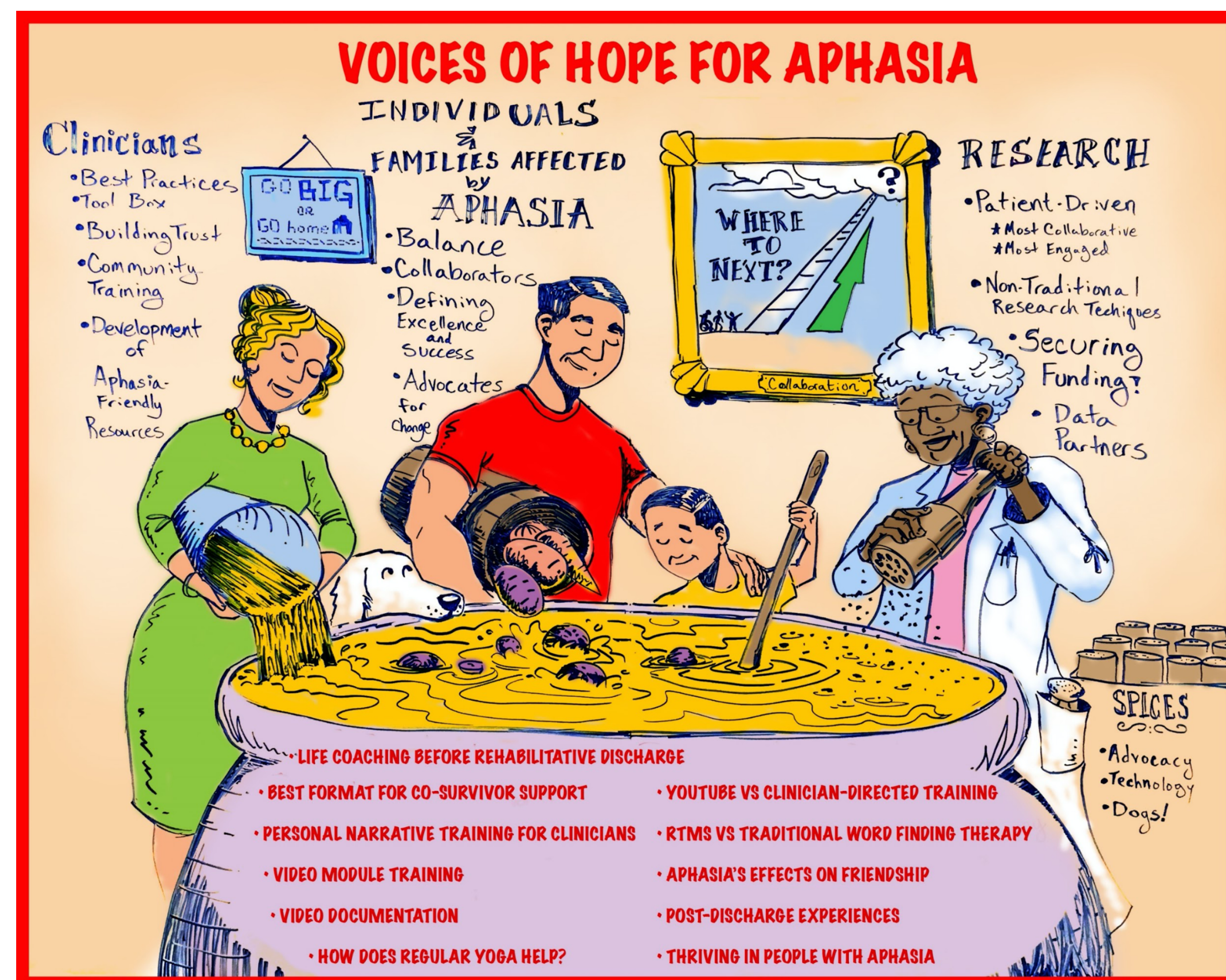


Beyond Universal Design: Lessons Learned about Communication Accessibility for Patient Partners

