Hi, I’m Melanie Fried-Oken and this is a webcast on augmentative and alternative communication for persons with primary progressive aphasia, moving from research to practice. This webcast is sponsored by the Rehabilitation Engineering Center on community enhancement a NIDRR funded center known as the AAC-RERC.

We are going to spend about an hour today and there are three learning outcomes from today’s session. First you will leave with an understanding of the symptoms of primary progressive aphasia. Then you will become familiar with an experimental study that I am conducting at the Oregon Health and Science University on AAC for persons with primary progressive aphasia. And then finally, you will leave with some AAC tools and strategies that you can implement immediately in communication treatment for folks with PPA. So let’s get started.

There are a group of individuals who cannot participate in conversation successfully as they used to because they are slowly losing their language. They have what's known as primary progressive aphasia. I would like to introduce you to a couple that is dealing with primary progressive aphasia. In this short video you will see a husband asking a wife with PPA to say his name.

Let’s talk a little bit about what PPA is. Generally individuals between the ages of 55 to 65 years old are diagnosed with PPA. We see it more in men than in women, and often people are diagnosed with Alzheimer’s disease, but in fact their nonverbal memory is intact and they are having problems with language not with other cognitive skills.

There are three types of progressive aphasia that have been discussed in the literature. The first type is called progressive non-fluent aphasia. In this situation individuals are pretty much losing their expressive language skills.
first. A second type is called semantic dementia, and in this syndrome individuals are losing their ability to understand language and to come up with words. And the third type is referred to as logopenic progressive aphasia and it refers to individuals who are losing words, having problems understanding, but mainly because of speech sounds more than because of word parts.

8) Traditionally, a neurologist diagnoses primary progressive aphasia based on seven symptoms. The first one is a gradual loss of word finding or object naming while comprehension is intact. So you see yourself losing words. The second symptom is that activities of daily living are compromised due to language problems for at least two years. The third one is that individuals have intact language skills before this problem. We don't see any other symptoms that are related to brain disease, frontal lobe brain disease, such as apathy, disinhibition, forgetfulness, visual spatial problems that are usually associated with types of dementia and this is clear for the first two years of the disease.

9) We can see some problems with numbers and with calculations. There might be some problems with other areas of daily living. But they are attributable to a language problem. And finally, there is no general cause, so the person hasn’t had a stroke. There will be ruling out lots of other diseases through MRIs and neuroimaging.

10) There is still a lot of confusion about primary progressive aphasia. It often overlaps with a lot of other brain diseases.

11) I am going to go into some specifics about the language symptoms now. So the first, most prominent symptom is anoma or trouble thinking of or remembering specific words when you are talking or writing. And we can talk about different kinds of anoma. We can talk about different manifestations of anoma. For example, substituting words. So an individual might want to say “I saw Michael Jordan” and instead might say “I saw basketball” and can’t come up with the specific word, "Michael Jordan". We also see individuals who use a lot of circumlocutions, or talking around a word. Such as they want to say teacher, and what comes out is “The one who stands in front of the class and talks. You know the adult with students sitting in a classroom.”

12) We also see increases in speech problems. So being able to say the sounds in words. For example individuals might substitute sounds. Like instead of saying “drink” they might say “brink” or instead of saying “thought” they might say “fought.” And also we see distorting sounds in words. So instead of saying “joyful” they might say “johful” or instead of saying “dodgeball” they might say “dodball".
13) Often the speech is slow and hesitant, and there are long pauses or filler words. A lot of “uh, um you know, uh, that thing” or “I can’t think of that word”. So we see a lot of fillers. There is a struggle sometimes for speech sounds. So they know what they want to say but the wrong sounds are coming out. Generally we see difficulty understanding quickly spoken words in noisy environments and that worsens over time. And problems with numbers or arithmetic, so often someone can’t recite their phone number or tell you what their ATM code is.
I’d like to show you a quick video clip of Amy, who has classic primary progressive aphasia and is struggling for some words.

14) (Video)
   - Melanie: So, is it easier to have conversation with people who know you?
   - Wife (Amy): Oh yes. Than new people that I see?
   - Melanie: Yes.
   - Wife: Yeah, because, I don’t look like what people would think. And, I feel, you know, then when sometimes when I have to I don’t get it, like this. And then, you have to tell them what you’re doing. And, I don’t think you have to tell them all the time, you know?

