



# **Building Positive Relationships with Direct Support Professionals / Personal Attendants: Recommendations from AAC Users**

**April 3, 2024**

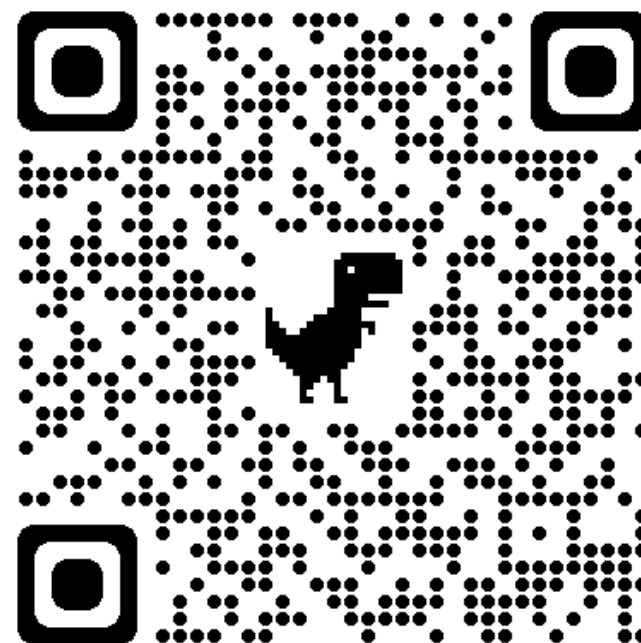
**Presenters: Lance McLemore, David McNaughton,  
Tracy Rackensperger and Hannah Springfield**

**Facilitator: Alison Pentland**

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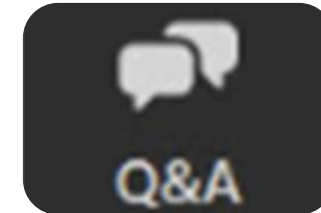
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# Webinar Logistics

Chat box and microphones are disabled for attendees

Enter questions in the Q&A box at the bottom of the screen  
(we will answer as time permits)



ASHA CEU form will be shared at the end of the webinar

# Tonight's Webinar

Support professionals such as Direct Support Professionals (DSPs) and Personal Care Attendants (PCAs) play vital roles in the lives of many users of AAC. DSPs and PCAs enable many AAC users to participate in such areas as education, employment, communication, community events, transportation, health care, safety and security, friendships and relationships, leisure, and faith communities. AAC users must have access to DSPs and PCAs who can support them appropriately. This webinar will highlight findings of an ongoing research project regarding the [experiences of AAC users in working with DSPs and PCAs](#), including how effective communication with support professionals can enhance participation in independent living and community activities for AAC users.

# Tonight's Learning Objectives

Participants will be able to:

- Define the role of support professionals in the lives of people using AAC
- Describe ways support professionals can assist AAC users in community participation.
- Describe ways support professionals may hinder AAC users in community participation.
- Share strategies for building positive relationships with support professionals.

# Tonight's Presenters



Lance McLemore  
Springfield



David McNaughton



Tracy Rackensperger



Hannah

# Tonight's Disclosures

## Financial:

Lance McLemore and Hannah Springfield are paid by the RERC on AAC.

David McNaughton is a salaried faculty member at Pennsylvania State University, and part of his salary is paid by RERC on AAC.

Tracy Rackensperger is a salaried faculty member at the University of Georgia and is compensated by the RERC on AAC.

Alison Pentland has no financial disclosures.

## Nonfinancial:

Lance McLemore, Hannah Springfield and David McNaughton have no nonfinancial disclosures to report

Tracy Rackensperger is the president of USSAAC and Alison Pentland is on the USSAAC board.





