Participation-Focused Strategies for PPA: Communication Bridge Studies

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Disclosures

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Learning Objectives

By the end of this session, you will be able to:

01

ANALYZE Telehealth Efficacy

Evaluate service delivery models for PPA using recruitment and access data from Communication Bridge trials.

02

IDENTIFY Communication Strategies

Recognize evidence-based, participation-focused strategies that facilitate functional goal attainment within the PPA care dyad.

03

DIFFERENTIATE Outcome Metrics

Contrast impairment-based metrics and participation-focused outcomes to support goals despite disease-related decline.

The PPA Care Gap

THE PROBLEM

- PPA affects individuals in prime working years (mean onset <65)
- Progressive language impairment devastates communication & QOL
- Few disease-modifying pharmacologic treatments

THE CARE DESERT

- Under-referral for SLP services
- Geographic barriers to specialized PPA care
- Limited SLP expertise with neurodegenerative language disorders
- Insurance terminates services after 'plateau'

PRIOR EVIDENCE

Estimated >90% of PPA intervention studies = non-experimental designs

References: Mesulam 2003; Taylor et al. 2009; Wauters et al. 2023

Aligning with the Life Participation Approach

A-FROM FRAMEWORK (Kagan et al., 2008):

Four interconnected domains:

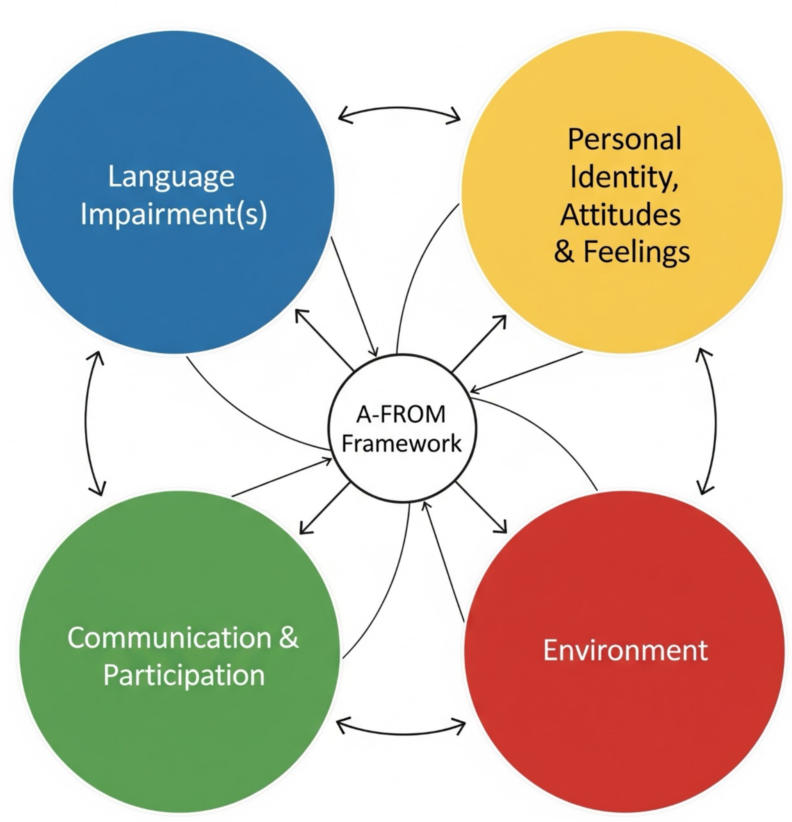
- Language Impairment(s)
- Personal Identity, Attitudes, & Feelings
- Communication & Participation
- Environment

COMMUNICATION BRIDGE PHILOSOPHY:

✓ Multi-component intervention consistent with A-FROM

✓ Addresses all four domains

✓ SUCCESS = engage in everyday activities independent of disease severity



References: Kagan et al. 2008; Roberts et al. 2022

Clinical Trials Program

PHASE 1: PILOT

2016

- N=34 participants (21 states + Canada)
- 8 sessions telehealth
- Feasibility demonstrated

PHASE 2: CB2 RCT

2018-2023

- FIRST international Phase 2, Stage II RCT for PPA
- N=95 dyads, 4 countries
- 15 sessions over ~12 months
- Active control design

PHASE 3: CB3

2024-Current

- NIH funding, Phase 2, Stage III
- N=100 dyads
- Implementation focus: SLP + SW, Wearable sensor pilot

