Slide 1

"*Make them see you as a person*":

Recommendations for
Improving Patient-Provider Communication
from Adults with CP who use AAC

David Chapple, David McNaughton, Tracy Rackensperger
Karley Baker & Madison Cherry

RERC on AAC

NiDILRR
NATIONAL INSTITUTE ON DISABILITY,
INDEPENDENT LIVING, AND
REHABILITATION RESEARCH

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Slide 2

David Chapple

- Co-Leader of Training and Dissemination Team for the RERC on AAC

- Vice-President of Accessible Housing (Austin, Texas)

- Employee of "Training 4 Transformation"

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Karina Arellano

As a Certified Nursing Assistant (CNA) Karina Arellano started working in a nursing home about three years ago. Currently, while pursuing a Criminal Justice degree she is working as a Personal Care Attendant for two individuals who use AAC, to be specific, they both use an Accent 1400. She works with them from Monday to Friday.

Anthony Arnold

Anthony Arnold uses an Accent 1400 with Unity 144 sequenced and the built-in word prediction system. Other times he uses the LAMP Words For Life app or a couple of different word prediction apps loaded on his iPad and iPhone for more portable communication. He went on to say:

Dr. Joe Urquidez

Dr. Joe Urquidez (Dr. Joe) is the Medical Director and founder of the Physical Medicine and Neurotoxin Institute where he specializes in the use of Medical Botox and Baclofen Pump Management. His clientele is primarily people who have cerebral palsy, stroke patients and brain injury. Currently Dr. Joe treats about five patients who communicate exclusively with AAC and another fifteen who speak as much as possible and use AAC for clarification.

The biggest challenge interacting with patients who use AAC according to Dr. Joe is the time it takes to communicate. Most physicians

David Chapple's Blog
Speaking with Professionals - Alternatively

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Patient-Provider
Communication

HOME ABOUT PPC TOOLS & RESOURCES CASE EXAMPLES RESEARCH AND PRESENTATIONS THE PPC FORUM COVID-19 POLICY CONTACT US

FREE COVID-19 COMMUNICATION TOOLS & RESOURCES

✓ FREE
✓ READY TO USE
✓ SINGLE PATIENT USE
✓ PATIENT DIGNITY

PATIENT-PROVIDER COMMUNICATION
Roles for Speech-Language Pathologists and Other Health Care Professionals

SARAH W. BLACKSTONE
DAVID R. BEUKELMAN
KATHRYN M. YORKSTON

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Interacting with Healthcare Professionals

- Almost 20% of admissions result in harm
  - Over 60% were preventable

- Patients with communication challenges are 3x more likely to experience an adverse event

WHAT IS MY PROGNOSIS?

WHAT WILL HAPPEN NEXT?

I'M IN PAIN.

WHAT ARE MY OPTIONS?

I WANT TO DISCUSS MY OPTIONS.

I HAVE ANOTHER QUESTION.

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Tracy Rackensperger (Ph.D)

- Co-Leader of Training and Dissemination Team for the RERC on AAC

- University of Georgia

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Slide 7

AAC Consumer and Technology Forums

- Four consumer-led research projects to identify challenges and solutions to communication
  - Community participation
  - Access to healthcare
  - Employment
  - Education
  - Independent living

- Focus group and survey methods
  - current barriers
  - needed features of AAC technology solutions

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AAC Consumer and Technology Forum:
Patient-Provider Communication (2022)

- Experiences of adults with cerebral palsy who use AAC

- Key action steps to support positive outcomes

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https://rerc-aac.psu.edu/

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Recruitment

- Facebook
- Twitter
- Instagram
- Presentations

New research project: The patient-provider experiences of people with CP who use AAC

November 4, 2021 by David McNaughton

We are interested in learning more about the experiences of people who have cerebral palsy (CP) and who use AAC to communicate with medical professionals. The results of this research will be discussed at the AAC Consumer and Technology Forum at ATIA 2022, and will be used to improve service delivery and AAC technology development for persons with CP.

