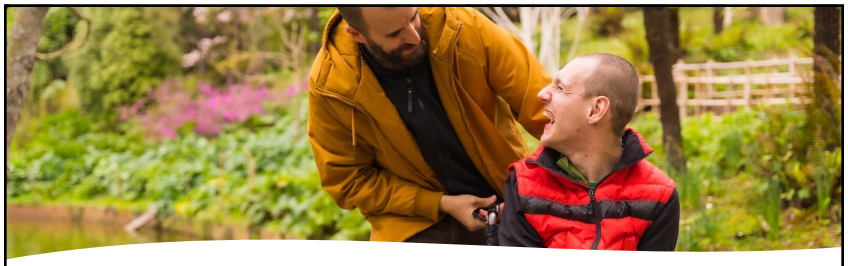

Direct Support Management and Community Participation For AAC Users

Tracy Rackensperger, Lance McLemore, David McNaughton, Hannah Springfield

RERC on AAC

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1

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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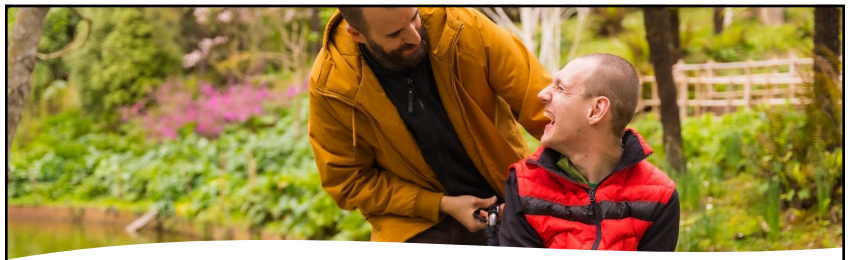
2

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

3



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- For more information, **please visit our website at rerc-aac.psu.edu**

Tracy Rackensperger

David McNaughton

Lance McLemore

Hannah Springfield

5

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

6

Tracy Rackensperger (Ph.D)

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

7

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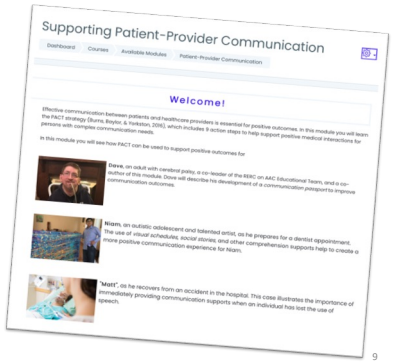
Supporting Patient-Provider Communication (Stroschein et al, 2021)

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



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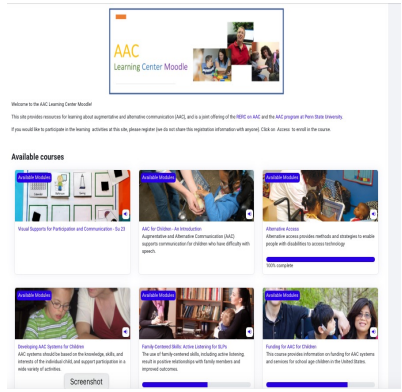
AAC Learning Center



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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

11

Pittsburgh Employment Conference (2006)

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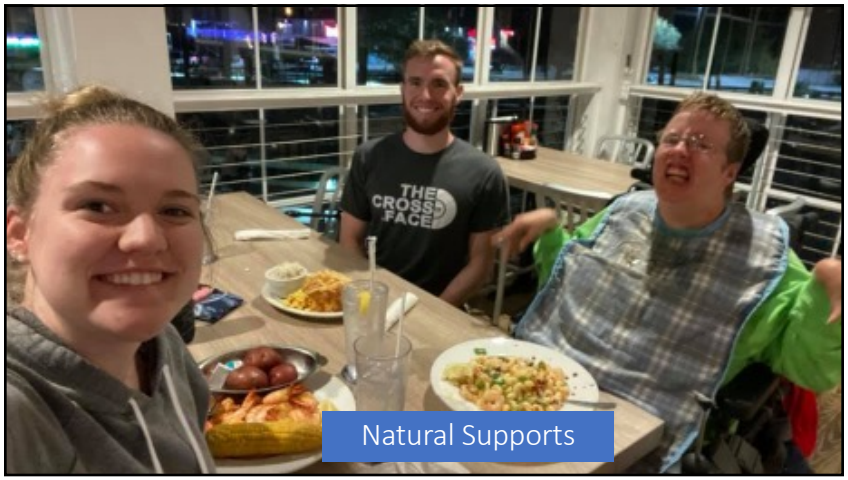

