



Direct Support Management and Community Participation For AAC Users

Tracy Rackensperger, Lance McLemore, David McNaughton, Hannah Springfield

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Lance McLemore

- Graduated University of Alabama in Huntsville with a BA in studio art and philosophy.
- Works as an ambassador for PRC-Saltillo and the Center for AAC and Autism.
- Speaks at state, national, and international conferences.
- Paid member of the Training and Dissemination Team for the RERC on AAC

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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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- For more information, [please visit our website at rerc-aac.psu.edu](http://rerc-aac.psu.edu)

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Learning Objectives

- Describe 3 key supports to positive relationships with Direct Support Professionals for AAC users.
- Describe 3 key recommendations from experienced AAC users to younger AAC users for managing personal care
- Describe 3 technologies (in addition to the AAC system) to assist in managing personal care

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Tracy Rackensperger
(Ph.D)

RERC on AAC

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

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2021: Patient-Provider Interactions for AAC Users

Emergency Room

- 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)*

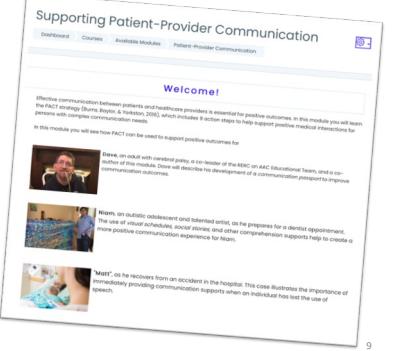
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Supporting Patient-Provider Communication (Stroschein et al, 2021)

P	Prepare for the visit
A	Ask questions
C	Create a plan
T	Take away material

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AAC Learning Center



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Direct Support Professionals & Personal Care Management

No matter where someone lives, their quality of life depends to a great extent on the degree to which they can direct the services of the person who provides attendant care

- Barbara Collier, 2010

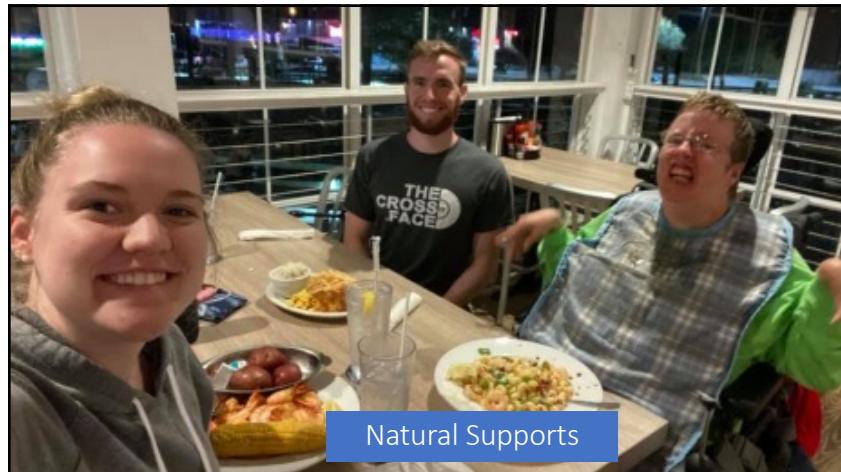
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Pittsburgh Employment Conference (2006)