Who can participate?
We would like to learn from persons with CP that make use of AAC technology to communicate. This could include the use of:

- Dedicated AAC devices (e.g., PRC Accent, Saltillo NovaChat, Tobii-Dynavox I-Series, Attainment GoTalk)
- Specialized AAC apps or programs on laptops or tablets (e.g., Assistiveware Proloquo2Go on an iPad or Laptop)

Surveys

- 5 surveys using Google forms
- 34 respondents

Patient-Provider Communication - Survey 2

Thank you for your participation. This is Survey 2 of 4 surveys.

Survey 2 asks about your communication experiences with medical providers, and what advice you would give someone who is preparing to meet with medical providers.

You can use the "tab" on your keyboard to move between questions and response options. Hitting the "space" bar will select (or deselect) a response option. If you have any technical difficulties, please email David McNaughton at dbm2@psu.edu
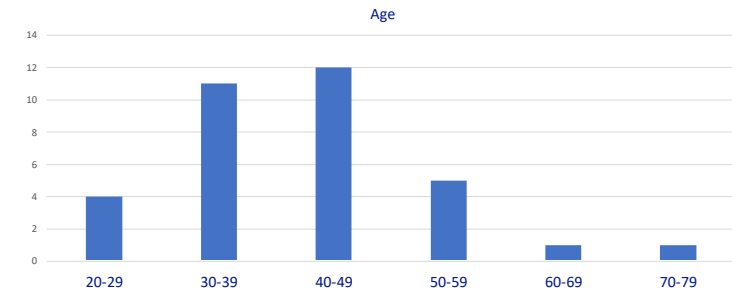
34 participants

- **Race**
  - 29 white
  - 4 black
  - 1 American Indian or Alaska native

- **Ethnicity**
  - 32 not hispanic or latino
  - 2 Hispanic or latino

- **Language with doctors**
  - 32 English
  - 1 Russian
  - 1 English and sign language

- **Gender identity**
  - 22 men
  - 2 women
  - 2 gender fluid

- **Sexual orientation**
  - 31 straight/heterosexual
  - 1 bisexual
  - 1 gay
  - 1 asexual

RERC on AAC

34 participants

Age

	20-29	30-39	40-49	50-59	60-69	70-79
count	4	11	12	5	1	1

RERC on AAC

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34 participants

- AAC technology
  - PRC/Saltillo – 22
  - Tobii-Dynavox – 5
  - Assistiveware – 4
  - Smartbox – 1
  - EZ keys – 1
  - Wordboard – 1

- When communicating with a UNFAMILIAR medical provider, how would you respond to the question "What brings you in today?" Pretend that you want to communicate the phrase "I have had a pain in my lower back for the last three days."

  - AAC system – 18
  - Look to family member or PCA – 9
  - Send message in advance – 4
  - Mixture (speech, AAC, look to others) - 2
  - Speech with AAC as back-up – 1

RERC on AAC

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Most negative experience: Interactions with unfamiliar medical providers

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Slide 15

Most negative experience

- Appointment with a NEW medical provider (35%)
- Emergency room (35%)
- Overnight stay in a hospital (24%)
- Appointment with a FAMILIAR medical provider (6%)

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Most negative experience

- Appointment with a NEW medical provider (35%)
  - Doctor (75%)

  - *The doctor asked questions about me to my attendant, and not me, I hate that!* (T-D)

  - *The doctor didn't assume competence. He thought I was retarded.* (S-S)

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Most negative experience

- Appointment with a NEW medical provider (35%)
- **Emergency Room (35%)**
  - Emergency Room Personnel (75%)

- *They didn't talk to me. They didn't know I could communicate. They assumed that I had an intellectual disability (C-J)*

- *They were moving too fast. They were in too much of a hurry and I couldn't really get out my thoughts (D-M)*

- *A doctor told us that a person with CP cannot feel pain (T-D)*

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Most negative experience

- Appointment with a NEW medical provider (35%)
- Emergency Room (35%)
- **Overnight stay in a hospital (24%)**
  - Nurse (67%)

- *Yelled at me for trying to tell them my IV was out and completely ignored my calls (R-O)*

- *When there's no natural communication, they sometimes assume it's mental retardation. Sometimes they think my communication device is used to entertain me because of the colorful icons. (A-M)*

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Partner strategies

Made sure you were positioned appropriately	Asked for clarification when they did not understand a message
Arranged the environment so it was quiet and your AAC system could be heard	Confirmed their understanding of your message
Made sure you had access to your AAC system	Asked if you had any questions for them
Asked questions directly to you (e.g., not your PCA)	Worked to make the conversation private, as appropriate
Waited while you prepared your response or used your AAC system	Documented key information (e.g., key information was sent electronically)

