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### **Financial Disclosures**

I am an employee of Lingraphica and thereby receive financial compensation from the Lingraphica Company.

MSHA is providing me with an honorarium and covering my travel expenses.

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## **Learning Objectives**

- Define difficult conversations
- Identify the SLP's role in facilitating difficult conversations
- Identify two factors that increase risk of abuse for AAC users
- Discuss two scenarios where AAC was successfully utilized to facilitate a difficult conversation

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## Agenda

- Client Profiles
- Defining Difficult Conversations and the SLPs Role
- Tips for Difficult Conversations
- Use Your Resources
- Special Topics
- Case Studies
- Q&A

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## **Client Profiles**

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My client is 23 and gay. He really wants to be in a relationship and wants the words to meet and connect with others easily accessible on his AAC device.

My client wants pick up lines programmed into his device so that he can talk to women at bars.

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Mr. Smith misses being intimate with his wife since his stroke.

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My client has a court hearing coming up for a domestic violence case and needs to use her device to communicate.

My client's wife keeps bringing up a topic my client is clearly sensitive about, but he doesn't have the words to tell her how he feels.

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# Defining Difficult Conversations and the SLPs' Role

## What is a "Difficult Conversation?"

Difficult conversations are anything an individual finds hard to talk about.

#### Any topic that makes us:

- Feel vulnerable
- Implicates our self-esteem
- Has uncertain outcomes
- Care deeply

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Stone et al, 2010

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## **Topics May Include:**

- End-of-life
- Relationships
- Intimacy
- Legal
- Abuse/Neglect
- Hygiene
- Medical procedures
   Transitions

- Conflict
- · Religious beliefs
- · Racial disparities
- Housing insecurity
- · Disability rights
- Inclusion



#### Time to Share!



- Share some examples of difficult conversations you've had in your life or with clients
  - Raise your hand or text confidentially to (732)743-8847

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## **ASHA Scope of Practice**

"The role of the SLP in the counseling process includes interactions related to emotional reactions, thoughts, feelings, and behaviors that result from living with the communication disorder, feeding and swallowing disorder, or related disorders."

- · Two of the activities listed:
  - provide support and/or peer-to-peer groups for individuals with disorders and their families
  - provide individuals and families with skills that enable them to become self-advocates

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ASHA, 2016

## **Communication Bill of Rights**

#### **Fundamental communication rights:**

- Interact socially, maintain closeness, and build relationships
- Make comments/share opinions
- Express personal preferences/feelings
- Request/reject desired objects, actions, events, or choices
- Make choices from meaningful alternatives
- Access interventions/supports that improve communication
- Have access to functioning AAC/other AT services and devices at all times



Brady et al, 2016

19

## **World Health Organization**



Assistive technology:

 Enables people to live healthy, productive, independent, and dignified lives

Without assistive technology:

Exclusion and isolation



World Health Organization, 2018

## **Types of AAC**



No Tech



Light Tech



High Tech

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## **No Tech Communication**



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- Gestures
- Facial expressions and body language
- Establish if there is a reliable Y/N response
  - Head nod/shake
  - Thumbs up/Thumbs down
- Ask yes/no questions
- Description of a word or use of synonym

## **Light Tech Communication**

- Communication Boards
  - Topic boards, Alphabet boards, Rating Scales, Pain Scales, Y/N boards
- Pen and Paper
- Key Word Writing
- Pictures
- Interest Inventory
- Communication books





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## **High Tech Communication**



- Apps
- Dedicated Speech Generating Devices

## **Tips for Difficult Conversations**

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# How do medical providers make a conversation more difficult?

#### What is a "Difficult Conversation"?

Those in which the provider displays a lack of:

- Knowledge
- Confidence
- Skill
- Comfort to adequately address particular topics with clients

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Wilcox et al, 2019

# AAC users surveyed on experiences communicating with medical providers

- Almost ALL participants described feeling that their physicians were rushed/they didn't have enough time to communicate.
  - Resulted in insufficient discussion of their concerns and guestions.
- EVERY participant reported experiences of physicians and other providers making inappropriate assumptions about them, typically about their cognitive abilities.
- Caregivers often spoken to first
  - Some physicians seemed to prefer talking with the caregiver
  - Negative impact on patient-provider relationship and building rapport
- Several participants reported physician moving on to a different topic before they had finished composing their message

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Morris et al, 2013

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# Perspectives from verbal communicators: Veterans and service members

#### Importance of Provider Communication

- Majority of service members who acknowledge a mental health problem are not interested in receiving professional help due to:
  - · Poor patient-provider communication
  - Lack of Trust
  - Embarrassment
- Female Veterans who have experienced military sexual trauma or intimate partner violence often don't seek treatment due to providers not being well-versed in trauma-sensitive communication



Wilcox et al, 2019

## **Models for Difficult Conversations**

**ABCDE** 

**SPIKES** 

**NURSE** 

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## **ABCDE Model**

- Advance Preparation
- Build Therapeutic Relationship
- Communicate Well
- Deal with Patient and Family Reactions
- Encourage/Validate Emotions

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Vaynshtok, 2019

## **SPIKES Model**

- Setup
- Perception
- Invitation
- Knowledge
- Empathy
- Summary and Strategy

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Svarovsky, 2013

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## **NURSE Model**

- Naming
- Understanding
- Respecting
- Supporting
- Exploring

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Svarovsky, 2013

## **Ask for Permission**

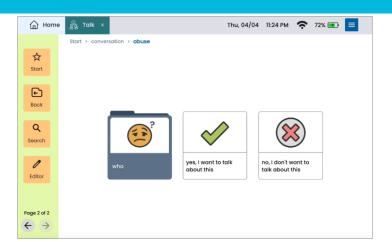


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## **Permission**



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# Recognize When You Are Not the Right Person For the Job.