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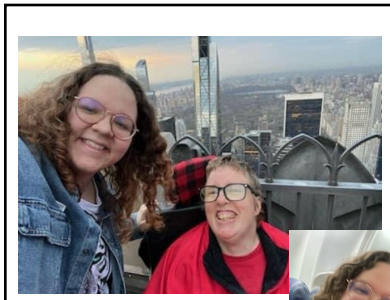
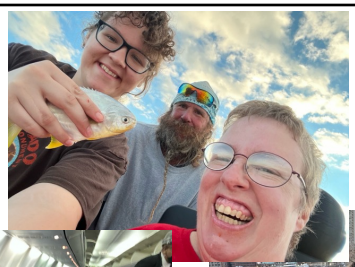
Current home

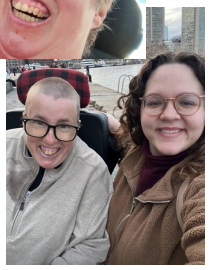
14

Terminology

15







Hannah and Tracy

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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?

17

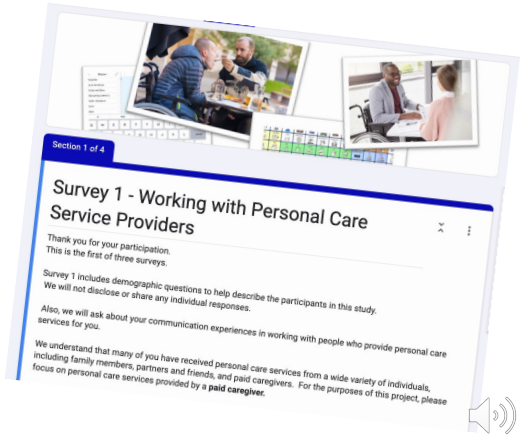
Recruitment

- Facebook
- Twitter
- Instagram
- Presentations

18

Surveys

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



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17 participants

Language in home
15 English
1 Spanish
1 Hebrew

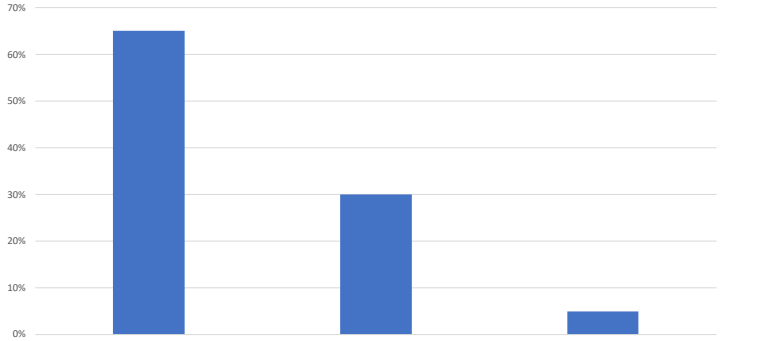
Gender identity
9 men
7 women
1 Trans man

