers to communication access in acute care AAC in ICU/acute care
- Patient profiles
- Phases of communication need
- Trends and patterns of care
- Domains of assessment at bedside
- Intervention practices

Outpatient:
- AAC assessment center structure
- Model of service delivery/follow-up
- referral sources and team collaborators
- Hospital programs benefitting from AAC clinic collaboration
- Assessment considerations: Domains of Assessment and feature matching
- Community connections/collaboration

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AAC Program(s)

At Boston Children's Hospital:

- Outpatient Augmentative Communication Program founded in 1979.
  - Autism Language Program founded in 2006
  - INPATIENT Augmentative Communication Program founded 2007
  - ALS Augmentative Communication Program founded in 2015
- 15 Speech Language Pathologists (soon to be 17)
- 3 Occupational therapists
- Outpatient: approximately 6900 OUTPATIENT evaluations and consults (and some therapy sessions) per year
- Inpatient: approximately 1450 INPATIENT evaluations and consults per year

Boston Children's Hospital patient care is founded on an institution wide philosophy of exceptional care and exceptional service

- Excellence
- Communication
- Innovation
- Respect
- Accountability
- Teamwork

Welcoming culture and a heightened awareness of these tenants combined with continuous effort to collaborate and educate

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scheduling is based on staff review of intakes to triage

Intakes for:

❖ACP Pediatric

❖ACP Adult

❖ACP ALS Program

❖ACP Assistive Technology/OT Access

▪ Example: Pediatric ACP Intake

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Our clinical practice is based upon the foundations of Feature Matching* and Evidence Based Practice

Feature Matching

"The feature matching process focuses on identifying the strengths, skills and needs (current and future) of a person who is a candidate for augmentative communication and matching the features of available (or potentially available) augmentative communication tools, devices and strategies to that person"

- Shane and Costello, 1994

The 12 domains of Assessment and Feature Matching framework

The 12 domains of Assessment and Feature Matching
(these slides offer a FRAMEWORK and are not inclusive of all options/considerations)

- Intended to provide a framework for considerations for:
  - ✓ assessment
  - ✓ Goal development
  - ✓ Intervention
  - ✓ Used as the basis for outpatient and inpatient Augmentative communication assessment and intervention

Historic Domain

- Previous communication intervention
- Previous AAC techniques
- Medical history
- Social history
- Environmental history
- Educational history
- Vocational history
- Length of time - static/progressive

Patient Centered Domain

- What does the patient want?
- What are his/her priorities?
- What does the patient expect of you?
- What is the patient's personality?

- **** primary AND secondary consumer

© costello and shane. 1994, 1997, 2006, 2011, 2016, 2019

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Emerging Communicator

CASE examples:

Pediatric: 7 year old

- DX: Miller Diecker Syndrome, seizure disorder, severe motor impa... and hearing compromise. No symbolic communication, will reac... environment and responds positively when others engage her. L... siblings and attends an educational collaborative.

Adult: 47 year old

- DX: Severe to profound intellectual impairment, ambulatory, no c... near sighted, lived in an institutional setting now lives in commun... does not demonstrated symbolic knowledge, behavior is interpre...

Context Dependent Communicator

CASE examples:

Pediatric: 10 year old

- DX: Cerebral Palsy, moderate unilateral hearing impairment, no concerns with vision. Uses wheelchair for mobility. Used aide and unaided strategies including vocalizations, invented gestures, up to 30 standard signs, topic communication boards and a multi-level digitally recorded communication device with overlays changed by others. Will initiate communication of routine preferences and interests with familiar partners. Is integrated in 4th grade class with a 1:1 aid and an inclusion specialist who modified curriculum. Despite skill with current tools, sh... communicate beyond needs and rehearsed roo...

Adult: 29 year old

- DX: Global developmental delay, moderate inte... not like to wear glasses, lives in home support... communicate (yell) but with familiar partners w... overlays on device to access vocabulary that is... text and will use to communicate in routines at... favorite restaurant).

Independent Communicator

CASE examples:

Pediatric: 12 year old

- DX: Cerebral Palsy, drives power wheelchair, access technology with joystick control and, depending on position, head mouse or eye tracking. Use AAC to speak, fully participate in curriculum, do home work, internet, email, texting, telephone. Love getting on Facebook and posting photos (taken with AAC device).

Adult: 53 year old

- DX: Amyotrophic Lateral Sclerosis, no concerns with hearing, wears glasses for reading. Works as Information Officer for large technology firm. Married, father of three and grandfather of one. Currently uses wheelchair and do to respiratory difficulty, recently received a trach. Uses vent support inconsistently during day. Will continue to work for as long as possible but would like to transition to tele-commuting part time. Speech has rapidly changed and is now moderate to severely dysarthric. Wishes to use AAC for communication, writing, email, texting, journaling, writing his blog and all other situations of communication breakdown.

