Space for Everyone: Co-Designing AAC Trainings with Families & Providers

Jessica Gormley, PhD, CCC-SLP, Maryjan Fiala, MS, Brittany Steinfeld, MS, CCC-SLP

UNMC MUNROE-MEYER INSTITUTE

Disclosures

- Salary from the University of Nebraska Medical Center's Munroe-Meyer Institute
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Non-Financial Disclosures

Jessica Gormley, PhD, CCC-SLP is a co-organizer and content creator for the Patient-Provider Communication Network. She is also a member of the United States Society for Augmentative and Alternative Communication.

Maryjan Fiala, M.S., is a parent and community college instructor. She also serves on several non-profit boards/committees including PTI Nebraska, Embracing the ICU, and The Arc of Nebraska Resource Development Committee.

Learning Objectives

1. Describe at least two evidence-based techniques that promote effective communication partner training.
2. Identify at least 2 barriers that impact their collaboration with other stakeholders to develop communication partner trainings
3. Choose at least one other group of stakeholder to collaborate in the design of future communication partner trainings

Hello!

Let’s get to know each other!

Who are we?

Brittany Steinfeld,
MS, CCC-SLP

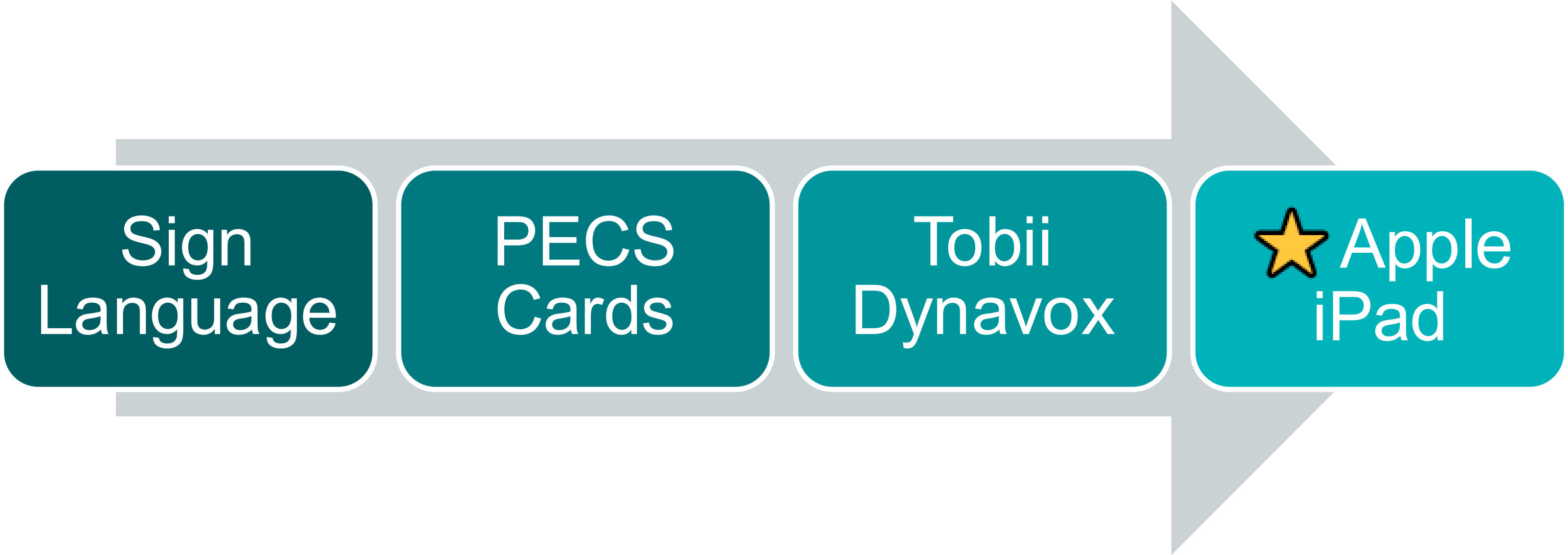
Maryjan Fiala,
M.S. Adult,
Occupational,
Continuing Education
(Parent)

Jessica Gormley,
PhD, CCC-SLP

General Introduction

We are going to talk about our experiences co-designing and implementing communication partner trainings from different perspectives as well as different settings.

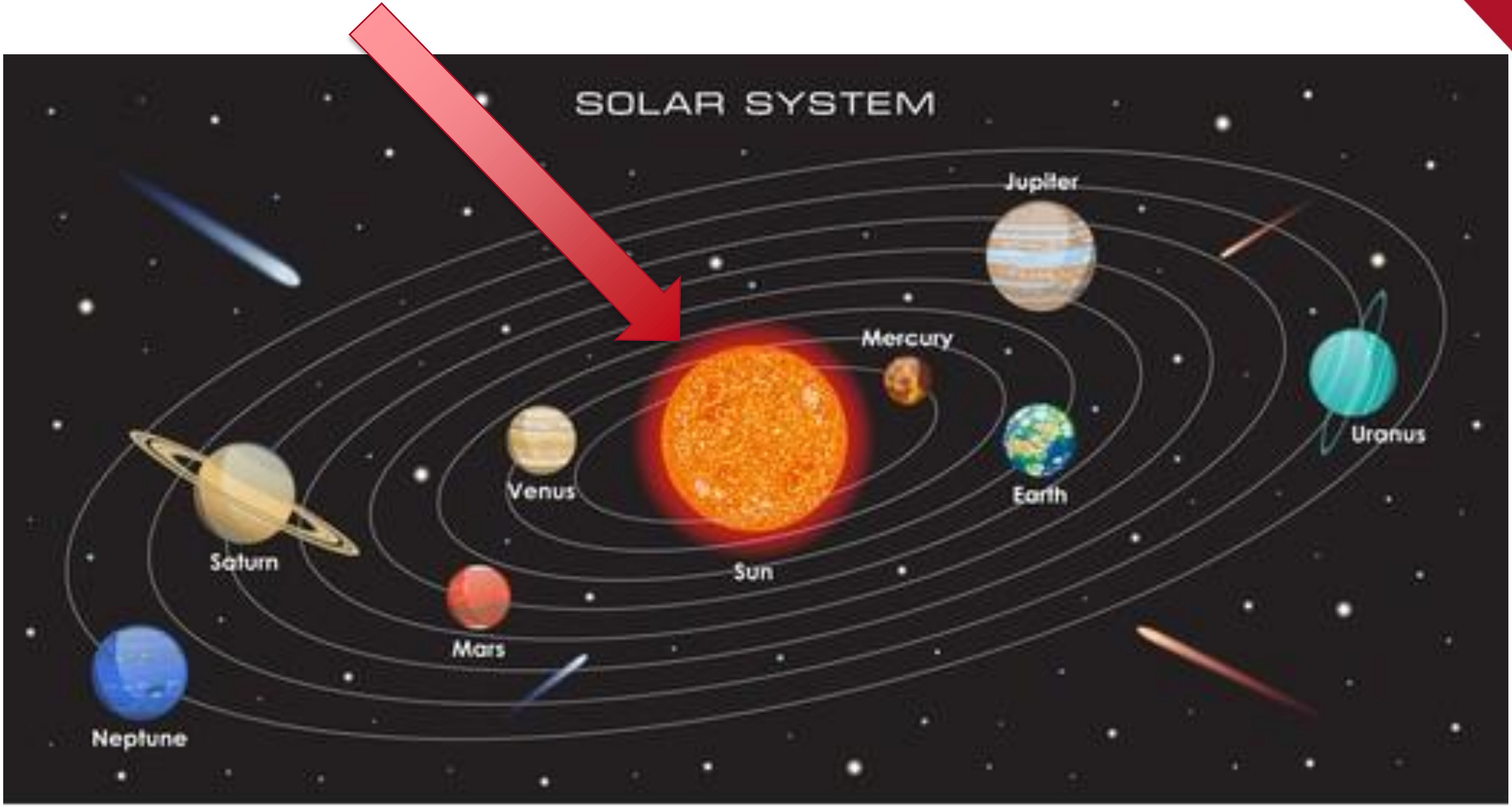
Augmentative and Alternative Communication (AAC)



