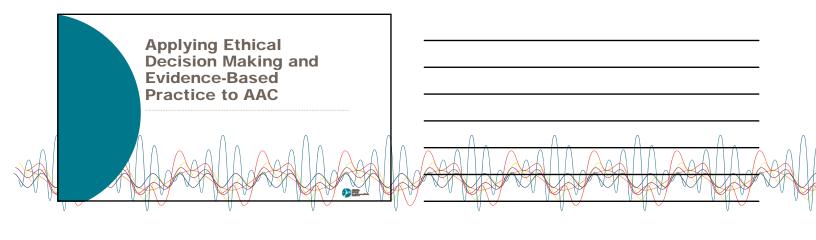
11/21/2019 **ASHA Orlando**



Overview Meher Banajee

Presenters

- Meher Banajee, PhD, CCC-SLP LSU Health Sciences Center
- Carole Zangari, PhD, CCC-SLP Nova Southeastern University
- Angela Standridge, M.S., CCC-SLP
- University of Texas (Texas Technology Access Program)
- Debora Downey, PhD., CCC-SLP
 Center for Disabilities and Development, University of Iowa Hospitals and Clinics • Diane Paul, PhD, CCC-SLP
- ASHA
- Nicole Tripp, M.S., CCC-SLP Spring Branch School District



Financial Disclosures

- Meher Banajee: 2019 Convention Topic Chair AAC registration waived.
- Carole Zangari:2019 Convention AAC Program Committee Member registration waived
- Angela Standridge: Full time employee of Texas Technology Access Program which is funded with federal grants, 2019 Convention AAC Program Committee Member – registration waived
- Debora Downey: 2019 Convention AAC Program Committee member registration wavied
- Diane Paul: Full-time ASHA employee; registration waived



Non-Financial disclosures

- Meher Banajee: Topic Chair AAC
- Carole Zangari: Owner/author of an educational website, PrAACtical AAC
- Diane Paul: ASHA ex officio for the National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC); ex officio for former ASHA Ad Hoc Committee on Facilitated Communication and the Rapid Prompting Method
- Angela Standridge: Member of the SIG 12 Coordinating Committee
- Nicole Tripp Coordinator SIG 12 Coordinating Committee

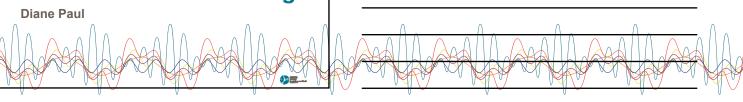


Learner Objectives

- Define how evidence-based practice (EBP) applies to ethical issues in AAC.
- List ethical concerns and potential strategies for AAC across service delivery options
- List ethical concerns and potential strategies for AAC in the schools.
- List ethical concerns and potential solutions for AAC in adult settings.
- Audience ethical concerns for AAC



ASHA Perspective and Resources: EBP and Ethical Decision-Making



ASHA Position on Evidence- Based Practice

It is the position of the American Speech-Language-Hearing Association that audiologists and speech-language pathologists incorporate the principles of evidence-based practice in clinical decision making to provide high quality clinical care.

Position Statement: Evidence-Based Practice in Communication Disorders



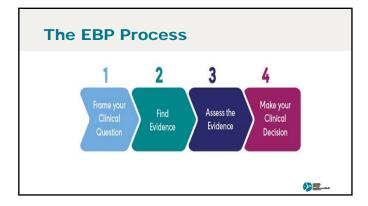
Evidence-Based Practice

Evidence-based practice is the integration of:

- clinical expertise/expert opinion;
- external scientific evidence;
 and
- client/patient/caregiver perspectives.