# Direct Support Management and Community Participation For AAC Users

Tracy Rackensperger, Lance McLemore,  
Hannah Springfield, David McNaughton,



# Lance McLemore

- Graduated University of Alabama in Huntsville with a BA in studio art and philosophy.
- Works as an ambassador for PRC-Salttillo 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



# AAC Consumer and Technology Forums

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- 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







# Direct Support Management and Community Participation For AAC Users

Tracy Rackensperger, Lance  
McLemore,  
David McNaughton, Hannah  
Springfield



**Tracy Rackensperger  
(Ph.D)**



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





# 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

# Pittsburgh Employment Conference (2006)







Natural Supports



# Current home





# Terminology





Hannah and Tracy



Do the best you can until  
you know better.

Then when you know better,  
do better.

-Maya Angelou



# AAC Consumer Forum

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- 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?





A large orange circle with a white outline, partially visible on the left side of the slide.

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

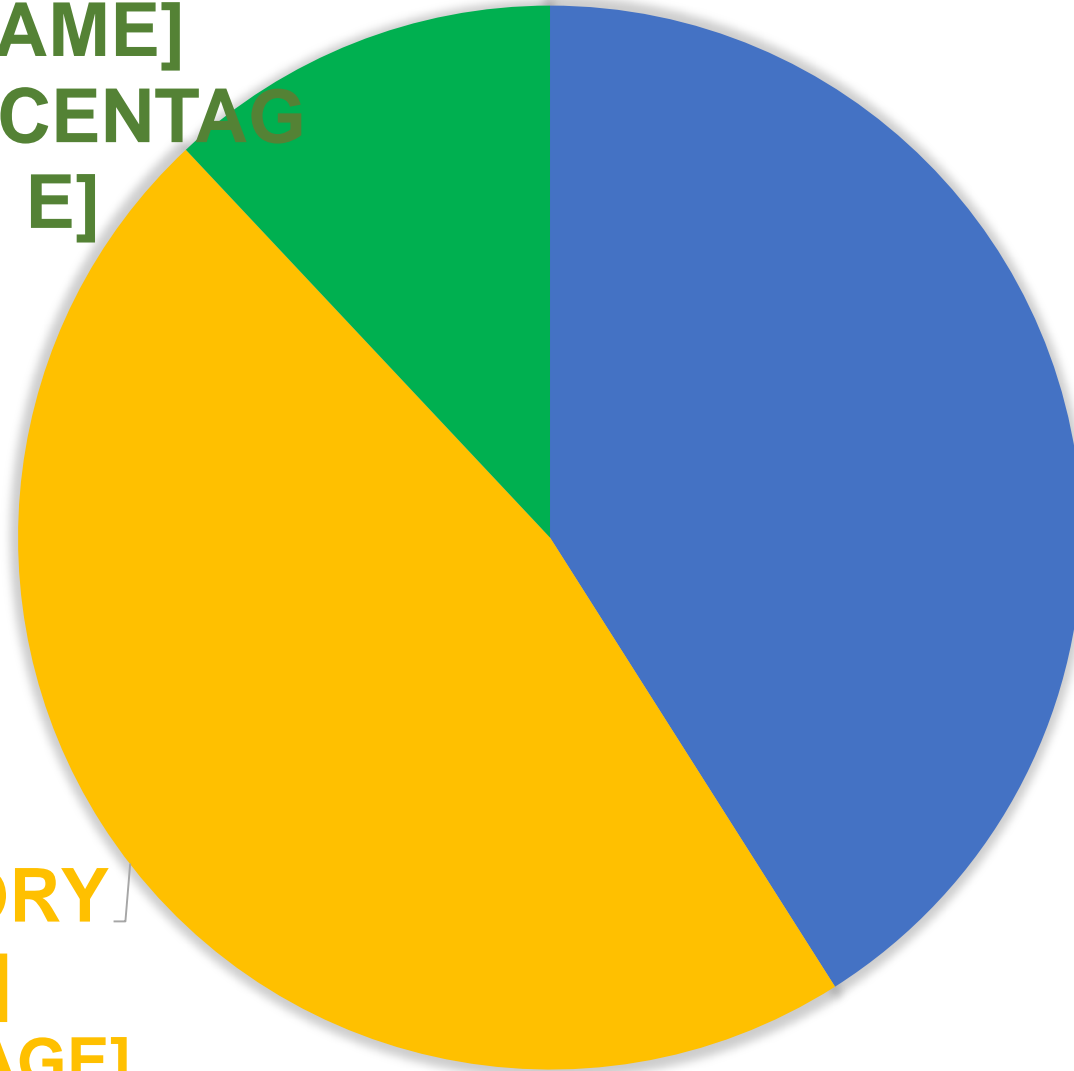
2 gay/queer

# Current living arrangements

[CATEGORY  
NAME]  
[PERCENTAGE]

[CATEGORY  
NAME]  
[PERCENTAGE]

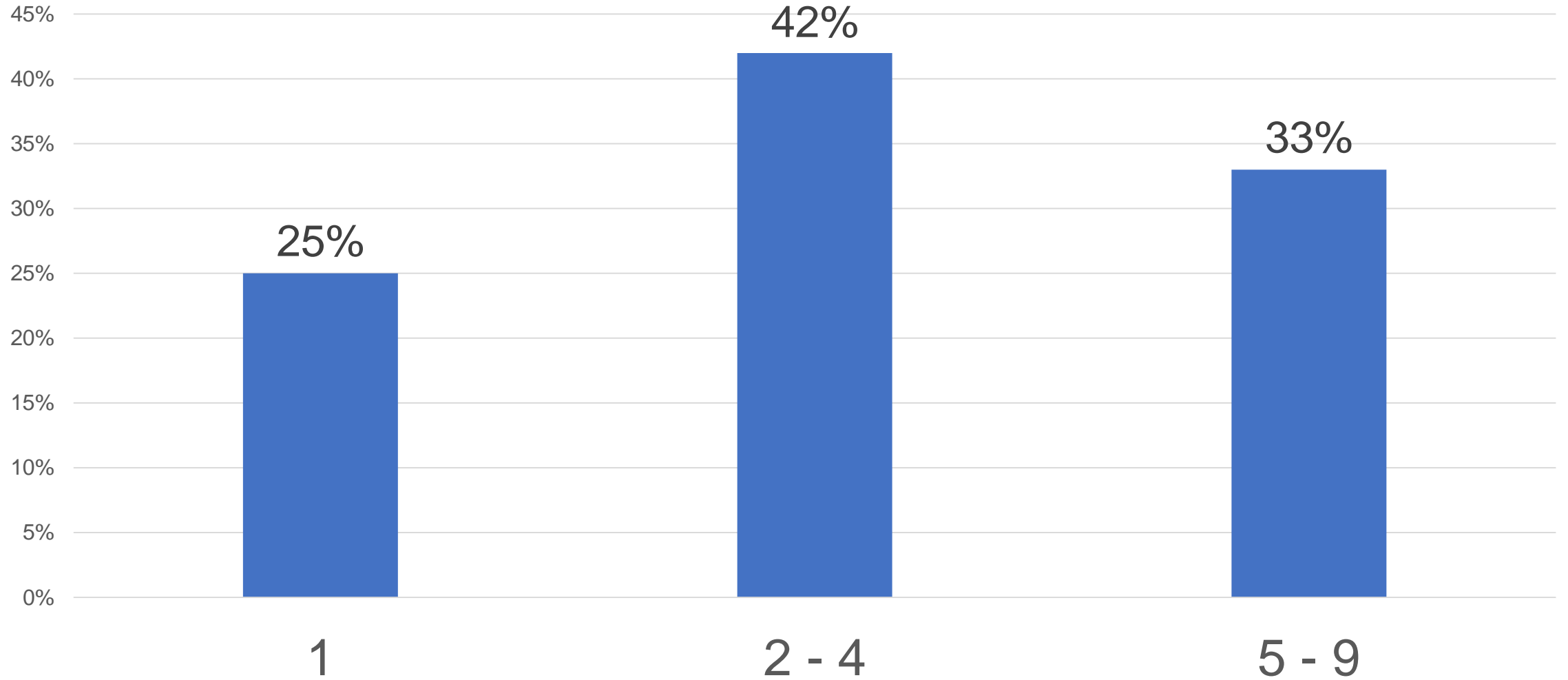
[CATEGORY  
NAME]  
[PERCENTAGE]