Disability status
16 CP
1 acquired disability

Sexual orientation
15 straight/heterosexual
2 gay/queer

20

Access techniques



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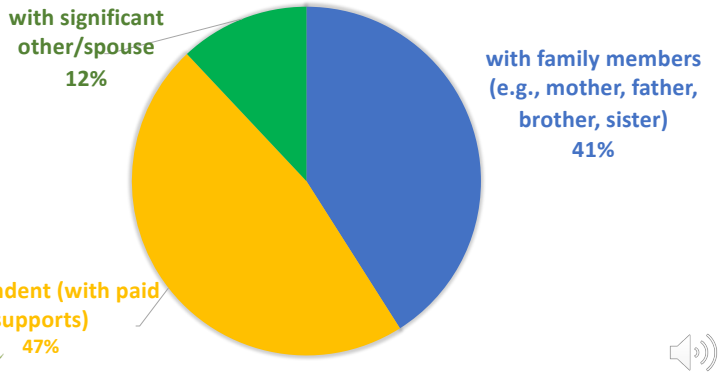
Current living arrangements



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- High levels of support wanted and received
  - Transfers
  - Dressing
  - Food preparation
- High levels of support wanted but not received
  - Support for AAC technology (e.g., charging device)
  - Community transportation

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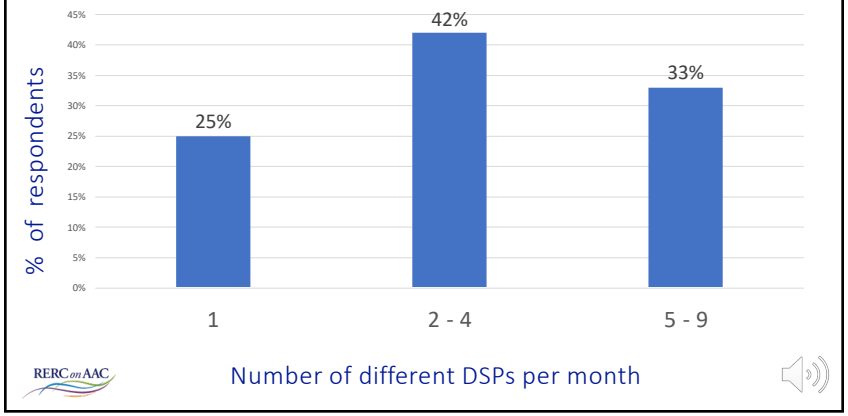

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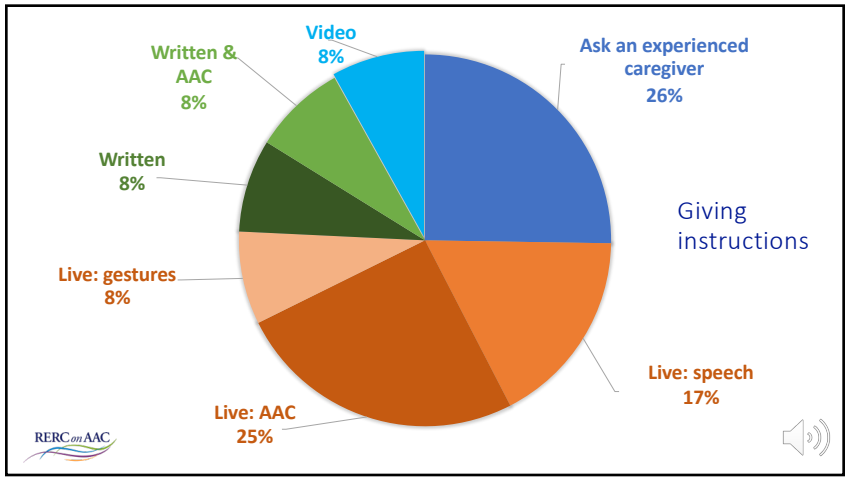

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Positive experiences: showering and night routine