If the topic makes you uncomfortable, you could still be the right person for the job.

If YOU bringing up the topic would make THEM uncomfortable, you may not be the right person for the job.



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## **Tips**

- Give your client an easy way in bring up issues they may be having
  - Takes stigma off
  - Allows for more reflection from client
- Pause frequently
- · Continuously seek consent

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## **Tips**

- Make and break eye contact
- Practice your judgement free face
- Read up on a diversity of topics, especially those not aligned with your lifestyle/interests
- Be confident this will make your client more comfortable
- Have fun getting to know your client better

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## **Silence**

- "Some of the most valuable lessons, thoughts and ideas have come from...moments of silence that have led to important and powerful conversations with patients and family members"
  - Jody Vaynshtok MS CCC-SLP

- "Silence can be enriching, comforting, affirming, and safe. Silence can also be used to allow the patient and the clinician time for understanding and mutual respect"
  - Back et al

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Vaynshtok, 2019; Back et al, 2009

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#### **Considerations for AAC users**

- Collaborative treatment and programming
- Providing choices can increase expression and discussion of feelings
- Closely observe their reactions and responses for opportunities for
  - Elaboration
  - Personalized statements
  - Triggers

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#### **AAC Best Practices**

#### Instead of this:

- Too many conversational turns
- Only yes/no questions
- Few opportunities for initiation/response
- Interrupting
- Focus on technology

#### Do this:

- · Set the environment
- · Allow time
- Confirm understanding
- Create "shared communication spaces"
- Honesty about communication breakdowns

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Beukelman et al, 2013

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The most important quality in a communication partner is to be personcentered. A good communication partner takes the time to find out the preferences of the AAC user themselves.



Assistiveware, 2024

## Strategies recommended by AAC Users

- Respect the effort
- Be patient and wait as long as necessary for response
- · Manage noise and physical space
- · Watch the person, not the device
- · Pay attention to the message and other cues
- · Don't dominate the conversation
- · Respect AAC user's voice
- · Ask before looking or touching
- · Accept that communication is on the AAC user's terms

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Assistiveware, 2024

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## **Teaching Persistence**

- Presume competence
- Be persistent when breakdowns occur
- Decide together if it's time to move on



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## **Emotional Expression and AAC Use**

- Express emotions
- Limitations of expressing emotions with SGD due to decreased inflection/tone
- Strategy use in emotionally charged situations
- · Access to emotion words
- · Role playing for situations that involve emotion
- "Encourage emotion talk in natural settings"

Blackstone 2010



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## **Necessary vocabulary**

## Adult AAC users identified the need for devices to contain vocabulary relating to:

| Employment                           | College                       | Sexuality                  | Reporting crime or abuse   |
|--------------------------------------|-------------------------------|----------------------------|--|
| Managing personal assistant services | Managing one's<br>health care | Managing<br>transportation | Communicating in times<br>of man-made and<br>natural emergencies |



Bryen et al, 2018

## **Use Scripting Sequences**



Create connection and validation:

- · Elicit opinions
- · Promote decision making
- Encourage venting
- Create opportunities to have tough conversations
- Initiate role play and positive practice within the treatment room

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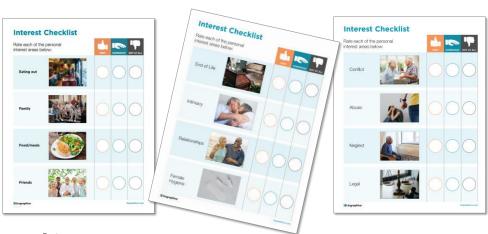
Difficult conversations won't always feel uncomfortable because with practice your comfort zone will expand.

## **Use Your Resources**

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## Interest Inventory



## **Mental Health Communication Board**



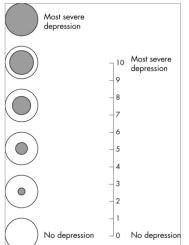




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## **Depression Intensity Scale Circles**



The Numbered Graphic Rating Scale (NGRS) and the Depression Intensity Scale Circles (DISCs) are displayed on separate laminated cards.

L Turner-Stokes et al. J Neurol Neurosurg Psychiatry

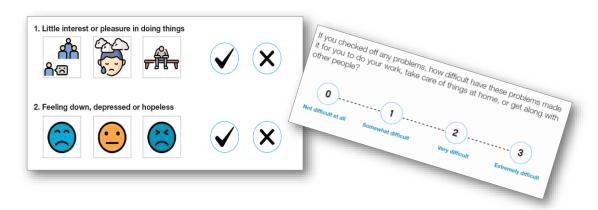
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INNP

2005;76:1273-1278

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## **Personal Health Questionnaire**



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(Kroenke et al, 2001)

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## **Special Topics**

## **Intimacy and Health**

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## Communication Disorders can lead to...