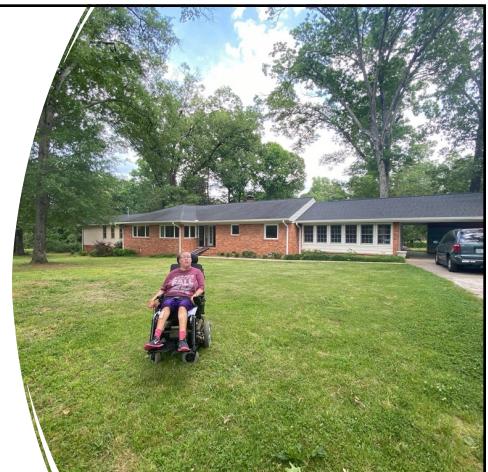


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Current home

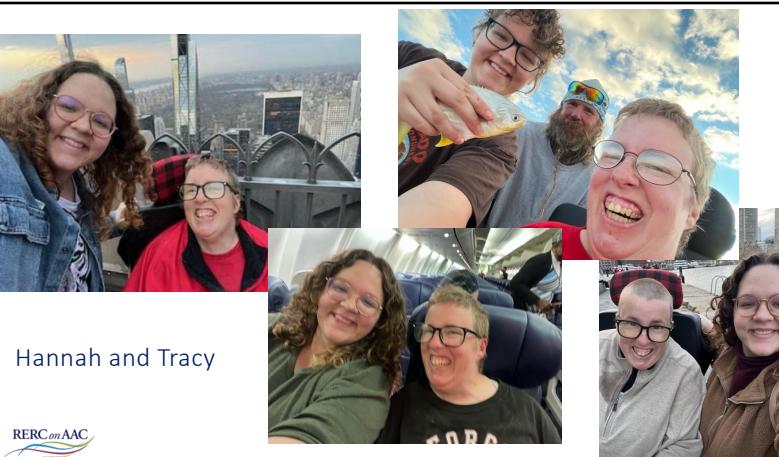


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Terminology



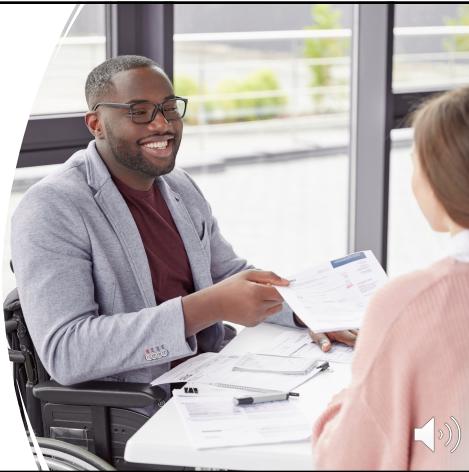
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AAC Consumer Forum

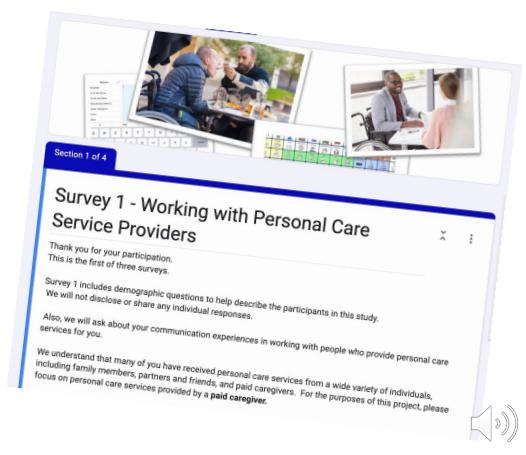
- What have been your experiences with personal care providers?
- What advice do you have for younger AAC users about working with personal care providers, including Direct Support Professionals?



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Surveys

- 4 surveys using Google forms
- 1 Zoom interview
- 17 respondents



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Recruitment

- Facebook
- Twitter
- Instagram
- Presentations

In our current project (DS04), we are gathering information about the experiences AAC users in direct personal care. We are especially interested in learning about how effective communication with Direct Support Professionals (i.e., personal care attendants, group home workers) can make participation in independent living, education, and leisure activities for AAC users. If you are an adult who uses AAC, and if you have ever provided directions for your personal care to a paid individual (e.g., a personal care attendant, a group home worker, a hospital staff), you are eligible to participate in this study.