- 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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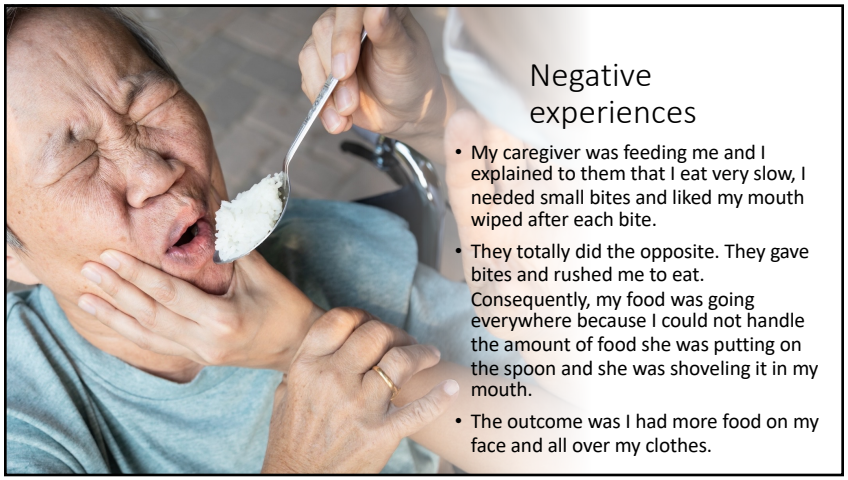

Negative experiences

- 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.

30

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 themself

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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 AFIs 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 principall gave me the final say.

35

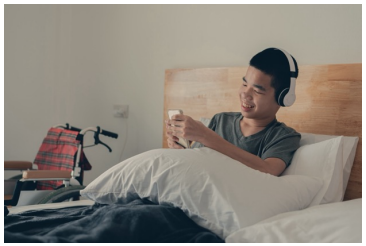
3) Teach safety skills

- 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

36

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

41

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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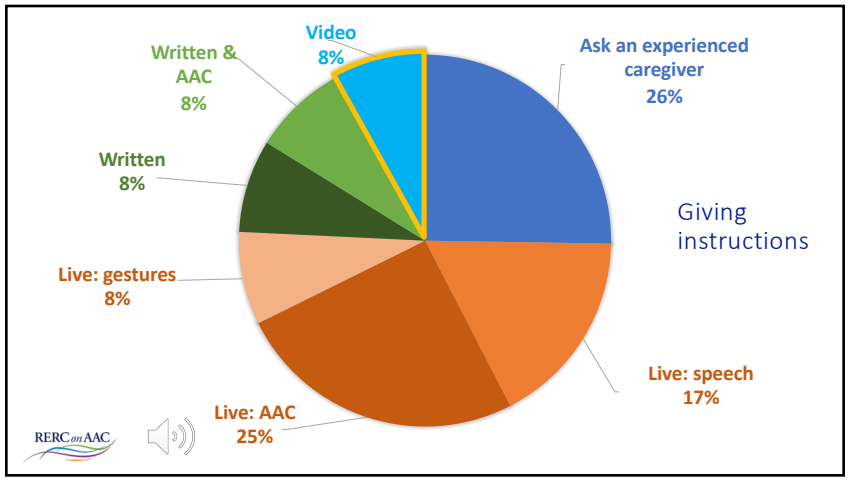

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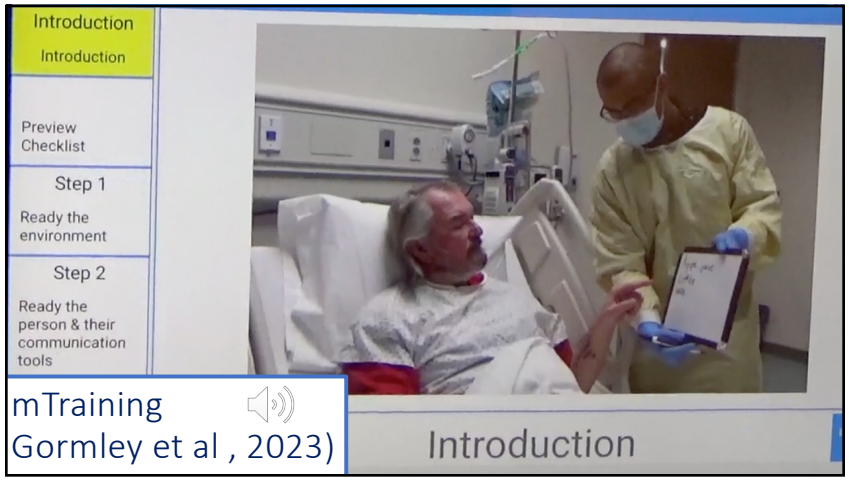

