

## Goals for this afternoon Describe symptoms of PNFA Describe experimental study on AAC for PNFA Present videos showing subjects conversing with and without AAC Discuss implications for PNFA treatment

There are a group of older adults who cannot participate in conversations successfully because they are slowly losing their language.

They have primary progressive aphasia (PPA).

## Age of onset 55-65 years old Preponderance of males In the community, they are still being diagnosed with Alzheimer's disease, but their nonverbal memory is intact.

# Types of primary progressive aphasia Progressive nonfluent aphasia (PNFA) Resembles a degenerative expressive aphasia Semantic dementia Resembles a degenerative receptive aphasia Logopenic progressive aphasia

### **Diagnostic Criteria for PPA** Mesulam, M. Annals of Neurology, 49 (4), April, 2001 2. ADL limitations attributable to 1. Insidious onset and gradual loss of word language impairment, for at finding, object-naming or least 2 yrs after onset; word-comprehension 4. Absence of significant skills in spontaneous apathy, disinhibition, forgetfulness for recent events, visuospatial 3. Intact premorbid language impairment, visual recognition deficits or sensory-motor dysfunction within initial 2 yrs of L impairment;

- 5. Acalculia & ideomotor apraxia may be present in first 2 yrs.
- Other domains possibly affected during 2 yrs, but language most impaired fn.
- Absence of specific causes (i.e., stroke, tumor, infection, metabolic disorder) on neuroimaging.
  - etabolic disorder) on uroimaging.

### PPA is a clinical syndrome

There are overlaps with:

- Alzheimer's disease
- Frontotemporal dementia
- Corticobasal degeneration
- Dementia-lacking-distinctive-histology (DLDH)
- CJD
- ALS
- ACD (Asymmetric cortical degeneration; Caselli, 1995)

Kertesz & Munoz, Amer. J. of Alzheimer's Disease, (2002), 17(1)



### First Symptoms

- Anomia or "trouble thinking of or remembering specific words when talking or writing" (PNFA and SD)
- Slow, hesitant speech frequently punctuated by long pauses and filler words (PNFA).
- Marked increase in speech errors (substitutions or distortions; PNFA).
- Struggle for speech sounds, initial apraxia (PNFA)
- Difficulties understanding spoken words (SD).



### Progression of disease varies

- Yes/No confusion for responses
- Apraxia of Speech
  - Articulatory groping with difficulty self correcting
  - · Vowel distortions and inconsistent errors
  - Increased frequency of articulatory errors as word or phrase length increases
- \_ Mutiem
- Written language generation often mimics spoken language generation.



### **Communication Treatment Goals**

- #1: To compensate for progression of language loss (NOT stimulate the language system to regain skills).
- #2: To begin compensatory treatment EARLY. Be proactive so patient can learn to use communication tools.
- #3: To include primary communication partners in all aspects of training, with outreach to multiple partners.



### The Treatment Challenge:

To put the patient's residual lexicon visually in front of him so that the patient can access needed vocabulary to participate in daily activities as language skills decline.



### The research challenge

There is little empirical evidence that AAC helps people with PNFA with their daily expression. We only have case studies and clinical descriptions.

### Our purpose

To provide evidence that low tech AAC (communication boards) support adults with PPA during conversations.

To provide AAC to support lexical access so that individuals can participate in daily activities as language skills decline.



### Three studies

- Study 1: Do personalized AAC boards in controlled conversations with research assistants improve expressive communication?
- Study 2: Do personalized, daily activities AAC boards used in conversations with frequent partner (spouse, child, caregiver) improve daily communication?
- Study 3: Is there generalization and maintenance of AAC over 6 months?



### Study 1: Controlled conversations 3 questions for target word: KENAI



### Study 1 Methods\*

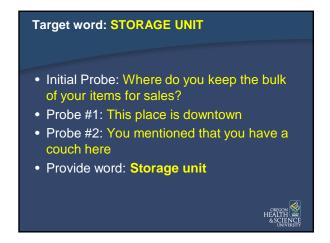
- 1. Determine topic of conversation with participant and partners based on autobiographical memory.
- 2. Make 16-item personalized boards with photo + label in open file folder.
- 3. Train individuals how to use boards during conversation in their residences.
- 4. Conduct 6 VERY controlled conversations with 10 scripted questions, with and without boards.

