

MAKING RESEARCH COLLABORATION ACCESSIBLE TO THOSE WITH COMMUNICATION DISABILITIES

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MAKING RESEARCH PERSON-CENTERED

We can make research person-centered when we actively involve the patient's point of view into conducting research. When patients or others who will be affected by research are incorporated into planning, prioritizing, or preparing research methods or activities, research is improved in **quality, relevance, and efficiency**, among other benefits (Ahmed & Palermo, 2010; Oliver, Armes, & Gyte, 2009; Tallon, Chard & Dieppe, 2000; IOM, 2011; Tallon, Chard, & Dieppe, 2000).

Recommended practices for including patients in research (Dudley et al, 2015; Elberse, Caron-Flinterman, & Brower, 2011; Panofsky, 2011) involve

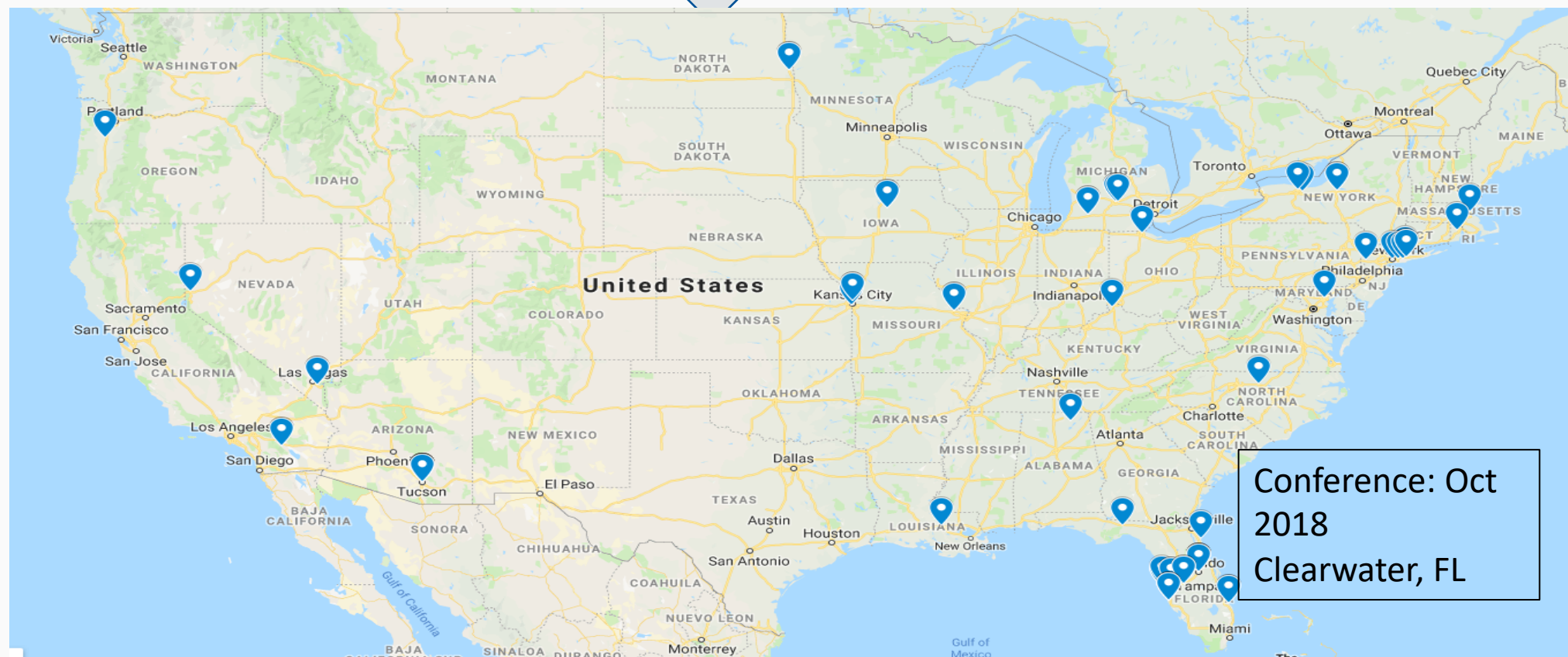
- 1) preparing patient partners and researchers beforehand in separate meetings, and
- 2) maintaining ongoing relationships between informed researchers and patient partners through regular meetings, workshops, or conferences.

APPROACH

Project BRIDGE (Building Research Initiatives by Developing Group Effort) was a 2 year project that trained patient partners and researchers via a webinar series, and then brought them together to collaborate on research teams.