We want to learn about effective strategies for direct care providers to provide assistance with activities of daily living, such as:

- eating
- dressing
- personal hygiene
- transferring, from a bed to a wheelchair

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17
participants

Language in home

15 English
1 Spanish
1 Hebrew

Gender identity

9 men
7 women
1 Trans man

Disability status

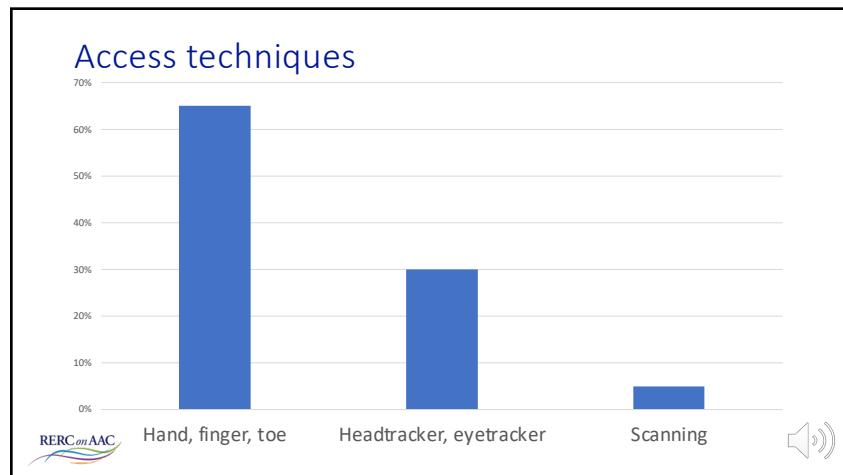
16 CP
1 acquired disability

Sexual orientation

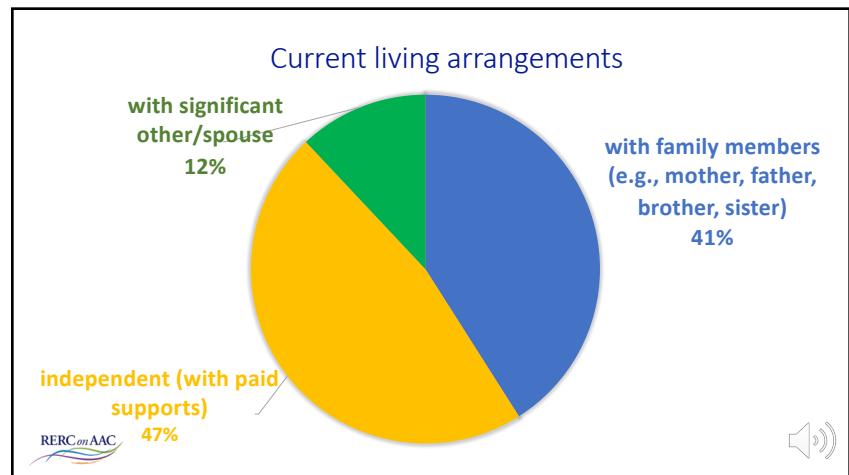
15 straight/heterosexual
2 gay/queer



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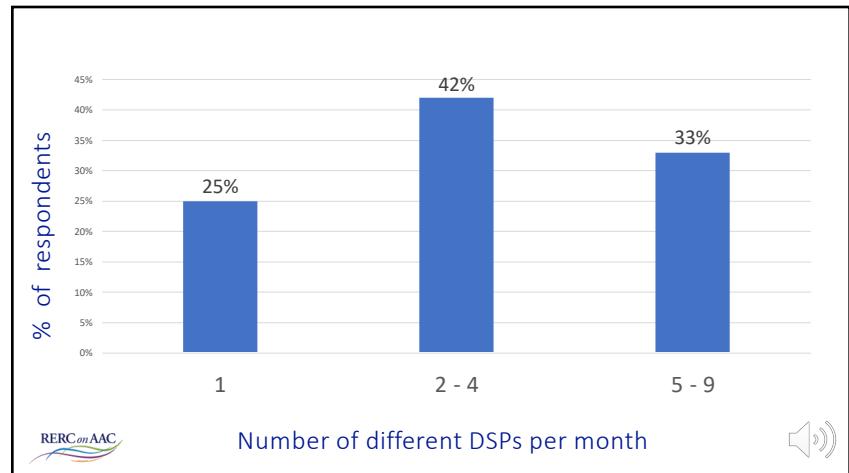
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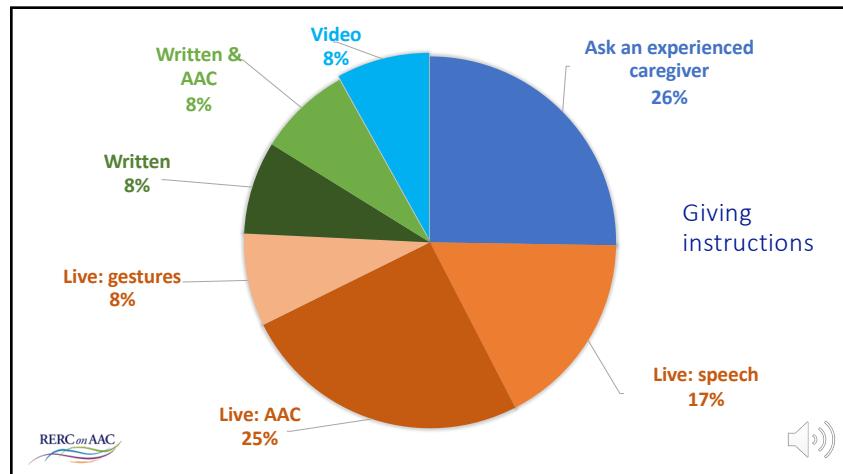
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Positive experiences: showering and night routine

