



The U.S. Society of Augmentative & Alternative Communication is approved by the Continuing Education Board of the American Speech-Language-Hearing Association (ASHA) to provide continuing education activities in speech-language pathology and audiology. See course information for number of ASHA CEUs, instructional level and content area. ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.



Program Planner/Instructional Personnel Relationship Disclosure Form

In compliance with American Speech-Language Hearing Association's Continuing Education Board's Requirements, ISAAC Conference 2016 requires program planners and instructional personnel to disclose information regarding any relevant financial and non-financial relationships related to course content prior to and during course planning.

Based on the information provided, ISAAC Conference 2016 will engage the program planner /instructional personnel in a guided interview process which seeks to understand how the relevant financial or nonfinancial relationship may influence the content of the course.

Program Planner/Instructional Personnel's Name:

Course Title: AAC and MND/ALS: Seeking Improved Outcomes through Early Engagement in Assessment, System Design and Implementation

HIPAA REQUIREMENTS

To comply with the Health Insurance Portability and Accountability Act (HIPAA), we ask that all program planners and instructional personnel insure the privacy of their patients/clients by refraining from using names, photographs, or other patient/client identifiers in course materials without the patient's/client's knowledge and written authorization.

I am in compliance with these policies: JMC

(INITIAL HERE)

Relevant financial relationships are those relationships in which the individual benefits by receiving a salary, royalty, intellectual property rights, gift, speaking fee, consulting fee, honoraria, ownership interest (e.g., stocks, stock options, or other ownership interest, excluding diversified mutual funds), or other financial benefit. Financial relationships can also include "contracted research" where the institution gets the grant and manages the funds and the individual is the principal or named investigator on the grant.

Do you have relevant financial relationships to disclose?

No

Yes (if yes complete Financial Relationship Disclosure Form)

Relevant non-financial relationships are those relationships that might bias an individual including any personal, professional, political, institutional, religious or other relationship. May also include personal interest or cultural bias.

Do you have relevant non-financial relationships to disclose?

No

Yes (if yes complete Non-Financial Relationship Disclosure Form)

I attest that the information in this disclosure is accurate at the time of completion and I agree to notify ISAAC Conference 2016 (conference2016@isaac-online.org) of any changes to this information between now and the scheduled presentation date. **I also understand that all completed Disclosure Forms must be incorporated within my paper proposal, as part of my Long or Extended abstract upload to the ISAAC Conference 2016 paper submission system.**

Signature

Date 27.10.15



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Financial Relationship Disclosure Form

Copy this page as many times as you need to complete information regarding each of your relevant financial relationships. Program Planners/Instructional personnel have a relevant financial relationship if that relationship could influence the information presented in the course and could be perceived as a conflict of interest by learners.

Planner/Presenter name: John Costello

Financial relationship with (name of Company/Organization): Boston Children's Hospital

Date form completed: October 27, 2015

What was received? (Check all that apply)

- | | |
|---|--|
| <input checked="" type="checkbox"/> Salary | <input type="checkbox"/> In kind |
| <input type="checkbox"/> Consulting fee | <input type="checkbox"/> Grants |
| <input type="checkbox"/> Intellectual property rights | <input type="checkbox"/> Gift |
| <input type="checkbox"/> Speaking fee | <input type="checkbox"/> Ownership interest (e.g., stocks, stock options or other ownership interest excluding diversified mutual funds) |
| <input type="checkbox"/> Royalty | |
| <input type="checkbox"/> Honoraria | |
| <input type="checkbox"/> Hold patent on equipment | |
| <input type="checkbox"/> Other financial benefit (please describe): | |

For what role? (Check all that apply)

- Employment
- Management position
- Teaching and speaking
- Board membership
- Ownership
- Consulting
- Membership on advisory committee or review panels
- Independent contractor (including contracted research)
- Other activities (please describe):

Declaration of Interest Statement:

Financial interest/disclosure:

-Full time clinician/ employee of ***** Hospital

Non-financial interest/disclosure:

-none

Extended Abstract:

For most people, having to learn a new tool or strategy when fatigued, uncomfortable or in pain; when unable to ask questions or engage partners or; when having difficulty physically engaging, results in confusion, misunderstanding and personal compromise. Indeed, this is a major challenge for many who rely on augmentative communication for expressive communication.

For people with degenerative conditions that will impact the ability to speak, it is critical that a proactive and aggressive focus on early introduction and trials with augmentative communication strategies, is implemented. Why is it so critical? Because first considering AAC strategies only when speech difficulties are evident, when significant motor difficulties emerge or when breathing difficulties and overall fatigue is prevalent, one has lost the 'window of opportunity' to participate in several critical communication supports.

Through close collaboration with neurologists and other members of the ALS/MND medical and clinical team, all of whom advocate for extremely early referral for AAC services; a model of AAC counseling, assessment, customization and implementation has emerged. This model has been further bolstered by positive feedback from people with ALS and their families who have been exposed to a proactive approach to exploring a range of augmentative communication strategies.

While there are always individual differences in how any person with ALS is introduced to AAC following a feature matching process, a core list of considerations are part of the protocol of proactive strategies. The appropriate considerations may, in some instances be all addressed in the first session but are often addressed over two or more sessions, scaffolding previous strategies, skills and learning on new considerations. Each of these considerations will be discussed in detail during this workshop and as appropriate, further highlighted through video demonstration including:

1. Introduction of voice amplification, even when symptoms suggesting concern with volume and breathe support integrity are not evident.
2. Review of strategies to enhance speech clarity of speech production
3. Define and introduce the strategy of Message Banking developed at this center. This strategy requires digitally recording and storing 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 be

linked to messages in a variety of augmentative communication technologies or sound storage files.

- Introduce concept
 - Practice recording with a hand held recorder to support high quality recordings 'in the moment'.
 - Share clinical stories and outcomes and provide concrete examples
 - Download, playback, label and store audio files, providing guidance for improving quality if needed.
 - Review potential technologies that could accommodate message banking across varied platforms.
 - Provide person with ALS with their own recorder to take home and use to functionally record.
4. Define and introduce Voice Banking, a process of recording a large inventory of one's own speech that is then used to create a synthetic voice that approximates one's 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. Patients and their families are introduced to audio samples of synthesizers created with leading technologies including: Model Talker, CereProc and Acapela, and personalized voices created by this clinician.
 5. Introduce the concept of 'quick access' low-tech tools in which the person with ALS is fully involved in creating and designing his/her own tools. Alternative access strategies including partner-assisted scanning are also reviewed.
 6. Laser pointer with low tech boards are tried as alternative access
 7. Review of varied text to speech apps (as appropriate for literacy) or symbol based apps.
 8. Head mouse access review
 9. Eye tracking access review
 10. Discuss current access and possible needs to identify alternative access to computer, environmental control, telephone, etc.

A list of current tools and resources will be provided along with a web link to downloadable PDFs and video tutorials.

Time Ordered Agenda

5 minutes

- Introduction and Disclosure

10 minutes.

- Overview of communication considerations for people who have ALS, differentiating types of ALS and typical symptoms, needs and communication symptoms (case study vignettes)
- Review of typical domains of assessment questions and considerations for identifying AAC and Assistive Tech strategies.

30 minutes

- Detailed review of each strategy, supported with patient video and visual supports

10 minutes

- Review of outcome data to date including overview of fields collected and overall trends to date.

5 minutes Q & As

Keywords: ALS, MND, Proactive approach

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