\*Input from participant with PPA who was an SLP & now attends staff meetings.



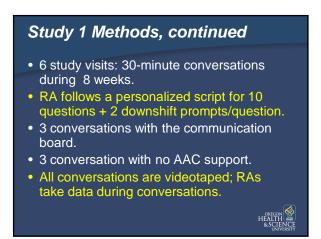
Note: Board template in ASHA handouts

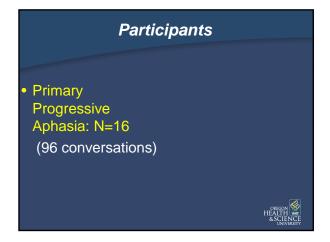


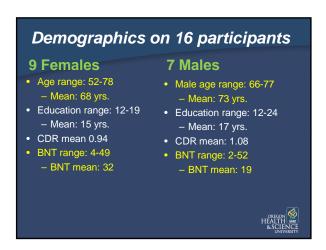






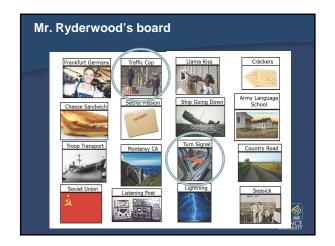






### Demographics on 16 Participants

- Living environment: single family households (urban, suburban, rural farm), and assisted living facilities
- Conversational Partner: 1 female friend; 1 female paid caregiver; 6 male spouses, 6 female spouses
- Length of relationship between participants and communication partner: 1.5 to 60 years (mean 35.25)



### Sample of scripted questions

- You had an old Volkswagen in the Army, what was particularly unique about this car? [Turn signal]
- 2. Who broke off one of these turn signals while you were in Germany? [Traffic Cop]



Mr. Ryderwood's control conversation

### Mr. Ryderwood's experimental conversation



## Outcome measure: What is a correct response?

- In experimental condition: Production of a target word or synonym by verbal and/or pointing to the symbol.
- In control condition: Verbal production of the target word or its synonym.
- RA tallies correct responses for each of 1 to 3 probes and for each of 10 questions.

### Weighted conversation score

Point values

- 3 points correct answer 3 points: "How do you to the initial probe
- to downshift #1
- to downshift #2
- 0 points correct response provided by RA to participant after 3 trials without correct response

**Target word: SIGN** 

- advertise for a sale?'
- 2 points correct answer 2 points: "You use cardboard & a marker to make this."
- 1 point correct response 1 point: "You post it outside for people to see your sale."
  - 0 points: "SIGN"



- Total raw score 0 to 30 (30 = 10 questions get 3 points each as responses to initial probe). Score is converted to a % of total points possible.
- Score combines accuracy and level of support required by participant. Higher scores indicate greater lexical accuracy by participant and less support required.
- Hypothesis: Conversations with AACsupport, in comparison to unsupported conversations, will yield greater weighted conversation scores.

### Establishing Inter-Rater Reliability

• Independent researcher coded 2 conversations per participant for 12 participants

% Agreement	Control	Experimental	Total
# Probe	93%	92%	93%
Verbal	95%	94%	94%
			OREGON HEALTH &SCIEN



### Study 1 data on 13 participants have been analyzed to date



### Study 1 Results: Verbal Responses

- Number of correct verbal responses to questions was higher in the experimental condition (with AAC) than in the control condition (without AAC).
  - Mean Experimental: 6.2
  - Mean Control: 4.2
  - -F(1,75) = 8.393, p = .005
- With AAC support, participants with PNFA are more successful at retrieving the correct verbal responses to questions.

### Study 1 Results: Response to initial question

- Number of correct responses to initial questions was higher in the experimental condition (with AAC) than in the control condition (without AAC).
  - Mean Experimental: 6.5
  - Mean Control: 3.5
  - -F(1,74) = 19.635, p = .000
- With AAC support, participants with PNFA retrieve the correct responses to questions more quickly, requiring less effort by caregivers (downshifting).

