



"Make them see you as a person"

Strategies for Improving Patient-Provider Communication: Recommendations from Adults with Cerebral Palsy who use AAC

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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
 - Hurtig et al., 2018



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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
- 5 surveys using Google forms
- 34 respondents



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34 participants

• Race	• Gender identity
<ul style="list-style-type: none"> • 29 white • 4 black • 1 American Indian or Alaska native 	<ul style="list-style-type: none"> • 20 men • 12 women • 2 gender fluid
• Ethnicity	• Sexual orientation
<ul style="list-style-type: none"> • 32 not hispanic or latino • 2 Hispanic or latino 	<ul style="list-style-type: none"> • 31 straight/heterosexual • 1 bisexual • 1 gay • 1 asexual



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Most negative experience

- Appointment with a NEW medical provider (35%)
- Emergency room (35%)
- Overnight stay in a hospital (24%)
- *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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Partner strategies (most used) in negative experiences

• 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) in negative experiences

• 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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Most used AAC user strategies in 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

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

RERC on AAC

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Partner strategies (most used) in positive situations

• 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)

RERC on AAC

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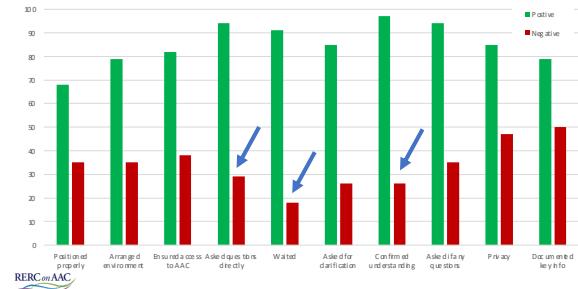
Partner strategies (least used) in positive situations

• 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 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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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.*



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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

- *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”



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Resources

- <https://www.patientprovidercommunication.org/>
- <https://communicationfirst.org/abcd/>
- <https://aac-learning-center.psu.edu/moodle/supporting-patient-provider-communication/>



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