15) Now the disease progresses over time. We begin to see problems with yes/no confusion. So someone means "yes" and they say "no", or the mean "no" and they say "yes" and it comes out quickly, or we see more groping and struggling for sounds in words. So words are coming out wrong and the person knows that there are errors. By the end of the disease an individual can become mute. And we often see that the written language mimics the spoken language problem.

16) Now someone who recognizes they are having a problem with language might go through the following course. First the person themselves and family members, or peers might become aware that communication skills are impaired. They might start by saying, “I am really tired”, or “I can’t think of things as well”, and they might notice their language is becoming more and more difficult. So they approach a medical team and they get a comprehensive assessment. Often the medical team will include a neurologist, and the neurologist office staff, a neuropsychologist, a speech language pathologist, and a psychiatrist, or a social worker. After the diagnosis the individual is often recommended for communication treatment and that is where we are going to go now – to talking about communication treatment.

17) There are three major goals for all of treatment related to primary progressive aphasia. The first goal would be to compensate for the progression of language loss. What I mean here is we’re not going to stimulate the language system to regain skills. No drill and practice to get
back all the words that begin with “b” or have to do with animals. At an early stage we need to say we are going to compensate for what the person is losing by offering them visual language strategies and tools, and since you don’t communicate just to yourself all of the people who are your communication partners also must be involved in treatment. We must reach out to multiple partners and make sure that they are involved in the dyadic or the two-way communication and support.

18) So our big treatment challenge then, is to put the person’s residual lexicon, or their internal dictionary, in front of them – visually in front of them so they can see needed vocabulary that they can’t come up with by themselves. And they can participate in daily activities without any loss. So that’s our treatment challenge.

19) Now we are going to see how that plays out in a research study. We are going to start. I am going to let you know that there is very little empirical evidence that augmentative communication helps people with primary progressive aphasia. We have a bunch of case studies where people have described the treatment they have done, and we have a bunch of clinical descriptions of over time giving different tests and trying different treatment options. But we don’t really have any experimental study that looks at the value of augmentative communication. So that was our purpose.

20) We decided as a team at Oregon Health and Science University, to provide evidence that shows that augmentative communication – and in our case we used low-tech communication boards. We wanted to provide evidence that communication boards, which are low-tech augmentative communication, will support adults with primary progressive aphasia during conversation. We wanted to provide augmentative communication for individuals so they could participate in daily activities.

21) I am going to describe to you three studies that we are conducting now. They go from very structured to very natural. For the first study we asked: “Do personalized augmentative communication boards in very controlled conversations with researchers improve conversations?” And I am going to go into specifics of what that means.

22) Our second study which I will describe to you asked: “Do personalized augmentative communication boards about daily activities, that are used in conversations with familiar partners (such as spouses, or children, or care providers), do they improve daily conversation?”

23) Then in the third study we wanted to see if these communication boards would generalize and be used six months after the study finished.
So let’s go into the specifics of each of these studies and the results. So study one: what we did was we went into the home of individuals with primary progressive aphasia and we spoke with them about what topic of conversation they enjoyed talking about but couldn’t talk about so well anymore. We decided what that topic was together, and then we made a communication board, with the individual that included 16 photos plus a word or phrase written above the photo. We taught individuals how to use these boards for conversations. Then when we were comfortable using the boards for conversations we conducted six very controlled conversations with them using a script. Three of the conversations with the script included the communication board, and three of the conversations did not include the communication board.

Here is an example of a board, and I am going to show you conversations and boards as we go. So this is a board about garage sales, which is the topic that was chosen by Judy. Here are the examples of the 16 items. Take a look at the item that says storage unit because I want to show you the scripted questions that we asked Judy when we were looking to get the word, "storage unit".

First we would say to her, “Where do you keep the bulk of your items for sale?” If she found the word "storage unit" and said it, then we were finished with that question. If she could not find that target word, then we would supply her with another probe. In this case we would say, “This place is downtown.” If she still couldn’t come up with the word, we would say, “You mentioned that you have a couch here.” And finally we would provide the word for her. I’d like to share with you a video of an individual in a scripted conversation. In this conversation the researcher, and the participant are talking about Alaska and the word that the researcher is looking for is Kenai. You’ll see the researcher going through many different questions or probes to get at the word Kenai.