### Study 1 Results: Weighted Conversation Score

- Weighted Conversation Score was higher in the experimental condition (with AAC) than in the control condition (without AAC).
- Mean control: 43%
- Mean experimental: 76%
- F(1, 74) = 22.414, p = .000
- With AAC, conversations between people with PNFA and researchers are more successful in terms of generating correct responses with less support.

### **Study 1 Results: Nonverbal Responses**

- In experimental conditions, participants pointed to pictures on the board an average of 5 times per conversation.
- Low tech AAC provides support to people with PNFA during conversation.

### Interpretation of results

- Low tech AAC provides meaningful lexical support during structured conversations for people with PPA.
- Low tech AAC significantly reduces lexical scaffolding provided by the conversation partner.
- This approach should be part of a PPA treatment protocol.

### Study 2: Conversations with natural partners

Does AAC support conversation between participants with PPA and their spouses, family members, care providers?

- More natural conversations
- About daily activities
- With frequent familiar partners



### **Study 2 Methods**

- Choose 4 functional daily activities with participant and partners.
- Make new communication boards with 4 pictures for each daily activity.
- Train partners how to converse using communication boards.
- Videotaped and transcribed 3 conversations with the board (AAC-supported) and 3 conversations without the boards.
- Randomly choose 8 words (2 per activity) to target during each conversation.



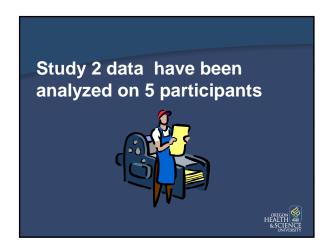




### **Study 2 Outcome Variables**

- # partner prompts for 8 target versus nontarget words
- # correct verbal responses by participant for 8 target versus non-target word
- # correct nonverbal responses in experimental condition (points to board)





### Study 2 Results: # partner prompts

- Number of partner prompts for target words was higher in the control condition (without AAC) than in the experimental condition (with AAC), but the difference was not significant.
  - Mean Control for targets: 11.9
  - Mean Experimental for targets: 8.1
- AAC support reduces the need for partner prompts, but the result is not yet significant.



### Study 2 Results: # Verbal responses

- Number of correct verbal responses to prompts was higher in the experimental condition (with AAC) than in the control condition (without AAC) for the 8 Target words.
  - Mean Control: 2.1
  - Mean Experimental: 4.8
  - -F(1,16) = 10.274, p = .005
- With AAC support, participants with PNFA are more successful at retrieving the correct verbal responses to questions regarding 8 targeted words in functional conversations with partners.

### Study 2 Results: # Verbal responses

- Number of correct verbal responses to prompts was higher in the experimental condition (with AAC) than in the control condition (without AAC) for the 8 non-targeted words.
  - Mean Control: .47
  - Mean Experimental: 2.1
  - -F(1,17) = 4.772, p = .043
- With AAC support, participants with PNFA are more successful at retrieving nontargeted words represented on the board in functional conversations with partners.

### Study 2 Results: Nonverbal responses

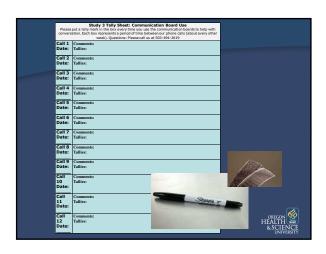
 In experimental conditions (with AAC), participants responded by pointing to pictures on the board an average of 3.6 times per conversation for Targeted words and 1.5 times per conversation for Nontargeted words.



## Study 3: AAC maintenance and generalization over 6 months

- Does AAC knowledge and use continue after training and videotaping is discontinued?
- Communication partners are taught:
  - What are natural AAC supports
  - How to use natural AAC supports during the day
  - How to tally board use with tracking tools





### Questions asked via telephone or e-mail

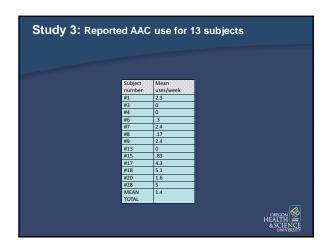
- 1) Since last time we talked, how many times has the person with PPA used the communication board?
- 2) Since the last time we talked, how have you used the communication board(s) for conversations (e.g., in what context)?
- 3) Do you have any other examples of ways conversation has changed in the past week (e.g. the use of a skill from the guidelines sheet helped, we used a map to talk about travel, other AAC)