AAC Toolbox

Unaided

Facial Expressions / Body Language / Poster
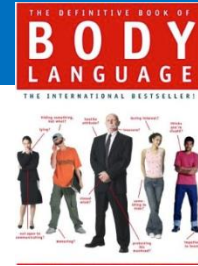
Natural / Conventional Gestures

Manual Sign Languages

Vocalizations / Word Approximations
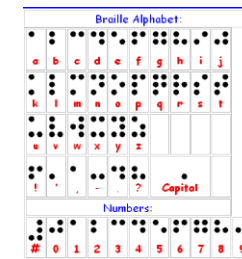
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AAC Toolbox

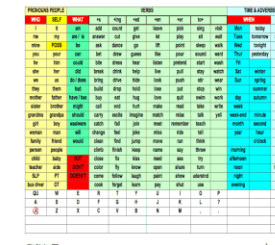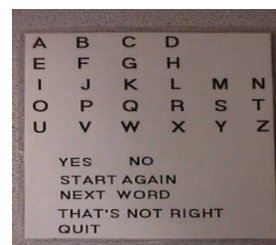Aided; Non-Electronic

Object-Based

Picture-Based

Picture-Based

Text-Based

AAC Toolbox

Aided; Electronic

Single Button

Multi-Button, Static

Dynamic

Keyboard/

Spelling-Based

What is Evidence Based Practice?

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"The goal of EBP is the integration of: (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver values to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve. Conceptually, the trilateral principles forming the bases for EBP can be represented through a simple

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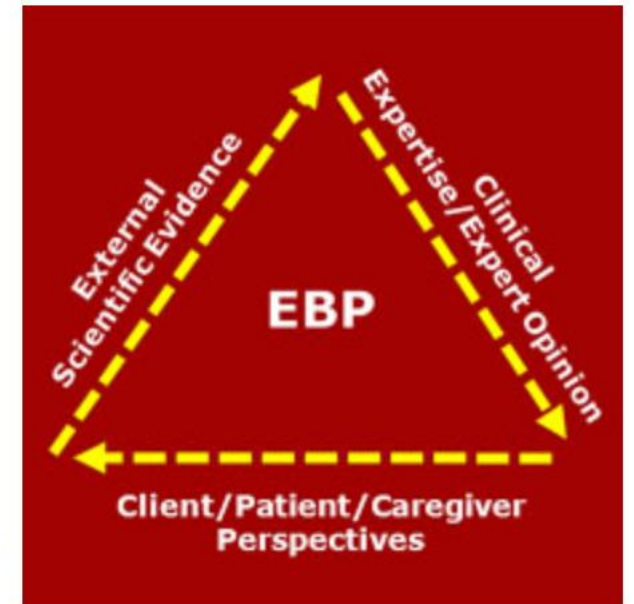
Evidence Based Practice in AAC.
- Costello, 2018

External Scientific Evidence

Clinical Expertise/Expert Opinion

Client/Patient/Caregiver Perspective

Data Driven Functional Clinical Trials

External Scientific Evidence

Client/Patient/Caregiver Perspective

Clinical Expertise/Expert Opinion

EBP

Data Driven Functional Clinical Trials

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We are an **interprofessional** practice, not an **Interdisciplinary** practice

Interprofessional Practice

Interprofessional Practice (IPP) is a collaborative **practice** which occurs when healthcare providers work with people from within their own profession, with people outside their profession and with patients and their families.

Interdisciplinary Practice

An **interdisciplinary practice** involves team members from different disciplines working collaboratively, with a common purpose, to set goals, make decisions and share resources and responsibilities.

Hospital Outpatient Programs requesting/requiring Augmentative Communication Program Collaboration/consultation

- Cerebral Palsy Clinic
- Tracheostomy Clinic *
- Down Syndrome Program
- Rett Syndrome Program
- Cornelia De Lange Program
- Spinal Muscular Atrophy
- Audiology
- Orthopedics

- Muscular Dystrophy
- Developmental Medicine Program
- Autism Center
- Deaf and Hard of Hearing Program
- Cochlear Implant Program
- Wheelchair clinic

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- **My Hospital Story** is a collection of **hospital narratives** designed to help **children** prepare for medical visits and procedures at **Boston Children's Hospital**. This app allows you to choose from several **stories** and shows step-by-step photos of an upcoming procedure or appointment from your child's perspective.
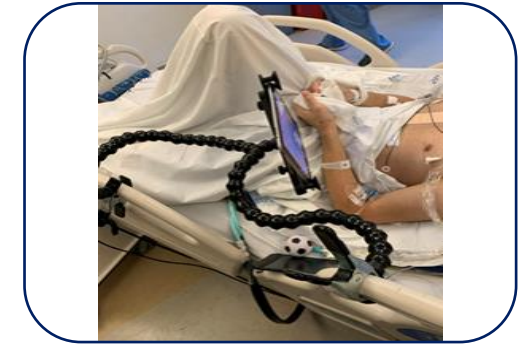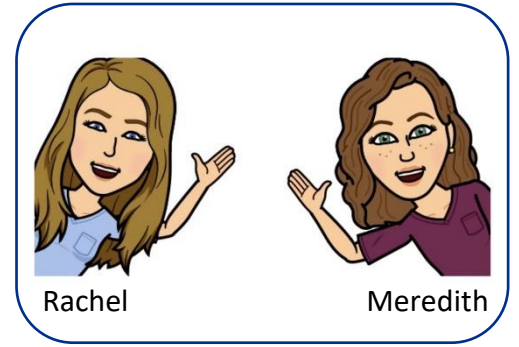
INPATIENT