(Video)

- Researcher: So where was it that you caught that thirty pound salmon?
  - Participant: It’s in Ana … Alaska.
- Researcher: That’s right. And more specifically? There’s a certain place where you caught it in Alaska.
  - Participant: It is…
- Researcher: You’re about to say it.
  - Participant: It is…Ken…Kenad…called…
- Researcher: So, maybe this will help. It’s a peninsula.
  - Participant: Yes
- Researcher: And it’s also a river.
  - Participant: Yes
- Researcher: And I believe you caught your fish on the river, your salmon on the river.
  - Participant: Yes.
Researcher: Okay, so, what is the river called in Alaska?
Participant: It is...it’s Kenai... (approximation).
Researcher: Kenai. That’s right.

28) Now that you understand what a scripted conversation looks like, let me tell you about the specific study and who was involved. As of April 2011, we have 17 individuals with progressive aphasia who are enrolled in the study. Each one has 6 conversations for study 1, that means we have 102 conversations taped.

29) We have nine women, and eight men. They range in age from 52 to 78. They are highly educated. They have all finished high school with a lot more schooling. In fact their mean education years is 17. They have a clinical dementia rating scale score between .94 and 1.08, which means they don’t have dementia. And the next score BNT, that means Boston Naming Test, which is a test that you show pictures and ask someone to name what they are. There are 60 pictures. These individuals have scores that range from 2 to 52.

30) The 17 participants either lived in family homes, and that was in a city, in a suburb, or even on farms, to assisted living facilities. We are concerned with who their conversational partner is. Most individuals have spouses who would converse with them. We also had paid caregivers and friends. The length of the relationship between the participants and partners is important to us, how well they know each other, and their vocabulary. They ranged from 1.5 to 60 years, so most of the individuals were married for at least 35 years.

31) Here’s another board I want to show you because I want to introduce you to Mr. Riderwood. This board is about his travels, and the two pictures I want you to pay attention to are the top one which says traffic cop, and the one in the middle that says turn signal. And now I will have you listen to Chris, the researcher, as he converses with Mr. Riderwood about these two items, with and without a communication board.

32) These are the questions that Chris will ask: “You had an old Volkswagen in the army, what was particularly unique about this car?” and Chris is looking for the answer “turn signal.” Then the other question was: “This broke off of one of the turn signals while you were in Germany” and Chris is looking for the answer “traffic cop.” Now take note of the struggling and the difference between coming up with those words when Mr. Riderwood does have a communication board and when he doesn’t.