Jacqueline Hinckley, Ph.D., CCC-SLP & Alejandro Brice, Ph.D., CCC-SLP

LESSONS LEARNED

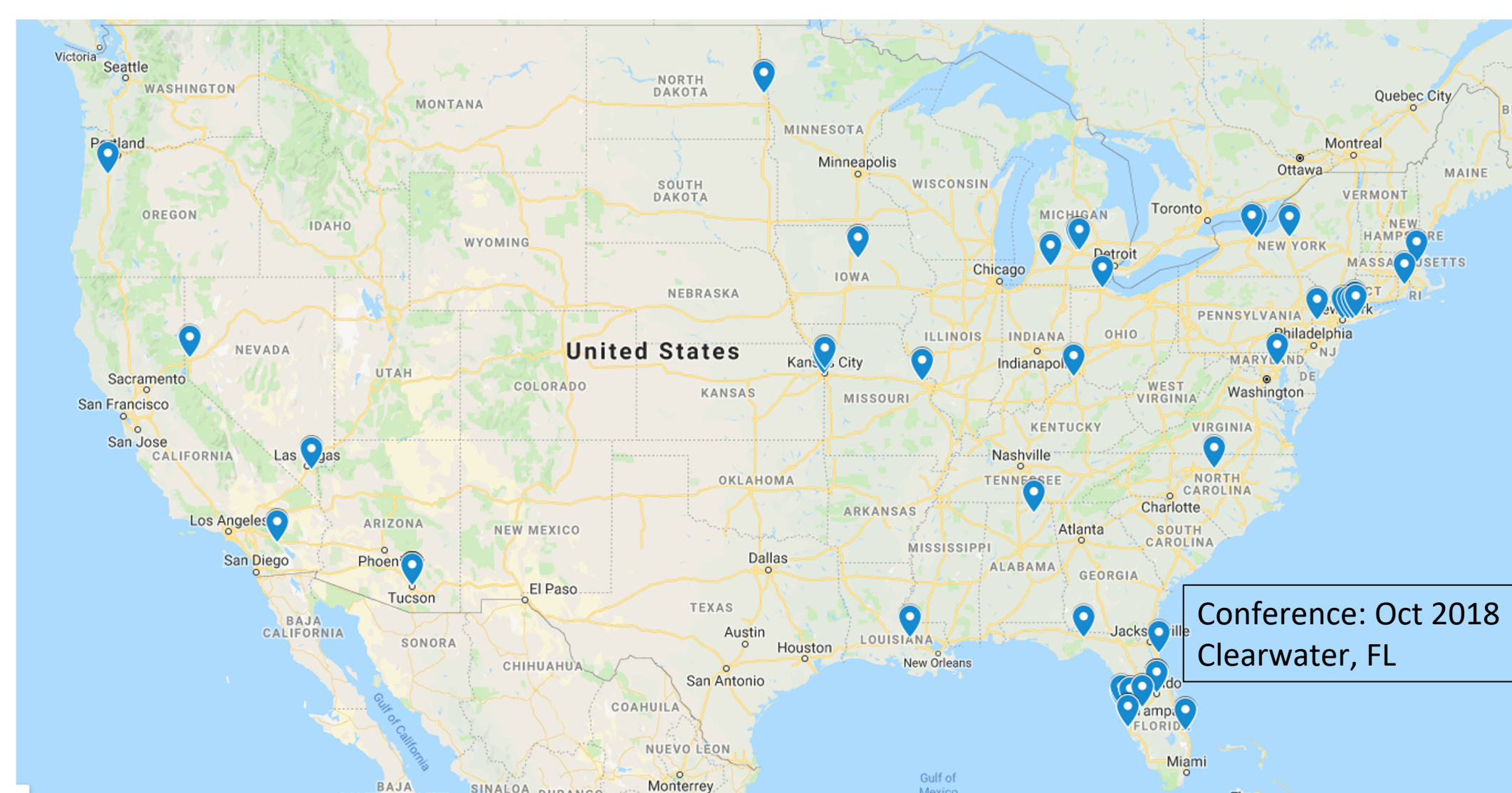
When engaging persons with communication disabilities or differences in the research process, the principles of Universal Design are critical. During our two-year project, we also learned that aspects of Team Leadership make the difference between successful, engaged research teams and those that are less engaged and less productive. Teams that established co-leadership or provided roles for “accountability partners” were among our most successful teams.