- Sign Language
- PECS Cards
- Tobii Dynavox
- ★ Apple iPad

Co-Designing Trainings to Support Effective Communication

When designing our trainings, who are we orbiting?


SOLAR SYSTEM
Jupiter
Mercury
Uranus
Venus
Earth
Saturn
Sun
Mars
Neptune

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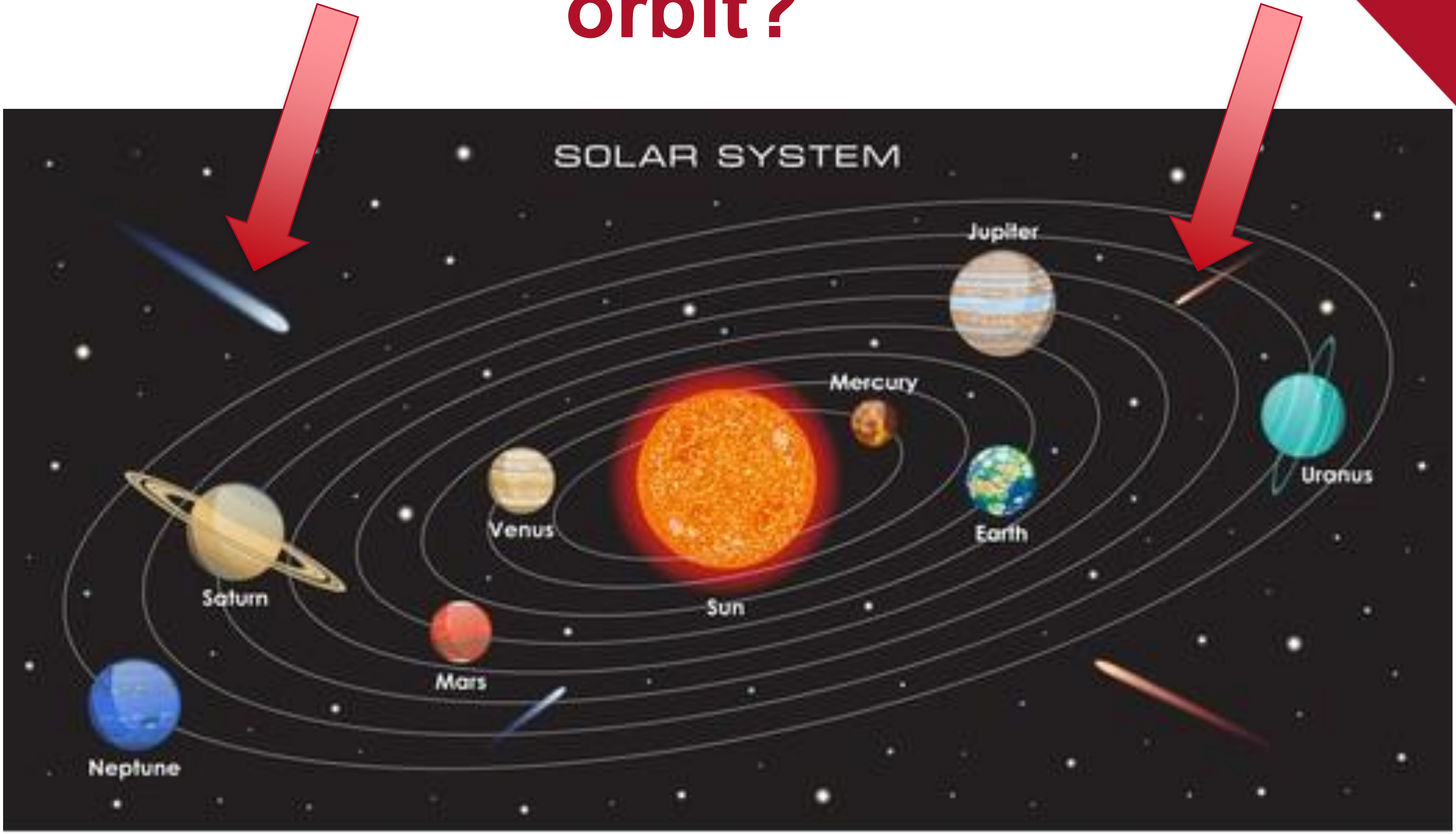
What might knock us out of orbit?


SOLAR SYSTEM
Jupiter
Mercury
Uranus
Venus
Earth
Saturn
Sun
Mars
Neptune

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Barriers that impact collaboration

- Limited cultural humility
- Differing ideas of "competence" or "expertise"
- Differences in opinion or treatment approaches
- Power differential across healthcare providers and families and individuals
- Time!!!

Effective Communication Partner Training Strategies + Evidence Based Formats + Meaningful Collaboration

= Our “defense system” ☺

AAC Communication Partner Training

1. Pretest and commitment to instructional program
2. Strategy description
3. Strategy demonstration
4. Verbal practice of strategy steps
5. Controlled practice and feedback
6. Advanced practice and feedback
7. Posttest and commitment to long-term strategy use
8. Generalization of targeted strategy use

(Kent-Walsh & McNaughton, 2005; Kent-Walsh et al., 2015)