AAC in Acute Care Settings

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Program Description

Inpatient Augmentative Communication Program

Rachel   Meredith

- AAC service delivery ~30 years

- Dedicated bedside consultation service for communication enhancement ~15 years

- 2 full time SLPs

- Bedside assessment and intervention throughout 400+ bed hospital

- Staff education and training

- Interdisciplinary programming

- Research

- Program development

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Background

Nonspeaking patients are at risk for:

- Preventable adverse events (Bartlett et al., 2008; Hurtig, Alper, & Berkowitz, 2018)
- Serious medical events (Cohen, et al., 2009)
- Poor medication compliance (Andrulis, et al., 2002)
- Increased risk of leaving AMA (Flores, 2003)
- Increased fear, stress, and sleep disturbance (Happ, et al., 2004)
- Loss of ability to participate in own care (Garret, et al., 2007)

Benefits of AAC:

- Augmentative and Alternative Communication (AAC) is used by individuals for whom speech is not a primary method of communication
- Patient-provider communication is paramount to patient care and patient satisfaction
- Policies in place support communication access (The Joint Commission, 2010)
- Patients who have access to an effective communication system:
  - Receive less sedation
  - Transition more quickly to lower levels of care
  - Provide increased patient satisfaction scores

(Happ et al., 2004; Patak et al., 2008)

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Who does communication vulnerability impact?

Patient:

Loss of control
Limited participation in own care
Low mood, anxiety, depression, worry, etc.

Family:

Fear of family member's inability to gain attention, seek help
Fear of family member's inability to express wants/needs
Distress over temporary loss of family member's personality
Ability to support and advocate on child/loved one's behalf

Staff:

Delivery of quality care
Don't have time to "figure it out"
Education, discharge, and follow-through
Limited communication attempts beyond the essential
Supporting patient from emotional, psychological, and developmental perspective
(especially long-term patients)

(Happ et al., 2004 ; Magnus and Turkington, 2005 ; Costello, 2000)

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Barriers

Why is bedside AAC not a formal, required, or standard service at all hospitals?

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Common Barriers in Acute Care

Practice Barriers
- Focus on life sustaining/saving measures
- Clinical priorities: medical > communication
- Institutional or professional complacency

Attitudinal Barriers
- Doctor/RN knows best
- Less interference or interruptions by patient = easier bedside care
- Lack of buy-in for implementation

Knowledge Barriers
- SLP education on bedside AAC
- Frontline staff education on bedside AAC
- Accessibility of RN resources, trainings, educational materials
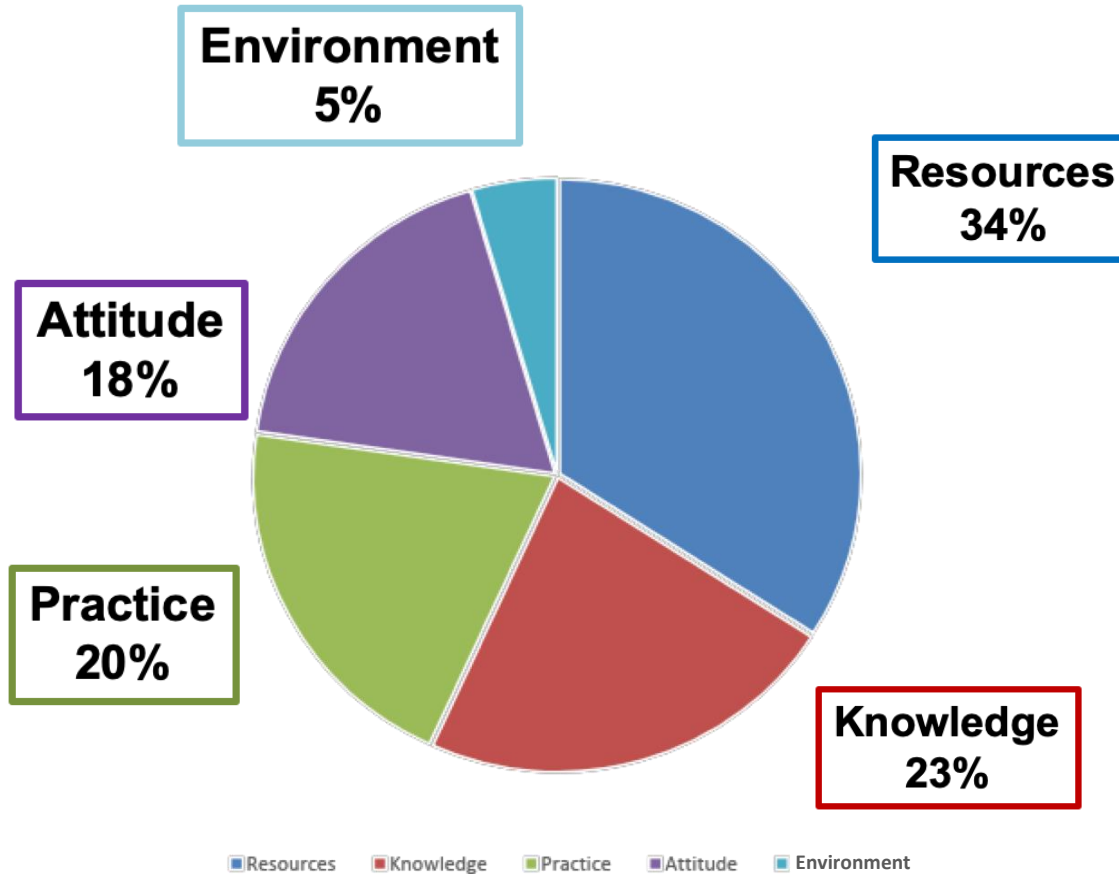
Resource Barriers
- Lack of tangible materials
- Lack of staff with clinical expertise
- Time

