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CONTINUED

Five Fresh Perspectives on Applying LPAA Principles to Treatment for Neurogenic Communication Disorders

Guest Editor: Audrey Holland, PhD, CCC-SLP, BC-ANCDS

CONTINUED

ONLINE CONTINUING EDUCATION FOR THE LIFE OF YOUR CAREER

C.A.P.E: 4 Essential, Evidence-Based Categories for Aphasia Assessment and Treatment

Roberta Elman, PhD, CCC-SLP, BC-ANCDS, ASHA Fellow Aphasia

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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- Two opportunities to pass the exam

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C.A.P.E.: Four Essential and Evidence-Based Categories for Aphasia Assessment and Treatment

Roberta J. Elman, Ph.D., CCC, BC-ANCDS
Aphasia Center of California
Oakland & Menlo Park

www.aphasiacenter.org
Twitter: @aphasia_acc
www.facebook.com/AphasiaCenterofCalifornia

CONTINUED

My Disclosures

- **Financial**:
  - Receive royalties on my book, "*Group Treatment of Neurogenic Communication Disorders: The Expert Clinician's Approach*" published by Plural Publishing
  - Salaried position at Aphasia Center of California
  - The Aphasia Center of California receives royalties for two MedBridge Courses about Aphasia Conversation Groups
- **Nonfinancial**:
  - Serve on committees or advisory boards for Clinical Aphasiology Conference, National Aphasia Association, ANCDS, and Aphasia Hope Foundation

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Learning Outcomes

After this course, participants will be able to:

- Identify literature and data that support the use of life participation models.
- List the four C.A.P.E. categories of aphasia intervention that are appropriate across a variety of healthcare settings.
- Describe 3 specific examples of how the C.A.P.E. framework can be used in a variety of clinical settings.

CONTINUED

What if tomorrow….?

- You have a stroke with moderate-to-severe aphasia
- Your speech-language pathologist has only 16 sessions to work with you
- What do you want him/her to focus on in treatment?

Elman, R.J. (2018). Social and life participation approaches to aphasia intervention. In L. LaPointe & J. Stierwalt (Eds.). Aphasia and related neurogenic language disorders (5th edition). N.Y.: Thieme Medical Publishers.

Rehabilitation:

- Regain function in order to participate in life as fully as possible
- ASHA SLP Scope of practice
  - "The overall objective of speech-language pathology services is to optimize individuals' ability to communicate and swallow, thereby improving quality of life." ASHA, 2016

American Speech-Language-Hearing Association (ASHA)
Making effective communication, a human right, accessible and achievable for all.

Models of Health Care

- **Medical Model** - Traditional Model in Western Health Care
- Problem is within patient
- Expert provides treatment
- Goal is cure of disorder

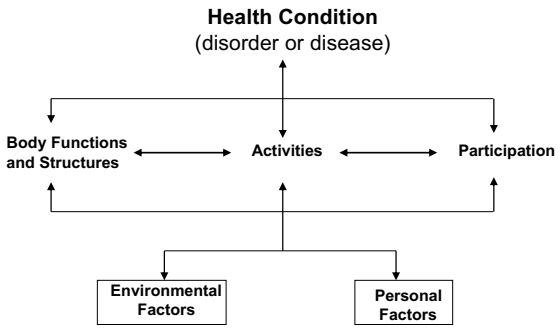
- **Social Model** has evolved – applied to disability in 1970s
- Problem is interaction of personal, physical, environmental, and societal factors
- Treatment is collaborative
- Goal is to promote positive change even when cure is not possible

World Health Organization (ICF)

Framework consists of two parts:

- **Functioning and Disability**
  - Body Functions and Structures
  - Activities and Participation
- **Contextual Factors**
  - Personal Factors
  - Environmental Factors

ICF (WHO, 2001)



Mr. G vs. Mr. H

- Aphasia is a disorder at the body functions and structures level
- People with same impairment may have different activity limitations and participation restrictions

Mr. G.

Has a moderate Broca's aphasia:

- Single words and short phrases with omission of grammatical and functor words
- Auditory comprehension is unimpaired for basic information, but he has difficulty with more complex instructions and directions

Mr. G (con.)