- Reduced...
  - access to sex ed curriculum (Pugliese et al, 2020)
  - relationship and sexual satisfaction (Ford et al, 2018; Byers et al, 2013)
- Difficulty finding romantic partners (Kearney et al, 2020)
- Loss of intimacy (Kitzmüller & Ervik, 2015)
- Divorce (Trygged et al, 2011)

## **Insights from AAC Users**

- 88% of participants in the Speak Up Project reported "no means" for communication about healthy sexuality & related topics
- In a study of adult AAC users most participants reported no opportunity to discuss healthy sexuality at all
- · AAC underequipped when it comes to
  - Sex
- Genitals
- Sexuality
- Sexual/Reproductive
- Gender

Healthcare

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Collier et al, 2006; Denome, 2020

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#### **Ableism and Infantilization**

- Medical providers asking questions of caregiver rather than device user
- Staff removing words from a device they feel they aren't appropriate
- Disabled youth not taught about sex education with assumption they can't/shouldn't/won't have sex
  - Unable to learn about sex and related issues, limits safety and self advocacy



Northwest Augmentative Communication Society, 2024

## **Sex Ed Best Practices**

#### Sex education must include:

- Development of effective communication and decision-making skills
  - Assertiveness
  - Ability to say "no"
- · Ways to create satisfying relationships
- Sexuality is an integral part of being human

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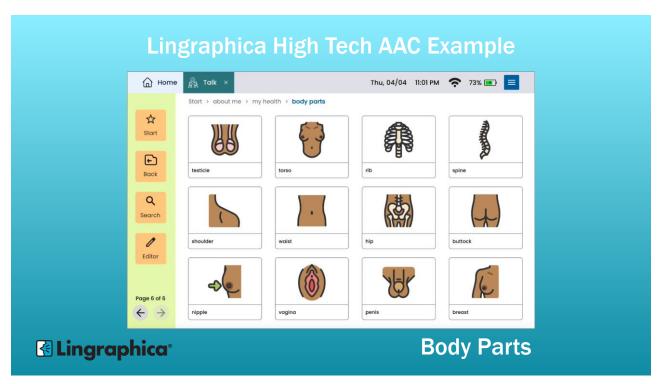
Neufield et al, 2002

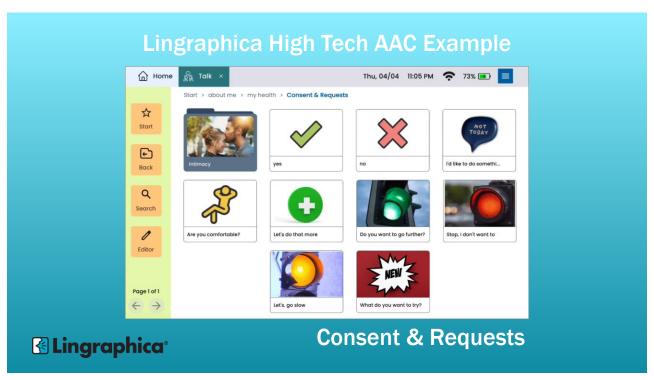
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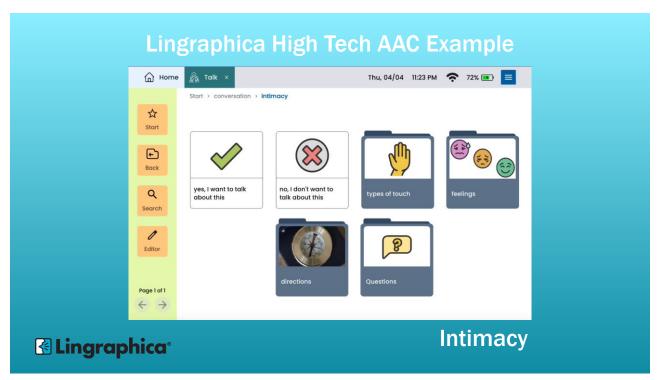
While AAC clinicians typically do not become involved in sexuality education, they often are the gatekeepers of communication tools and strategies that can be used within the context of sexual health education and communicating about sexuality, abuse, and dignity.



