

Day 2: Welcome and Agenda Review

Jackie Hinckley, Ph.D., Executive Director, Voices of Hope for Aphasia
Alejandro Brice, Ph. D., Professor, University of South Florida St. Petersburg



Rebecca Watson, Facilitator, Collaborative Labs, St. Petersburg College:

Good morning everyone and welcome back. We are going to get started. Before Dr. Brice frames the day, I would like to introduce new members of our team. Dr. Sheron Brown is your documenter today. She will be capturing your ideas to complete the Real-time Record that Karin began yesterday. You will receive it as one complete document. We also have P.J. joining us. He will be our technology guru this morning in place of Mike and will help facilitate our use of technology. We have Dru and Geoff again with us today. At the end of the day, Geoff will present his artwork. Now I would like to ask Dr. Brice to say his words.



Alejandro Brice, Ph. D., Professor, University of South Florida St. Petersburg:

Good morning. Did you enjoy your evening last night? Are you ready for Day 2? Yesterday I greeted you in Spanish and today I will greet you in Japanese. *Dr. Brice spoke in Japanese language.* Do you know why I spoke in Japanese? For about one year, I taught karate to Voices of Hope. *Participants indicated their understanding.* Now I would like to ask Dr. Hinckley to share her words.



Jackie Hinckley, Ph.D., Executive Director, Voices of Hope for Aphasia:

Good morning everyone.

we are
want to
United
like this
could be



I am so impressed with all of you. I received suggestions to revisit our information so that all on the same page. First, I remind you that no one in the States has ever done anything before. *Applause.* So, maybe this better, but right now we are

figuring it out. Today, you will have a chance to give us comments on what went well and what can be improved. We are all on a giant experiment. Keep calm and embrace the chaos. *Laughter.* If there is chaos, it is probably telling us that something great is going to happen.

Role expectations: What could our teams do?

Researchers can:

- Write a research question

Consumers can:

- Provide input on which topics or questions are most important to them
- Help create materials that explain the research in an understandable way

Dr. Hinckley: I want to remind you what our teams can do. We are going to work on the idea of a research question. Researchers bring the expertise of how a research question is written. People with aphasia and their family members bring balance to the research.



Ask an answerable clinical question
 Components of an answerable question
(<http://healthlinks.washington.edu/etp/pico.html>)

P: Patient, population, or problem
 What are the characteristics of the patient/population or problem?

I: Intervention or exposure
 What do you want to do with the client?

C: Comparison
 What is the alternative to the intervention of interest?

O: Outcome
 What are the relevant outcomes?

Hinckley 3/28/09-MSSA

Dr. Hinckley: With regard to research questions, I want to share a way of thinking about research questions. On the slide are the elements of a good research question.

PICO examples
(from ASHA, "Framing the Question")

Patient/ Population	Intervention	Comparison	Outcome
Stroke patients with aphasia	Treatment during acute phase	Treatment during chronic phase	Functional Communication Abilities
17 year old male with TBI	Cognitive rehab	No cognitive rehab	Return to work/school

Hinckley 3/28/09-MSSA

Sample Research Questions

What are the vocational outcomes (O) of a personally-relevant, functional individual treatment (I) compared to linguistic-specific treatment (C) in adults with chronic nonfluent aphasia (P)?

Do people with aphasia (P) who participate in yoga one hour before their speech therapy session (I) make greater clinical gains in word-finding (O) treatment than those who don't (C)?

Does structured dog training (I) improve life satisfaction measures (O) more than simply owning a pet dog (C) among people with aphasia (P)?

Hinckley 3/28/09-MSSA

Dr. Hinckley: Here are examples of research questions with all of the elements embedded within the question. These questions lend themselves to comparative effectiveness research.

**Role expectations:
 What could our teams do?**

<p>Researchers can:</p> <ul style="list-style-type: none"> • Write a research question • Explain and select the appropriate research design 	<p>Consumers can:</p> <ul style="list-style-type: none"> • Provide input on which topics or questions are most important to them • Help create materials that explain the research in an understandable way • Provide input on which outcome measures might be most meaningful to people living with aphasia
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This morning we are going to try to write research questions. You may have arrived here with a question that you are interested in. It is okay to put it on the table and get input. We do not all have to start from ground zero. Researchers, you may already have in mind how you want to study a particular question. It is fine to get input from the team.

**Role expectations:
What could our teams do?**

<p>Researchers can:</p> <ul style="list-style-type: none"> • Write the IRB application • Analyze the data 	<p>Consumers can:</p> <ul style="list-style-type: none"> • Help ensure that recruitment materials and consent process are appropriate and effective • Help recruit participants by distributing information or posters • Discuss and provide a different perspective on your data or results that you might choose to pursue
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Dr. Hinckley: While the researchers have to write the IRB, the consumers can help to make sure the process is understandable. This is a critical activity. Also, if you are in the area, you can help recruit people to participate in the research.

**Role expectations:
What could our teams do?**

<p>Researchers can:</p> <ul style="list-style-type: none"> • Write an article or otherwise disseminate results 	<p>Consumers can:</p> <ul style="list-style-type: none"> • Suggest channels of dissemination that will be important to people living with aphasia (and your future research participants) • Provide feedback on any drafts that are intended for patient partners or other lay audiences • Have a great discussion about what they think should come next
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When it comes to the end of the project, consumers can suggest to you where the results should go, if the written article is understandable and help lead us to the next steps. If every team wants to start from scratch, that is fine, but you do not have to.

Now, have I confused you or did I clarify?
Laughter.

Participants indicated that she clarified.

Dr. Hinckley: The purpose of our shopping experience yesterday was to match people

to research interests. It is important that we end up on a team that is in the world where we want to live. I want everyone to have a match. Also, I want you to have faith that when you leave today, your team will have a plan. Trust the Collaborative Labs team. We will get there.