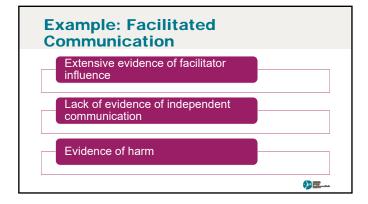
www.asha.org/research/ebp/evidence-based-practice/

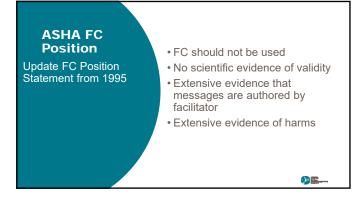


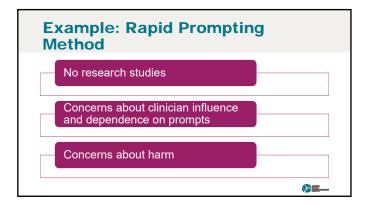


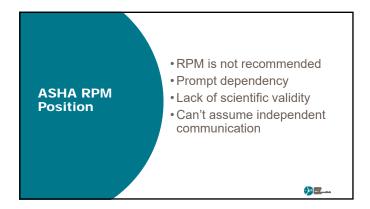
ASHA Code of Ethics and EBP Principle of Ethics I Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally or who are participants in research and scholarly activities, and they shall treat animals involved in research in a humane manner. Rules of Ethics M. Individuals who hold the Certificate of Clinical Competence shall use independent and evidence-based clinical judgment, keeping paramount the best interests of those being served. American Speech-Language-Hearing Association. (2016). Code of ethics [Ethics]. Retrieved from www.asha.org/policy/

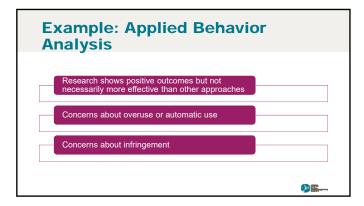












Acknowledge that some SLPs may face infringement from ABA practitioners; others are creating collaborative models.
 ASHA ABA Messages
 Consistent with IDEA, ASHA supports multiple treatment options based on individual needs.





ASHA Code of Ethics and Civility

Principle of Ethics IV

 Individuals shall uphold the dignity and autonomy of the professions, maintain collaborative and harmonious interprofessional and intraprofessional relationships, and accept the professions' self-imposed standards.

Rules of Ethics

 A. Individuals shall work collaboratively, when appropriate, with members of one's own profession and/or members of other professions to deliver the highest quality of care.



Code of Ethics and Civility

Principle of Ethics IV

Rules of Ethics

C. Individuals' statements to colleagues about professional services, research results, and products shall adhere to prevailing professional standards and shall contain no misrepresentations.

D. Individuals shall not engage in any form of conduct that adversely reflects on the professions or on the individual's fitness to serve persons professionally.

E. Individuals shall not engage in dishonesty, negligence, fraud, deceit, or misrepresentation.



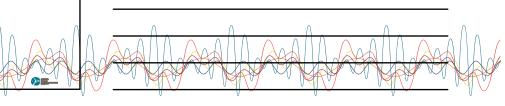
Applying Ethical Decision Making and Evidence-Based Practice to AAC



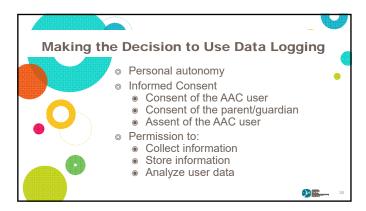
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Ethical Issues Service Delivery Settings