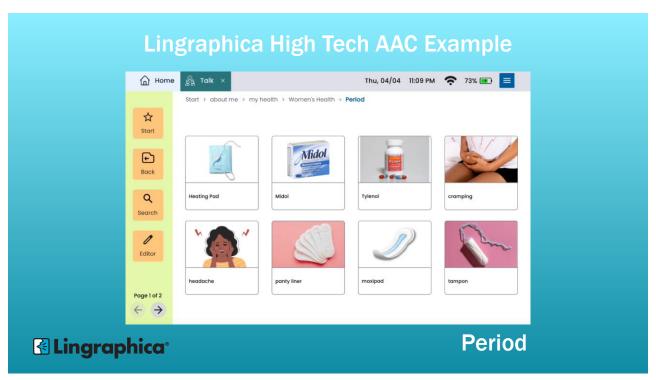
Collier et al, 2006

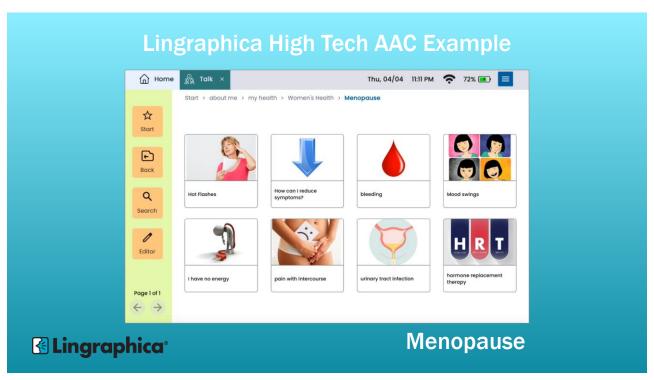


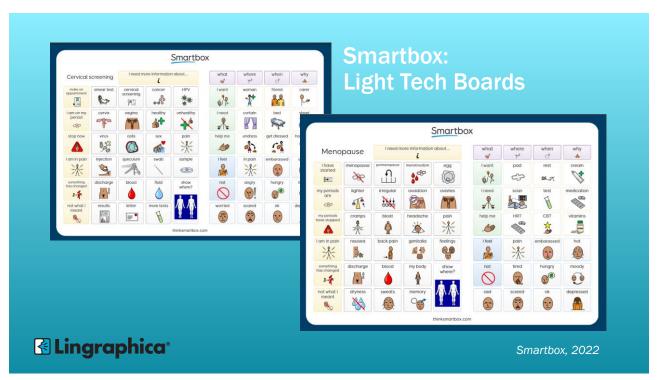












## Abuse

#### **Prevalence of Abuse**

- Disabled people are 2x as likely to be victim of a violent crime than non-disabled peers
  - Particularly those with behavioral, intellectual, and communication disabilities
- Estimated that large proportion of abuse occurs by family, peers, and service providers

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Northwest Augmentative Communication Society, 2024

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### **Prevalence of Abuse**

In study of adult AAC users:

45% experienced crime or

abuse

experienced unwanted sexual touch 22% were forced to

have sex

17%
were forced
to touch
someone
sexually

reported to police

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Bryen et al, 2003; Collier et al, 2006

### **Prevalence of Abuse**

Victims of crime who cannot communicate effectively less likely to

- Have ability to prevent or report crimes
- Access justice system and counseling services



Sullivan, 2000

71

### Reduce the risk!

- Proper names of body parts is important across the lifespan
  - Medical, hygiene, self-care needs
  - Reporting abuse
- Ensure adequate vocabulary to talk about sex and intimate relations and report such a crime or abuse
- Encourage development of strong social networks



Bryen et al, 2018

#### **Considerations**

- AAC users often need assistance adding/editing their software
- Any parent, partner, professional or other communication partner can prevent an AAC user from talking about
  - Genitalia
  - Abuse
  - Attraction
- Prevent user to cover abuse OR assume user has no need to communicate about these topics

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Denome, 2020

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#### **Vocabulary Considerations**

 By signaling that these are "adult topics" it's signaling that children and young people who are forced to confront these "adult topics" have to choose between their youth and the ability to communicate what's going on.

"We know that the best victim is one who can't tell"



Denome, 2020

#### **Abuse Victims**

- Must overcome immense:
  - Shame
  - Discomfort
  - Potential retaliation
  - Trauma response
- AAC users
  - All of the above plus communication barriers and not having access to the words they need for reporting

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Denome, 2020

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#### The SLPs Role

#### Professionals must ensure three key supports:

- Access to needed socially-valued vocabulary
- Rich social networks
- Strategies to increase personal safety and to reduce the risk of becoming a victim of a crime



Bryen et al, 2018

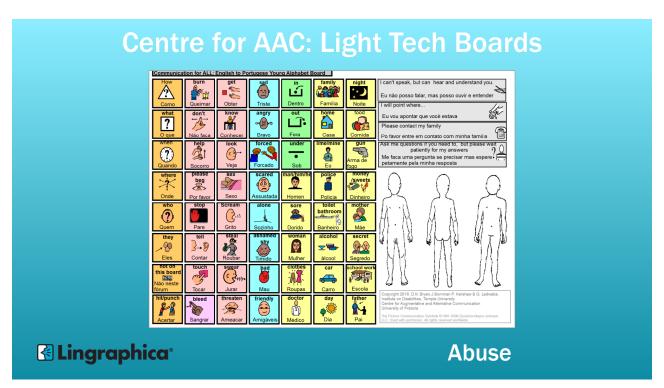
People who use AAC need communication aids with relevant and accessible vocabulary so that they can reduce the risks of being victimized; report crime and abuse when it happens and, most importantly, be believed when they do report.