Are there any questions?

Speaker: I would love for the researchers to have the opportunity to share what each of them is working on because we will only have the opportunity to sit at one table today, and

- We are trying to find matches between researchers, clinicians, consumers and family members.
 - Some research topics that you want to work on may not have a match at this conference.
 - We will work to get you a match!

At the end of today, each group will have a plan.

yesterday we only went to three. If we allow the researchers to share out, then we can have an idea of what is being worked on.

Rebecca: Would that be something that we can do during lunch with the synced microphones? We can do it, but allow me the time to figure out where it can live in the agenda.

Dr. Hinckley: Thank you for bringing this up. It helps us think about how to do the shopping next time, and we will never forget it because it lives in the Real-time Record. *Laughter.*

Speaker: To her point, if we hear it now, it would help us determine our area of interest.

Rebecca: We have an idea, but it requires a question for Dr. Hinckley.

The facilitator and Dr. Hinckley conferred to determine how to move forward given the question on the floor.

Rebecca: Thank you everyone for remaining calm in the mini-chaos. *Laughter.* We will allow the researchers to speak now. Here is my loving yet stern ask. We have got to keep this to one minute each because we have a really big agenda and we need the research teams to have the time that they need to leave with a plan. I will use my timer to keep us on track.

Dr. Hinckley: Since this is not planned, we do not have written words to follow what will be said. If you need written support, please raise your hand and one of our students can come to help you.



Speaker: At the medical school at the University of Washington, we are training medical students how to communicate with people who have communication problems. We are using actors to behave as people with aphasia. It is an interesting project.

Speaker: growth. stroke. and that is



At the University of Nevada Reno, we are working on post-traumatic We are taking the crisis and looking at how people grow after the The three studies prior to this one has excluded people with aphasia not okay. We are at table 13.



Speaker: At Central Michigan University, we are helping people with aphasia tell their stories. We are training speech pathologist and other clinicians to help people with aphasia tell their stories. We are at table four.

Speaker: are



At the VA Medical Center in Pittsburg at the University of Pittsburg, we are looking at technology and telepractice. We are looking at a comparative effectiveness study option.



Speaker: At Western Michigan University in Kalamazoo, we are looking at the best practices for speech services for people with aphasia, the post discharge experiences and how we can improve that.



Speaker: At the University of North Carolina, we are empowering people with aphasia in therapy to help them make decisions. I am interested in motivation and finding out how speech pathologist can help people get what they really want.

Speaker: changes



At Louisiana State University, the research focus is on how the brain with aphasia therapy over a long period of time.



Speaker: Also, in Louisiana, we have been looking at assistive technology now that they have moved to phones, as opposed to big clunky devices. I am working on debunking the myth that AAC inhibits language recovery.



Speaker: At St. Cloud State University, I am working on hand gestures. We are looking at do you have access to the four types of hand gestures that humans use after aphasia with the goal of creating interventions.



Speaker: At Hofstra University in New York, we are working on naming and word finding and what modality helps someone with aphasia. We are in the assessment phase right now. We may branch into eye tracking.



Speaker: I am a Ph.D. student and at Spalding Rehab in Boston looking at where we will be a year from now. We wonder how a person responds to cuing and how it helps recovery.



Speaker: At Florida State University, we are studying the changes in reading and spelling after aphasia. We have been piloting a nine-week treatment study focused on helping people relearn the correspondence between letters and sound.



Speaker: I am at the University of Central Florida, and here I am at the yoga table. We are interested in the effects of exercise and reducing stress on the effects on aphasia recovery.



Speaker: At the University of Central Florida, we are looking at literacy, community literacy and the outcomes for those who participate in aphasia education.



Speaker: At the University of Pittsburg, we are looking at how people with aphasia respond to their language problems. I am also interested in resilience and coping.



Speaker: I am a doctoral student and at Lingraphica, where we are looking at the lack of SLP training and how it affects the level of care partner training.

Rebecca: Thank you everyone. Please note that this is the last time we will be in this room today, so as we prepare to leave, remember to take all of your belongings.

Session Agenda

Day 2- Saturday October 20th

1. Welcome & Agenda Review
2. Define **Success**
3. Elevate Priority **Next Steps & Timelines**
4. Wrap Up

Collaborative Labs
National Institute on Deafness and Other Communication Disorders

Here is what we want to accomplish today. We will use yesterday's thoughts as a springboard. We will spend some time defining success by brainstorming research questions. Every team will move one research question forward this afternoon. We will then move into what are the next steps and time frames that are needed to bring your work to life. Your action plans will not be super stringent, but we want you to have key milestones to be able to keep the momentum going forward once you leave today.

Collaborative Process

1. Deploy to Breakout Teams
2. Appoint a **Keyboarder**
3. Appoint a **Spokesperson**
4. Move When The **Music Plays!**
5. "Other"

Collaborative Labs
National Institute on Deafness and Other Communication Disorders

Rebecca: This is our process at the labs. We made room size adjustments today based on your recommendations from yesterday. The stack of paper in the center of your table has your room and team assignments. Once you arrive to your team station, we ask that you appoint a team keyboarder and spokesperson. We use music to help you know when it is time to stop working

and start moving whether it be to rooms, for lunch, etc. Be sure you use the sheet to get yourself to the correct room. Before you go, Debbie would like to share.



Debbie: Do you all know that the mega lottery is now \$1.6 billion, but our pot is now over \$600. *Laughter.* If you get the winning ticket, you get half of the pot and the other half goes to our aphasia work. We will draw the winning lottery ticket during lunch. The silent auction will also go through lunch.

Participants transitioned to their room and team assignments.