## Communication modes reportedly used by 13 subjects during generalization probes

- Address book (2/13)
- Ads
- Calendar (2/13)
- Children's bible stories
   Carrage Bases (9/43)
- Comm. photo booklet (5/1
- Computer
- Cookbook
- Electronic photo frame
- F-mai
- Entertainment program
- Flashcards
- Gestures/ sign language/ pantomime (3/13)
- Guideline sheets (4/13)

- o. a...<u>\_</u> ...
- Magazine (2/13)
- Mail
- Maps (2/13)
- Museum
- Newsletters
- Newspaper (5/13)
- Paper & pen/writing (3/13
- Photos & photo albums (8/1
- Post it notesResident/staff directory
- Scrap book
- Show Me
- Singing





### Examples of spontaneous use in Study 3

- Pointing to weather pictures in newspaper to indicate time of day
- Pointing to framed boards on the family picture wall at eye level
- Discussing health conditions using pain intensity continuum line
- Flipping through photos in address book during a family visit
- Visiting a museum: Using photos to discuss what the home town looked like HEACHER

  HEACH

### Benefits of boards

- Facilitated communication between 2 adults with language impairments
- Facilitated communication between husband and wife with dysarthria from TBI
- Taught communication partners how to incorporate AAC tools into daily conversations
- Provided means for sharing new information: "Our granddaughter came by while you were out."
   Subject initiated message with board.
- Augmented existing lexicon: Subject with severe PPA said "rock grill;" stimulated "build, steel"



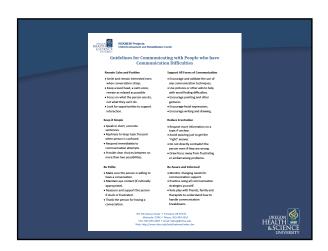
### **Next Steps**

- Increase number of participants in all studies.
- Compare conversations to data collected from control groups (AD and normal aging).
- Develop practice guidelines with characteristics of participants with PPA and their partners who benefit most from low tech AAC.

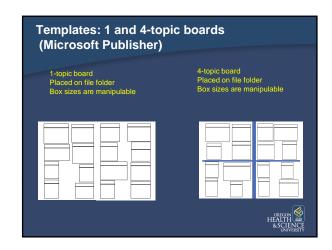


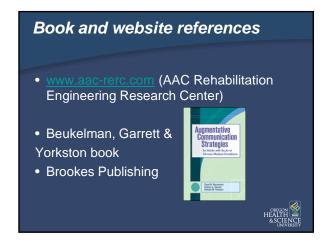
- "Guidelines for communicating with persons who have language difficulties"
- "Helpful hints for conversation"
- Templates for 1-topic and 4-topic boards
- Powerpoint slides
- Reference list

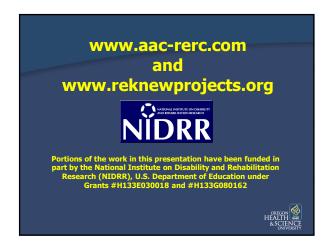












Disclosure Statement
I have no financial interest in any commercial entity whose products or services are described, reviewed, evaluated or compared in the presentation.

### Guidelines for Communicating with People who have Communication Difficulties

### **Remain Calm and Positive**

- Smile and remain interested even when conversation strays.
- Keep a level head, a calm voice, remain as relaxed as possible.
- Focus on what the person can do, not what they can't do.
- Look for opportunities to support interaction.

### **Keep it Simple**

- Speak in short, concrete sentences.
- Rephrase to keep topic focused when person is confused.
- Respond immediately to communication attempts.
- Provide clear choices between no more than two possibilities.

### **Be Polite**

- Make sure the person is willing to have a conversation.
- Maintain eye contact (if culturally appropriate).
- Reassure and support the person if stuck or frustrated.
- Thank the person for having a conversation.