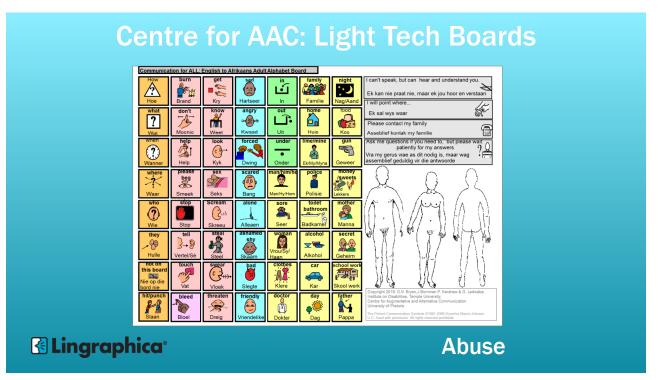
#### Lingraphica®

Bryen et al, 2003

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#### **Access to Justice System**

- Communication through AAC is not familiar to judges, attorneys, and court recorders within most courtrooms
- SLP should
  - Orient attorneys and judges prior to the trial to the use of AAC, types of vocabulary and characteristics of appropriate question techniques
  - May be responsible for requesting accommodations on behalf of the individual

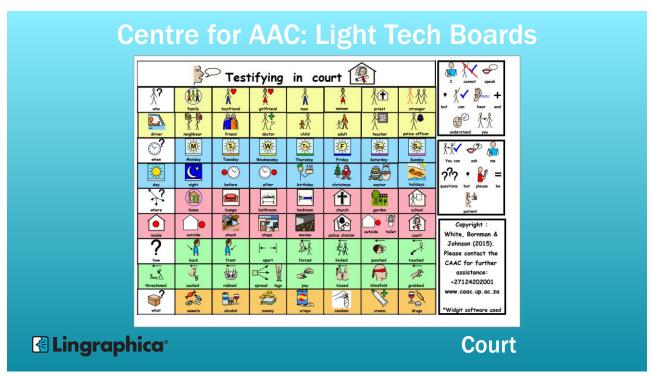
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Blake Huer et al, 2006

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#### **AAC** in the Justice System





#### Self-Advocacy

#### **Ways to Support Self-Advocacy**

#### Ensure access to appropriate vocabulary and messages reflecting the AAC User

- Words and prestored messages for protesting and rejecting, messages that allow expression of disagreement or negative opinions
  - · This is unfair
  - This doesn't work for me
  - I don't think so
  - That's disrespectful
  - · What part did you not understand?

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PrAACtical AAC, 2018

85

#### **Ways to Support Self-Advocacy**

- Proactive self-advocacy statements
  - Please do what I ask
  - I have a right to be heard
  - You are ignoring me
  - I already told you no
  - It's on my IEP
- Model It and Role Play
- Consider adding the Communication Bill of Rights

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PrAACtical AAC, 2018



have been inspired by others' medical boards full of phrases like information." I haven't yet made my own folder for medical selfadvocacy, but being around folks who are confident in standing up for themselves and communicating in whatever way works best for them has really empowered me...

endever\* corbin

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Corbin, 2021

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#### **AAC User Perspective**

#### Recommendations

- AAC users should surround themselves with strong selfadvocates
- Providers and caregivers should make sure the AAC user they support has every opportunity to be in community with disabled advocates who can role model what it looks like to assert their right to equal access.
- Remember that self-advocacy often starts with refusal
  - AAC user gets to say "no" however works best for them



Corbin, 2021

#### **Communication Bill of Rights**

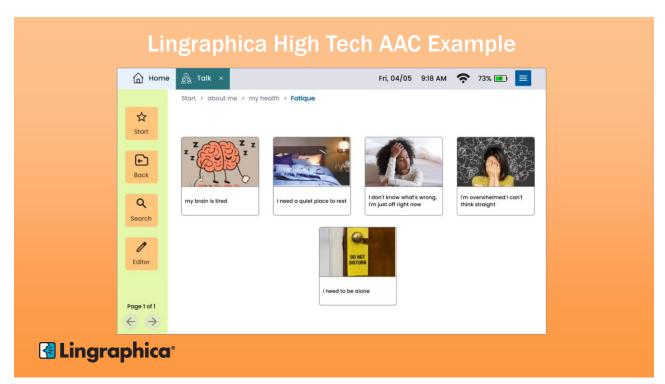


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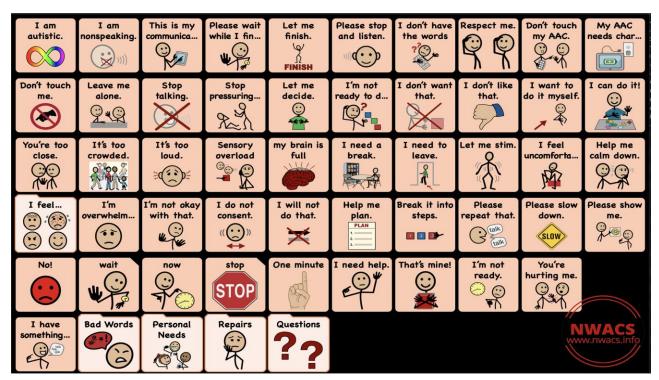
PrAACtical AAC, 2018

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## End-of-Life

#### **End-of-Life Considerations**

- Effective communication during end-of-life is crucial for health care delivery
- Misinterpretation can influence how the quality of care is rendered and perceived
- AAC assists with energy conservation and communication
- Without adequate communication options, AAC users report loss of dignity due to inability to express end-of-life wishes

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Cullen, 2021; Fried Oken, 2018