33) (Video)
• Researcher: Now, apparently you had this old Volkswagen in the Army.
• Mr. Ryderwood: Uh huh.
• Researcher: And compared to cars nowadays there was something fairly unique about this car.
• Mr. Ryderwood: Oh, yeah.
• Researcher: Do you remember what was unique about that car that we could talk about?
• Mr. Ryderwood: Well, there were several things, but one thing is if you need to turn your tile that way or that way, there's a procedure. If you're driving on the right side and you have to turn to that, then you've got this gizmo. It swings out there, and that's says that I'm trying to turn, and conversely on the other side. I don't know how they do it that way 'cause I never saw them do it.
• Researcher: It's pretty cool. So what do you call those things?
• Mr. Ryderwood: I have no idea.
• Researcher: They're not electric.
• Mr. Ryderwood: No, no.
• Researcher: And so they're very unique. They only stuck out there when you needed them.
• Mr. Ryderwood: Right. I mean, you would do whatever's things and then there's stick out there like a whatever.
• Researcher: A wing or something.
• Mr. Ryderwood: Something out there.
• Researcher: It's a turn signal.
• Mr. Ryderwood: Yeah.
• Researcher: So these turn signals flipped up. I still think it's a great idea, even today.
• Mr. Ryderwood Yes, I agree.
• Researcher: I mean to me that would work just as well as a flashing light. Well, maybe not at night, but as a backup to your flashing light. So, someone broke off one of these turn signals while you were in Germany.
• Mr. Ryderwood: Yes.
• Researcher: Who broke off that turn signal?
• Mr. Ryderwood: Well, it was ... no, not Friday ... it was Friday, and it was late in the afternoon. Everybody's going as fast as they could to get everywhere to wherever they were gonna go. So they have these people who tell people, "Go this way," or, "Go that way," or whatever or whatever, and one of the guys ... one of the persons there wanted to make a left turn, and the ... 
• Researcher: This was right in the middle of an intersection?
• Mr. Ryderwood: This was right in the middle of an intersection. The guy said that ... can't ... whatever he was doing. He said, "No, you ... we can't. ... you gotta go that way, you can't go that way," and then he went through the process again, and again he said, "You can't do that. Go that way." Third time, he said, the guy said, "Ah, but I gotta ... " so the guy got down off his pedestal, reached in the window of the guy's window ... well, yeah ... took that thing off there, threw it in the window, and he went where he was supposed to go.
• Researcher: That's amazing.
• Mr. Ryderwood: I'm just standing there. I wasn't doing anything.
• Researcher: So he wanted the driver to go straight instead of turn.
• Mr. Ryderwood: Right.
• Researcher: So what was he? Did he work for the city?
• Mr. Ryderwood: Yes, yeah.
• Researcher: OK.
• Mr. Ryderwood: They've got this big pedestal.
• Researcher: So it's like a traffic cop.
• Mr. Ryderwood: Yeah.
• Researcher: OK, gotcha. The last thing I want to mention is that there's a great story you tell about a very close encounter with an animal, and you describe this as a near miss with a . . .
• Mr. Ryderwood: Llama, I think it was a llama.
• Researcher: And what was that llama gonna do? What was the near miss?
• Mr. Ryderwood: We were . . . a lot closer than I wanted him to be.
• Researcher: What was . . . state the intentions of the llama. What was the llama intending to do? You have a near miss with a . . .
• Mr. Ryderwood: Well, the llama had, well, the llama . . . somebody had a llama, had two, two of them, actually . . . and, down the hill a way, somewhere . . . and somebody killed one of the two.
• Researcher: Oh, that's unfortunate.
• Mr. Ryderwood: It was not good, but one of them got killed, and the other one jumped the thing, jumped the fence, over there, and finally got up as far as it could go. Sissy and a couple other people were milling around a bit and they all went inside eventually, so it's just down to me and the llama, and I'm just standing there. I'm not doing anything. I'm just standing there.
• Researcher: Yeah.
• Mr. Ryderwood: And he was . . . he or she? I can't remember. It would come down the hill a little ways in this direction, and it would come back, and he kept down, down, down, down, down, down, down, and I just stood as still as I could be, 'til it got to his nose to my nose, and it was a bit much.
• Researcher: So you had a near miss with a llama kiss?
• Mr. Ryderwood: Oh, you bet.
• Researcher: So that llama must have sensed that you were a lover, not a fighter. He figured, "You know what? He's not gonna kill me. This guy, if I kiss him he might actually save me."

34) (Video)
• Researcher: Well, you had, apparently, an old Volkswagen in the Army that had a unique . . . had something very unique on it that we wanted to talk about.
• Mr. Ryderwood: You mean about the turn signal?
Researcher: Exactly. And what was different about that turn signal than what you see today?

Mr Ryderwood: Well, it's got . . . it has to be done by hand.

Researcher: Oh, so it's a manual . . .

Mr. Ryderwood: It's a manual device.

Researcher: Right so you literally flip . . . so is there another lever that extends inside the car here?

Mr. Ryderwood: I don't know.

Researcher: I'd be curious to find out because I wonder if they have a wire that goes down somewhere that you pull, or if you literally have to flip a . . .

Mr. Ryderwood: I think you've got to flip something up there. Well, I don't remember.

Researcher: Apparently one of these was broken off in Germany by someone.

Mr. Ryderwood: Well, there was a guy who was standing up over there.

Researcher: What do you call him?

Mr. Ryderwood: Well, he's a traffic cop, and when it's 4:00 or 5:00 in the afternoon, and everybody's going . . . all wound up, and these guys keep everything running, so to speak.

Researcher: Sure, sure.

Mr. Ryderwood: And some dodo . . . well, OK, the traffic cop is standing over there, telling, "You go this, you go that," and well, some dude wanted to turn right there, and the guy on the pedestal said, "No, you can't do that," and he said it three times. The third time, he took this thing off of this car, and he just broke it off, and shoved it through the window, and he went where he was supposed to go.

Researcher: It almost makes you wonder if that wasn't the first time he'd broken one of those off. At some point you have to wonder about that behavior. Alright, well the last question I have for you has to do with what you describe as a very close encounter with an animal, and something that you call--

Mr. Ryderwood: I'll never live it down.

Researcher: --a near miss with something.

Mr. Ryderwood: That's her right there.

