Dr. Hinckley: I want to tell you I was not a planned speaker when we started organizing this conference, but I am honored to speak with you. I want to talk about where are we going to go now.

This is Jennifer Keelan in 1990, a young girl with cerebral palsy. They were fighting in Washington D.C. for the Americans with Disabilities Act (ADA). One of the organized protests was to have people get out of their wheelchairs and climb up the steps of the Capitol building. At the time, there was no way for a person with a disability to get into the Capitol.

Dr. Hinckley: A few months later, we ended up with the Americans with Disabilities Act. Today, you can watch a video of Jennifer as an adult. People see her as a heroine for getting that Act signed.

President George Bush signs the ADA

It has been thirty years since that has been signed. We have ramps, curb cuts, phone and video services, and transportation. There is still a lot of work to be done. Things have changed
so much from then. Now, we have an opportunity to go somewhere independently.

Dr. Dorothea Wender’s experiment

- Worked on Greek
- Greek improved
- NO work on Latin
- Latin stayed the same

She was convinced that practice helped over many years.

Dr. Hinckley: Dr. Dorothea Wender was a professor of Classics: Greek and Latin. She had a stroke with aphasia. She noticed that as she worked on things, she got better at them. It used to be you would get a little therapy at the beginning and then that was it. She did an experiment: she worked on her Greek, but not her Latin. In three years, her Greek was almost as good as before the stroke, but her Latin was not good at all. She published a paper about the experiment she did on herself in the *Archives of Neurology*! She did it because she was personally convinced that doctors and others needed to know that if you kept working on something, you would improve.

You may have some ideas of some things that you want known. You may want to communicate that with your therapists and doctors. You do not have to do it alone. We have researchers that can do it with you.
Dr. Hinckley: In the 1990s, a lot of people with aphasia and clinicians were realizing there were techniques the people with aphasia could use in communication.

One of the tools was the Supported Conversation for Aphasia. We now know there is a toolbox and we can use those tools.

This came about because we have people with aphasia, therapists, and researchers coming together. Information was gathered about Supported Conversation. Now they share information with others.
Dr. Hinckley: Now we know Supported Conversation is one of the best things to do. These are just a few of the best practices; there are ten in total. Doing the research added up to a recommendation across many countries.

Best Practice Recommendations For Aphasia

- Aphasia United has compiled guidelines, and their levels of evidence, in an international best practice guideline for aphasia
  - Information intended for people with aphasia should be available in aphasia-friendly formats
  - All health and social care providers should be educated about aphasia and trained to support communication
  - Family members should be included in the rehabilitation process
    - Should receive information about aphasia
    - Should be trained to communicate with the person with aphasia

Q: What can help collaborative research?

A: Being able to make information aphasia-friendly

People with aphasia & family members: 78%
Researchers and Clinicians: 100%
Dr. Hinckley: Supporting communication and everything we know about it took all of us. We do not have to crawl up the stairs; we have tools.

When we get to the top of the ramp, where are we going to go? I woke up this morning so excited.

To warm us up a little, I want to point out a couple of research questions that people with aphasia and their families came up with from an aphasia support group. There were 22 questions they wanted to know. They are questions that I never would have come up with.
Dr. Hinckley: I do not know what our groups are going to come up with today and tomorrow. We are all here, standing at the top of something, and we are going somewhere new. I thank you for being a part of it.

Applause.

Dr. Brice: We have fifteen minutes for questions.

Speaker: Going forward, how are we going to be divided into our groups?

Dr. Brice: We are not going to dictate that, you are going to choose.

Kathy Caputo: Why hasn’t research been done in this manner before?

Kathryn: We came from a medical model that understood “the condition,” and that was a big job. It is the evolution of our discipline. A lot of people say we have not gone far enough.

Pat Boyle: The federal agencies and nonprofits expect a certain testable product. Many years ago, I wanted to test our program and look at outcomes. I submitted
a grant and my colleagues blew it out of the water with controls that were needed. The reason it has taken so long is that the funding agencies that might be interested have certain expectations for funding research.

**Speaker:** We have fallen into the trap of aiming for a certain outcome, but as we know, people are different and cannot be categorized into a particular group.

**Speaker:** I think it stems from how researchers are evaluated in terms of productivity. Until you get tenure, you cannot focus on what you want and take the time necessary. Now that I am tenured, I can think about this. That is what prevented me from coming this route for so long.

**Speaker:** In Massachusetts, we advocated. It needs funding on a basic level. You need the research and the advocacy to get people’s attention.

**Speaker:** I want to thank the women on the panel doing this work for so many years. You have impacted us in the field and taught us. I wanted to thank you.

**Speaker:** I was a paramedic and now speak with emergency response teams about aphasia. I want to bring awareness to people in the hospitals.

**Speaker:** I would like to have more training for counselors, therapists, and psychologists.

**Speaker:** When you talk about the ADA, a person who is deaf gets a translator; why doesn’t a person with aphasia have a speech pathologist available as a standard practice?

**Audrey:** I do not know if that could be a standard practice without the hospital approving it.

**Kathryn:** Some places do it better than we do, such as in Sweden; they have support people that will go with you. We are behind in that area.

**Scott Johnson:** My wife had a stroke a few years ago. Our hospital in Orlando did a great job.
doctors are very knowledgeable about aphasia. It can be done. It is good to highlight the places that are doing it well.

**Speaker:** I am grateful to be here today. As a professor pre-tenure, I think these are the risks worth taking if we are willing to do it. We need to think about other research models. There are new models out there. Precision medical for example. If you get enough information from all the treatment out there, you can do an analysis of what is working. *Applause.*

**Speaker:** Work on resources and tools for being empowered. People are routinely excluded because of communication difficulties.

**Dr. Hinckley:** Being involved in this project, I daydream what will be at the end of this. My fantasy is to bring the tools we use here together to do what you just said. We do not know what the tools are right now, but we are going to find out today and tomorrow.

**Speaker:** I have aphasia and have been in three research studies. They would say, “This is where you have to go.” I drive, but researchers said it would take up to three years to get all the people with aphasia to come to them. I asked why they cannot pay for people to come, but they were not willing to do that.

**Speaker:** What do people do with aphasia that do not have any friends or family?

**Speaker:** We have Facebook groups. My son had a stroke 20 years ago. Depression and isolation are horrible. People with aphasia are starving for attention. It is tough. You might want to have a Facebook group for this group. *Applause.*

**Rebecca:** Let’s give our panelists another round of applause. *Applause.*

*Lunch break.*