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Partner strategies (most used)

Made sure you were positioned appropriately	Asked for clarification when they did not understand a message
Arranged the environment so it was quiet and your AAC system could be heard	Confirmed their understanding of your message
Made sure you had access to your AAC system – 38%	Asked if you had any questions for them
Asked questions directly to you (e.g., not your PCA)	Worked to make the conversation private, as appropriate – 47%
Waited while you prepared your response or used your AAC system	Documented key information (e.g., key information was sent electronically) – 50%

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Partner strategies

Made sure you were positioned appropriately	Asked for clarification when they did not understand a message
Arranged the environment so it was quiet and your AAC system could be heard	Confirmed their understanding of your message
Made sure you had access to your AAC system – 38%	Asked if you had any questions for them
Asked questions directly to you (e.g., not your PCA)	Worked to make the conversation private, as appropriate – 47%
Waited while you prepared your response or used your AAC system	Documented key information (e.g., key information was sent electronically) – 50%

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Partner strategies (least used)

Made sure you were positioned appropriately	Asked for clarification when they did not understand a message – 26%
Arranged the environment so it was quiet and your AAC system could be heard	Confirmed their understanding of your message – 26%
Made sure you had access to your AAC system – 38%	Asked if you had any questions for them
Asked questions directly to you (e.g., not your PCA) – 29%	Worked to make the conversation private, as appropriate – 47%
Waited while you prepared your response or used your AAC system – 18%	Documented key information (e.g., key information was sent electronically) – 50%

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Partner strategies

Made sure you were positioned appropriately – 35%	Asked for clarification when they did not understand a message – 26%
Arranged the environment so it was quiet and your AAC system could be heard – 35%	Confirmed their understanding of your message – 26%
Made sure you had access to your AAC system – 38%	Asked if you had any questions for them – 35%
Asked questions directly to you (e.g., not your PCA) – 29%	Worked to make the conversation private, as appropriate – 47%
Waited while you prepared your response or used your AAC system – 18%	Documented key information (e.g., key information was sent electronically) – 50%

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AAC user strategies in most negative situation

Prepared and used an Introduction Statement – 65%

Prepared patient questions – 41%

Prepared for provider questions – 41%

Identified communication and decision–making roles – 38%

Prepared communication supports – 35%

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Most positive experience: Interactions with familiar medical providers

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Most positive experience

- Appointment with a FAMILIAR medical provider (85%)
- Emergency room (9%)
- Appointment with a NEW medical provider (6%)
- Overnight stay in a hospital (0%)

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Most positive experience

- Appointment with a FAMILIAR medical provider (85%)
  - Doctor (59%)

  - The doctor listened to me and he interacted with me. (C-M)
  - *Listened while I spoke and took notes* (I-D)
  - *Asked me questions and not my dad* (J-A)

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Most positive experience

- Appointment with a FAMILIAR medical provider (85%)
  - Doctor (59%)

  - The most important things the medical provider did to make this a POSITIVE communication experience were speaking directly to me, expressing willingness to both learn about my communication methods and continue communication online, and then tried to be patient while using a combo of AAC, my voice & having my mom repeat what I say. I can have my communication partner help by redirecting the doctor's questions to me. I can also ask any questions I may have myself with my communication device or a list instead of my communication partner doing all the talking. I also gave a few of my doctors a copy of my all-time favorite book whose main character like me has verbal speech but hard to understand so she used AAC as well

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Most positive experience

- Emergency Room
  - Emergency room staff

  - *Was very calm and kind and comforting and knowledgeable*

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Slide 30

Most positive experience

- Emergency Room
  - Emergency room staff

  - *Was very calm and kind and comforting and knowledgeable*

  - *With my support people, well in advance of needing it, we set up scenarios for listing medications, medical needs and concerns. I pre think situations that may happen and program my ACC accordingly. I also have a prepared emergency room page that can be used in the doctor's office as well. It contains my personal information as well.*