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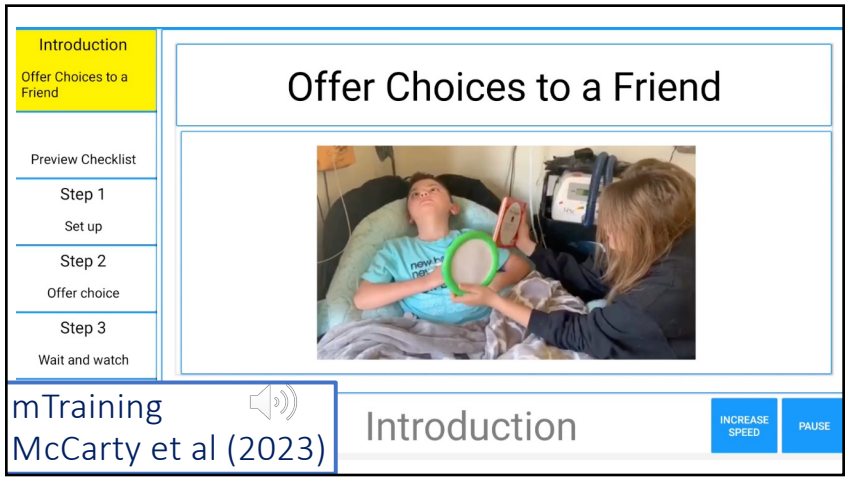
Introduction
Offer Choices to a Friend
Preview Checklist
Step 1
Set up
Step 2
Offer choice
Step 3
Wait and watch
Offer Choices to a Friend
mTraining
McCarty et al (2023)
Introduction
INCREASE SPEED
PAUSE

45

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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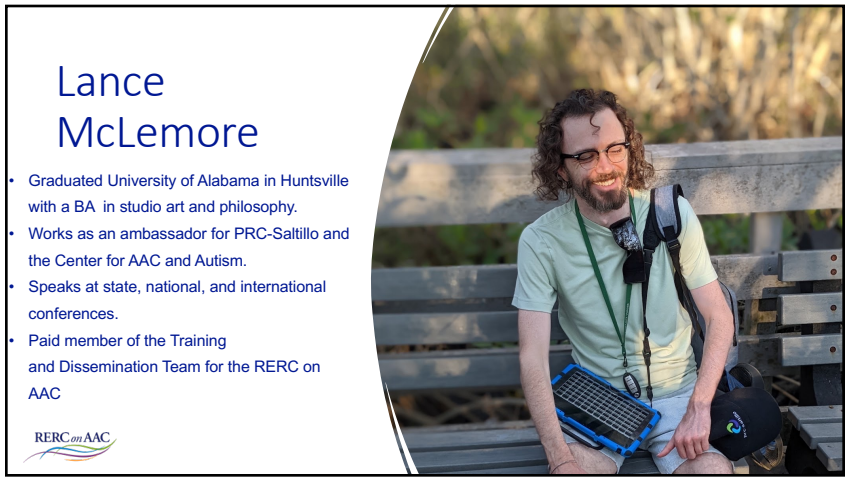
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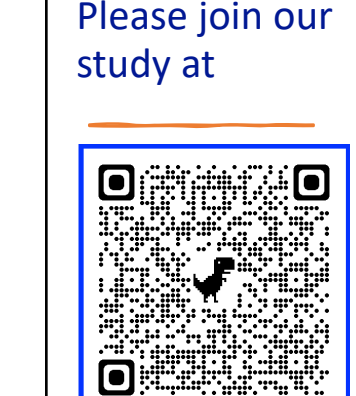

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