Evidence-Based Time-Saving Techniques

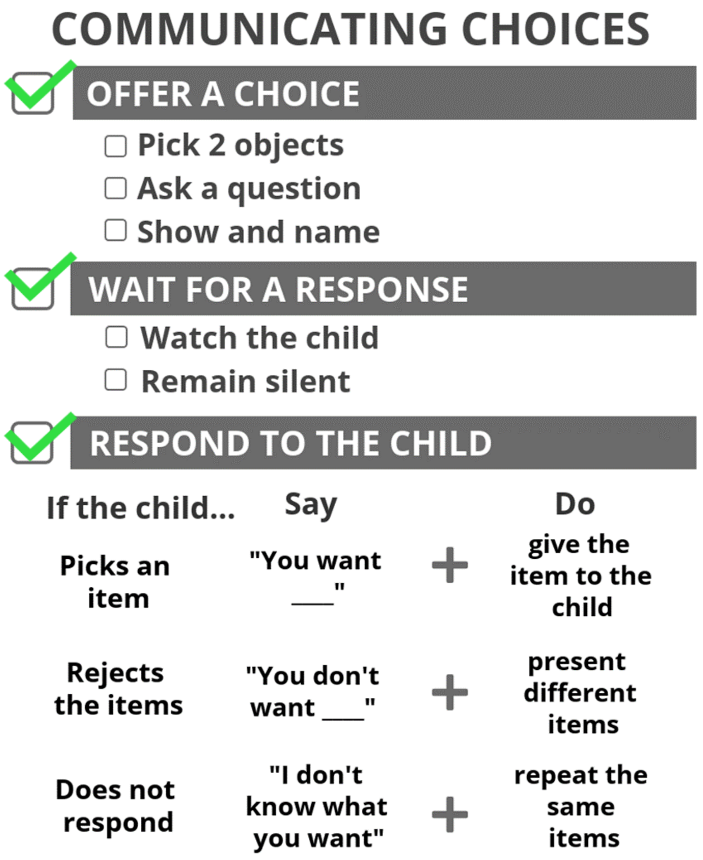
CHECKLISTS

VIDEO-MODELING

JUST-IN-TIME TRAINING FORMATS

Checklists

- Linked to reduced errors and improved adherence to practice guidelines (Hales & Pronovost, 2006)
- Presents the minimum steps necessary to complete a procedure
- Serves as a memory aid for busy healthcare providers



COMMUNICATING CHOICES

☑ **OFFER A CHOICE**

- ☐ Pick 2 objects
- ☐ Ask a question
- ☐ Show and name

☑ **WAIT FOR A RESPONSE**

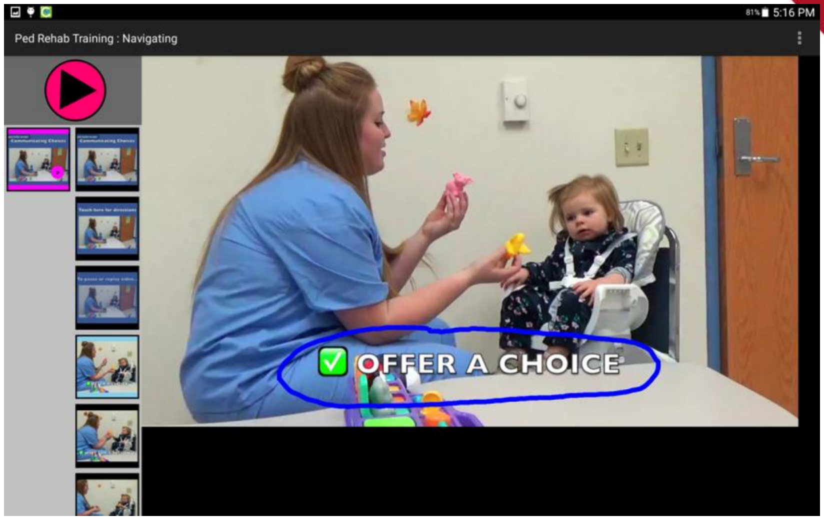
- ☐ Watch the child
- ☐ Remain silent

☑ **RESPONDING TO THE CHILD**

If the child...	Say		Do
Picks an item	"You want ___"	+	give the item to the child
Rejects the items	"You don't want ___"	+	present different items
Does not respond	"I don't know what you want"	+	repeat the same items

Video Modeling

- Demonstrates the procedure being taught using examples filmed in a real-world context (Moore & Fisher, 2007)
- Can be very short to capture and watch
- Don’t underestimate the power of seeing success!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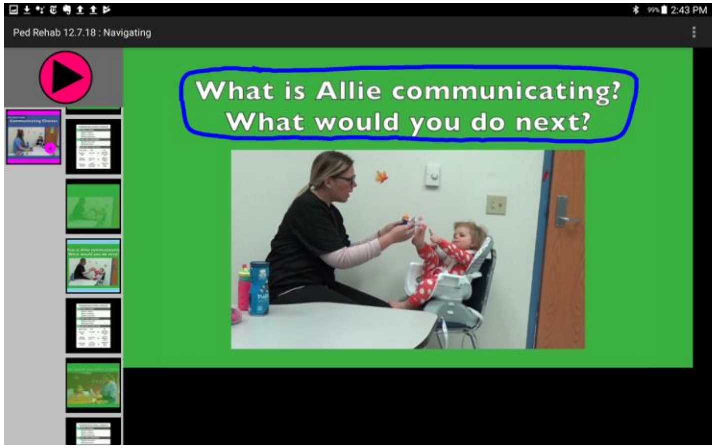
Ped Rehab Training : Navigating

✅ OFFER A CHOICE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Ped Rehab 12.7.18 : Navigating

What is Allie communicating?
What would you do next?

Just-in-time Training

(e.g., Branzetti et al. 2017; Mangum et al., 2017)

Brief	• 15-minutes in duration
Portable	• Housed on a tablet
Task-Driven	• Focused on procedural learning of a single, well-defined task (i.e., choice-making)
Multimedia Elements	• Video cases, audio narration, and text used to explain and demonstrate content
User-driven & Instructor-driven	• Instructor pre-programmed pause points & explanation • User controlled the rate of completion and navigation

Collaboration with SLPs, Nursing, and Families for AAC Implementation in Surgical Intensive Care Unit (SICU)

UNMC/Nebraska Medicine ICU Communication Project

1. Identify a common goal

Unite to solve a meaningful problem on the unit

2. Collaborate regularly

Bi-weekly 30-min meetings to discuss challenges, leverage strengths, and share progress

3. Create the toolkit

Create, print, and purchase unit-focused tools & training

4. Pilot the project

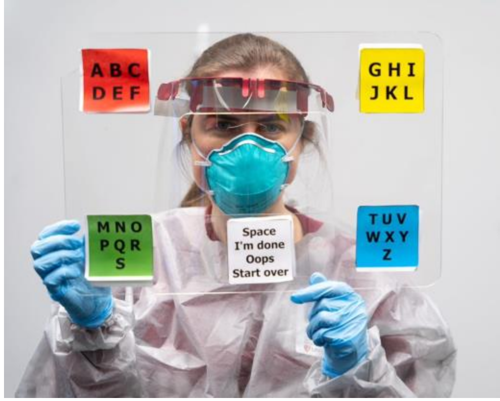
Collect data about nursing + SLP knowledge, train staff, "go live" for a set period, modify based on staff feedback