Environmental Barriers
- Storage space
- Clean equipment policies
- Equipment handling, pick up, bedside safety, bedside interference

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Barriers to AAC Implementation by SLPs

Environment 5%
Resources 34%
Attitude 18%
Practice 20%
Knowledge 23%

Resources Knowledge Practice Attitude Environment

(Santiago & Altschuler, 2018)

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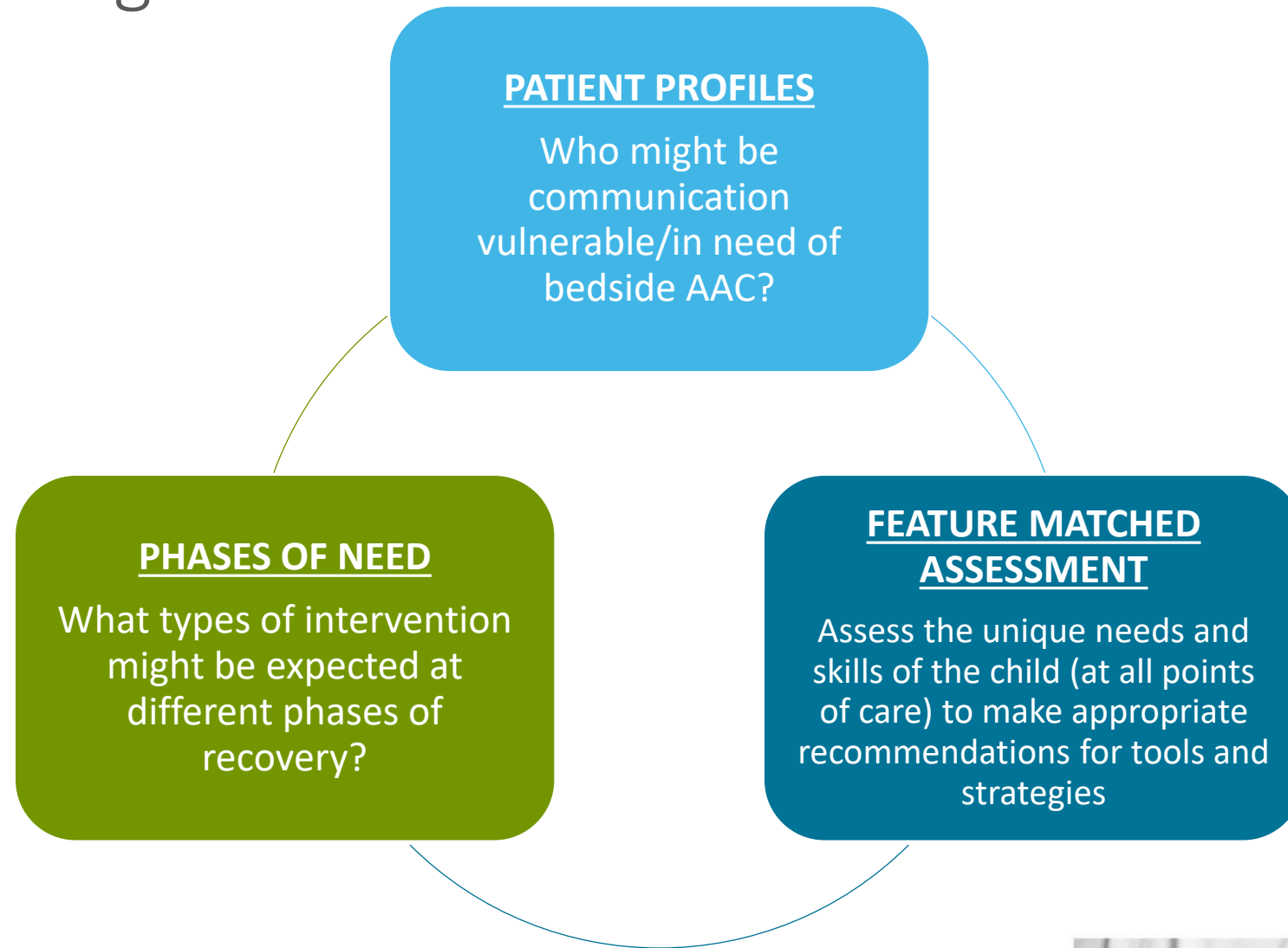# What is commonly done to address communication vulnerability?

- Lip reading (by patient, by staff)
- Reliance on family/caregiver to interpret
- Gestures
- Pen/paper
- Alphabet board
- Hand drawn pictures
- Yes/no questions
- Non-English speakers
  - Ad hoc interpreters
  - Interpretation applications and software

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Where to begin?