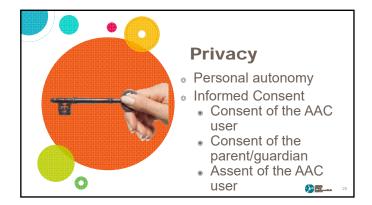
Carole Zangari



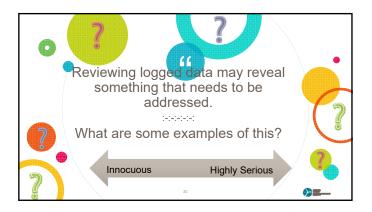


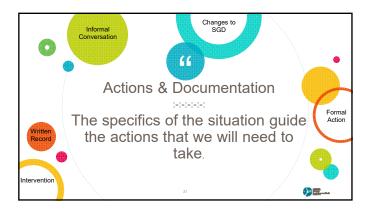








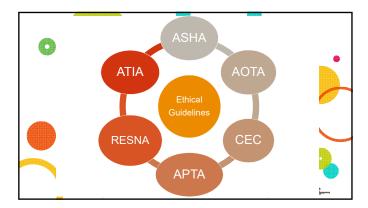








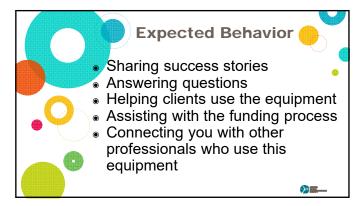


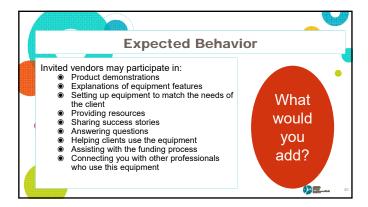




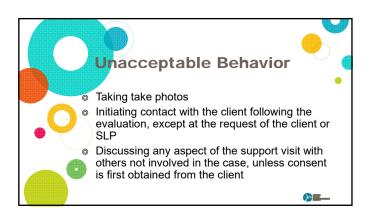


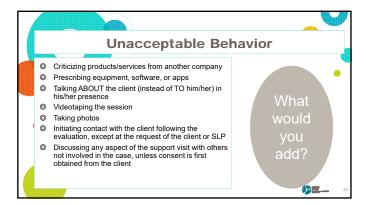
Invited vendors may participate in: Product demonstrations Explanations of equipment features Setting up equipment to match the needs of the client Providing resources

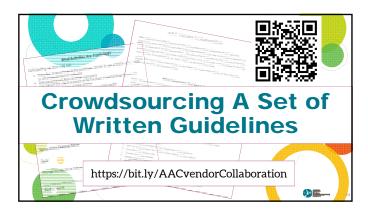




Unacceptable Behavior Criticizing products/services from another company Prescribing equipment, software, or apps Talking ABOUT the client (instead of TO him/her) in his/her presence Videotaping the session









AAC Ethical Dilemmas in the School Systems So many issues, let's explore just five...



Angela Standridge, Nicole Tripp



- Provision of FAPE
- Provision AT devices and services
 - Procurement
 - Training
 - Timely manner
 - Connection to IEP and access to the curriculum?
 - Monitor and adjust
- Your state's education code
- Case Study



Student Focused

- Academic success
- Communicative succes
- Access to the curriculu
- Continual improvement
- Monitor and adjust
- Team engagement
- Case study



Stakeholder Support

- Training
- Communication and engagement
- · Implementation with fidelity across environments
- Accountability
- Case Study



Cultural Competence

- Assessment
- Language(s)
- Implementation fidelity
- Parent/caregiver training and support
- Case Study

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FERPA

https://www2.ed.gov/policy/gen/guid/fpco/ index.html

- Family Educational Rights and Privacy Act in the provision of AAC services?

 - ConfidentialityStudent as "owner" of information
 - Records
 - Personal information and AAC
- Case Study



Facilitated Communication & Rapid Prompting Method: Ethical Considerations Meher Banajee

Meher Banajee

What is FC? (Also called "Assisted Typing," "Facilitated

•FC is a <u>technique</u> that involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically <u>with</u> <u>physical support</u> from a "facilitator."

Communication Training," and "Supported Typing")

• This physical support usually occurs on the hand, wrist, elbow, or shoulder or on other parts of the body.

What is RPM? (Also called "Informative Pointing", "letterboarding," and "Spelling to Communicate")

- The *Rapid Prompting Method* (RPM), is described as a teaching method "leading towards communication for persons with autism" (Helping Autism Through Learning and Outreach [HALO], 2018; Mukhopadhyay, 2008).
- According to the HALO website, RPM involves pointing to letters "to form words on a letter board, typing device, and/or by handwriting."
- Untested assertions are that RPM assists with motor planning and that "prompting is necessary in order for the student to initiate a response" (Mukhopadhyay, 2008, p. 139).

Comparison of RPM with FC

- Procedures used to elicit responses
- Assumptions about communication and literacy skills
- Hypothesized mechanism of action
- Research base/evidence for claims of benefit
- Autonomous communication
- Adverse events/risk of harm



FC and RPM and Pseudoscience

Pseudoscience is a system of theories, assumptions, and methods erroneously regarded as scientific (Gardner, 1997).