Breaking Down Barriers to AAC in Acute Care

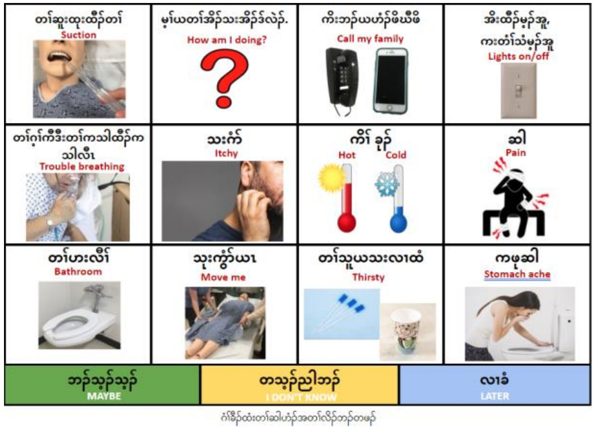
Domain	Common Inpatient Opportunity Barrier (Santiago et al., 2021)	UNMC/Nebraska Medicine Solutions
Attitudes	• Communication access is not prioritized in hospitals.	• Fostering empathy through family and patient stories • Working collaboratively with family members, people who use AAC, SLP + nursing staff to identify areas to address, learn from each other, and create solutions based on this knowledge • Biweekly meetings to maintain momentum

Domain	Common Inpatient Opportunity Barrier (Santiago et al., 2021)	UNMC/Nebraska Medicine Solutions
Knowledge & Skills	• Staff do not know about communication supports, effective communication strategies nor how to use them.	• Reviewed literature related to addressing cost savings, quality & safety, etc. • Created collaborative training related to importance and use of communication supports.

Domain	Common Inpatient Opportunity Barrier (Santiago et al., 2021)	UNMC/Nebraska Medicine Solutions
Resources	• Hospitals/units do not have access to communication supports or are not staffed with AAC/AT professionals that can help meet the needs of patients with limited motor, speech, cognitive, or diverse linguistic needs.	• Identified unit funding to create pilot communication toolkit of (mostly) low-tech communication supports. • Created unit toolkit for SICU, including bilingual supports for top 7 language spoken in the medical system. • Scaled up to all ICUs based on pilot unit feedback and suggestions, nursing staff strong advocates to make this happen.


ABC
DEF
GHI
JKL
MNO
PQR
S
TUV
WXY
Z
Space
I'm done
Oops
Start over

E-tran Board

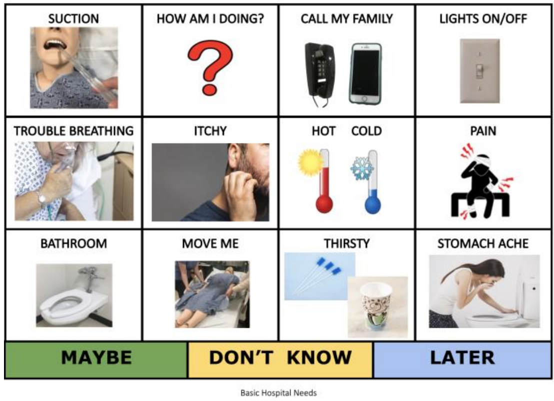


တၢ်ဆူးထုးထီၣ်တၢ် Suction	မ့ၢ်ယတၢ်အိၣ်သးအိၣ်ဒ်လဲၣ်. How am I doing?	ကိးဘၣ်ယဟံၣ်ဖိဃီဖိ Call my family	အိးထီၣ်မ့ၣ်အူ, ကးတံၢ်သံမ့ၣ်အူ Lights on/off
တၢ်ဂ့ၢ်ကီဒီးတၢ်ကသါထီၣ်ကသါလီၤ Trouble breathing	သးကံၢ် Itchy	ကိၢ် ခုၣ် Hot Cold	ဆါ Pain
တၢ်ဟးလီၢ် Bathroom	သုးကွံာ်ယၤ Move me	တၢ်သူယသးလၢထံ Thirsty	ကဖုဆါ Stomach ache

ဘၣ်သ့ၣ်သ့ၣ် MAYBE	တသ့ၣ်ညါဘၣ် I DON'T KNOW	လၢခံ LATER

ဂံၢ်ခီၣ်ထံးတၢ်ဆါဟံၣ်အတၢ်လိၣ်ဘၣ်တဖၣ်

Bilingual Communication Boards



SUCTION	HOW AM I DOING?	CALL MY FAMILY	LIGHTS ON/OFF
TROUBLE BREATHING	ITCHY	HOT COLD	PAIN
BATHROOM	MOVE ME	THIRSTY	STOMACH ACHE