PATIENT PROFILES

Who might be communication vulnerable/in need of bedside AAC?

PHASES OF NEED

What types of intervention might be expected at different phases of recovery?

FEATURE MATCHED ASSESSMENT

Assess the unique needs and skills of the child (at all points of care) to make appropriate recommendations for tools and strategies

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Patient Profiles:

Baseline:

- Baseline speech, language, and/or communication impairments
- Patients who use AAC or AT outside the hospital environment
- Intellectual disability
- Tracheostomy or other form of mechanical ventilation
- Language difference
- Baseline motor skills that impact use and access to nurse call system

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Patient Profiles:

Acute:

- Intubation or other form of mechanical ventilation
- New tracheostomy
- Medical procedure, treatment, or device that impedes a patient's ability to effectively speak
- Brain injury, aphasia
- Aphonia, dysphonia or new onset vocal chord paresis
- Dysarthria, unintelligible speech
- Altered mental status; sedation
- Psychiatric disorder
- Decreased motor skills needed to effective use and access the nurse call system

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Patient Profiles:

Communication Planning:
- 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

At Risk:
Risk for intubation or other form of mechanical ventilation
Pre-tracheostomy
Anticipated medical procedures or treatments
Degenerative condition
Positional restrictions

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AAC Considerations:
Bedside Feature-Matched Assessment

Assessment Domain	Example Considerations	Assessment Domain	Example Considerations
Cognition	Sedation/wakefulness Attention Premorbid status	Sensory Profile	Vision Hearing Swelling, incisions, etc.
Physical Access	Fine/gross motor skills Strength/coordination Use of physical communication behaviors Positioning restrictions	Vocabulary Selection	Needs, desires, personality, interests Participation in: medical discussions, play, social interactions Ask/answer questions
Respiratory Status/Ventilation Needs	Invasive vs. noninvasive Breath support	Bedside Environment	Lighting, noise Impact of equipment Storage of tools at bedside
Expressive-Receptive Communication Skills	Primary language Pre-/post-morbid skills (speech + language)	Communication Partners	Primary language Caregivers & staff present Partner training
Literacy	Reading Writing/typing		

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AAC Considerations:
Phases of Communication Need & Vulnerability

Communication vulnerable patients in the pediatric ICU: Enhancing care through augmentative and alternative communication

John M. Costello[a],*, Lance Patak[b] and Jennifer Pritchard[a]
[a]Department of Otolaryngology and Center for Communication Enhancement, Augmentative Communication Program, Children's Hospital Boston, Boston, MA, USA
[b]Department of Anesthesiology, University of Michigan Health Systems, USA

Phase I: Emerging from sedation

- Yes/no/I don't know board
- Adapted nurse call system
- Simple voice-output communication aid (VOCA) to gain attention + environment and leisure 'control'

Phase II: Increased wakefulness

- Additional vocabulary
- Simple picture board
- Alphabet board:
- QWERTY
- ABC
- Body/positioning board
- General comfort board
- Customized communication board
- Voice amplification
- Multi-message voice output devices
- Digitally recorded messages

Phase III: Need for broader communication access

- Broader range of vocabulary
- More sophisticated page sets
- Generative communication with alphabet
- Word/grammar prediction
- Internet access

(Costello, Patak, and Pritchard, 2010)

AAC Considerations

Tools and Strategies

- AAC is NOT one size fits all
- WIDE range of potential tools and strategies
  - No-tech → Low-tech → High-tech
- Feature-matched assessment at *every* point of care & recovery is key!
- Children are not small adults

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AAC Tools & Strategies *(to name a few…)*

Unaided/No-tech Strategies

- Eye blinks, eye contact, eye gaze
- Facial expressions or movements
- Gestures
- Body language
- Sign language
- Speech

"pain"

THINGS I SAY:

When I say:	It may mean:
Dah dah	food/hungry
Manda	medicine
Ah ah	poo-poo

When I:
Click my tongue Get my letter board

www.lifeprint.com

Aided/Low-tech Strategies

- Letter boards
- Writing tools
- Picture-communication boards
- Single-message targets
- Social stories

The nurse will put a q-tip into the back of my nose. My nose might feel itchy and uncomfortable, and I might want to sneeze! I can remember to sit still and my test will be over soon.

Aided/High-tech Strategies

- Single message devices
- Multi-message devices
- Dynamic systems
- Text-to-speech
- Adapted nurse-call system

I want

…to watch TV

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AAC and Nurse-Call Access

- Baseline skills and needs
- Anticipated effects or surgery or medical event (i.e. IV boards, incision sites, halo traction)
- Anticipated environmental considerations (i.e. lay supine 48 hrs. post op, nurse-call wall adapter)
- Sedation
- Weakness