References: Rogalski et al. 2016, 2025a; UChicago 2024

Beyond Feasibility: The Reach of Telehealth

CB2 GLOBAL RECRUITMENT

- 95 dyads enrolled
- 4 countries (USA, Canada, UK, Australia)
- No geographical restrictions
- Mean age: 67.1 years
- 48% female
- All 3 PPA subtypes

ATTRITION

- <10% dropout over 12 months
- Significantly lower than typical dementia trials (20-30%)

References: Rogalski et al. 2025a,b

Environmental Validity

STRATEGY IMPLEMENTATION

- Practice in actual daily environments
- Partners present in natural role

ENVIRONMENTAL MODIFICATIONS

- Lighting, noise, visual supports assessed in real time
- Technology tested in actual use contexts

ECOLOGICAL VALIDITY

- Generalization built into intervention
- Goals address real-world situations

References: Roberts et al. 2022

Facilitators and Barriers

FACILITATORS

- Study-provided technology kit
- Remote tech support team
- Flexible scheduling
- Portable technology
- Web application for practice

BARRIERS ADDRESSED

- Technology training at enrollment
- Written handouts
- Tech support available
- Backup scheduling

Technology barriers reduced through support infrastructure, not participant exclusion

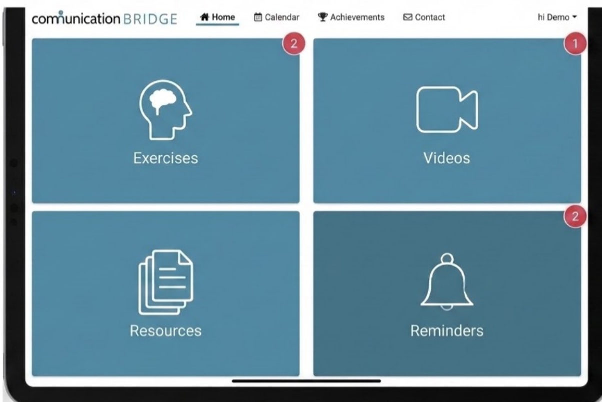
The Web Application Innovation

CORE FEATURES (BOTH ARMS)

- Dashboard with appointments
- Achievement tracking
- Practice modules

EXPERIMENTAL ARM ADVANTAGE

- Personalized training stimuli
- Individualized scripts tied to GAS goals
- Weekly 'Reminders' from clinician
- Full resource library (34 docs, 39 videos)