- Activity limitations
  - Not answering telephone
  - Not engaging in conversation with friends
- Participation Restrictions
  - Decreased socializing with friends
  - Loss of job
- Contextual Factors
  - Barriers =
    - Limited family support
    - Lack of awareness of aphasia among friends and former colleagues

Mr. H

Has a moderate Broca's aphasia

- Single words and short phrases with omission of grammatical and functor words
- Auditory comprehension is unimpaired for basic information but he has difficulty with more complex instructions and directions

Mr. H (con.)

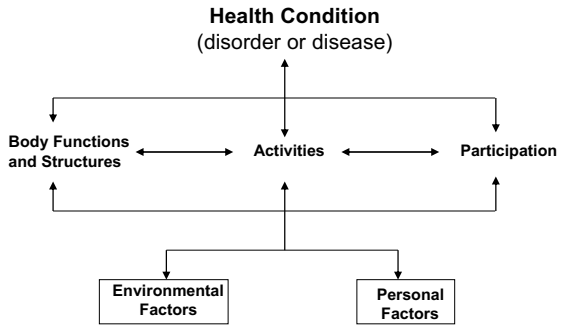
- Participation Restrictions
  - Loss of job (but now volunteers at Humane Society)
- Contextual Factors
  - Facilitators = Excellent Family Support; friends and family received training in supported conversation techniques
  - Aphasia Group Program = ongoing
- SLP Treatment
  - Has learned strategies to ask for clarification when he does not understand directions
  - Aphasia Group treatment provides him with suggestions such as triggering answering machine to record long messages

A-FROM—Living with Aphasia Framework for Outcome Measurement

Living with Aphasia: Framework for Outcome Measurement (A-FROM)

Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, W., Threats, T., & Sharp, S. (2007). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology, 22*(3), 258-280.

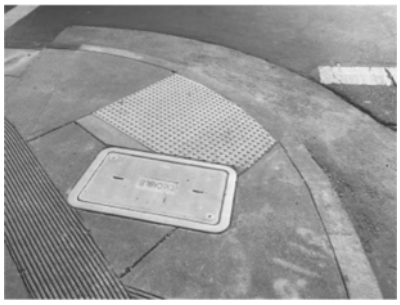
ICF (WHO, 2001)



Reducing Environmental Barriers

- What are some examples of physical barriers that people with disabilities have in our communities?
- How are these barriers modified to allow access?

Reducing Environmental Barriers



Reducing Environmental Barriers

A “homework” assignment for you:

- Please list several barriers that relate to **communication** that currently exist in your clinical setting?
- Brainstorm some “solutions” for these barriers—what would need to be done to remove or reduce them?

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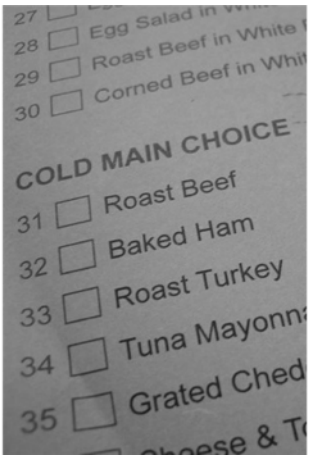
Reducing Environmental Barriers



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Reducing Environmental Barriers

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Reducing Environmental Barriers

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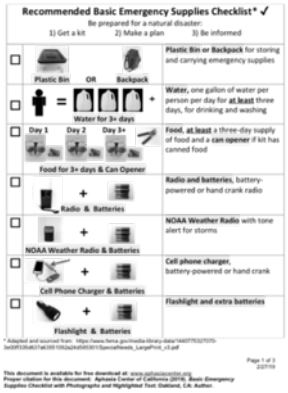
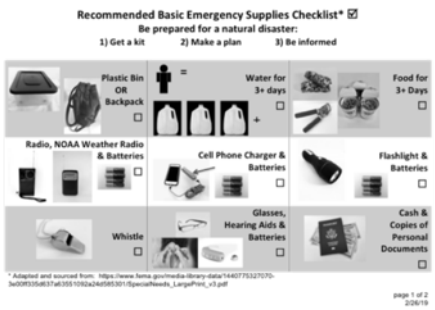
Reducing Environmental Barriers
Emergency Kit and Disaster Planning
www.aphasiacenter.org





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Reducing Environmental Barriers

- My dream: That the US could become the most aphasia friendly country in the world!
- My challenge to you: Which barrier could you begin to remove or reduce next week?