MAYBE	DON'T KNOW	LATER

Basic Hospital Needs

English Communication Boards

WHITE BOARD MARKER

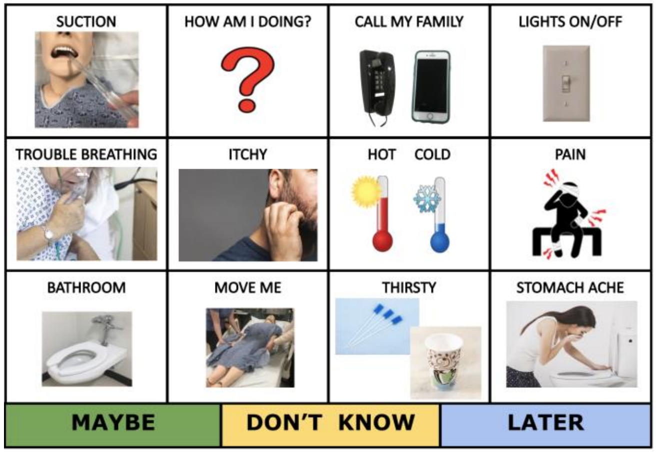
Dry Erase
Boards

Full TD Snap
App

Clear
Masks

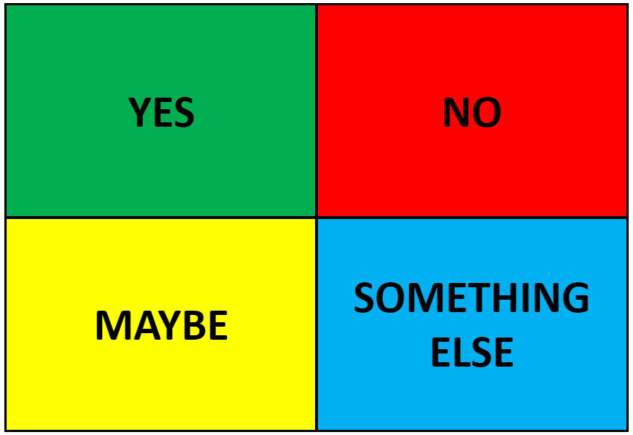
Binder Clips

Communication Boards



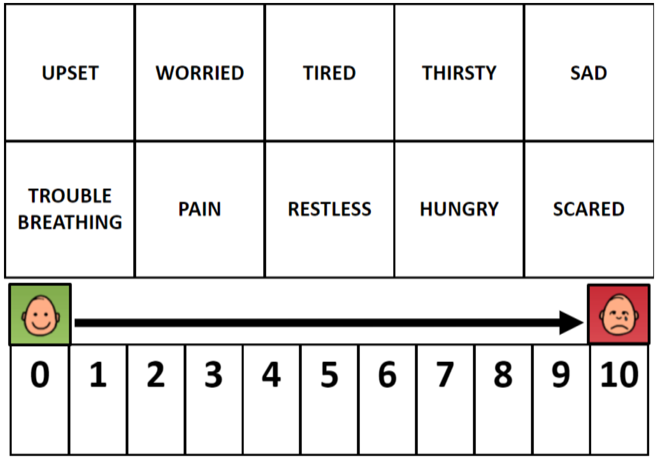
SUCTION	HOW AM I DOING?	CALL MY FAMILY	LIGHTS ON/OFF
TROUBLE BREATHING	ITCHY	HOT COLD	PAIN
BATHROOM	MOVE ME	THIRSTY	STOMACH ACHE
MAYBE	DON'T KNOW	LATER	

Basic Hospital Needs



YES	NO
MAYBE	SOMETHING ELSE

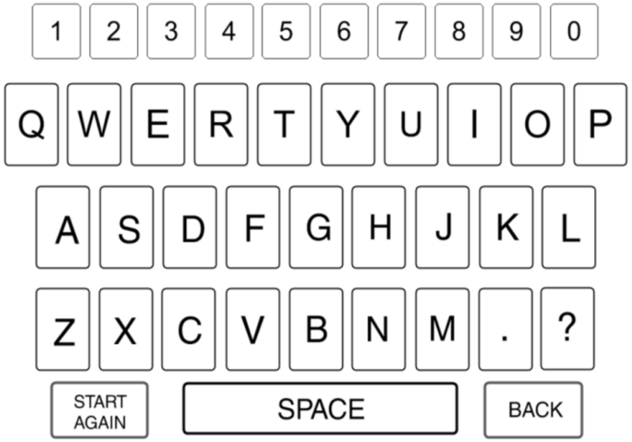
Yes/No/Maybe/Something Else



UPSET	WORRIED	TIRED	THIRSTY	SAD
TROUBLE BREATHING	PAIN	RESTLESS	HUNGRY	SCARED

0	1	2	3	4	5	6	7	8	9	10

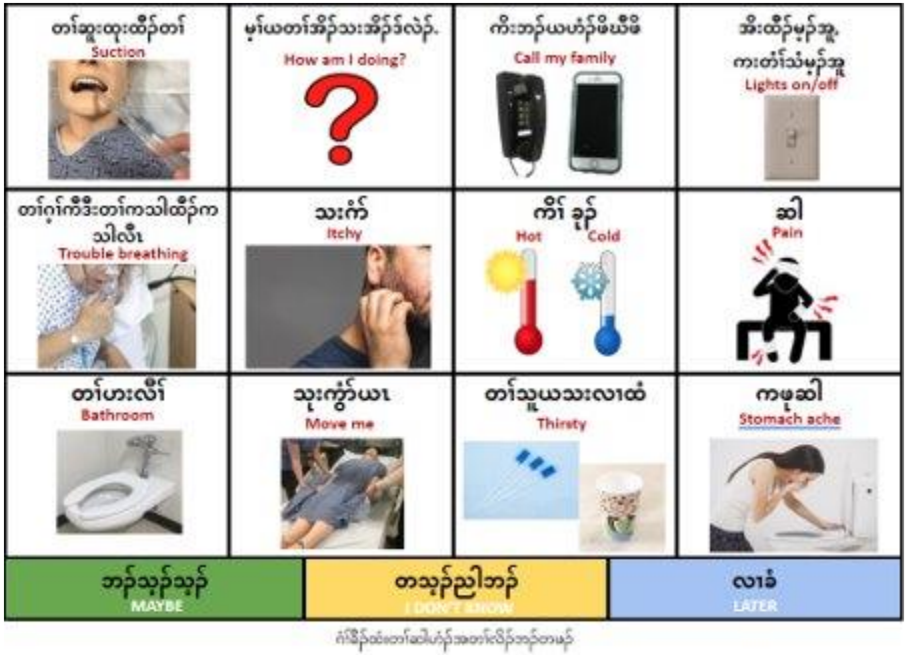
Communicating Symptoms & Feelings



1 2 3 4 5 6 7 8 9 0
Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M . ?
START AGAIN SPACE BACK

Letter Board

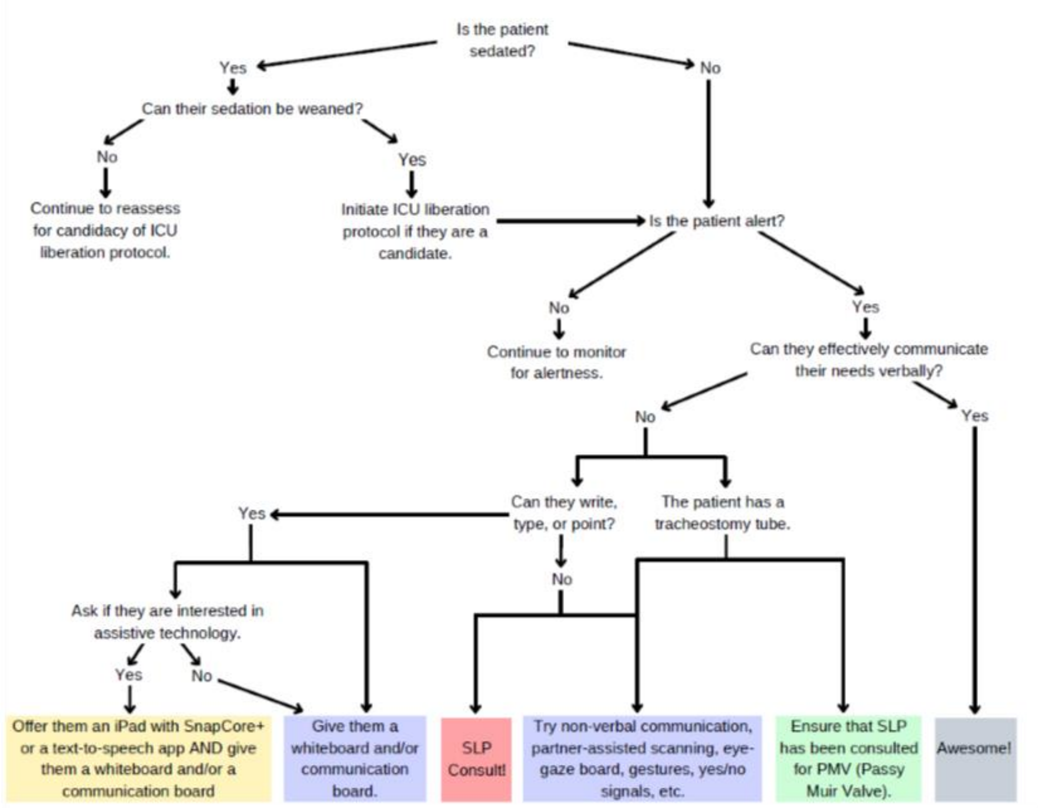
Bilingual Communication Boards


Suction
How am I doing?
Call my family
Lights on/off
Trouble breathing
Itchy
Hot
Cold
Pain
Bathroom
Move me
Thirsty
Stomach ache
MAYBE
I DON'T KNOW
LATER