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Partner strategies

• Made sure you were positioned appropriately	• Asked for clarification when they did not understand a message
• Arranged the environment so it was quiet and your AAC system could be heard	• Confirmed their understanding of your message
• Made sure you had access to your AAC system	• Asked if you had any questions for them
• Asked questions directly to you (e.g., not your PCA)	• Worked to make the conversation private, as appropriate
• Waited while you prepared your response or used your AAC system	• Documented key information (e.g., key information was sent electronically)

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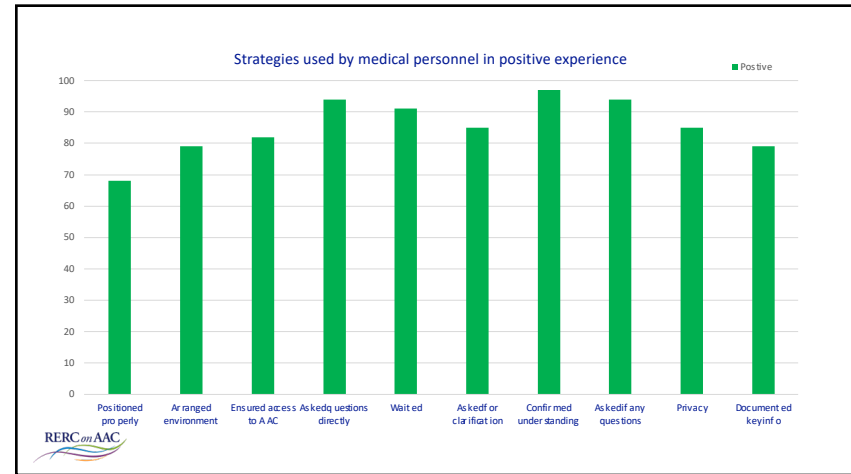## Partner strategies (most used)

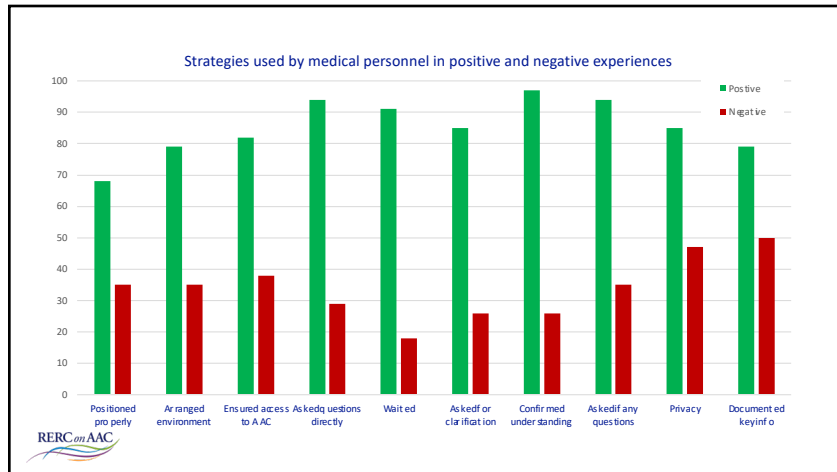|	
• Made sure you were positioned appropriately	• Asked for clarification when they did not understand a message
• Arranged the environment so it was quiet and your AAC system could be heard	• Confirmed their understanding of your message – 97%
• Made sure you had access to your AAC system	• Asked if you had any questions for them – 94%
• Asked questions directly to you (e.g., not your PCA) – 94%	• Worked to make the conversation private, as appropriate
• Waited while you prepared your response or used your AAC system	• Documented key information (e.g., key information was sent electronically)

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Partner strategies (least used)