Researcher: That's right, and what's happening?

Mr. Ryderwood: Oh, there's a kiss.

Researcher: Yeah.

Mr. Ryderwood: I bet you never did that.

Researcher: No, and I have no interest in it. I like llamas. In fact, I've talked about it before. If we were ever lucky enough to get out of this city and have a little . . . I wouldn't mind having a llama and or couple of goats, but I have absolutely no interest in kissing them. My dog does enough of that.
35) Now you can see huge differences with and without a board. When you are doing a study you have to figure out a way to measure that one is much better than the other or that there are big differences between one condition and the other condition. So with the communication board we are going to measure how many times the subject says the target word or a synonym with speech or by pointing to the picture on the board. This is called the experimental condition. Without augmentative communication, we are going to see how many times the subject says the target word or a synonym. This is called the control condition. What we did, was we added up the number of correct responses for all the questions that were asked for the 10 words.

36) Here is an example of what we did. We came up with what's called a weighted conversation score. I know this is little busy, so I am going to describe it to you. We gave point values to each response. So if the participant got the word on the first question, they got three points. Remember that example of garage sale? so if the participant responded with the word “sign” after the researcher asked “How do you advertise for a sale?” – then she got three points. If she didn’t get it after the first time, and the researcher had to ask “You use cardboard and a marker to make this,” then she got two points. If she still couldn’t get the response, then the researcher would ask “You post it outside for people to see your sale.” If she responded correctly on the third question she got one point. Then finally, if the participant could not get the word at all, then we provided it and she got a score of zero. So for each of the 10 questions, you could get a score of 0, 1, 2, or 3.

37) So there was a total raw score that ranged from zero (which was no responses correct for all ten questions) to thirty (which means the 10 questions were responded to on the first question for three points each). Then we converted this score to a percentage of the total points possible. This score combines accuracy, how well the person answered, with the level of support, how many questions the person needed. A higher score indicates good word accuracy by the participant, and less questions asked, so less support needed by the conversational partner. When you do an experiment like this you start with a hypothesis. We proposed that conversations with AAC support (with those communication boards), in comparison to conversations with no boards, would yield greater weighted conversation scores. So we have higher scores when the person used the board, and lower scores when the person had no help.

38) Here are the results from that question. Here is the first result. The number of correct spoken words was much higher when the AAC support available, than when there was no support. You can see the differences here with no AAC, and with AAC support. What this means is that people with progressive aphasia retrieve the correct words to questions more frequently when there
is AAC support. So they do better when the boards are available.

39) Let’s look at another result. This result has to do with the number of responses to that first, initial question. The number of correct responses to the first question was much higher with the augmentative communication support than without the support. You can see differences here that are very significant. This means that people with primary progressive aphasia retrieve the correct response to questions much more quickly and require less effort by the partners when there is augmentative communication support than when there are no boards at all. The boards seem to be helping with how fast someone retrieves responses as well as how accurate they are.

40) Let’s look at another result. Here we looked at that weighted conversation score and we saw that in general it was much higher for augmentative communication support than for those conversations where the person didn’t have anything to help them. This means that conversations with people with progressive aphasia and researchers are more successful when the AAC support is in place. There are fewer probes, fewer questions from the communication partner when they have some shared referent, or when they have pictures between them that they can both use, and that the person with progressive aphasia can rely on to help get words.

41) One more result that I’d like to share with you, and this is about pointing or those nonverbal responses. So we provide the board for three of the conversations and no board in the other three. We found that participants, when they had augmentative communication boards in front of them were pointing to pictures on the board, an average of five times per conversation. People with primary progressive aphasia are using the boards to express themselves and find words during conversations. They are not just glancing at the boards to get cues. They are actually doing more pointing than we had expected.

42) So what does this mean? It’s a lot of results from experimental studies, and it means that low tech AAC, in the form of communication boards, gives people with primary progressive aphasia meaningful language support during very structured conversations, and it means that augmentative communication significantly reduces the amount of support that is needed by a conversational partner. This approach we recommend, should be part of a primary progressive aphasia treatment protocol. Ok, not only do I recommend this, but so does one of our participants. I’d like to show you her response using the board, when she is talking about a vacation she took with her son. You won’t see her struggling in a conversation without a board when she couldn’t come up with the name of the place that they went on for vacation and she had a hard time saying her son’s name. So enjoy watching this.
43) (Video)
- Participant: He really is a fisherman, you know?
- Researcher: Well, you and Ben went on a fishing trip.
- Participant: Yes, we did, and we went to the Sawtooth Mountains and, um, this really works.
- Researcher: What’s that? This really works?
- Participant: This kinda works.
- Researcher: Yeah, it does, huh?
- Participant: And um, and um, so we um, we went camping . . . or not camping, what was that? We went there for about four days, and Ben would fish all day . . .