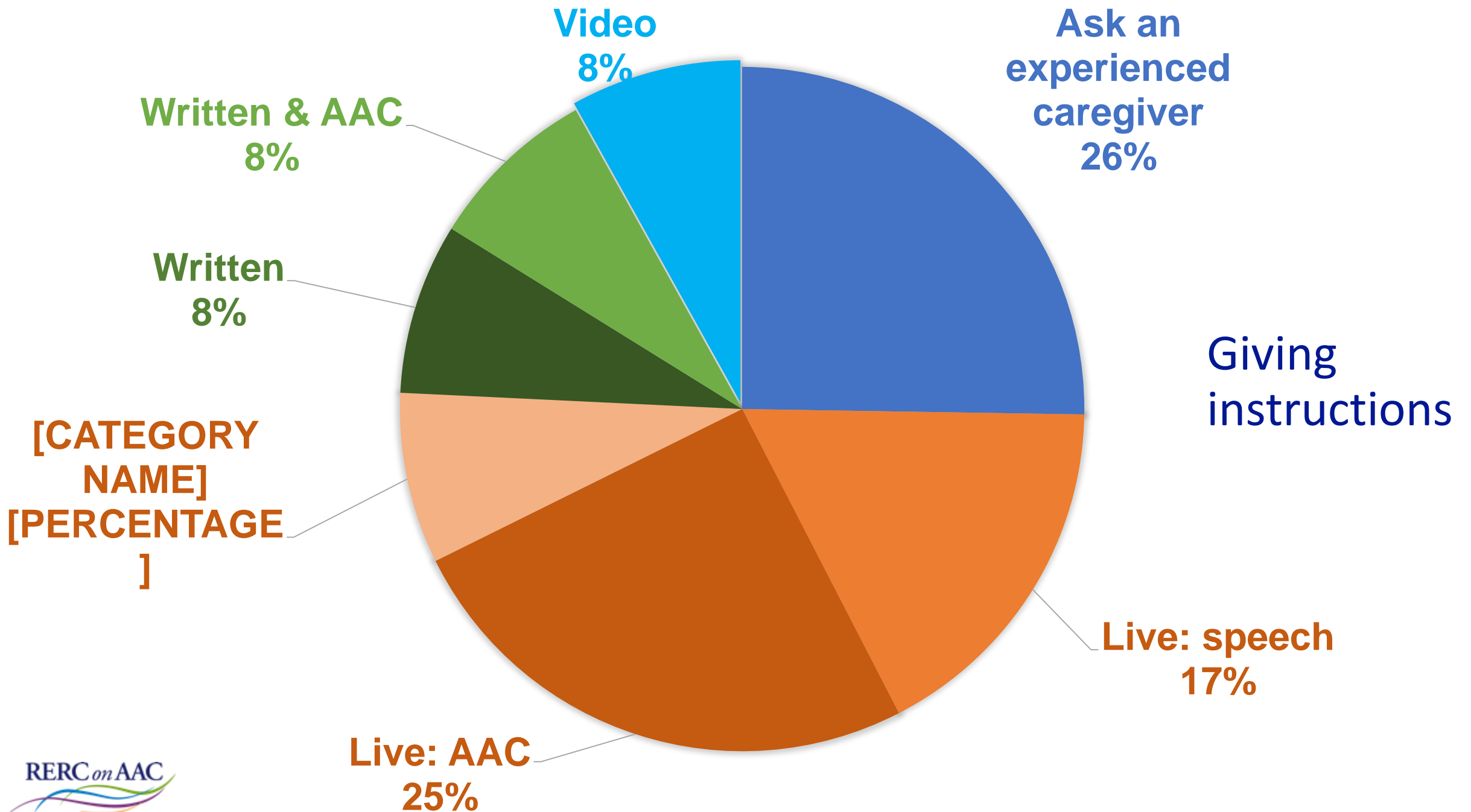


- High levels of support wanted and received
  - Transfers
  - Dressing
  - Food preparation
- High levels of support wanted but not received
  - Support for AAC technology (e.g., charging device)
  - Community transportation