ASYNCHRONOUS DOSING
30 min/day, 5 days/week

References: Roberts et al. 2022

Shifting the Unit of Care

TRADITIONAL MODEL

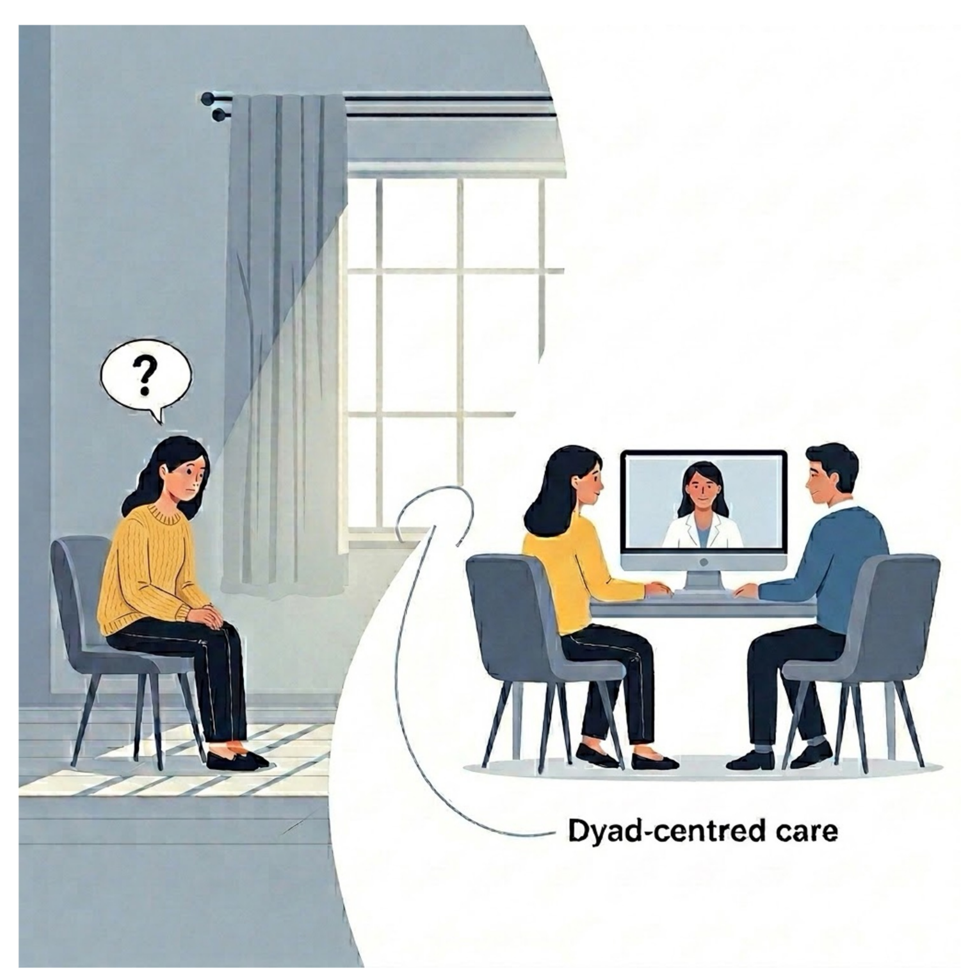
Person with PPA: Patient

Partner: Supporter / Informant

Focus: Remediate language impairment

DYADIC MODEL (CB)

- BOTH members are recipients
- Active dyadic participation
- Partner training & strategy use
- Focus: Optimize participation



Reference: Rogalski et al. 2022; Roberts et al., 2022; Rogalski et al., 2025

Experimental vs. Control Arm Design (CB2 trial)

EXPERIMENTAL ARM

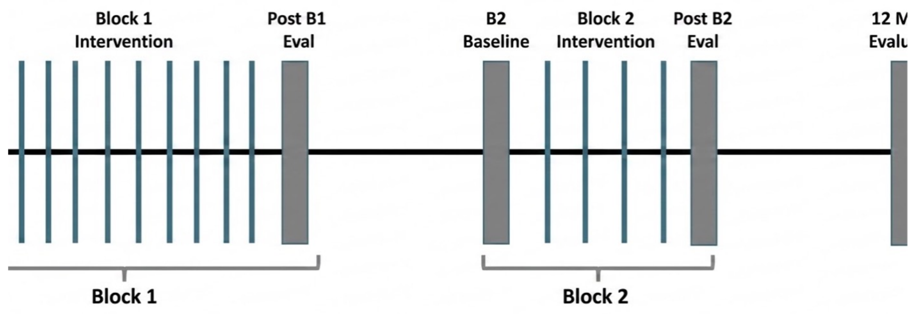
- Dyadic intervention
- Participation-focused (A-FROM aligned)
- Personalized stimuli
- Activities MAPPED to GAS goals
- Full resource library

CONTROL ARM

- Non-dyadic
- Impairment-focused
- Fixed stimuli
- Script training + cueing

BOTH GROUPS

- 15 sessions
- ~12-15 months
- Delivered via telehealth



Active control = *ethical + dose-matched*

Reference: Roberts et al. 2022; Rogalski et al., 2025

Communication Partner Engagement

OPERATIONALIZED AS:

- Attendance at sessions
- Active participation
- Between-session strategy implementation
- Home practice support

RESULTS:

WITH ENGAGED PARTNERS:

✓ Significant confidence gains

✓ SUSTAINED maintenance at 6 months

IMPLICATION: **Partner engagement is *CRITICAL* for sustained outcomes**

Reference: Rogalski et al. 2022

What Facilitates Partner Engagement?

DYAD RELATIONSHIP QUALITY

- Strength of pre-morbid relationship

INTERVENTION PHILOSOPHY

- Partners who understand the 'why' engaged more

PERCEIVED BURDEN vs. BENEFIT

- Role as empowering (not just caregiving) increased engagement

PRACTICAL BARRIERS

- Work schedules, health issues, technology comfort

cLINICAL TRANSLATION: Assess partner engagement capacity at initial evaluation

Traditional Metrics vs. Participation Outcomes

IMPAIRMENT-BASED METRICS

- Naming accuracy
- Script production accuracy
- Aphasia quotient scores (WAB-R)

STRENGTHS

Objective, reliable

LIMITATIONS

Expected to decline with disease progression

PARTICIPATION-FOCUSED OUTCOMES (CB2 Primary)

1. CPIB
   Communicative Participation Item Bank
2. GAS
   Goal Attainment Scaling
3. CCRSA
   Communication Confidence Rating Scale