- Spanish
- Arabic
- Karen
- Nepali
- Somali
- Burmese
- Vietnamese

Domain	Common Inpatient Opportunity Barrier (Santiago et al., 2021)	UNMC/Nebraska Medicine Solutions
Practice	• Staff do not know when or how to use the communication supports. • Tools are available on units but are not used. • AAC referrals are not routinely made.	• We did not stop at the "tool" phase – created a companion training and decision tree, including training videos. • Training to be incorporated into orientation, mandatory education on the unit, etc. • **In process of evaluating “just-in-time” trainings through research partnership with RERC on AAC to optimize clinical practice.

Communication Decision Tree for ICU


Is the patient sedated?

Yes

Can their sedation be weaned?

No

Continue to reassess for candidacy of ICU liberation protocol.

Yes

Initiate ICU liberation protocol if they are a candidate.

No

Is the patient alert?

No

Continue to monitor for alertness.

Yes

Can they effectively communicate their needs verbally?

No

Can they write, type, or point?

The patient has a tracheostomy tube.

Yes

Ask if they are interested in assistive technology.

Yes

No

No

Yes

Offer them an iPad with SnapCore+ or a text-to-speech app AND give them a whiteboard and/or a communication board

Give them a whiteboard and/or communication board.

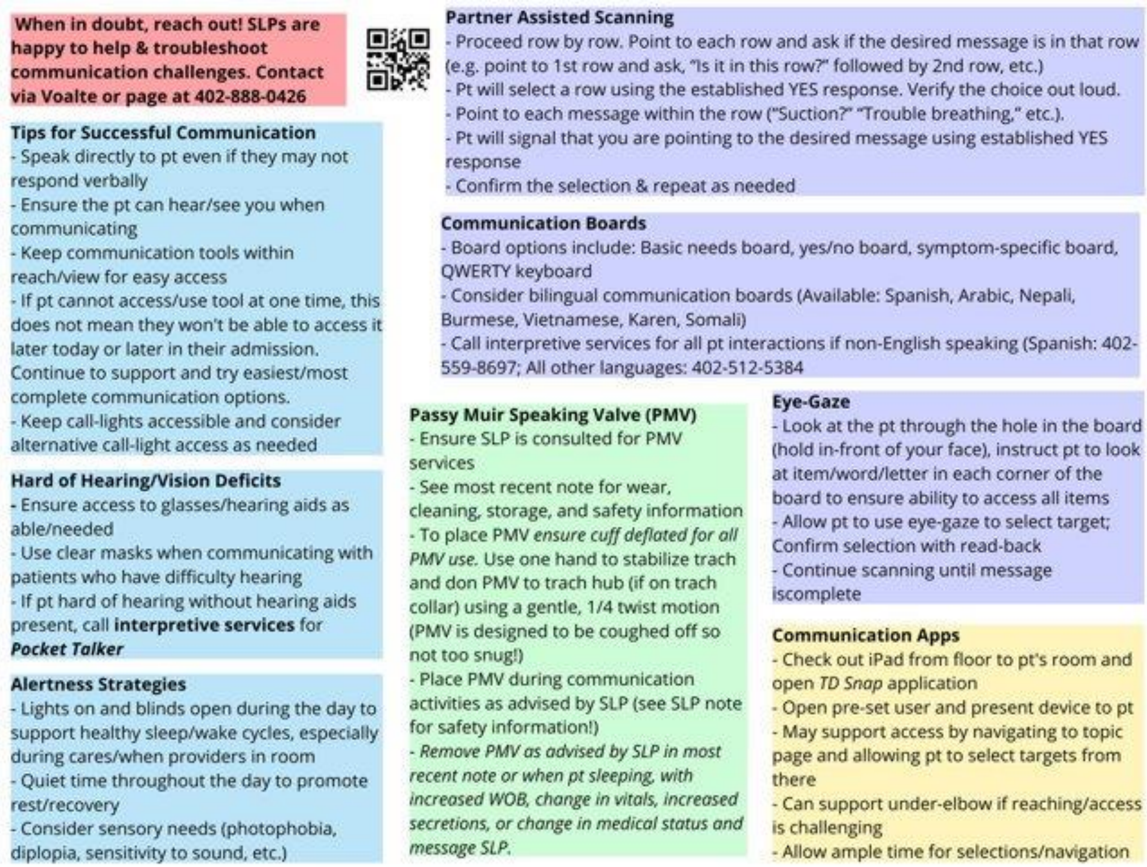
SLP Consult!

Try non-verbal communication, partner-assisted scanning, eye-gaze board, gestures, yes/no signals, etc.

Ensure that SLP has been consulted for PMV (Passy Muir Valve).

Awesome!

Communication Decision Tree for ICU



When in doubt, reach out! SLPs are happy to help & troubleshoot communication challenges. Contact via Voalte or page at 402-888-0426

Tips for Successful Communication

- Speak directly to pt even if they may not respond verbally
- Ensure the pt can hear/see you when communicating
- Keep communication tools within reach/view for easy access
- If pt cannot access/use tool at one time, this does not mean they won't be able to access it later today or later in their admission. Continue to support and try easiest/most complete communication options.
- Keep call-lights accessible and consider alternative call-light access as needed

Hard of Hearing/Vision Deficits

- Ensure access to glasses/hearing aids as able/needed
- Use clear masks when communicating with patients who have difficulty hearing
- If pt hard of hearing without hearing aids present, call **interpretive services** for ***Pocket Talker***

Alertness Strategies

- Lights on and blinds open during the day to support healthy sleep/wake cycles, especially during cares/when providers in room
- Quiet time throughout the day to promote rest/recovery
- Consider sensory needs (photophobia, diplopia, sensitivity to sound, etc.)