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#### **End-of-Life Topics**

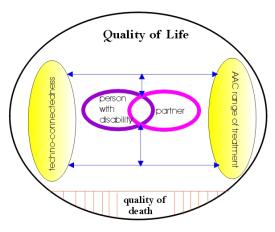
Essential topics identified by AAC users with ALS

- · details on daily care
- · health related issues addressed to providers
- quality of death
- · instructions to significant others after death
- funeral arrangements
- reminiscing



Fried Oken, 2018

#### Framework for End-of-Life Issues



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Fried Oken, 2018

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#### **Perspectives from Person with ALS**

- AAC Devices
  - Medical Necessity
  - · Provide dramatic impact on quality of life and will to live
  - · Only part of the solution
    - · Alternatives such as alphabet and communication boards are essential
    - · Need access to computer, email and Internet
      - Education
      - Entertainment
      - · Social Value

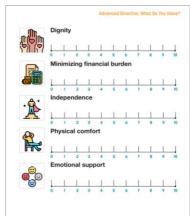


Fried Oken, 2018

#### **Advance Directive Communication**



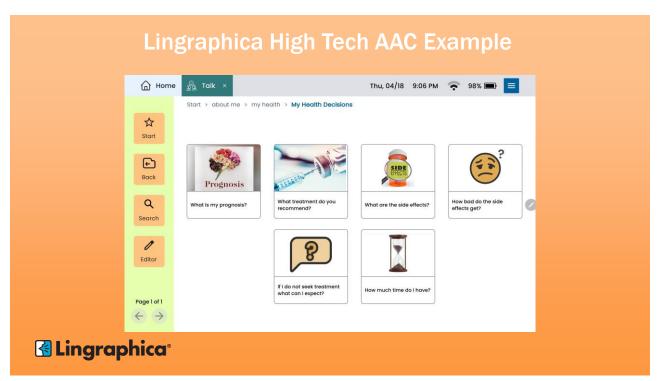




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#### Case Study 1

#### Person with Parkinson's Disease

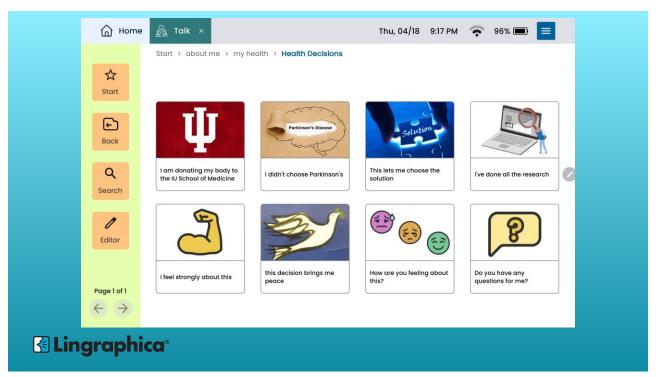
- Rapidly progressing symptoms
- Notified SLP she planned to donate her brain to science
- Had NOT discussed with physician or family
- Wanted to use AAC to communicate her wishes and prepare specifics for her funeral services

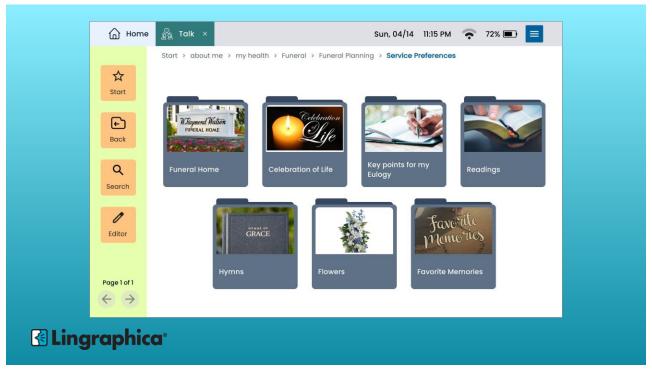
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#### **Group Discussion**

• How would you help your client communicate her wishes?





#### Case Study 2

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#### **Autistic AAC User**

- Approached by stranger on paratransit van, felt violated and uncomfortable
  - Personal space invaded
  - Stranger talked in tone appropriate for a child
  - Stranger demanded high five and pinky swear
  - Stranger responded aggressively to AAC user's attempts to back away
  - Stranger demanded better response next time they see them



Baggs, M. 2012

#### What AAC user needed to communicate

- I don't want to talk to you
- I don't want to touch you
- Don't ever make another attempt to touch me
- Don't lean towards me or get in my face
- I don't ever want to see you again

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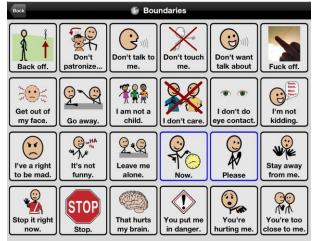
Baggs, M. 2012

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#### **Group Discussion**

- How would you help your client advocate for themselves in this situation?
- What considerations could have been made related to vocabulary on the device to give the client more control at the time of the incident?

#### **Outcome**



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Baggs, M. 2012

111

#### **Insights from AAC User**

- Advocacy page designed with intent of various levels of politeness and forcefulness
- Without this communication page she would have been trapped
- Not having this vocabulary leaves AAC users vulnerable
- "Without rehearsing, there's a big chance I'll never use a page like this" – Mel Baggs



Baggs, M. 2012

#### **Insights from AAC User**

"It is absolutely vital that people who use communication devices, have ways to respond to violation of our basic boundaries. Disabled people are far more likely than others to have others behave invasively with us, ranging from subtle to violent...and we have to have the means to say no forcefully, even rudely."