Life Participation Approach to Aphasia: LPAA (2000/2001)

LPAA Project Group: Chapey, Duchan, Elman, Garcia, Kagan, Lyon, Simmons-Mackie

Five core components:

- The explicit goal is enhancement of life participation
- All those affected by aphasia are entitled to service
- Both personal and environmental factors are targets of assessment and intervention
- Success is measured via documented life enhancement changes
- Emphasis is placed on availability of services as needed at all stages of life with aphasia

Advocacy efforts should be targeted to those components not available in healthcare systems

Life Participation Approach to Aphasia

- Begins with initial assessment and lasts until the consumer no longer elects to have communicative support
- The life concerns of those affected by aphasia form the center of decision making
- Emphasis is on life re-engagement by strengthening daily participation in activities of choice

Life Participation Approach to Aphasia

Some examples:

- Add information to standardized testing re: how the person with aphasia does with support
- Make the environment more "aphasia friendly" by reducing barriers and/or increasing facilitators
- Work with family members, friends, and colleagues on life participation goals

CONVERSATION GROUPS
SELF-ADVOCACY WORK
SUPPORTED CONVERSATION PARTNER TRAINING

***SFA, *TUF, *VNeST, *MIT, etc.**

****when* transferred beyond tx room**

Essentials for Aphasia Treatment

- Increasing demand for productivity means less time for treatment planning.
- Workshops and book chapters often provide many different treatments without any prioritization.
- Fewer sessions authorized for aphasia treatment means that we must make these sessions count. Don't waste them on treatments that are unlikely to benefit the patient or the family. Don't just pull a workbook (or an app) from the shelf!

Essentials for Aphasia Treatment

- Some of the treatment essentials that we are going to discuss are most appropriate for those with a moderate or severe level of aphasia.
- Other treatment essentials are appropriate for anyone affected by aphasia.
- These categories are not prescriptive or exhaustive!!
- They serve as a clinical checklist especially for the first few months of aphasia intervention.

Essentials for Aphasia Treatment

- Treatments suggested are all evidence-based approaches.
- These were selected based on research re: what people with aphasia (PwA), their family members, and their friends wished they had received in the first few months of treatment.
- My own clinical expertise from the last 30+ years meeting thousands of PwA.

C.A.P.E.: Aphasia Treatment Essentials

- **C**: Connecting People with Aphasia
- **A**: Augmentative & Alternative Communication
- **P**: Partner Training
- **E**: Education & Resources

(For C.A.P.E. see Elman 2013, 2016, 2018. For supporting evidence see: Aphasia United, n.d; Avent et al, 2005; Brown et al, 2012; Hilton et al, 2014; Hinckley, Hassekus & Ganzfried, 2013; Howe et al, 2012; Power et al, 2015, Wallace et al, 2017; Worrall et al, 2011, etc.)

C.A.P.E. (Elman, 2013, 2016, 2018)

C: Connecting People

"Why didn't I ever meet other people who had aphasia?"

C: Connecting People

- Aphasia is an isolating condition
- The language barrier limits access to information about the disorder
  = decrease in *Transactional* role of language
- The language barrier limits the ability to maintain and create social relationships
  = decrease in *Interactional* role of language

C: Connecting People

- Many people with aphasia feel that they are all alone--that no one else is living with the disorder.
- This can cause or exacerbate depression and/or frustration and lead to general psychosocial distress.
- Meeting other people with aphasia can provide hope and be an important way to see an example of living successfully with aphasia.
- I believe connecting with other PWA can also prevent maladaptive ways of dealing with the disorder.

C: Connecting People

- Few people have heard of aphasia.
- Studies suggest that only 5-10% of the population has a pretty good idea of what it is.
- Even fewer really understand its impact on all aspects of living.
- This lack of awareness of aphasia combined with the language barrier that the disorder causes is a huge double whammy!