References: Baylor et al. 2013; Cherney et al. 2011; Fegter et al. 2023

Functional Outcome Measurement: GAS Approach

WHY GAS ALIGNS WITH LIFE PARTICIPATION

- **Person-centered**
  Goals emerge from valued activities
- **Contextualized**
  Specific to real-world situations
- **Flexible**
  Accommodates heterogeneous profiles
- **Dyadic**
  Partner develops own goal

CB2 GAS DEVELOPMENT

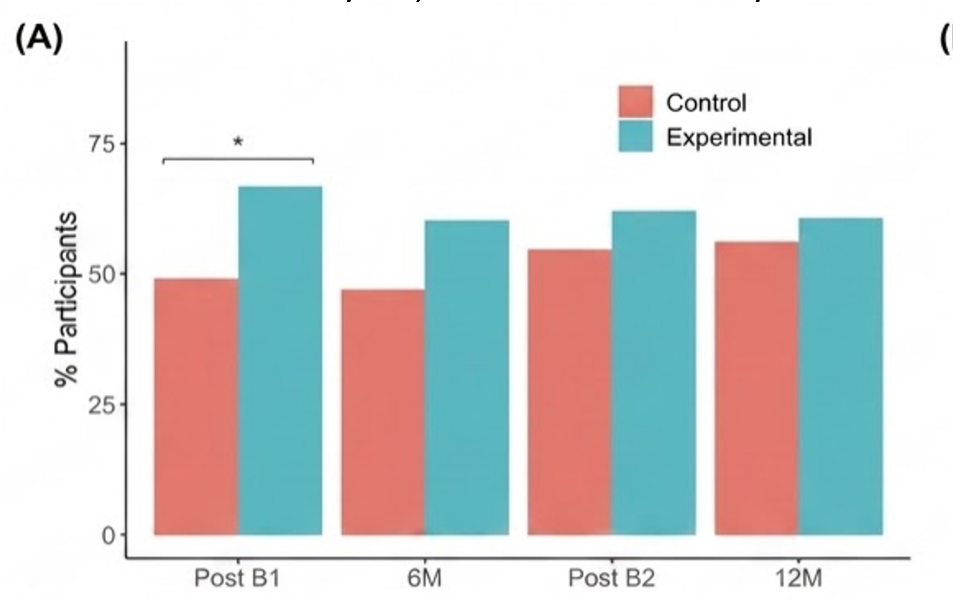
1. Dynamic assessment interview
2. Assessment of Living with Aphasia
   (A-FROM-based)
3. Social Networks Inventory
4. Triangulation
   3 goals (PwPPA) + 1 goal (partner)

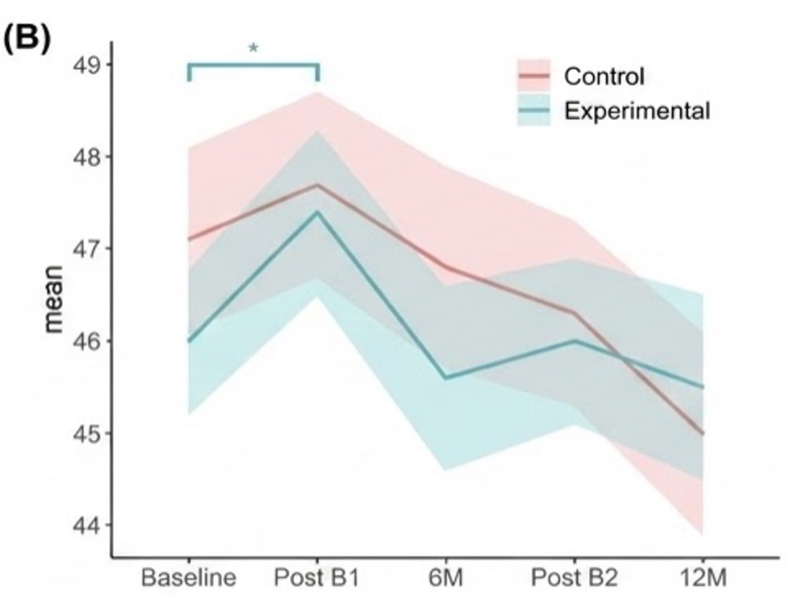
SCORING RANGE: -3 (decline) to +3 (best outcome)

References: Roberts et al. 2022; Fegter et al. 2023; Rogalski et al., 2025

CB2 Primary Outcomes: Summary Results

STUDY DESIGN: N=95 dyads, Intent-to-treat analysis





PRIMARY OUTCOME 1: GOAL ATTAINMENT SCALING

% Achieving Stable/Improved GAS Goals:

- Experimental: 66.7%
- Control: 49.1%
- p = 0.006 (SIGNIFICANT)
- Odds Ratio: 2.08 favoring experimental

PRIMARY OUTCOME 2: CPIB

- Experimental: Significant gain ($p<0.05$)
- Control: No significant gain

PRIMARY OUTCOME 3: CCRSA

- Low responsivity both arms

Reference: Rogalski et al. 2025

Stability vs. Decline: A Paradigm Shift

The Neurodegenerative Reality

- Progressive, insidious language decline expected
- 'Improvement' in traditional sense may be unrealistic

BUT: Participation & confidence CAN stabilize or improve

CB2 Success Definition

Stable OR improved performance = success

RATIONALE:
Maintaining baseline function = slowing symptom decline

References: Roberts et al. 2022; Rogalski et al. 2025

Post-Study Interview Data

SEMI-STRUCTURED INTERVIEWS AT 12 MONTHS

DATA FAVORED EXPERIMENTAL ARM

- Positive changes in communication in daily activities
- Emotional well-being
- Overall helpfulness of intervention
- Meeting expectations

REPRESENTATIVE THEMES

"I'm doing things now I had stopped doing—like ordering for myself"

"I feel more confident speaking up instead of just listening"

"My family says I'm more 'present' in discussions now"

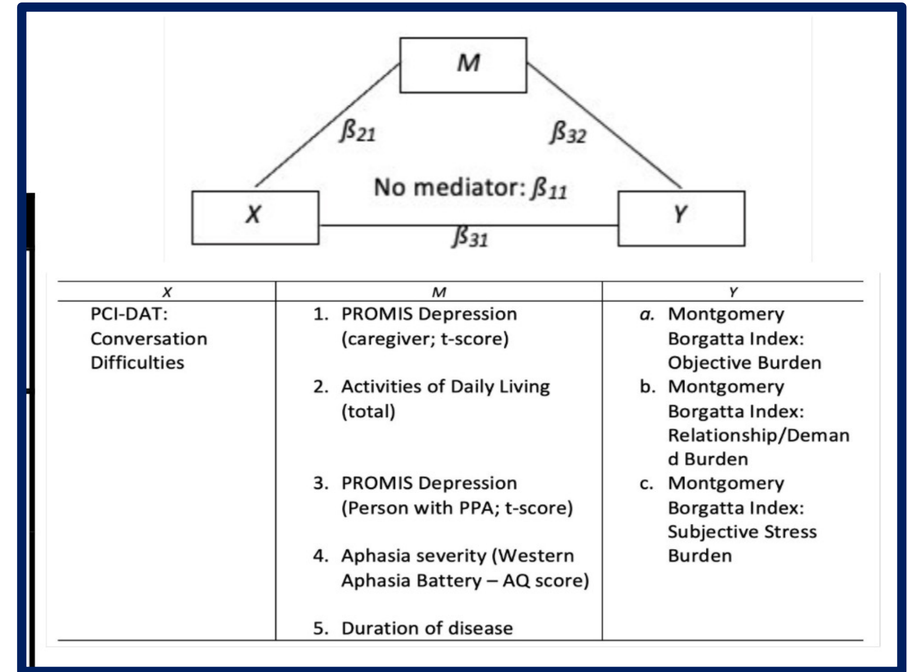
THE ALIGNMENT:
Qualitative interview data corroborates quantitative GAS findings

Reference: Rogalski et al. 2025

Caregiver Burden Outcomes

PERCEPTION OF CONVERSATION INDEX & MONTGOMERY BORGATTA INDEX

- Care partners of persons with mild-moderate PPA, on average, experienced a moderate degree of caregiving burden and conversation difficulties.
- The severity of conversation difficulties was associated with increased caregiving burden for both objective burden ($p < 0.001$) and subjective stress burden ($p = 0.001$), with higher severity predicting higher burdens.
- The relationship between conversation difficulties and objective burden was mediated by dependence on activities of daily living and care partner depression scores.
- The relationship with subjective stress burden was mediated by care partner depression only.