- Mel Baggs



Baggs, M. 2012

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#### Case Study 3

#### **Person with Aphasia**

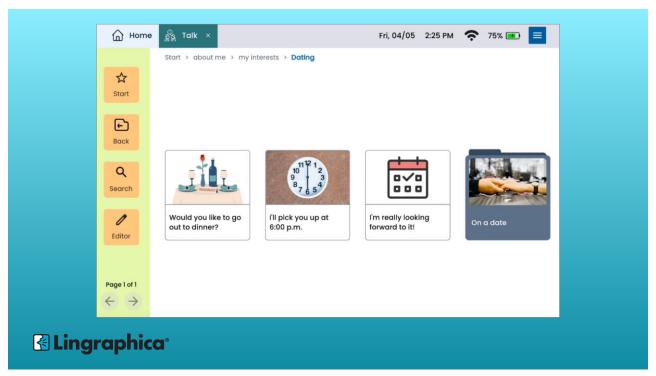
- Communication Profile:
  - 1 -2 word utterance length
  - Multimodal strategies of spelling and writing
- Collaborative goal setting discussion:
  - Language for dating and navigating relationships
  - Quick access to longer phrases
  - Benefits from predictive text and picture support

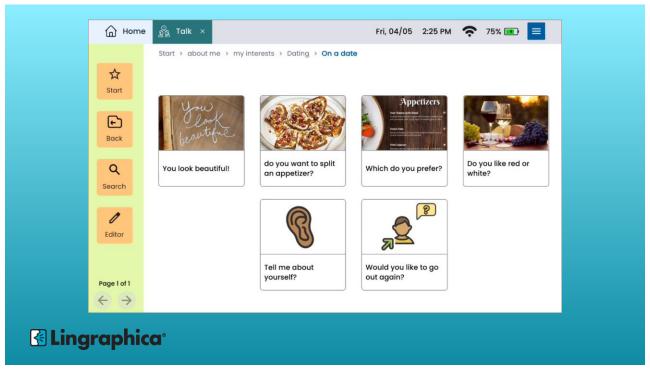
#### **Lingraphica**°

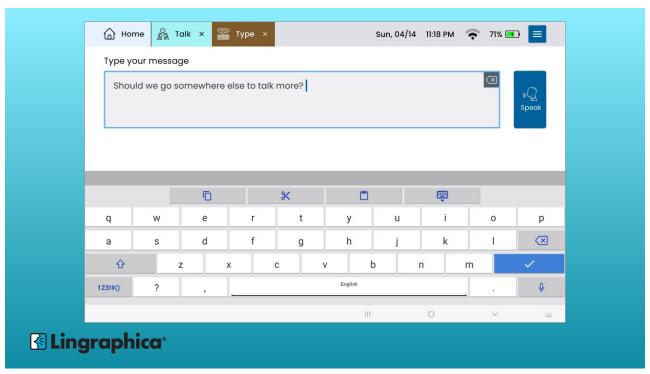
115

#### **Group Discussion**

- What AAC options could you provide for this client?
- What might help him feel more comfortable using AAC when meeting new people or on a date?







# Case Study 4

#### **⚠** Lingraphica®

#### Assessing AAC needs in acute care

- Admitted to hospital s/p acute myocardial infarction
  - Subsequently developed multiple brain infarcts, hemiplegia, mental status changes, acute respiratory failure requiring tracheostomy
- Displayed agitation and uncontrolled pain
- Palliative care consulted
  - Initiated SLP consult

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Radtke et al., 2011

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#### **Group Discussion**

- What would you do during assessment?
- What AAC options would you attempt with the client to assess unmet needs?

#### **Outcome**

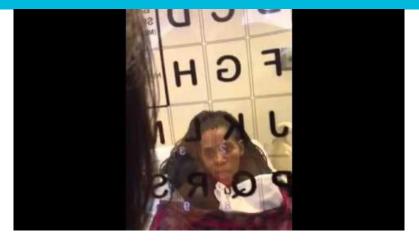
- Topic notebook
  - Patient able to communicate hygiene needs
- · Alphabet Board
  - Patient spelled her occupation and job location
- · Written Choice
  - Patient signaled Y/N or pointed to different options

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Radtke et al., 2011

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#### **Alphabet Board Example**



EyeLink2: Demonstration (youtube.com)

#### **Additional Considerations**

- · Required breaks and frequent cueing
- PMV initiated, able to produce single words, phrases mostly unintelligible
- Communication supported with combination of AAC and verbalization with PMV
- Strategies posted in room, reviewed with nursing and family