% of respondents





# Positive experiences: showering and night routine

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- 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





# Positive experiences

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- 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.





# Negative experiences

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- 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.





## 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.



# Negative experiences

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- 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.

# Negative experiences

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- 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



# Positive experiences

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



# 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



# 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



## 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.





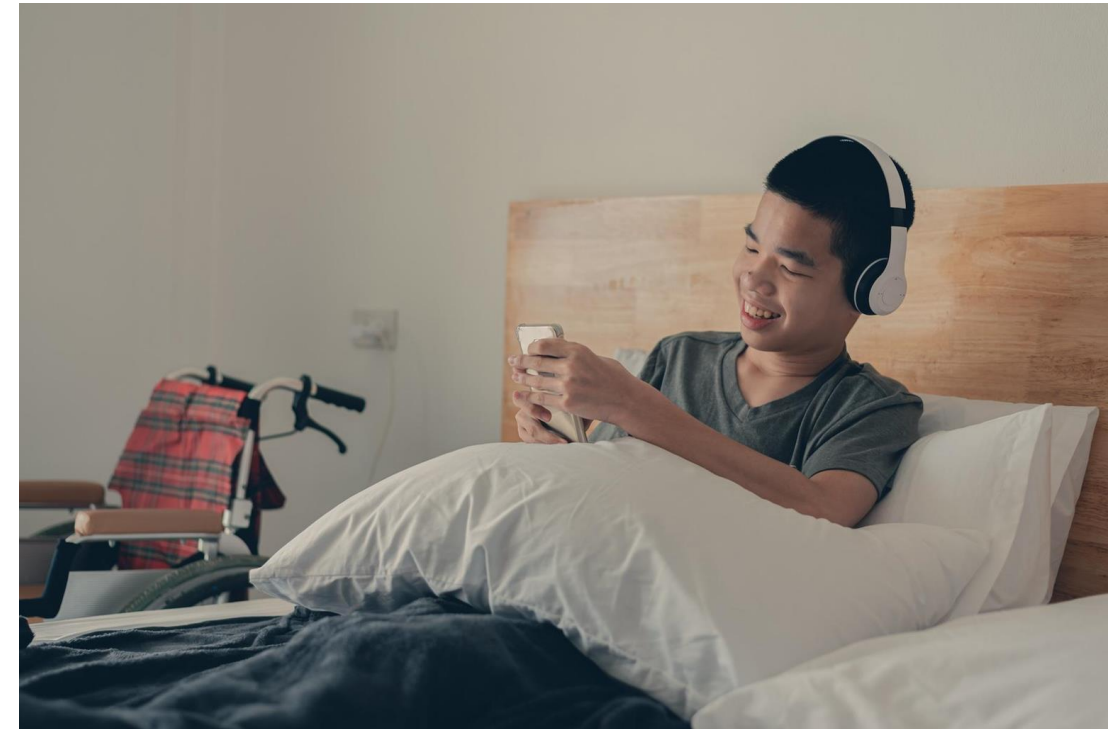
### 3) Teach safety skills

- 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



## 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





# 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

# Common Supports

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



# Documenting Service Routines

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



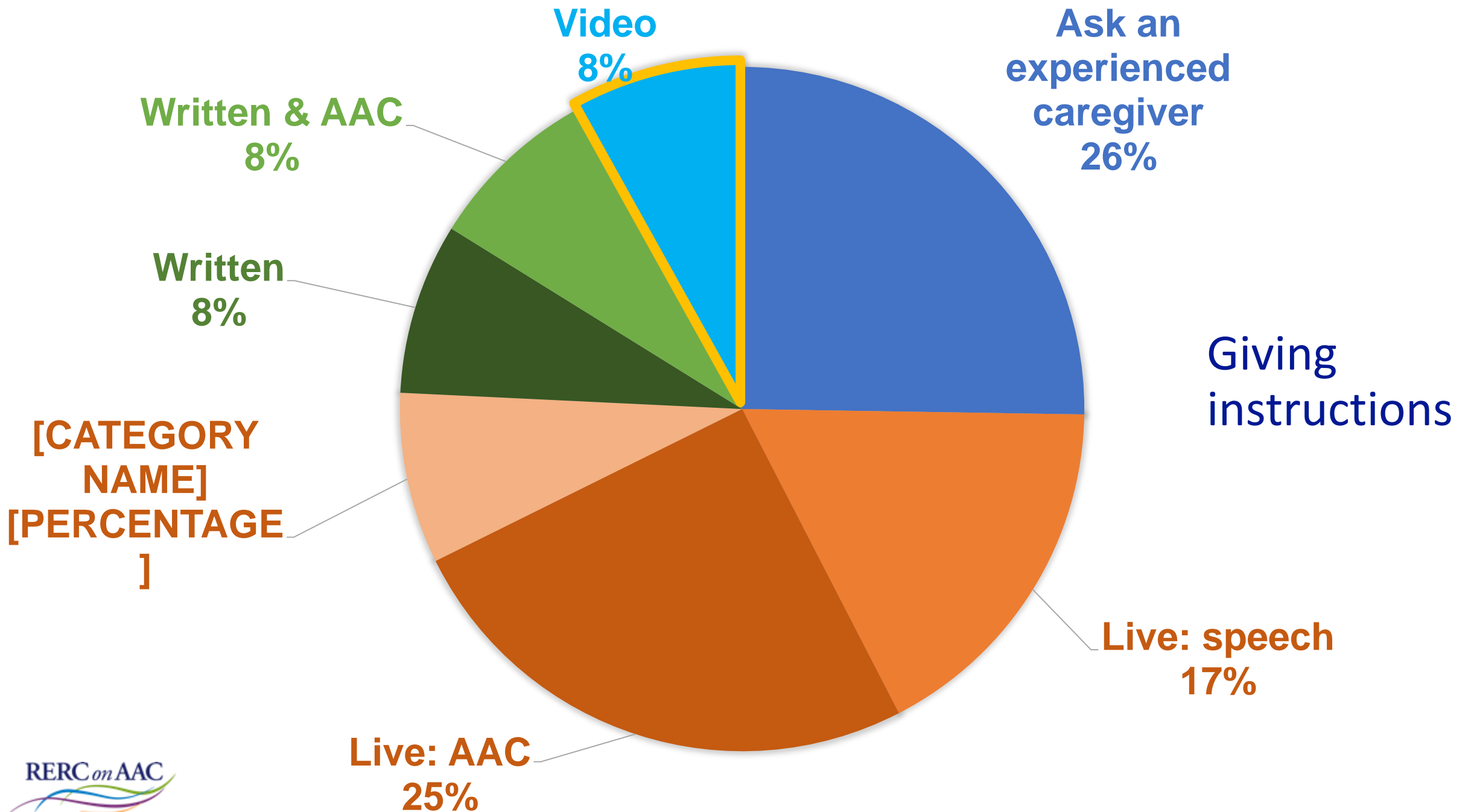


# Service Routine for Nail Care

(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





## Introduction

### Introduction

#### Preview Checklist

#### Step 1

Ready the  
environment

#### Step 2

Ready the  
person & their  
communication  
tools



mTraining  
Gormley et al , 2023)