APPROACH: PROJECT BRIDGE

Open Access to Project and Training Webinars

3 webinars completed



102 participants:
33 patient partners, 25 family members, 18 clinicians, 26 researchers created

11 research teams

“Universal design is the design and composition of an environment so that it can be accessed, understood, and used to the greatest extent possible by all people regardless of their age, size, ability or disability.”

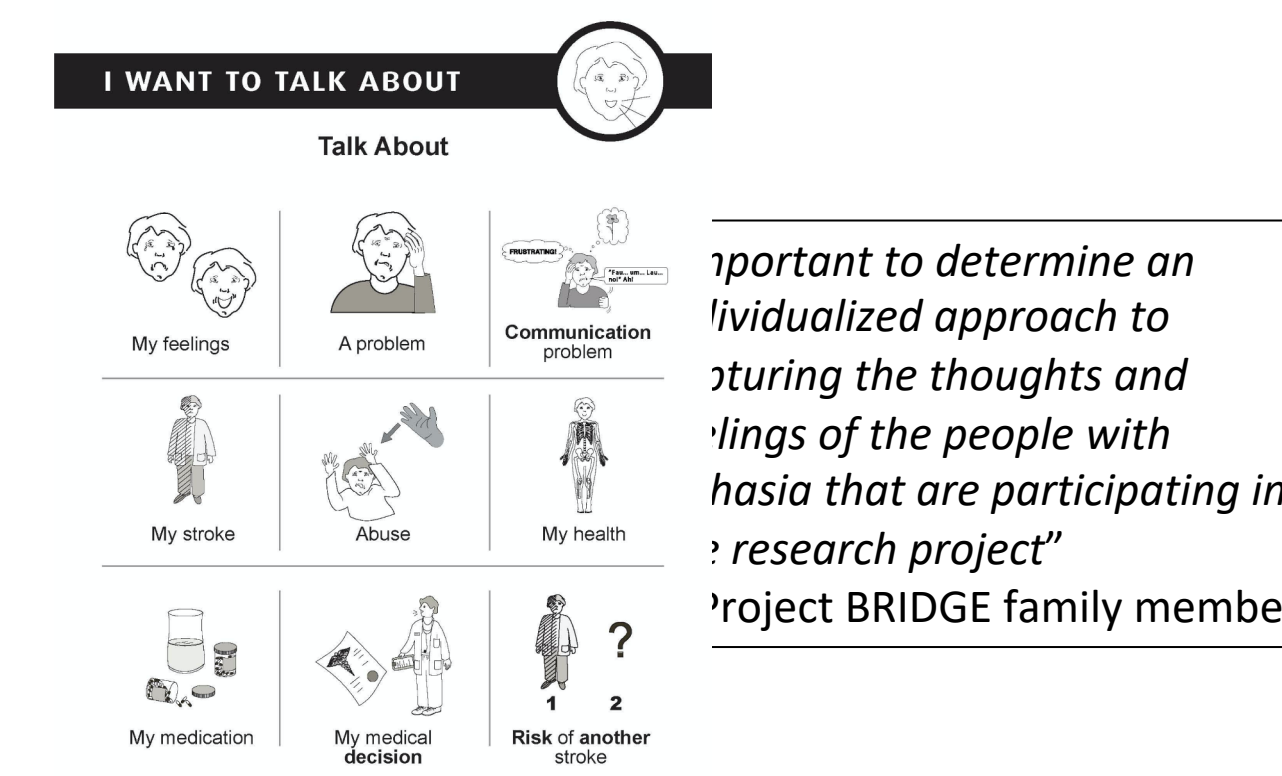
—Center for Excellence in Universal Design