Open Access to Project
and Training Webinars

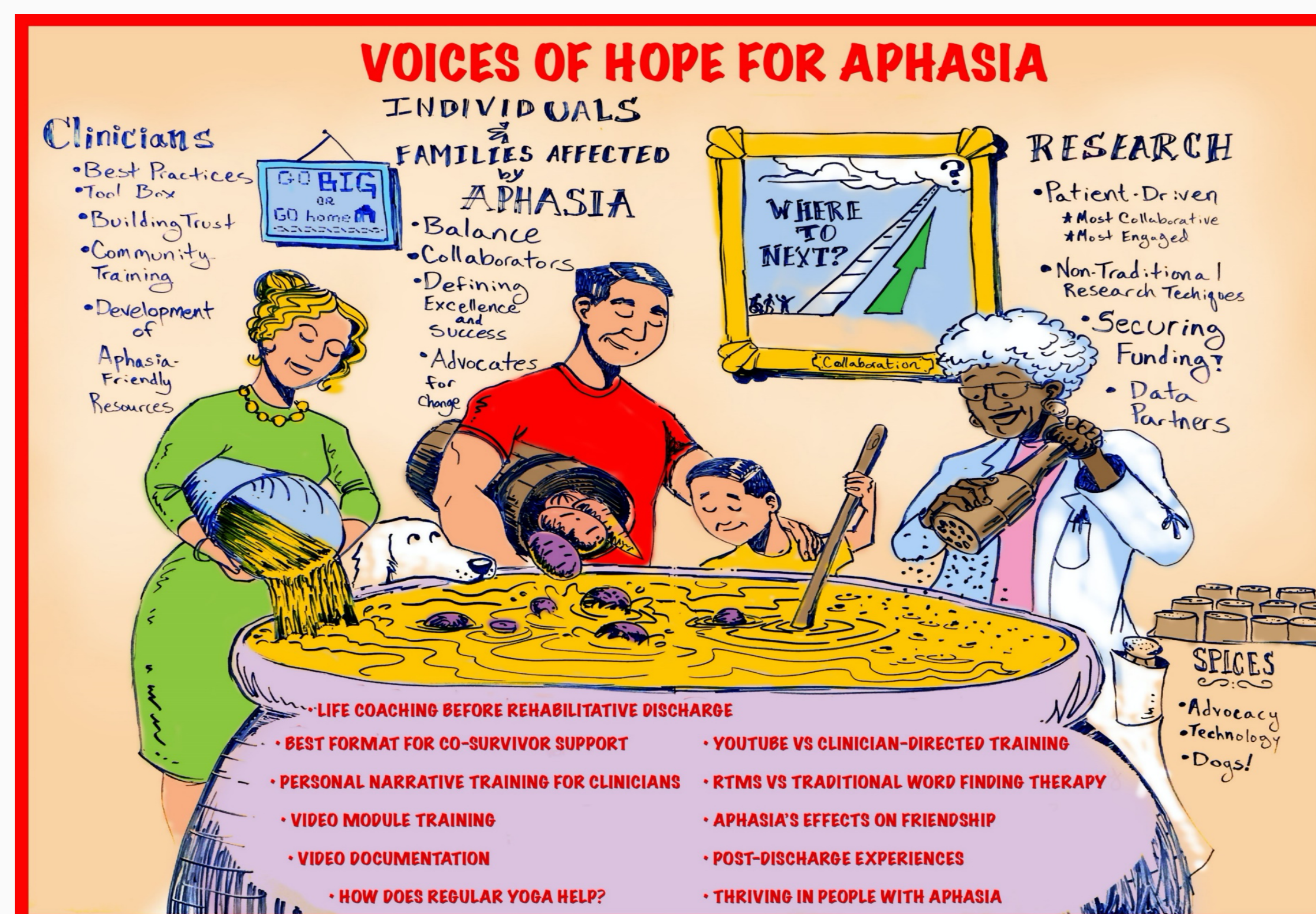
3 webinars completed



102 participants:

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

11 research teams



WHAT WE LEARNED



"important to determine an individualized approach to capturing the thoughts and feelings of the people with Aphasia that are participating in the research project"
- Project BRIDGE family member

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

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

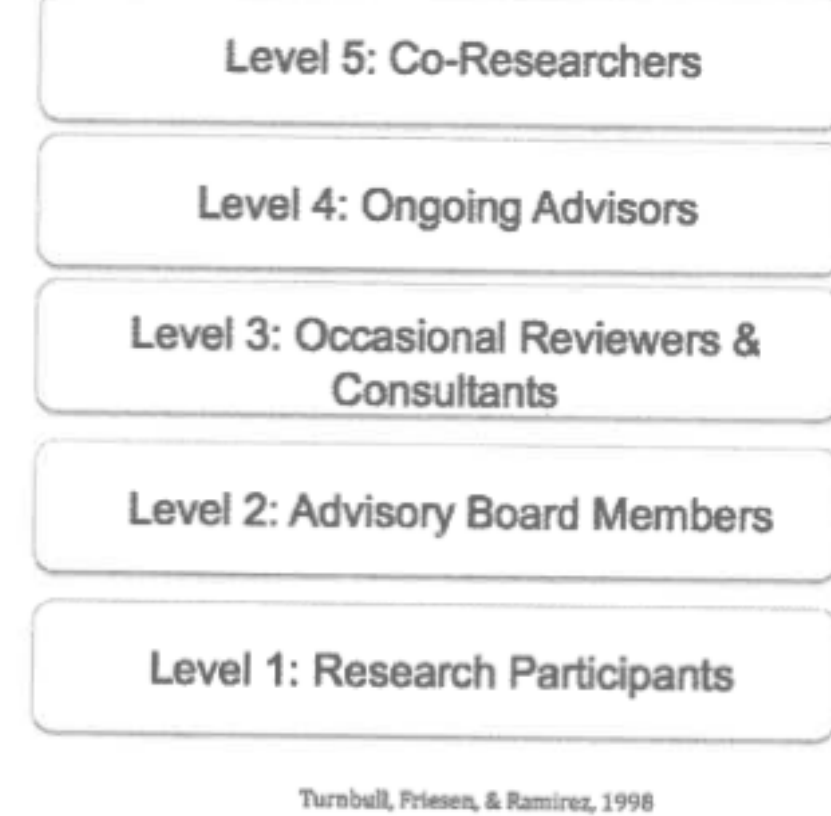
Guidelines for Supporting Language Disabilities & Differences

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

Some Strategies that Worked

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

A Model for Collaborative Research



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



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



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.

Collaboration with patient partners and family members can change research priorities, recruitment methods, consent procedures, measurement selection, and dissemination choices. Collaboration can make research projects more applicable to the people who will be affected by the research, more usable, and more efficient.

MORE INFORMATION

Access transcripts, webinars, and other materials at:

www.aphasia.org/projectbridge/overview

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