Partner Assisted Scanning

- Proceed row by row. Point to each row and ask if the desired message is in that row (e.g. point to 1st row and ask, "Is it in this row?" followed by 2nd row, etc.)
- Pt will select a row using the established YES response. Verify the choice out loud.
- Point to each message within the row ("Suction?" "Trouble breathing," etc.).
- Pt will signal that you are pointing to the desired message using established YES response
- Confirm the selection & repeat as needed

Communication Boards

- Board options include: Basic needs board, yes/no board, symptom-specific board, QWERTY keyboard
- Consider bilingual communication boards (Available: Spanish, Arabic, Nepali, Burmese, Vietnamese, Karen, Somali)
- Call interpretive services for all pt interactions if non-English speaking (Spanish: 402-559-8697; All other languages: 402-512-5384

Passy Muir Speaking Valve (PMV)

- Ensure SLP is consulted for PMV services
- See most recent note for wear, cleaning, storage, and safety information
- To place PMV *ensure cuff deflated for all PMV use.* Use one hand to stabilize trach and don PMV to trach hub (if on trach collar) using a gentle, 1/4 twist motion (PMV is designed to be coughed off so not too snug!)
- Place PMV during communication activities as advised by SLP (see SLP note for safety information!)
- *Remove PMV as advised by SLP in most recent note or when pt sleeping, with increased WOB, change in vitals, increased secretions, or change in medical status and message SLP.*

Eye-Gaze

- Look at the pt through the hole in the board (hold in-front of your face), instruct pt to look at item/word/letter in each corner of the board to ensure ability to access all items
- Allow pt to use eye-gaze to select target; Confirm selection with read-back
- Continue scanning until message iscomplete

Communication Apps

- Check out iPad from floor to pt's room and open *TD Snap* application
- Open pre-set user and present device to pt
- May support access by navigating to topic page and allowing pt to select targets from there
- Can support under-elbow if reaching/access is challenging
- Allow ample time for selections/navigation

Domain	Common Inpatient Opportunity Barrier (Santiago et al., 2021)	UNMC/Nebraska Medicine Solutions
Environment	• Strict infection control policies. • Patients interact with many people and in different units. • Dense presence of medical equipment at bedside.	• Identified practical storage and cleaning solutions. • Instructions are kept with the tools and freely available online.

Collaboration Tip: ASK!!

Pre-Pilot Survey

91% of nurses and CNAs reported having difficulty communicating with patients

28% of nurses, CNAs, and SLPs reported participating in formal training related to communicating with patients

86% of nurses, CNAs, and SLPs knew where to locate communication tools on the unit

Post-Pilot Survey

97% of nursing staff knew where to locate communication tools on the unit

51% of nursing staff reported they had consulted with speech therapy to help patients communicate in the past year

- Of those who had worked with speech, 93% reported that it was helpful

74% of nursing staff reported that they knew how and when to initiate the process to consult with speech

Next Steps…

- Expanding toolkits to other units
- Implementing nurse training videos to new staff and adding to annual in-services
- Weekly “Communication Check-Ins”

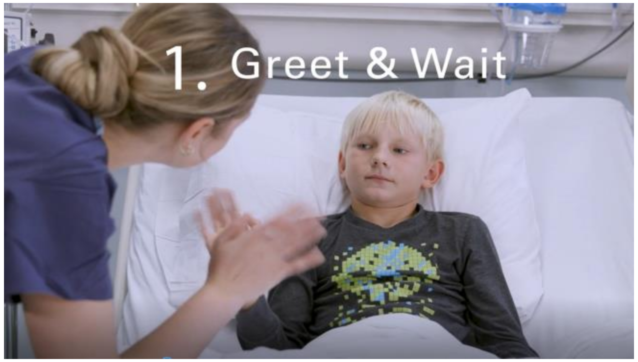
Unit	Toolkits Available	Communication "Check-Ins"
Surgical ICU	✓	✓
Cardiovascular ICU	✓	✓
Medical ICU	✓	
COVID ICU	✓	
Neurosurgical ICU	✓	
Werner (Cancer) ICU	✓	✓
Step-Down Critical Care	✓	
Bellevue ICU	✓	
Pediatric ICU	✓	
Neurology Unit		

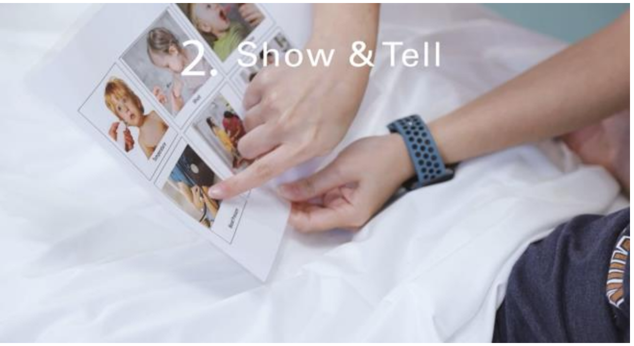
Creating Communication Opportunities for Children in the Hospital

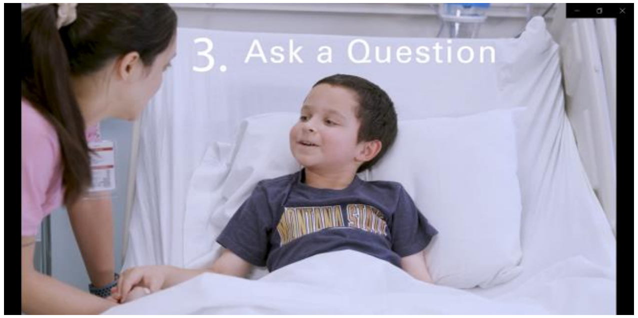
Information about the project

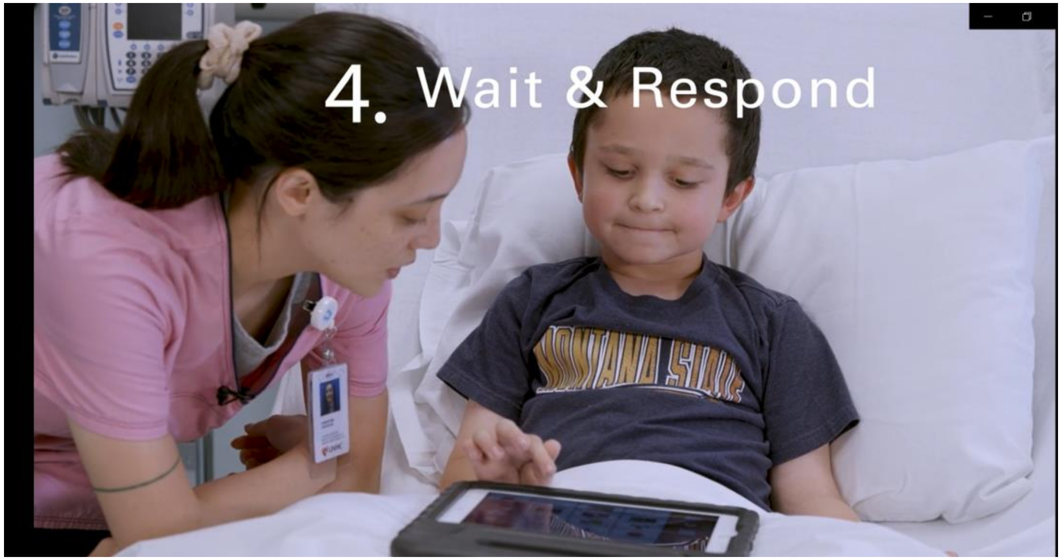
- Collaborative project involving multiple perspectives
- Open dialogue with feedback encouraged
- Consideration of hospital experiences
- Training that can be immediately implemented
- Next steps: Parent training
- Unintended benefits: Additional requests for parent/child representation in training materials