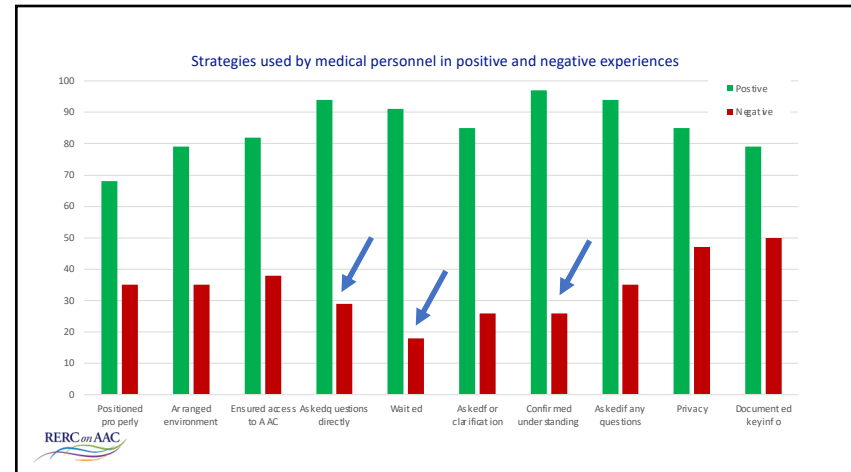|	
• Made sure you were positioned appropriately. - 68%	• Asked for clarification when they did not understand a message
• Arranged the environment so it was quiet and your AAC system could be heard – 79%	• Confirmed their understanding of your message – 97%
• Made sure you had access to your AAC system – 82%	• Asked if you had any questions for them – 94%
• Asked questions directly to you (e.g., not your PCA) – 94%	• Worked to make the conversation private, as appropriate
• Waited while you prepared your response or used your AAC system	• Documented key information (e.g., key information was sent electronically)

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Strategies used by medical personnel in positive experience

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Slide 35

Strategies used by medical personnel in positive and negative experiences

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Slide 36

Strategies used by medical personnel in positive and negative experiences

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Strategies for AAC User (advice to others)

Discuss purpose in advance	Anticipate provider questions
Prepare communication supports	Review agenda of meeting
Prepare and use an Introduction Statement	Identify communication roles and decision making
Prepare and use a Communication/Medical Passport	Document key information
Prepare patient questions	

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Strategies for AAC User (advice to others)

Discuss purpose in advance	Anticipate provider questions
Prepare communication supports	Review agenda of meeting
Prepare and use an Introduction Statement	Identify communication roles and decision making
Prepare and use a Communication/Medical Passport	Document key information
Prepare patient questions	

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Strategies for AAC User (advice to others)

Discuss purpose in advance	Anticipate provider questions
Prepare communication supports	Review agenda of meeting
Prepare and use an Introduction Statement	Identify communication roles and decision making
Prepare and use a Communication/Medical Passport	Document key information
Prepare patient questions	

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If you could go back in time … What would you tell your younger self?

- **Prepare (AAC System)**
  - *brainstorm some questions and phrases for programming into an appointment page on my speech device and practice it before the appointment. also program a page that would have some helpful questions and phrases and answers etc that would be ready to use for emergency room use.*
  - *I would tell my younger self to increase my vocabulary in the medical field to understand my medical issues.*

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If you could go back in time … What would you tell your younger self?

- Create a plan – communicate who you are
  - *Be more prepared when speaking to providers. Know that I have to lead the conversation to get the help I need*
  - *I would tell the younger me to take more control of the medical conversations and decisions. Yes, I did that with my therapists, but I didn't do that with the doctors. I allowed my parents to talk for me instead of me talking for myself. I should have learned better at a younger age to self advocate for myself. Really, I believe that is the important lesson! We need everybody to believe and then develop those self advocacy skills.*
  - ***Make them see you as a person***

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"Make them see you as a person"

Medical personnel — AAC — Person who uses AAC

- Knowledge, skills, and dispositions
- Policies and procedures

- Easy and quick to use
  - preprogrammed
  - on the fly
- Transparent to interaction
- Communicate individuality

- Knowledge, skills, and dispositions
- Self-advocacy and communicative competence

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Acknowledgements

- We are grateful to the individuals who rely on AAC who have allowed us to be part of their lives and have inspired our work.
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- For more information, **please visit our website at rerc-aac.psu.edu**

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https://aac-learning-center.psu.edu/moodle/supporting-patient-provider-communication/

Effective communication between patients and healthcare providers is essential for positive outcomes. In this module you will learn the PACT strategy (Burns, Baylor, & Yorkston, 2016), which includes 9 action steps to help support positive medical interactions for persons with complex communication needs.

You will see how PACT can be used to support positive outcomes for
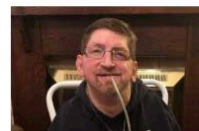
Dave, an adult with cerebral palsy, a co-leader of the RERC on AAC Educational Team, and a co-author of this module. Dave will describe his development of a *communication passport* to improve communication outcomes.