Four characteristics of Pseudoscience:

- (1) Make contradictory, exaggerated, or unfalsifiable claims
- (2) Reliant on bias rather than rigorous attempts at use of scientific
- (3) Lack openness to evaluation by other experts
- (4) Lacking in systematic practices for developing theories



Proposed Position Statements

Committee proposed position statements based on systematic reviews and similarities between techniques.

- •FC is a discredited technique that should not be used
- RPM is not recommended

Difference between the statements is due to extent of scientific research.



ASHA Position Statement on Facilitated Communication

Position Statement: Facilitated Communication

It is the position of the American Speech-Language-Hearing Association (ASHA) that Facilitated Communication (FC) is a discredited technique that should not be used. There is no scientific evidence of the validity of FC, and there is extensive scientific evidence—produced over several decades and across several countries—that messages are authored by the "facilitator" rather than the person with a disability. Furthermore, there is extensive evidence of harms related to the use of FC. Information obtained through the use of FC should not be considered as the communication of the person with a disability.



ASHA Position Statement on Rapid Prompting Method

Position Statement: Rapid Prompting Method

It is the position of the American Speech-Language-Hearing Association (ASHA) that use of the Rapid Prompting Method (RPM) is not recommended because of prompt dependency and the lack of scientific validity. Furthermore, information obtained through the use of RPM should not be assumed to be the communication of the person with a disability.



FAQs: Practice Implications

- What are effective communication interventions for individuals with severe communication disabilities?
- What is the SLPs responsibility to follow EBP when there is little scientific evidence to support a technique?
- What are appropriate ways for SLPs to use prompts?
- What should SLPs do if asked to use FC or RPM?
- What should an SLP do if concerned about harms of FC/RPM?

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What are effective communication interventions for individuals with severe communication disabilities?

- AAC systems and strategies: speech or vocalizations, gestures, manual signs, and aided communication (e.g., keyboards, alphabet/letter/ picture boards, speech-generating devices)—and the individual's full and multimodal communication abilities
- AAC-related assessment and interventions, see the ASHA Practice
- Scientific evidence for the use of many types of AAC and there are proven strategies for communicating with individuals who have severe communication disabilities, see ASHA Evidence Maps

What is the SLPs responsibility to follow EBP when there is little scientific evidence to support a technique?

ASHA's Position Statement on Evidence-Based Practice in Communication Disorders (ASHA, 2005):

"It is the position of the American Speech-Language-Hearing Association that audiologists and speech-language pathologists incorporate the principles of evidence-based practice in clinical decision making to provide high quality clinical care."

According to ASHA, the goal of evidence-based practice is the integration of

- clinical expertise/expert opinion;
- external scientific evidence; and
- client/patient/caregiver perspectives

to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve.

What are appropriate ways for SLPs to use prompts?

SLPs COMMONLY use prompts when teaching someone to communicate using $\ensuremath{\mathsf{AAC}}$

- Hand-over-hand prompting,
- Verbal prompts, and/or
- Gestural prompts to point or to activate a speech-generating device using direct or indirect methods).

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What are appropriate ways for SLPs to use prompts?

Which prompts to use?

- Consider the linguistic, cognitive, sensory, and motor needs of the individual
- The communication goal in using prompts should be independent communication, not prompt-dependent communication.

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What are appropriate ways for SLPs to use prompts?

Be familiar with **prompting hierarchies** and **documentation methods** that verify fading of prompts and increasing independence in communication

- Response prompts (verbal instructions, modeling, physical guidance) and stimulus prompts (movement, position, and redundancy cues)
- "Transfer stimulus control from the response and stimulus prompts to the naturally existing stimulus" (Cooper et al., 2007, pp. 402-403)



What are appropriate ways for SLPs to use prompts?

The SLP should acknowledge and document

- Which prompts are being used (e.g., type, timing, frequency);
- How the prompts will be "faded" (i.e., systematically removed);
- The prompter's influence over the message produced—that is, the SLP should acknowledge that the prompter may influence the person's action, even if the prompt is faded or changed (e.g., changing to a different prompt location or to a different type of prompt)



What should SLPs do if asked to use FC or RPM?

Students, caregivers, parents, teachers, administrators, or employers may not know or understand the true opportunity costs of using FC or RPM—in terms of lost time, lost money, lost energy, and lost opportunities at practicing skills for independent access to an AAC system and other communication strategies.