C: Connecting People

Some ways to connect people with aphasia:

- Aphasia groups and programs
- Formal visitation programs
- Aphasia conferences
- Aphasia camps
- Arrange informal meetings with past clients
- Online options-e.g. Aphasia Recovery Connection

C: Connecting People

Aphasia Groups and Programs

(See Kearns & Elman, 2008; Elman, 2000, 2007a,b; 2016, 2018; Lanyon, Rose & Worrall, 2013, etc)

C: Connecting People

- History of Group Treatment
- Published Efficacy & Effectiveness Data
  Aphasia Group Treatment
- Wertz & colleagues (1981)
- Aten, Caligiuri & Holland (1982)
- Bollinger, Musson & Holland (1993)
- Van der Gaag et al, (2005)
- Elman & Bernstein-Ellis (1999a,b)
- Attard et al, 2017
- And others!!

C: Connecting People

BOOK:

Elman, R. J. (2007)

Group Treatment of Neurogenic Communication Disorders: The Expert Clinician's Approach (2nd Ed.) published by Plural Publishing.

C: Connecting People

Conversation Group Treatment—Possible Benefits

(see Elman 1999, 2001, 2004, 2007a,b, 2016, 2018; Elman & Bernstein-Ellis, 1999a)

- Groups promote interaction and variety of communicative functions or speech acts
- Groups provide opportunity for wider array of partners = more generalization
- Groups promote language improvisation
- Groups improve psychosocial functioning
  - Benefit of Community
- Groups involve more complex language (CATE—
- Thompson et al.)
- Groups are cost effective
- Others?

C: Connecting People

Book Connection™

Materials available for 30+ books via download www.aphasiacenter.org

Reading Ramps to support reading for pleasure

- **Chapter highlights**
- **Worksheets**
  - Multiple choice
  - Short answer/drawing
  - Sentence and longer

CONTINUED

C: Connecting People

Communicative Partners
(Lyon, 1989, 1996, 1997a,b; Lyon et al, 1997; McVicker, Parr, Pound & Duchan, 2009)

- Volunteers are trained to communicate with individuals who have aphasia
- Typically not family members
- SLP provides training on successful strategies and methods of communicating
- Once dyad is effective, they begin independent participation in community activities of choice

CONTINUED

C: Connecting People

Formal Befriending Program (UK Connect)

- Volunteers trained on Supported Communication and other needed skills
- They visit hospitals with people who have recently acquired aphasia
- Similar to laryngectomy visitation programs

CONTINUED

C: Connecting People

Aphasia conferences

- Regional aphasia conferences sponsored by a variety of organizations

C: Connecting People

Aphasia Camps

A few examples:

- Portland, Oregon
- Eau Clare, Wisconsin
- Squamish, British Columbia

C: Connecting People

- Could you arrange meetings with past clients at your service delivery sites?
- What training or support would you want to provide for these volunteers?

C: Connecting People

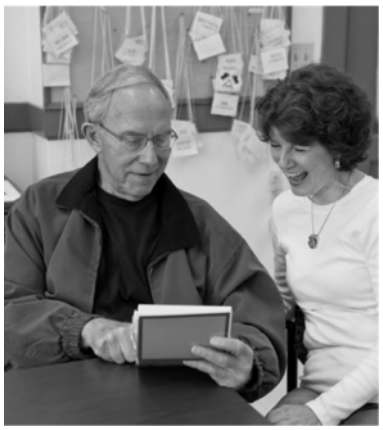
Connecting via the Internet

e. g. Aphasia Recovery Connection (ARC)

Several Facebook groups

A: AAC

"Another way to communicate?"



A: AAC

- Let's consider walking for someone after a stroke.
- What happens in physical therapy?

  Equipment that may be used to *support* walking:
  - Wheelchair
  - Walker
  - Quad Cane
  - Regular Cane
  - Brace/AFO

A: AAC

- Let's consider ADLs for someone after a stroke.
- What happens in occupational therapy?

  Equipment that may be used to *support* ADLs:
  - Grab bars
  - Bath bench
  - Long handled sponge
  - Bedside commode
  - Button hook
  - Etc!!

A: AAC

- Every person with aphasia needs at least one way to communicate!
- We need to provide effective *communication ramps* to *support* the exchange of information as well as social interaction
- What communication supports will help make communication easier for each person with aphasia?
- First it's wise to consider the low tech options.

A: AAC

Some low tech communication options:

- *Individualized* Communication books
- Talking photo book
- Pen & Paper
- Yes/No in some format (pointing, head nod/shake, etc)
- Gestures/pantomime
- Communicative drawing
- Writing of word(s) or part of words
- Use of props such as 1-10 number line, scales, maps, calendars, numbers, photos of meal choices etc.