- I explained my shower routine and the assistance I would need in great detail prior to starting the routine while I still had access to my AAC device •
- the caregiver asked clarifying questions about my routine before we started and I left my chair and AAC device. The caregiver also used common sense and multimodal communication while I didn't have access to my AAC device
- all went great. I showered and got into bed and went to la la land

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Positive experiences

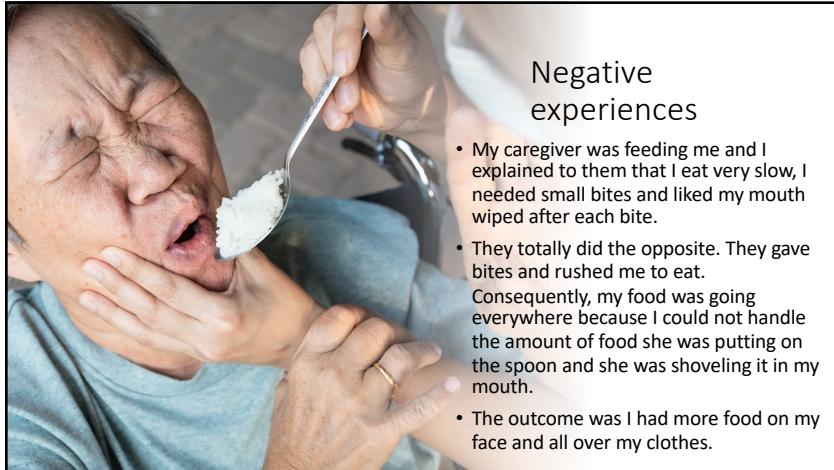
- I was giving them reasons for why I do things differently from the norm. I explained do A, B, C and then D with my DynaVox. They listened and followed directions without giving me pushback.

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Negative experiences

- They learned my word chart, but refused to use it. Even after I put a copies of it in every room. Then they became frustrated because they didn't know what I was trying to say.

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Negative experiences

- My caregiver was feeding me and I explained to them that I eat very slow, I needed small bites and liked my mouth wiped after each bite.
- They totally did the opposite. They gave bites and rushed me to eat. Consequently, my food was going everywhere because I could not handle the amount of food she was putting on the spoon and she was shoveling it in my mouth.
- The outcome was I had more food on my face and all over my clothes.