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What should SLPs do if asked to use FC or RPM?

Provide the following:

- ASHA's position statements on FC and RPM
- Information about the lack of scientific studies supporting FC or RPM
- Evidence against the use of FC
- Evidence about harms of using FC or RPM



What should SLPs do if asked to use FC or RPM?

- Information about the importance of validating authorship of messages produced using FC or RPM
- Evidence and information about scientifically based effective interventions, including
- ASHA Position Statement and Technical Report on <u>Evidence-Based Practice in Communication</u> Disorders
- ASHA Evidence Maps



What should an SLP do if FC/RPM is already included on a student's IEP?

- School-based SLPs must implement the IEP as written and may not change a student's IEP without an IEP team meeting.
- •The SLP's concern and information about using FC or RPM should be shared with the IEP team—including evidence, ASHA position statements, the potential for harm, and the opportunity costs.

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What should an SLP do if FC/RPM is already included on a student's IEP?

•SLPs should have sufficient student-specific assessment data (formal and informal) to justify their position and recommendations as a member of the IEP team.



What should an SLP do if FC/RPM is already included on a student's IEP?

In light of ASHA positions and resources on FC and RPM, SLPs working in a school setting have a responsibility to:

- Inform development and revisions of children's IEP goals (i.e., that they do not include FC or RPM) and
- Ensure that the student's goals can be targeted and addressed through evidence-based interventions and AAC approaches, in accordance with their legal and ethical responsibilities to offer FAPE as required by IDEA.



SLPs have a responsibility to ... Enable <u>independent access</u> to AAC systems

- Prompt dependence is characteristic of FC and RPM.
- Clinicians should use interventions that are demonstrated to support an individual's independent access to communication, shown to be of benefit, and shown to be of no harm.
- AAC may also involve communication partner support and, as in all communication interactions between two or more people, AAC relies on the co-construction of meaning.
- In AAC, any involvement of the communication partner in producing the message is acknowledged.

SLPs have a responsibility to address barriers to the use of AAC:

- Lack of communication partner involvement in design of AAC systems or other interventions,
- · Lack of generalization from one setting to another, and
- · Negative societal attitudes.
- The International Classification of Functioning, Disability and Health and the Participation Model for AAC provide useful frameworks for teams to address barriers and enhance communication success using empirically-supported interventions.



What are the potential harms related to FC/RPM?

- Educational harm
- Communication harm
- Legal harm
- Financial harm
- False hope

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What are the Ethical Implications of Providing FC or RPM?

- All ASHA members and certificate holders are "subject to the jurisdiction of the Board of Ethics for ethics complaint adjudication."
- SLPs should be mindful of their own legal and ethical responsibilities and risks; they are obliged to "provide services ...only when benefit can reasonably be expected" and not do harm (ASHA, 2016a).
- The Code speaks to the obligations of SLPs to inform "persons served about possible effects of not engaging in treatment or not following clinical recommendations."



Guidance to SLPs

- Document all efforts to inform and educate IEP team members and school administration
- · Specifically maintain documentation of:
 - Requests for IEP meetings
 - · Information shared with family and school staff
 - Any meetings to discuss disagreement with FC or RPM methods
 - Inquiries to ASHA, licensure board, or school board attorney



Summary

- ASHA is dedicated to making effective communication, a human right, accessible and achievable for all.
- ASHA's Board of Directors has approved new position statements that discourage use of FC and RPM.
- FC and RPM lack scientific validity and do not foster independent communication.
- Both statements were open to peer review by all interested parties.
- Numerous other organizations have issued similar cautions.



Ethics and the Adult Population

Debora A. Downey, PhD, CCC-SLP

Adult Populations

Congenital disabilities includes:

- autism spectrum disorder (ASD);
- · cerebral palsy;
- developmental disabilities;
- · intellectual disability;
- developmental apraxia of speech; and
- genetic disorders

Acquired disabilities includes:

- · cerebrovascular accidents;
- traumatic or acquired brain injuries;
- neurodegenerative diseases (e.g., amyotrophic lateral sclerosis [ALS], supranuclear palsy, primary progressive aphasia, and apraxia);
- disability following surgeries (e.g., glossectomy, laryngectomy); and
 temporary conditions (e.g., intubation) for patients in critical care settings.