A: AAC

BOOK:

Simmons-Mackie, King & Beukelman (2013)

Supporting Communication for Adults with Acute and Chronic Aphasia published by Brookes Publishing

A: AAC

What is important for that particular person?

- Once you know that, you can begin to create materials/props that will be motivating and useful.

A: AAC

- Questionnaire to get bio and social information about PWA
- Use this information in treatment

The Aphasia Center of California

Client Questionnaire

Name:_____ Birthplace: _____

Places you have lived: _____

_____

High school: _____

College: _____

Military service? _____

Occupation/places you have worked: _____

_____

_____

Religious affiliation: _____

Do you know any other languages?_____

FRIENDS & FAMILY

Marital status: _____Name of spouse/partner: _____

List children's **names, ages**, and where they live:_____

_____

_____

_____

A: AAC

- Questionnaire to get bio and social information about PWA
- Use this information in treatment

INTERESTS & ACTIVITIES

List your interests, activities and hobbies before and after your stroke (e.g. sports, gardening, politics, volunteer work, etc.): _____

List favorite kinds of movies or TV shows:

List your favorite foods and restaurants:

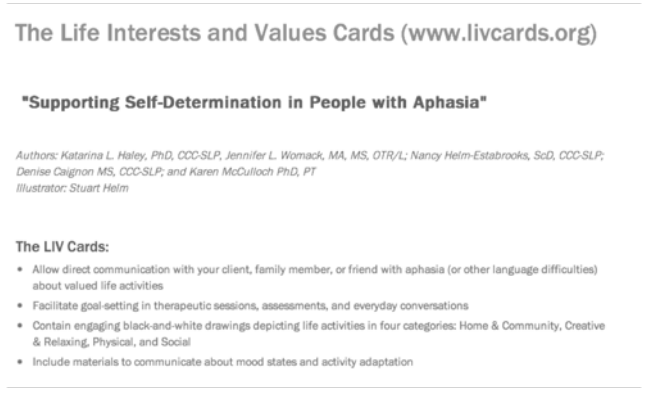
List places you have traveled: _____

A: AAC

- **LIV Cards:**

Haley et al. at Univ. of North Carolina, Chapel Hill

(these are similar to the OT Activity Card Sort test by Carolyn Baum)



The Life Interests and Values Cards (www.livcards.org)

"Supporting Self-Determination in People with Aphasia"

Authors: Katarina L. Haley, PhD, CCC-SLP, Jennifer L. Womack, MA, MS, OTR/L; Nancy Helm-Estabrooks, ScD, CCC-SLP; Denise Caignon MS, CCC-SLP; and Karen McCulloch PhD, PT
Illustrator: Stuart Helm

The LIV Cards:

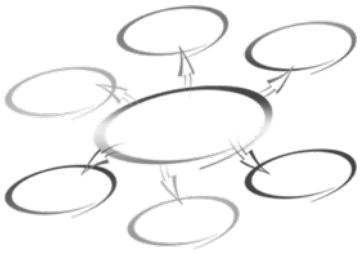
- Allow direct communication with your client, family member, or friend with aphasia (or other language difficulties) about valued life activities
- Facilitate goal-setting in therapeutic sessions, assessments, and everyday conversations
- Contain engaging black-and-white drawings depicting life activities in four categories: Home & Community, Creative & Relaxing, Physical, and Social
- Include materials to communicate about mood states and activity adaptation

A: AAC

Social Networks:

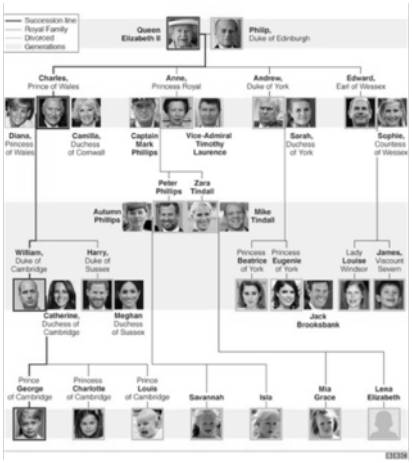
A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners

Blackstone & Berg (2003)



A: AAC

- Family tree with photos
- Reduce number of photos depending on needs of PWA



CONTINUED

A: AAC

- Business card holder for 3 ring binder
- Available from office supply stores
- Also can hold small artifacts
- Use pouches for bigger items

CONTINUED

A: AAC

- Maps—local, state, U.S., world etc.
- From a variety of sources
- Laminate

CONTINUED

P: Partner Training

"Why didn't anyone ever show me how to have a conversation with my husband?"