44) Let’s move on to the second study. We know now that the communication board helps individuals in very structured conversations when they are talking about one topic with a researcher, but how realistic and practical is that? So we asked another question to get much more practical. That would be study two where we asked, Does augmentative communication support conversations between people with primary progressive aphasia and their spouses or family members or care providers? This is a much more natural conversation, these conversations are about daily activities, and they are talking with people who are frequent communication partners. I’m going to show you a short video justifying the reasons we looked at these more practical, natural conversations as expressed by one of our families.

45) (Video)
- Man: You know here is something that as a family we’re dealing with and, you know as a husband and spouse, you want to be supportive, you want to do everything you can, and you struggle with sometimes how to best do that, how you can and whatnot, and Amy’s got a pretty independent streak also, just try finding that balance. And most of the days are really good, I mean you know, she’s positive and you can tell she’s a happy person and so that, that hasn’t been so bad. It’s just the transition, the whole thing, you know it’s just trying to figure out how I can be most supportive
- Amy: I have a good one. [laughter]
- Man: So do I.

46) So let’s get into the nitty gritty of study two. Study 2, instead of coming up with one topic of conversation that the individual enjoyed talking about, they are choosing four functional daily activities. So think about your day. You might want to talk about going to work, coming home, going out to dinner, watching a movie, exercising – going to the gym, helping your kids with homework, many different topics about daily activities. We made a new communication board for each of our participants that included four daily activities they chose with four pictures and labels on top of the pictures for each one of those activities. We called it a quad board because there were four activities on the board. Now we taught the partners – the
communication partners, spouses, children, care providers, how to use the board to have conversation. Once the partners were familiar, and the participants were familiar with the pictures and knew how to converse about these four topics, then we videotaped three conversations with the board, and three conversations without the board. What we did then was a little different. We identified eight words on each board, two in each of the activities and we asked the conversational partner to target those two words during the conversation.

47) Here is an example of a study two board. You can see some of the activities were outdoor activities, what you do at the beach, chores, and places you go, and then vacations.

48) Here is another board. This board is more about activities you do around the home - so going shopping, going out to eat, friends, and restaurants. I’d like you to hear a conversation using the board, between a man with primary progressive aphasia and his spouse.

49) (Video)

- Spouse: Tell them where we had lunch this week. When we were out doing errands we went to Tawalliton and we went to one of our favorite places.
- Man: Mhm.
- Spouse: Can you remember which one that is?
- Man: Sure. At Lee’s. At lunch here.
- Spouse: And what did we have?
- Man: Huh?
- Spouse: And what type of food did we have?
- Man: The Chinese.
- Spouse: The Chinese, right.
- Man: Yeah.
- Spouse: So next time we go to Sherwood we’re going to go to where?
- Man: Oh, Sherwood, a good place at Clancy’s, you been there?
- Spouse: Yes, she’s been there.
- Man: And then we eat the sandwich.
- Spouse: The sandwiches...
- Man: A lot of times there those good ones
- Spouse: See he likes to- see where we’re going here with this? And any way, where am I going maybe tomorrow with Peggy?
- Man: Well my sister where she used to work at Stockpot.
- Spouse: And what are we going to have when we’re there?
- Man: Well the happy hour. [laughter]

50) You saw how effective the communication board was for helping the individual find specific words and really participate in a meaningful conversation about those topics. So now, once we collected all of these
conversations, we again have to decide what we are going to measure, what
are the outcome variables for this study, and we are looking at three. The
first question we asked was: How many partner prompts or questions were
needed for the eight target words, versus the eight words that weren’t
identified for each conversation as target words. We also looked at the
number of correct verbal responses by the participant for those eight words,
versus for the eight words that weren’t targeted. Finally we looked at the
number of correct nonverbal responses, or how many times did the person
point to the board for the experimental condition.