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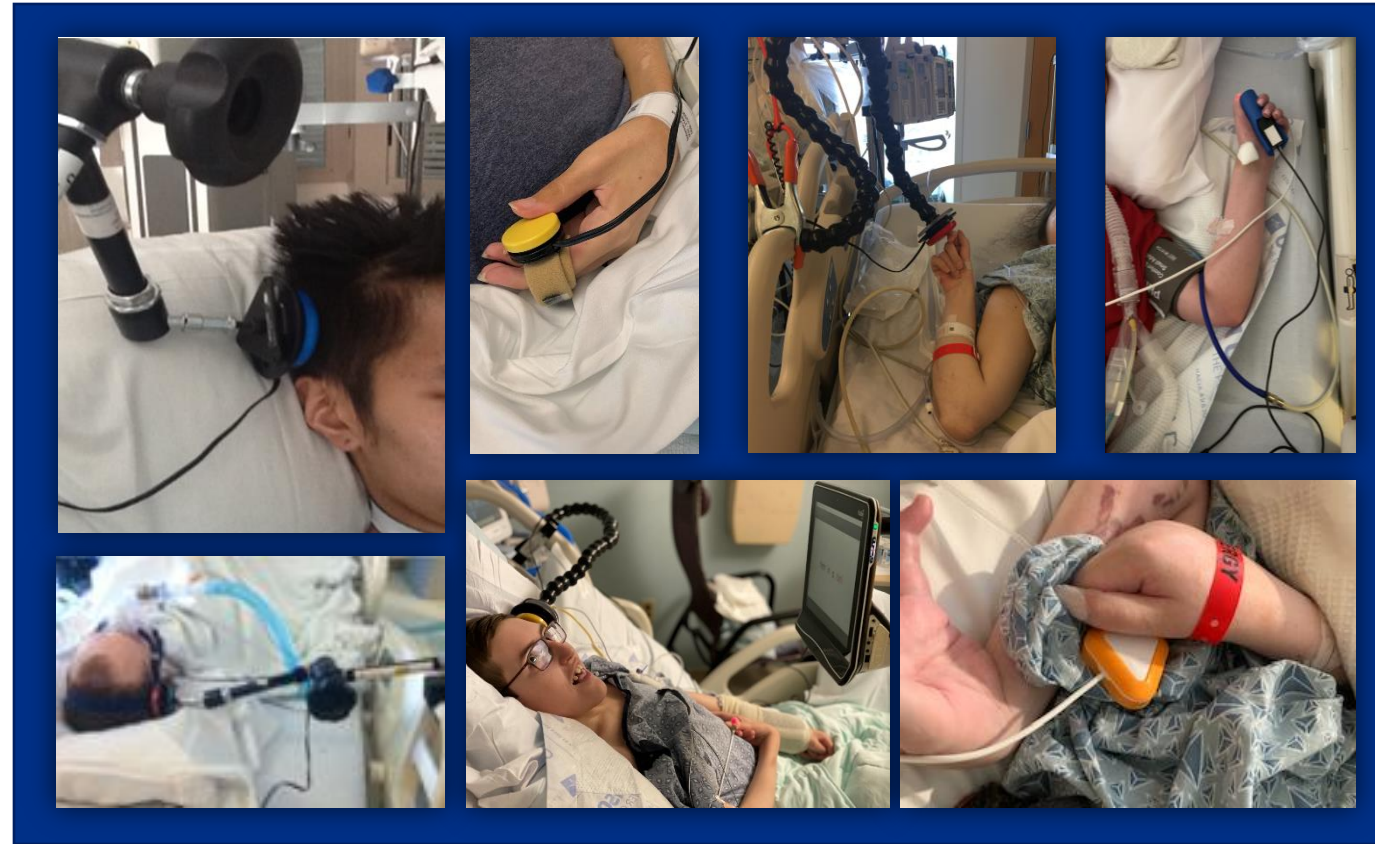
Tenets of Service Provision

- **Recognize & understand patients' communication rights**
  - "Communication Bill of Rights" or similar document
  - Look up state, regional, or national laws
  - Stay up to date on research

- **Knowledgeable staff**
  - Support AAC and patient-provider communication
  - Support assistive technology and access methods (e.g. adapted nurse-call systems)
  - Ongoing staff training (in-services, just-in-time at bedside, simulation training, etc.)
  - Identify communication champions to support program development, education, and bedside support
  - Partner with existing departments
  - Join existing or developing initiatives to enhance communication access
    - Examples:
      - Early mobility
      - Tracheostomy care team
      - Rehabilitation
      - Patient safety
      - Other...

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Tenets of Service Provision

- **Procurement & allocation of resources**
  - Tangible materials, time, professional development in AAC, program development, staffing needs
  - Communication kits
    - Include guidelines and decision trees
    - Ensure process of referral to SLP or AAC specialist
      - When to refer
      - How to refer
  - Availability of varied materials for assessment and intervention
    - *High frequency of low-tech need*
    - Provision of no-tech, low-tech, and high-tech strategies

- **Develop streamlined processes for referrals and documentation**
  - Specific consultation through EMR for AAC/Communication Enhancement
  - Daily documentation by therapy teams
  - Daily documentation by medical teams (e.g. rounds, PICU Up! Levels, goals of care)

- **Ongoing reevaluation**
  - Feature-matched assessment = gold standard
  - Diagnostic intervention
  - Reevaluation, modification, implementation, repeat

Free low-tech tools
(English)

Free low-tech tools
(Bilingual – 16 languages)