### **Support All Forms of Communication**

- Encourage and validate the use of any communication techniques.
- Use pictures or other aids to help with word finding difficulties.
- Encourage pointing and other gestures.
- Encourage facial expressions.
- Encourage writing and drawing.

### **Reduce Frustration**

- Request more information on a topic if unclear.
- Avoid quizzing just to get the "right" answer.
- Do not directly contradict the person even if they are wrong.
- Draw focus away from frustrating or embarrassing problems.

### Be Aware and Informed

- Monitor changing needs for communication support.
- Practice using all communication strategies yourself.
- Role play with friends, family and therapists to understand how to handle communication breakdowns.

### **Helpful Hints for Conversation**

Use the examples below to help you think about how to begin a conversation, keep a conversation going, redirect the conversation, or to expand the conversation beyond one topic.

### **Request Details**

- Can you give me a specific example?
- How did that happen?
- Why did you go?
- What were the names of the other people?

## Request More Information to Expand the Conversation

- Is there anything else you can think of?
- Tell me more about...
- Had you done similar things?

### **Ask About Context**

- Who else was there?
- What were you wearing?
- What color was it?
- Who did you travel with?
- What did you eat?
- How did the flowers smell?
- Had you ever been there before?

### **Ask About Time/Sequence**

- When did it happen?
- What day of the week was it?
- Was it dark or light?
- What time of year did it happen?
- How long did it last?
- What happened next?

### **Ask About Place**

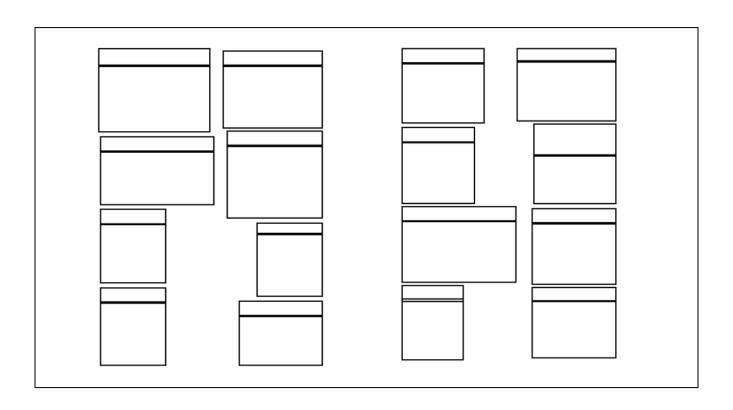
- Where did it happen?
- Were you inside or outside?
- What room were you in?
- Where were you sitting?
- What sorts of things were around you?
- Did you stay there or go somewhere else?

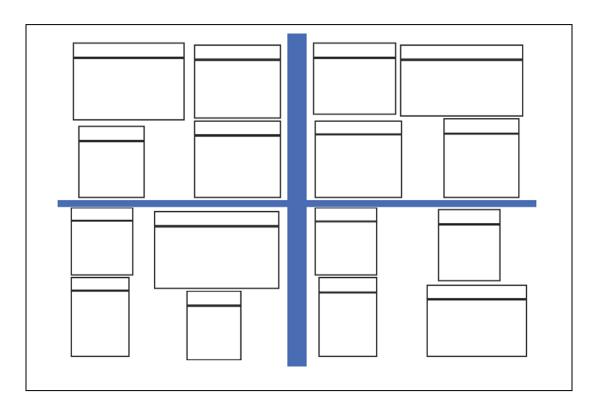
### **Acknowledge Any Response**

- Yeah, I like it there too.
- You're right, she is a wonderful friend.
- I remember doing that, and then we...
- That was a long time ago, but what I'm really asking is...
- I'd love to talk more about that.

Fried-Oken, et al. (2010). Communication boards support conversation in progressive nonfluent aphasia. ASHA Convention. Philadelphia, PA.

<u>Microsoft Publisher: Templates for 1-topic and 4-topic communication boards placed on file folders and laminated. Box sizes for photos and labels are manipulable.</u>





### Selected Reference List on Primary Progressive Aphasia

- Cress, C. J., & King, J. M. (1999). AAC strategies for people with primary progressive aphasia without dementia: Two case studies. *Augmentative and Alternative Communication*, *15*, 248-259.
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