Communication Vulnerable Patients

- Poor vision resulting in an inability to read hospital consent forms or patient-education materials, despite the use of corrective lenses;
- · Poor hearing resulting in an inability to understand loud speech despite the use of hearing aids;
- · Poor speech intelligibility resulting in inability to be understood by the health care team;



Communication Vulnerable Patients

- Poor or altered mental status;
- Poor literacy skills resulting in an inability to comprehend patient instructions and consent forms:
- Poor motor control due to disease that limit oral speech abilities;
- Limited English proficiency and different cultural expectations about medical care.



Medical Conditions Associated with Communication Vulnerability		
Medical Condition and/or Etiology Type of Communication Compromise		
Cerebral Palsy Amyotrophic Lateral Sclerosis Muscular Dystrophy Cerebral Vascular Accidents (old)	Chronic Neurogenic Speech/Language Compromise	
Cerebral Vascular Accidents (acute) Traumatic Brain Injury Autism Spectrum Disorder Intellectual Disabilities Other Developmental Disabilities	Cognitive/Language Compromise	
Sequela that lead to Intubation Spinal Cord Injuries Guillain-Barre Syndrome Brain Injury	Acute Speech/Language Compromise	

Regulatory Requirements & Ethical Considerations

- Communication Bill of Rights
- Americans with Disabilities Act
- Joint Commission Hospital Acc reditation Standards



Participation Model (Beukelman & Mirenda)

- · Identify participation patterns and co needs
- Assess Opportunity Barriers A wants
- Assessing Access Barriers
- Plan and Implement Interventions
 Evaluate Intervention Effectiveness



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Participation Model

Assess Opportunity Barriers

- Extrinsic Factors
 - Policy & practice
 - Knowledge & attitudes of members
 - · Environment absent of support or equipment

Assessing Access **Barriers**

- Intrinsic Factors
 - Linguistic Status
 - Motor function
 - Cognitive Status

Ethically it is our job to identify and ADDRESS these barriers!

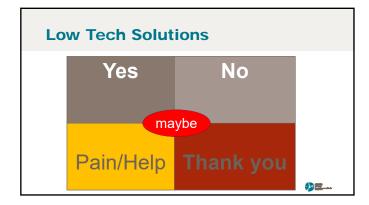


Participation Model

- · Identify participation patterns and communication needs
- Assess Opportunity Barriers
- · Assessing Access Barriers
- Plan and Implement Interventions so that the patient
 - · communicate needs & wants
 - transfer information
 - experience social closeness
 - demonstrate social etiquette
- Evaluate Intervention Effectiveness

· If not start over





What would you do?

Scenario

- You are an SLP working in a SNF with high productivity demands.
- You are the only staff member who "knows" AAC.
- After a successful trial with device your patient, you wrote a funding report for a 50-year old stroke patient with aphasia, including all relevant materials suggested through the vendor and other sources.
- However, the insurance company still denied the request.
- The family has asked you to assist them with the appeal.

Possible Solutions

- You recognize and state, you are unable to help at this point, because you will not get compensated unless direct patient care is involved.

- You communicate to the family that their options are:
 to find another SLP to help, or
 ask the social worker to follow up with the appeal.
- These are not solutions; they are ethical violations!



ASHA CODE of ETHICS Principle of Ethics Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally or who are participants in research activities, and they shall treat animals involved in research in a humane manner. Rule E. Individuals who hold the Certificate of Clinical Competence may delegate tasks related to provision of services to aides, assistants, technicians, support personnel, or any other persons only if those persons are adequately prepared an are appropriately supervised. The responsibility for the welfare of those being served remains with the certified individual. Served refinants with the Certificate of Clinical Competence shall not delegate tasks that require unique skills, knowledge, judgment, or credentials that are within the scope of the profession to aides, assistants, technicians, profession to aides, assistants, technicians over whom they have supervisory responsibility.

What could/should you do?