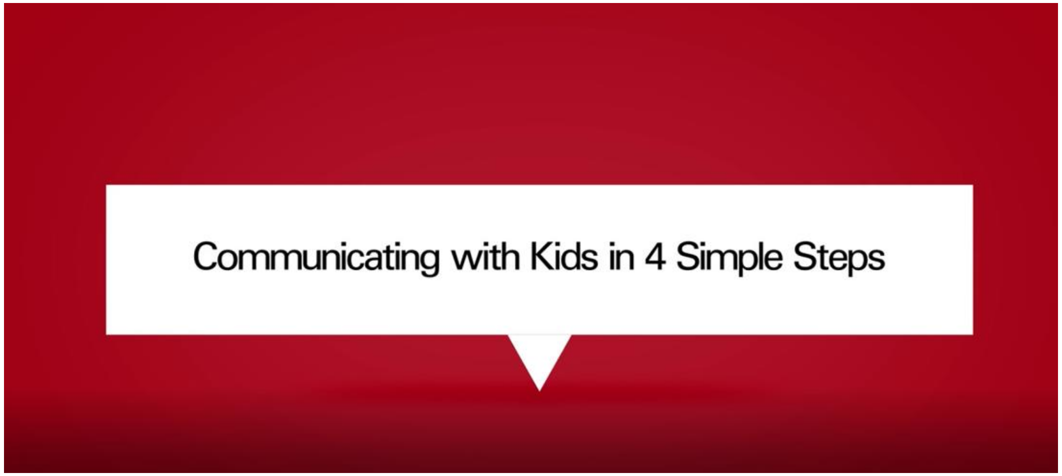
Examples


1. Greet & Wait


2. Show & Tell


3. Ask a Question


4. Wait & Respond


Communicating with Kids in 4 Simple Steps

Learning How to Effectively Use Augmentative and Alternative Communication (AAC) with Your Child

Stacey Carnazzo, LEND Family Trainee
Brittany Steinfeld, MS, CCC-SLP

Current Problem and Potential Solution

- Lack of understanding and guidance for parents to learn how to communicate using an AAC device with their child.
- Need for resources parents can easily access that can help support their skills in the home setting.
- Solution - Create brief, easily accessible AAC trainings that are reflective of both SLP and parent training priorities

Settings/Participants

- Survey: 10 SLPs, 10 parents who completed AAC training in the past
- Intervention:
  - Research will take place in outpatient clinic environment
  - 40 parents and their children who utilize limited speech who have never received parent training regarding AAC.

Identifying Training Topics

Strategies

Modeling	Providing Choices
Providing Praise	Prompting
Appropriate Vocab	Meaningful Contexts
Pausing	Communicative Temptations
Expansions	Recasts
Extension	Shared Reading
Keeping system close	Other

Strategy	Parent Response	SLP Response
Modeling	9	9
Providing Choices	6	2
Providing Praise	5	0
Prompting	7	5
Appropriate Vocab	2	6
Meaningful Contexts	5	9
Pausing	3	2
Communicative Temptations	1	5
Expansions	2	2
Recasts	1	0
Extensions	4	0
Shared Reading	1	4
Keeping System Close	7	6
Other	1	0

Creating Training Videos

- Recruited participants (children and their parents who use AAC)
- Recorded naturalistic interactions between child, parent, and SLP.
- Analyzed and coded all videos according to the AAC techniques outlined in the survey

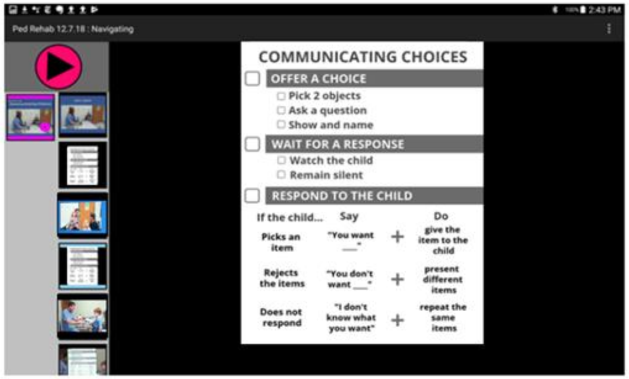
RERC on AAC

Rehabilitation Engineering Research Center on AAC

- The RERC on AAC is a collaborative center committed to advancing knowledge and producing innovative engineering solutions in augmentative and alternative communication (AAC).
    - Penn State University
    - Koester Performance Research
    - Madonna Rehabilitation Hospitals
- 3 research and 3 development projects focused on AAC
- https://rerc-aac.psu.edu/

D3: mTraining in AAC for Communication Partners

- Challenge
  - Communication partners are often unfamiliar & untrained in AAC.
  - Current approaches to partner training are often *inefficient*, *ineffective*, *not personalized*, and *limited in scope & reach*.
- Solution
  - Develop a user-friendly app to create partner mTrainings that can be deployed “just in time” to teach partners AAC strategies. The app will include step-by-step instructions and video demonstrations of each step.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Ped Rehab 12.7.18 : Navigating

COMMUNICATING CHOICES

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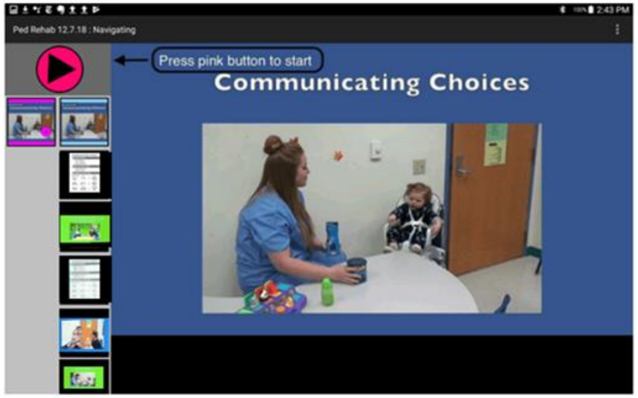
  - ☐ Show and name

☐ **WAIT FOR A RESPONSE**
  - ☐ Watch the child
  - ☐ Remain silent

☐ **RESPONSE TO THE CHILD**

If the child...	Say		Do
Picks an item	"You want __"	+	give the item to the child
Rejects the items	"You don't want __"	+	present different items
Does not respond	"I don't know what you want"	+	repeat the same items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Ped Rehab 12.7.18 : Navigating
Press pink button to start
Communicating Choices

Components to mTraining App

- Utilizes checklist of procedural steps
- Video models of each step
- Library of "generic" trainings freely available
- Ability to efficiently develop "personalized" trainings

We would love to hear from you!

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References

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