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Tenets of Service Provision

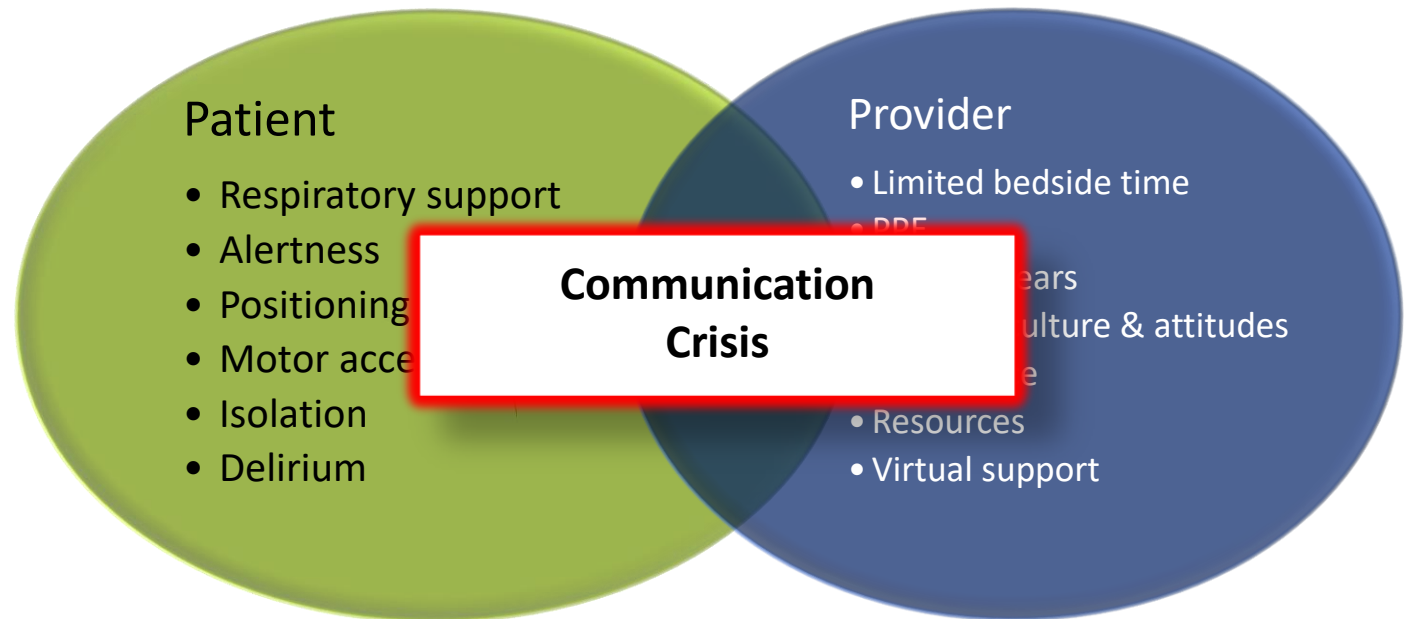- **Educate and inform through visibility**
  - Attend rounds
  - Collaborate through co-treatment
  - Connect with nurses and physicians
  - Connect with psychosocial providers (social workers, child life specialists, chaplains, PT, OT, etc.)
  - Just in Time Training (Knutson, Park et al. 2015)

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COVID-19

...has further revealed the need to address AAC and communication access in acute care and the gap that exists in addressing these needs.

- Communication difficulties & COVID-19:
  - Respiratory distress
  - Availability and access to hospital services
  - PPE requirements
  - Changes to the hospital environment
  - Visitation policies

Patient
- Respiratory support
- Alertness
- Positioning
- Motor acce
- Isolation
- Delirium

Communication Crisis

Provider
- Limited bedside time
- PPE
- ears
- ulture & attitudes
- e
- Resources
- Virtual support

(Altschuler, Gormley, & Santiago, 2020)

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A little reading to hold you over...

PERSPECTIVES — **SIG 12**

Clinical Focus

Improving Outcomes for Hospitalized Patients Pre- and Post-COVID-19

Richard R. Hurtig,[a] Rebecca Alper,[b] Tami Altschuler,[c] Sarah Gendreau,[d] Jessica Gormley,[e]
Sarah Marshall,[f] Rachel Santiago,[g] and Stephanie Scibilia[h]

AJSLP

Tutorial

Speech-Language Pathology Guidance for Tracheostomy During the COVID-19 Pandemic: An International Multidisciplinary Perspective

Charissa J. Zaga,[a,b,c] Vinciya Pandian,[d,e] Martin B. Brodsky,[e,f,g]
Sarah Wallace,[h] Tanis S. Cameron,[c] Caroline Chao,[c,i] Lisa Ann Orloff,[j]
Naomi E. Atkins,[k] Brendan A. McGrath,[l] Cathy L. Lazarus,[m]
Adam P. Vogel,[b,n,o] and Michael J. Brenner[p]

PERSPECTIVES IN HOSPITAL MEDICINE

Communicating Effectively With Hospitalized Patients and Families During the COVID-19 Pandemic