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Radtke et al., 2011

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#### Case Study 5

#### Person with Dysphagia and Dysarthria

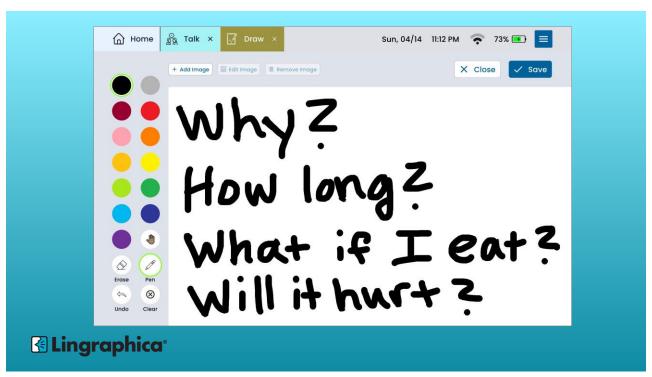
- In acute care, presents with severe dysphagia and dysarthria s/p brainstem infarct
- · Intact cognition and able to write
- VFSS performed, recommended NPO with g-tube

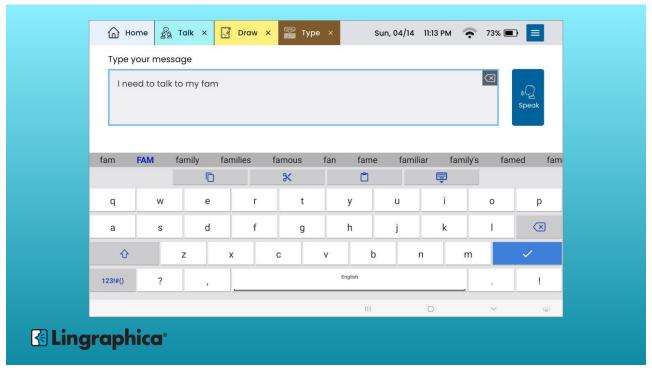
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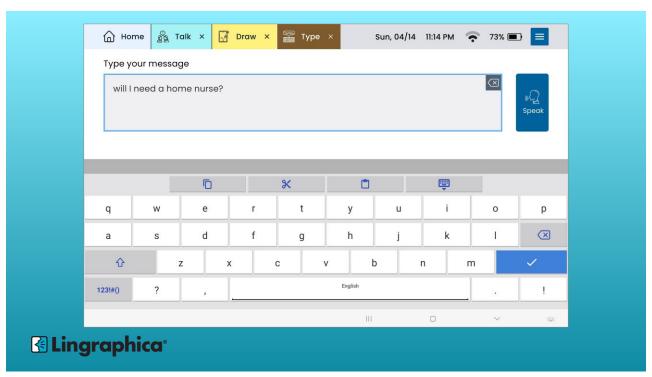
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#### **Group Discussion**

 How would you ensure clients understanding of recommendations and ensure he had needed communication tools to ask questions and express consent?









#### **Dysphagia and AAC**

#### Effective communication system required to discuss

- Consent
- · Quality of life
- Impact of dysphagia on health and well-being
- Facilitate involvement in dysphagia management decisions

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Hemsley and Balandin, 2009

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All efforts should be made to involve the person with dysphagia and complex communication needs. They are an important participant...and may require access to a variety of AAC modes in order to participate in discussions related to their assessment, intervention and management.



Hemsley and Balandin, 2009

#### Conclusion

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Choosing to avoid uncomfortable feelings offer immediate short-term relief, but avoidance can lead to long-term consequences. > Amy Morin, LCSW, author

#### Conclusion

- Client Profiles
- Defining Difficult Conversations and the SLPs Role
- Tips for Difficult Conversations
- Use Your Resources
- Special Topics
- Case Studies
- Q&A

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#### **Access Course Resources**



#### **Additional Resources**

- Centre for Augmentative & Alternative Communication: <a href="https://www.up.ac.za/centre-for-augmentative-alternative-communication">https://www.up.ac.za/centre-for-augmentative-alternative-communication</a>
- Northwest Augmentative Communication Society: https://nwacs.info/aac-and-consent-safety-dignity
- The Spice Institute: <a href="https://www.spiceinstitute.org/freeguides">https://www.spiceinstitute.org/freeguides</a>
- Smartbox: <a href="https://thinksmartbox.com/news/female-health-communication-boards/">https://thinksmartbox.com/news/female-health-communication-boards/</a>

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### Recommended Blogs for insight from people who use AAC

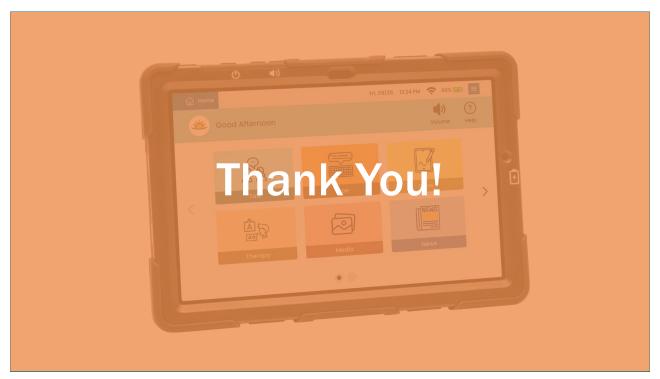
Donnie TC Denome: <a href="https://donnie.lgbt/">https://donnie.lgbt/</a>

Mel Baggs: <a href="https://ballastexistenz.wordpress.com/">https://ballastexistenz.wordpress.com/</a>

## **Questions & Answers**

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