51) Let’s look at the answers. For the question of having prompts when needed
for target words, we see that in fact the number of prompts for target words
was much higher when there was no communication board. Right now that
difference isn’t statistically significant, but we believe as we get more
subjects in this part of the study, we’ll see that this makes a bigger difference.
So we can say right now, that the augmentative communication support
appears to reduce the need for partner prompting, but we are not there yet.

52) Here is another result we looked at and that is the number of verbal
responses. Here we saw that the number of correct verbal responses to those
prompts was much higher with the augmentative communication device than
without the device for the eight target words. So they were coming up with
the words more when they had the board in front of them than when they
didn’t and this is significant and tells us that with augmentative
communication support people with primary progressive aphasia are more
successful at using verbal responses to questions for those eight words that
were targeted on the board.

53) So the last result we want to look at is about nonverbal responses, and we
found that in the experimental condition when a person had a
communication board that they were pointing to pictures on the board an
average of 3.6 times per conversation for the targeted words and half of that,
but still pointing to 1.5 times per conversation for the nontargeted words. So
they really were using the board for targeted and nontargeted words, but
when the person would ask specific questions for targeted words they were
using it even more. So we see that even in natural conversations with familiar
partners augmentative communication is making a difference for
conversation.

54) Let’s look at the third study. In the third study we asked, "Does this
knowledge that the partners and people with progressive aphasia have now
continue after training and after we finish videotaping and going to their
homes and telling them use communication boards? So do they use this stuff
on their own when we are not around?" We talked to the communication
partners and the persons with primary progressive aphasia, all about what
natural augmentative communication supports are. We showed them how to
use natural communication supports during the day, and we asked them to tally how often they were using the boards and other tools.

55) Then we called them for six months and we asked these three questions:
Since the last time we talked how many times has the person with aphasia used the communication board? Since the last time we talked how have you used the communication board for conversation? And finally, do you have any other examples of ways that conversation has changed since the last time we talked? For example have you used a map for travelling? Have you used any of the skills on the handouts we gave you? Have you gone through newspaper articles and looked at pictures? What else have you been using for augmentative communication?

56) I want to share some exciting and fun results with you. When we asked individuals what augmentative communication tools they were using after the study was completed, we got some really fun answers. In fact we got answers that showed the families indeed understand the importance of communication tools and how to take things from their natural environment and use them to support language. Individuals reported that they were using address books, that they were using children’s books, that they were using photo books, that they were using email or flashcards, or gestures, or magazines. One individual reported that they put post-it notes around and the person with progressive aphasia was reading the post-it notes. They were using scrapbooks, staff directories in assisted living facilities. So the partners and the persons with aphasia were recognizing natural augmentative communication tools.

57) They also told us about ways that they noticed how augmentative communication tools made a difference. So in one instance we were told that individuals were pointing at weather pictures in a newspaper to talk about the time of day. Another family actually took the communication boards we made, framed them, and put them on the wall in the house so that they were at eye level. And the person with progressive aphasia used to go to the wall and point to the framed board for pictures of family. Another individual reported using the communication board to discuss pain intensity with the continuum line that was placed on the board. Someone else flipped through photos in an address book during a family visit so they both could talk about the same person in the family. And one person reported that she took her mother to the local museum where they were doing a photo exhibit of what the town was like 50 years ago. And they together could have a conversation about the town by pointing to pictures.

58) They reported benefits of the boards also. One individual said that it really supported communication between two adults with language impairments in the assisted living setting. We had one couple where the husband had primary progressive aphasia and the wife had dysarthria, or speech
problems following an old traumatic brain injury and they used the board to help conversations so they both could be understood. One family reported that the husband with progressive aphasia was home alone and his granddaughter came to visit. When his wife got home he took the board and pointed to pictures to tell her new information that their granddaughter came by while she was out. A few people reported that the board helped them come up with different words. So for example, Walter had a lot of pictures on his board about travelling. And he had the word Rockgrill and a picture on his board. He did not have the words build and steel, but with the board he could point to the picture of rockgrill and utter build and steel. So it was used to help find other words in the person’s internal dictionary and stimulate other vocabulary.

59) So I have tried to demystify experimental studies for you and show you how the research can make a difference in clinic. Now I’d like to specifically give you tips on how this stuff can get into clinical practice. So what have we learned and how can you apply it. Before I talk I’d like you to hear one of our families talking about the value of augmentative communication and how you need to start early.

