Kathryn Yorkston, Ph.D., Professor of Rehabilitation, University of Washington: I want to also thank you. My research is in motor speech disorder. I am going to talk about the things we are doing right. I say “path,” because we are not there yet.

Dr. Yorkston: Clinicians and researchers are familiar with the World Health Organization model. It gave us a list of terms, which we continue to use.

Impairment is what has gone wrong with structure and function. Activity is the execution of tasks, and participation is involvement in life situations.

Traditionally, speech pathologists have focused on the impairment. The World Health Organization model has given us freedom to say that other consequences of aphasia are just as important.
Dr. Yorkston: Exchange is important because there are always two people involved, not just the person with aphasia.

Communicative participation: To take part in life situations where knowledge, information, ideas or feelings are exchanged.

Dr. Yorkston: One of my former students did a study on family members in this area. The speech pathology field embraced this third-party disability because the third-party is important in communication.
The other path is listening to the lived experiences of people that have had the disorder for a while.

We are adapting the research to the qualitative. To understand it, you have to understand it in the communication in which it occurs. They are not the expert in what it is like to live with aphasia.

Dr. Yorkston: It is more than just chatting with people. It is important to listen to the lived experience. It is rigorous, and the process takes time.
Helen Mach is beginning to publish research disorders associated with Parkinson’s disease. Parkinson’s is a different disease, but the consequences are very similar. When they interviewed family members, they talked about increasing decline in movement, but they also talked about finding a balance.

There are some similarities here between being supportive and giving a spouse autonomy. My mantra is, adult onset communication disorders have some similarities and we need to get out of our condition-related silos.

**Talking with Families**


**Finding a Balance**

- “...not to just jump in and try to fix it. Some of it he needs to do himself.”
- “Anything that encourages more dependence on me is not helpful. [My husband] needs to feel like he’s an individual person.”
- “It’s a balance of how much do I do..., it’s still hard to stop yourself from wanting to help.”

**Aging with Disability**

- Traditional definition; Successful aging
  - Absence of disease
  - Physical function
  - Longevity
  - Emotional vitality
  - Intact cognitive function

**Dr. Yorkston:** We have been funded in the last fifteen years in this project. There are many conditions that occur early in adulthood that result in living with a chronic disabling condition. We have how to measure successful aging with a condition, such as those here.

**Dr. Yorkston:** For our people, some of those items do not make sense, so we ask how we should measure it for them. I found it interesting and surprising to listen to what they said.
Dr. Yorkston: I think we are going in the right direction and expanding our description of communication problems. Listening to the lived experience forces us to define success in treatment.

Dr. Yorkston: In terms of expanding our description, we need to go beyond the impairment level. It needs to be defined by patient and families.
Dr. Yorkston: Back to our definition of success, we can perhaps apply it to communication disorders.

Aging Well with Disability

- Using of psychological, social support & healthcare resources
- To live a life consistent with my values
- In the context of ongoing disability

Dr. Yorkston: For the first one, I think education is critical, to let people know how to live with a disorder and an approach of self-management. Second, have treatment goals and outcomes patient- and family-centered. Third, have treatment available where and when it is needed.
Treatment should be

- Individualized
- Focused on developing psychological, social support & healthcare resources
- Strategies should be client/family generated

Applause.