Introduction



## 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



# Current home





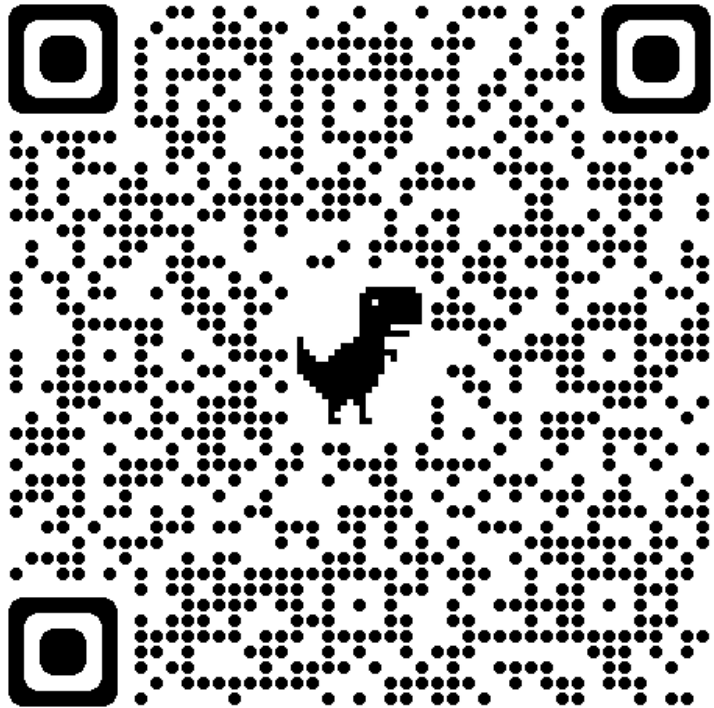
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## Communication with Direct Support Professionals: The Experiences of AAC Users

January 7, 2024 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 participation in independent living and community 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 directing paid caregivers to provide assistance with activities of daily living such as

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

# Financial disclosure

- This research was supported by grant #90REGE0014 to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC) from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This research does not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.
- For more information, **please visit our website at [rerc-aac.psu.edu](http://rerc-aac.psu.edu)**



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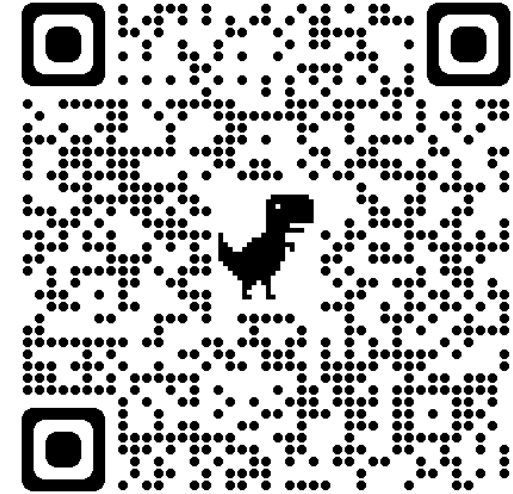
# Questions



# ASHA CEUs (live webcast only)

Submit by **April 17, 2024:**

[Google Form: April 3, 2024: RERC USSAAC Webinar](https://forms.gle/5Q5LKKJTX4xTaYLd6)  
(<https://forms.gle/5Q5LKKJTX4xTaYLd6>)



- FREE for USSAAC members
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If you have any questions, contact [education@ussaac.org](mailto:education@ussaac.org)

# Save the Dates for 2024!

**May 22: Transition from School to Adult Life for People Who Use AAC**  
Presented by Jennifer Seale

**June 12: Preparing Children with Complex Communication Needs for Adult Social Relationships**  
Presented by Richard Lytton and Barbara Weber (90-minute webinar)

**September 11: AI and AAC**  
Presented by Beth Poss

**November 6: Gestalt Language Processing and AAC**  
Presented by Caroline Gaddy

*All USSAAC webinars are held from 7:00-8:00 p.m. Eastern except as noted*

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