60) (Video)

- Melanie: So, I know you’ve helped us in our study and used communication boards with us. How did that work for you?
- Amy: I think they were helpful.
- Melanie: Mhm.
- Amy: Um, you could always, you know, p-, you know, do this little thing. And it will tell you what you were trying to communicate.
- Melanie: So you could point to the picture or the word?
- Amy: Yes.
- Melanie: And then Skip or Darlene or your son would know what you want to say.
- Amy: Mhm.
- Melanie: When you couldn’t come up with the word?
- Amy: Yeah.
- Man: Sometimes she would say it when she would see the written word, she’d, you know, that’s what she needed to get over that hurdle.
- Melanie. Right. That’s a great, yeah, So having your language in front of you and being able to read it out loud. Like I love the example of having the number on your license and using that - That’s a perfect example.
- Amy: Mhm.
- Man: Yes
- Melanie: And that board that you used for conversation it was about outdoor activities, is that correct?
- Man: There was some of that. It was vacation spots and things like that.
- Amy: Oh yes, uh huh.
- Man: We had a bunch of different subjects.
• Melanie: So it helped when we were having conversations?
• Man: I think so, but I also think that you know just kind of looking back on it it’s not something that- using the board is not something that’s easy. And what I’m seeing with the passage of time is that it’s not going to get any easier. And so what that suggests to me is that just the process of working with the boards needs to start early not late and when the person is most equip to do it. And that frankly for us has been the biggest challenge. Just having the discipline and the time to do that. And, I almost think it needs to be scheduled. It’s just, okay it’s 4 p.m., this is what we’re doing, you have a schedule. Kind of like you’re taking a class or something. Because it just doesn’t happen by itself. It’s something that requires a measure of discipline. Frankly, that’s an area that we didn’t bring to it. I think that- I see the promise of the concept, but I think that there’s some skills that need to be developed, and the sooner we start that process with discipline the more effective it probably will be for her and us in the long run.
• Melanie: Yeah, I have a colleague who says assistive technology without training is not assistive.

61) Indeed augmentative communication treatment and starting early is one of our important messages. The two big deliverables that I would like to suggest are that visual language is an excellent support when someone can’t get the words out of their internal dictionary or their lexicon, and by providing communication aids, whether they are low tech communication boards or communication devices or books – that providing these communication aids is very helpful for people with primary progressive aphasia. In fact the research shows that they need less support by their communication partners and they come up with more words when they have augmentative communication in front of them. We also know that including these aids early will make a difference as reported by the family. Because it is a huge task to find those words that go into the communication system, identifying that internal dictionary and learning how to use it

62) To help you with these things, we have added some handouts that are on the page of this webcast. So if you go to the webcast page you will see links to handouts for families. The first handout is called, "Guidelines for communicating with persons who have language difficulties". The second handout is called, "Helpful hints for conversation," and both of these were used in the experimental study I described. We’re also giving you the templates for making the communication boards. So in our study we actually used an open file folder and placed the pictures right on the file folder, and we’ve given you the templates for the one topic board, and the four topic board for the sixteen pictures. Another resource for a communication board template comes from the augmentative communication website at the University of Nebraska in Lincoln and I’ve included that reference here. You
can download templates for both boards, but you must use Microsoft Publisher for both of them.

63) As far as references go, where you can continue learning about augmentative communication for primary progressive aphasia, I refer you to three places. First the website that supported this webcast has other webcasts, references, and links that will help you. Second, a book was published in 2007 by Drs. Beukelman, Garrett, and Yorkston entitled Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, and there are chapters that relate to augmentative communication strategies for individuals with primary progressive aphasia as well as other conditions. I strongly recommend the book. It even comes with a DVD of handouts that you can use in clinic. Finally there is a website through the Cognitive Neurology and Alzheimer’s Disease Center at Northwestern University that really delineates treatment, diagnosis, and support for individuals and families with primary progressive aphasia.

64) I want to thank you for spending time with me today on “Augmentative and Alternative Communication for Adults with Primary Progressive Aphasia: Going from Research Study to Clinical Implications” and I would like to thank the funders who made this possible. I’d also like to acknowledge the researchers who were part of this study at Oregon Health and Sciences University and say thank you to Dr. Charity Rowland, Dr. Chris Gibbons, Glory Noethe, Darlene Daniels, Mayling Dixon, Caroline Mills and Aimee Mooney for making this happen. Have a good day.