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Negative experiences

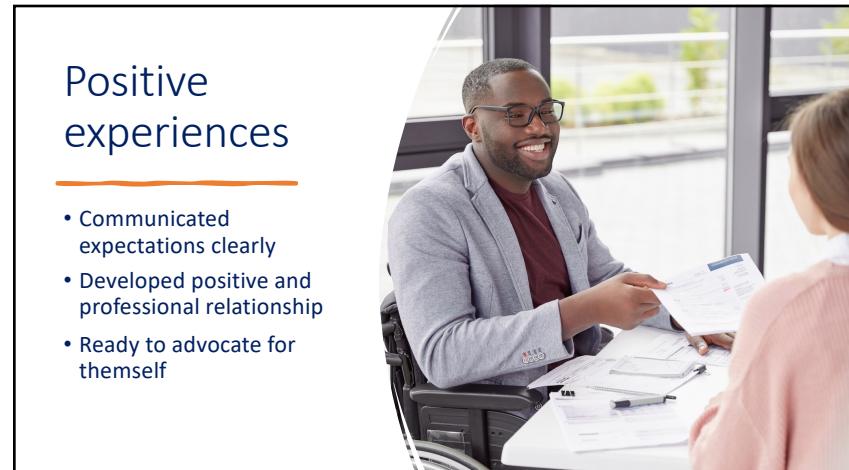
- A caregiver was feeding me lunch, but I occasionally coughed while eating due to my cerebral palsy.
- She got upset because of this. She withheld the rest of my meal as punishment and walked off the job.

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Negative experiences

- Communication breakdowns
 - They are impatient
 - They don't understand my gestures
 - They try to finish my sentences
 - They don't have patience to wait to see what I type and don't want to spend time reading
- Lack of respect
 - They always question my reasons

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Positive experiences

- Communicated expectations clearly
- Developed positive and professional relationship
- Ready to advocate for themselves

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Advice from experienced AAC users

1. Encourage young children to communicate about what they want done and how they want it done
2. Support independence and decision making
3. Teach safety skills
4. Encourage a sense of personal privacy

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1) Encourage young children to communicate about what they want done, and how they want it done

- Yes I definitely agree with this and wish I had more of an opportunity to do this as a child to improve my self-advocacy skills.
- I am very particular about certain things, such as my socks being folded over the top of my AFOs. There were some people who didn't do that when they put my shoes and AFOs on and I would complain about it to my mom. She strongly encouraged me to tell the person instead of complaining and being frustrated that they didn't do it how I prefer



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2) Support independence and decision making

- My parents let me go away to camp with high school friends as my pa's. They also encouraged me to go to college and get my own apartment.
- My parents strongly supported me going to college away from home and live on campus
- In junior high, my team was wrestling about taking me out of a certain class. The principal gave me the final say.

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3) Teach safety skills

- My parents installed electronic deadbolts at our house so I could enter and leave our house safely and independently
- From day one my Taekwondo instructors taught me to do anything to physically protect myself.
- don't talk to strangers

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4) Encourage a sense of personal privacy

- When I was 13, I got my own room and my parents taught me that everyone need their own time by themselves.
- When I was in elementary school and other people (paraprofessionals) were starting to be involved in my personal care (helping me use the bathroom), my mom had a conversation with me regarding people not touching my private parts and the importance of telling her if something happened



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Your experiences?

1. Encourage young children to communicate about what they want done and how they want it done
2. Support independence and decision making
3. Teach safety skills
4. Encourage a sense of personal privacy

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Common Supports

- Communicate expectations clearly and efficiently
- Develop positive and professional relationship
- Be ready to advocate for yourself



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Documenting Service Routines

- Identify important contexts
 - Transfers, mealtimes, toileting
- Document Service Routine
 - Step-by-step description
 - Photos
- Binders, pages on wall, programmed into devices

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Service Routine for Nail Care

(Collier et al., (2010))

- When cutting or cleaning my nails, it is important to know that my hand may clench. This is due to my spasticity. It does not help to ask me to relax or open my hand. I cannot control it.
- The best thing to do is
 - Gently pry open each finger
 - Hold each nail firmly when cut or clean the nail
 - Cut my nails short
 - File any jagged nails because I might scratch myself