- Agree to help with the appeal...that's your job!
- Integrate a low tech option while working on appeal.
- Enlist the vendor's funding department to help you.
- · Ask the vendor for a loaner or surplus device.
- · Locate loan closets in your area.
- Don't give up think about the participation model:
 - if it fails you start, again!!



Could you do this?



- You are an SLP working in a tertiary level hospital.
- · Your expertise is in dysphagia.
- You have been asked by a neurologist to see 21 -year-old male with a C-4 spinal cord injury secondary to a MVA to determine his need for a SGD.
- The patient is 48 hours post admission and vitals are stable; he is on a vent.
- The doctor indicated to you that this patient will be on the unit for at least the next 45 to 60 days.

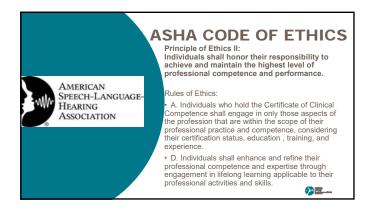


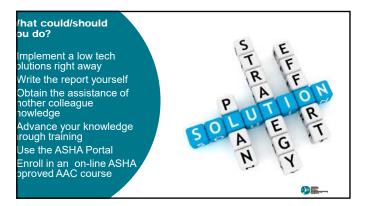
Could you do this?

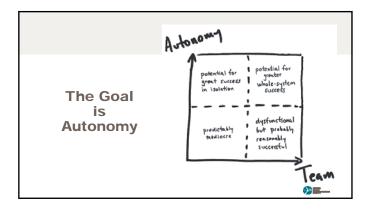


- You agree to see the patient but have never secured a device for anyone before.
- However, you know you're ethically mandated to help this patient and enlist the help of a vendor.
- The patient initially does not want anything to do you or a device.
- The vendor encourages you to keep offering the device and leaves one with you for a week.
- The patient begins to respond and eventually use the device.
- The vendor assist you in gathering all of the paper work and offers to write the funding report for you to sign and submit.

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Tell us what you think! https://padlet.com/ams1701/Intro Padlet to gather your thoughts and concerns about ethics

Breakout Discussions: Tricider

https://www.tricider.com/ad min/2UJrXZ2MEud/7m19w FUORwH

- Post a concern, idea, or case study
- Read others post and comment
- Vote on the concern idea, or case study that resonates with you most



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Closing Padlet:

https://padlet.com/ams1701/AACEthics

- What will you do differently?
- What will you share with a colleague?
- What could ASHA do to support you?





References and Resources

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- $.\\ 121(2), 121-138. \\ \underline{http://www.aha.org/advocacy-issues/communicatingpts/pt-care-partnership.shtml}$
- The Joint Commission (2010). Advancing effective communication, cultural competence, and patient-and family-centered care: A roadmap for hospitals. Oakbrook Terrace, IL: The Joint Commission.
- www.ada.gov/cguide.htm www.asha.org/Code-of-Ethics/



More ASHA Resources on EBP

ASHA Evidence Map on AAC

Provides summaries and appraisals of published research on AAC.

Evidence-Based Practice Tools for Practicing Clinicians

Webinar highlighting the principles of EBP and ways to integrate evidence into clinical practice (earn .05 ASHA CEUs; learning assessment and registry fees apply).

SIG 12 (AAC) Community and Perspectives



More Resources Connecting EBP, Ethics, and AAC

National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC) www.asha.org/njc

- Communication Bill of Rights
- Guidance documents
- Information on AAC and other areas of practice
- Interprofessional collaborative practice model
- NJC Network
- ASHA Practice Portal on AAC

www.asha.org/Practice-Portal/Professional-Issues/Augmentative-and-Alternative-Communication/





Resources



- Consensus Statement on Clinical Judgment in Health Care Settings
- ASHA, APTA, AOTA
- https://www.aota.org/~/media/Corporate/Files/Practice/Ethics/APTA-AOTA ASHA Conceptus Statement off
- Required Ethical Reporting
 - https://www.asha.org/Practice/ethics/Required-Ethical-Reporting/
- Issues in Ethics Statements
 - https://www.asha.org/practice/ethics/ethics issues index/
- Privacy & AAC (Issue of ACN)
 - http://www.augcominc.com/newsletters/index.cfm/newsletter_68.pdf

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