By: Glenn Rosenbluth, MD ✉, Brian P Good, MB BCh , Katherine P Litterer, BA , Peggy Markle, BA , Jennifer D Baird, PhD, MSW, RN , Alisa Khan, MD, MPH , Christopher P Landrigan, MD, MPH , Nancy D Spector, MD , Shilpa J Patel, MD , on behalf of the SHM I-PASS SCORE Study Group
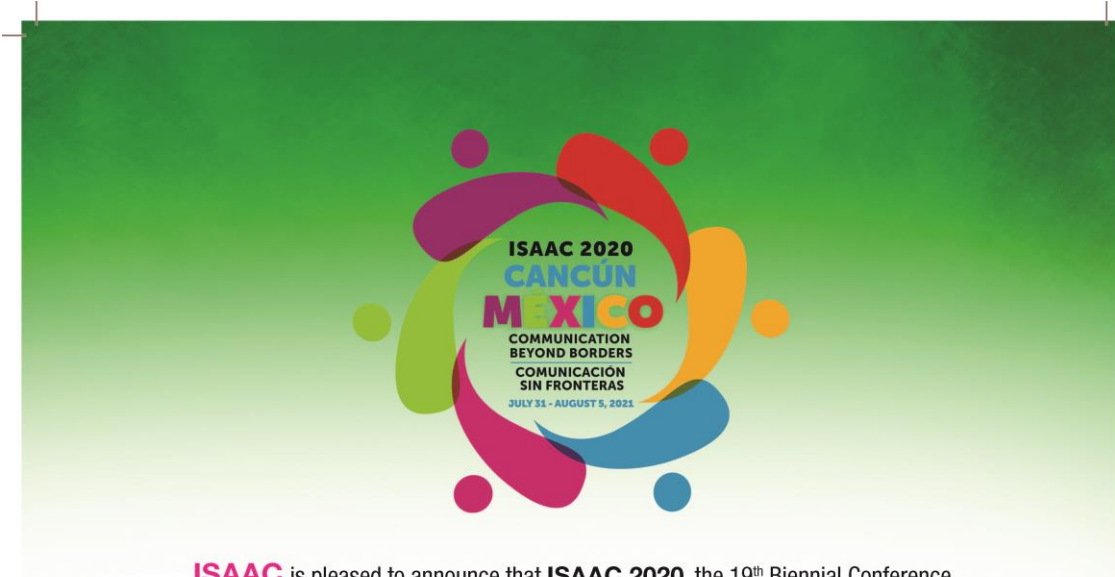
AJSLP

Clinical Focus

Speech-Language Pathology Management for Adults With COVID-19 in the Acute Hospital Setting: Initial Recommendations to Guide Clinical Practice

Ashwini M. Namasivayam-MacDonald[a] and Luis F. Riquelme[b,c]

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ISAAC 2020
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COMUNICACIÓN
SIN FRONTERAS
JULY 31 - AUGUST 5, 2021

International Society for
Augmentative and Alternative Communication

ISAAC 2020
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SIN FRONTERAS
JULY 31 - AUGUST 5, 2021

ISAAC is pleased to announce that **ISAAC 2020**, the 19th Biennial Conference of the International Society for Augmentative and Alternative Communication, has been rescheduled for 2021. As originally planned, the Conference will be held at the Cancún International Convention Centre (ICC) in beautiful **CANCÚN**, adjoining the Riviera Maya on México's Caribbean coast.

JULY 31 – AUGUST 1, 2021
AAC Camp, Pre-Conference Workshops, Executive and Council Meetings

AUGUST 2 - 5, 2021
Main Conference at the Cancún ICC, México

Surrounded by Mayan culture and with easy access to beautiful beaches, tours, shops and restaurants of both Cancún and the Riviera Maya, the ISAAC conference will feature AAC events and perspectives; cutting edge research and clinical innovations; workshops, seminars, exhibits, social events, and entertainment, all in a unique cultural setting.

**Mark your calendar today, and save
the date for ISAAC 2020 (now 2021) in Mexico!**

**For more information, visit us at www.isaac-online.org
and follow #ISAAC2020 on Twitter.**

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www.isaac-online.org

ISAAC se complace en anunciar que el próximo XIX congreso de la Sociedad Internacional de Comunicación Aumentativa y Alternativa se ha sido reprogramado para 2021. Según lo planeado originalmente, la Conferencia se llevará a cabo en el Centro Internacional de Convenciones (ICC) de la bella ciudad de **CANCÚN**, contigua a la Riviera Maya de la costa del caribe mexicano.

31 DE JULIO - 1 DE AGOSTO, 2021
Campamento de CAA, Talleres Preconferencia, Juntas Ejecutivas y del Consejo

2 – 5 DE AGOSTO, 2021
Congreso principal en el ICC de Cancún, México

Rodeado por la cultura maya y con fácil acceso a playas hermosas, tiendas, restaurants y tours tanto de Cancún como de la Riviera Maya, el congreso de ISAAC contará con eventos de CAA, perspectivas, lo último en investigaciones e innovaciones clínicas, talleres, seminarios, exposiciones de las compañías más importantes, eventos sociales y entretenimiento. Todo en un sitio culturalmente único.

**¡Anótalo en tu calendario y aparta
la fecha para ISAAC 2020 (ahora 2021) en México!**

**Para mayor información, consulta nuestro sitio web www.isaac-online.org
y síguenos en Twitter #ISAAC2020**

www.isaac-online.org

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