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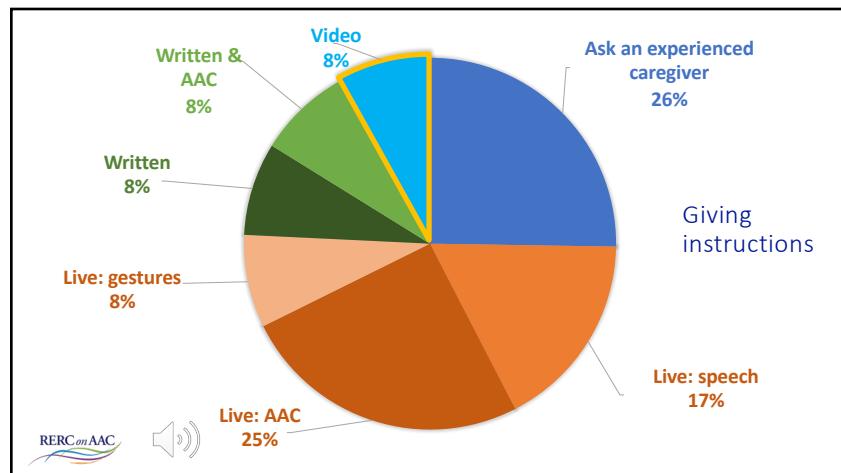
Communication and Self-determination

- Communicate what they want and how they want it done (requires specific vocabulary)
 - Give polite feedback
 - Problem solve when "mistakes" are made (during roleplay practice)
- Build expectation that they have the right to be listened to



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Introduction
Introduction

Preview Checklist

Step 1
Ready the environment

Step 2
Ready the person & their communication tools

mTraining  Gormley et al , 2023)

Introduction



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Introduction
Offer Choices to a Friend

Preview Checklist
Step 1
Set up
Step 2
Offer choice
Step 3
Wait and watch

mTraining McCarty et al (2023)

Offer Choices to a Friend

Introduction

INCREASE SPEED PAUSE

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Current home



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Do the best you can until you know better.
Then when you know better, do better.

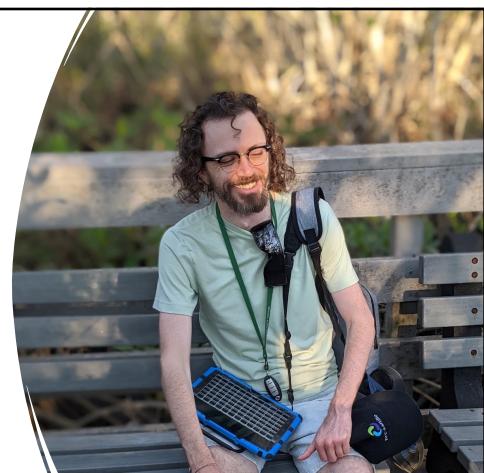
-Maya Angelou

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AAC Learning Center



ERIC on AAC



AAC Learning Center Moodle

Welcome to the AAC Learning Center Moodle

This site provides resources for learning about augmentative and alternative communication (AAC), and is a joint offering of the ERIC on AAC and the AAC program of Penn State University.

If you would like to participate in the learning activities at this site, please register (we do not share the registration information with anyone). Click on **Access to world** in the sidebar.

Available courses



Visual Supports for Participation and Communication - 36-23



AAC for Children: An Introduction



Alternative Access



Developing AAC Systems for Children

AAC systems should be based on the knowledge, skills, and interests of the individual child, and support participation in a wide variety of activities.

Screenshot



Family-Centered AAC: A Guide for Parents



Handing over AAC for Children

This course provides information on handing the AAC systems and services for school-age child on to the related states.

The use of family-centered skills, including active listening, result in positive relationships with family members and improved outcomes.

This course provides information on handing the AAC systems and services for school-age child on to the related states.



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Communication with Direct Support Professionals: The Experiences of AAC Users

Written by [David McNaughton](#)



In our current project (2024), we are gathering information about the experiences of AAC users in directing personal care.

We are especially interested in learning about how effective communication with Direct Support Professionals (e.g., personal care attendants, group home workers) can enhance participants' independence in performing everyday activities for AAC users.

If you are an AAC user, and you have ever provided directions for your personal care to a paid individual (e.g., a personal care attendant, a group home worker, a hospital staff) you are eligible to participate in this study.

We want to learn about effective strategies for directing paid caregivers to provide assistance with activities of daily living such as:

- eating
- dressing
- personal hygiene
- toileting (e.g., from a bed to a wheelchair)



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