Source: <https://www.section508.gov/blog/infographic-the-case-for-universal-design>



Source: <http://www.cast.org/our-work>

Communication Techniques: Comprehension & Expression Support



Source: <https://www.aphasia.ca/shop/working-together-the-complete-series/>

Guidelines for Supporting Language Disabilities & Differences

- Use simple sentences.
- Use short sentences.
- Simplify vocabulary.
- Offer pictures, gestures, or pictographs.
- Target reading level Grade 5-6.
- Avoid passive sentences.

Engagement: Roles, Responsibilities, Goals, Actions

The research process is a “...big scary mountain...” for clinicians, patient partners, family members.

“...kind of a tricky dance...”
— Project BRIDGE researcher

“our team also initially struggled with just understanding the responsibilities of each one of the team members and the roles that each one of us play”
— Project BRIDGE researcher

“I think the major challenge that faced our team was roles and responsibilities and we didn’t have a clear delineation of our leader of our group.”
— Project BRIDGE clinician

Some Strategies that Worked

- Training communication support volunteers
- Timely meeting agendas
- Getting out of the email rut: using video for agendas, meeting summaries, announcements
- Seeking, and then using, individual feedback between meetings
- Establishing an “Accountability Partner” (often a patient partner), who reminds the team about timelines
- Drafting “job descriptions” for different roles, involvement levels, and contribution types

“being in communication to keep us moving forward is a primary challenge and I think that links back to having a **team leader**”

— Project BRIDGE clinician

Leadership

Some Important Leadership Attributes

- Being adaptable: listening and adjusting based on input from all team members
- Follow-up on action items with individuals
- Prepared for meetings
- Protective of the group: Some of our teams did not want new members who had not been trained to join the group
- Attuned to group dynamics: When members leave or join, the leader should acknowledge and plan for changes in the group dynamic.

—Compiled from Project BRIDGE participants

WHY IS THIS IMPORTANT?

People with communication disabilities, such as aphasia, and communication differences, like low English proficiency, are often excluded from research participation or collaboration. For example:

- People with aphasia were excluded in over 70% of trials addressing information and education after stroke (Brady, Frederic, & Williams, 2013), and
- People with low English proficiency were excluded in 20% of all clinical trials in Australia in 2015 (Stanaway, Cumming, & Blythe, 2017).

An estimated **14% of the US population experiences some type of communication disability** (American Speech-Language-Hearing Association), and **roughly 8% of the US population was considered “Limited English Proficient”** in 2013 (www.migrationpolicy.org).

Therefore, insights, processes, and approaches to including individuals with communication disabilities and/or differences in research planning can be relevant to at least **1/5 of the US population**.

WHAT RESEARCH TEAMS SHOULD KNOW

After an initial investment of time and energy on **communication techniques**, engaged research teams can later focus more on research-specific issues. **Team Leadership and determination of roles and responsibilities** within each team continues to play a critical role in the functioning of the collaborative research team.

Team Leaders' Conversations: Follow-Up #1
4 months later



Team Leaders' Conversations: Follow-Up #2
7 months later



MORE INFORMATION

Access transcripts, webinars, and other Project BRIDGE materials at:
www.aphasia.org/projectbridge/overview

CONTACT US

Alejandro Brice (PI) aebri@usfsp.edu
Jackie Hinckley (Co-PI) jh988@nova.edu

ACKNOWLEDGEMENTS

Project BRIDGE: Building Research Initiatives by Developing Group Effort was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (Contract # EAIN-7111),

Many thanks to all our Project BRIDGE team members.