X	M	Y
PCI-DAT: Conversation Difficulties	1. PROMIS Depression (caregiver; t-score) 2. Activities of Daily Living (total) 3. PROMIS Depression (Person with PPA; t-score) 4. Aphasia severity (Western Aphasia Battery – AQ score) 5. Duration of disease	*a.* Montgomery Borgatta Index: Objective Burden b. Montgomery Borgatta Index: Relationship/Demand Burden c. Montgomery Borgatta Index: Subjective Stress Burden

References: Roberts et al. 2022; Roberts et al. 2024

Clinical Implementation

CORE FRAMEWORKS

✓ **DYADIC FRAMEWORK**

- Include partner as active participant

✓ **PARTICIPATION-FOCUSED GOAL SETTING**

- Use GAS or other approach for dynamic, person-centred goal setting
- Define success as stability in progressive disease

DELIVERY & TRAINING

✓ **MULTIMODAL COMMUNICATION TRAINING**

- Speech, gesture, writing, technology

✓ **TELEHEALTH DELIVERY**

- Reduces access barriers for those with rare disorders, like PPA

FOR FURTHER CONSIDERATION

- Dosing and dosing calibration
- Assessment battery and time for clinician/client for personalized material planning
- Sustainability model for web-based app
- Delivery model (hub and spoke with expert clinicians or local delivery)
- Technology and connectivity issues
- Intervention complexity (typical in SLP interventions)

References: Roberts et al. 2022; CB Manual 2022

Moving Communication Bridge to the Next Chapter (CB3 Trial)

1. Wearable Sensor Technology

- Objective measurement of daily activities
- Real-world, continuous, participation data

2. Interdisciplinary

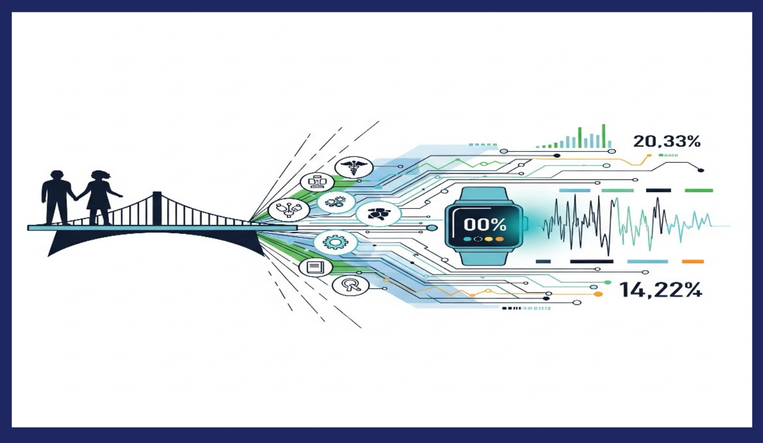
Social work for facilitating dyad self-efficacy and addressing barriers to communication and strategy uptake

3. Implementation Focus

- N=100 dyads
- Scalability testing: shifting workload to clinicians
- Cost-effectiveness analysis

4. Tool Development

- Further web app developments to facilitate data tracking
- Intervention delivery tools for deployment in real world practice by SLPs



References: UChicago 2024; UChicago 2025

The Communication Bridge Model: Core Principles

DYAD = UNIT OF CARE

- Both members are intervention recipients

PARTICIPATION = PRIMARY OUTCOME

- Success ≠ improved test scores
- Success = engaging in valued activities
- Stability in progressive disease IS success

CONTEXT MATTERS

- Real-world strategy implementation

MULTI-COMPONENT APPROACH

- Impairment work + Participation strategies + Partner training
- Web application

TARGETS: COMMUNICATION + PSYCHOSOCIAL

MEASUREMENT DRIVES PRACTICE

- Use participation-focused outcome measures

RIGOROUS TRIAL DESIGNS YIELD PRACTICE-CHANGING EVIDENCE

Key Takeaways

Clinical Insights

ACCESS
Telehealth minimizes geography as a barrier

WHO
Dyadic intervention > individual impairment-focused intervention

WHAT
Participation-focused strategies for personalized goals

HOW
Individualized goals + multimodal strategies + partner training > impairment only

SUCCESS
Stability or improvement = meaningful outcome

Research Insights

Rigorous RCTs of SLP interventions are feasible in rare clinical populations

Participation-focused outcomes capture meaningful change

Communication partner engagement is a critical ingredient

Contact

TRIAL DETAILS

Trial Location: All study components take place remotely via video chat (Zoom)

Trial Length: ~18 months

Trial Activities:

1. Participants will receive intervention sessions with licensed clinicians
2. Exercises through a custom web-application

Trial Costs: There are no costs to participate. Compensation will be provided.

If interested, contact the study team for more information:

CBtrial@uchicago.edu 1-855-824-7887 haarc.center.uchicago.edu/communication-bridge/

Study Title: Communication Bridge 3 Clinical Trial IRB 23-1175

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