P: Partner Training

- A trained **partner** is the **communication ramp** via the use of AAC "tools" and various communication strategies!

CONTINUED

Couples/Family Training

(Alarcon et al, 1997; Lyon, 1996, 1997a, 1999, 2000; Boles & Lewis, 2000, 2003)

- **Alarcon et al videotape sessions between family members and PwA**
  - Provide structured viewing/feedback of successful and unsuccessful interactions
- **Lyon provides tx to both PwA and spouse**
  - Reviews pre- and post-stroke activities--each person selects activities to resume
  - The therapist provides counseling and training
- **Boles & Lewis describe solution-focused aphasia therapy**
  - Couples are guided to find effective strategies and solutions for issues

CONTINUED

P: Partner Training

Aphasia Institute—Supported Conversation™
www.aphasia.ca

Search for:

"An Introduction to Supported Conversation for Adults with Aphasia (SCA™) Self-Directed Learning Module"

- Acknowledge Competence of PWA
- Reveal Competence of PWA
  - Getting the information IN
  - Getting the information OUT
  - VERIFY

SCA™--*Acknowledge* Competence of PWA

Are you treating the PWA respectfully?

- Speak naturally (with normal loudness), using an adult tone of voice
- Acknowledge the person's frustrations and fears of being thought of as stupid, "I know that you know"
- Use humor, when appropriate

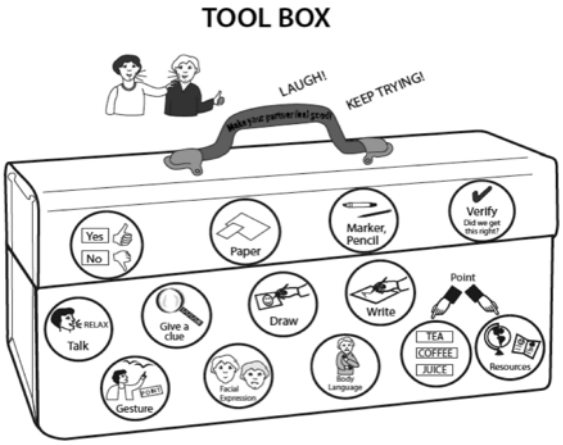
SCA™--*Reveal* Competence of PWA

Get and give accurate information

- **In**—communicate your message to the PWA
- **Out**—receive information from the PWA
- **Verify**—ensure your message is accurate

CONTINUED

Getting information IN and OUT



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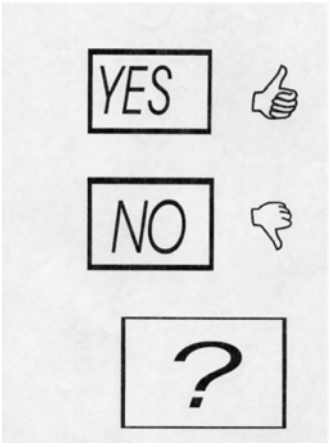
Yes/No Card



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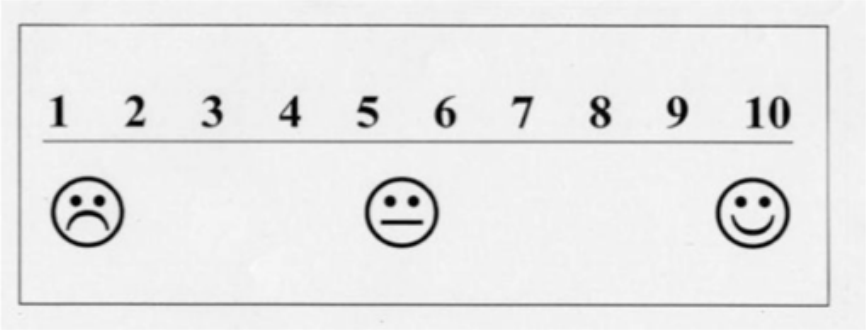
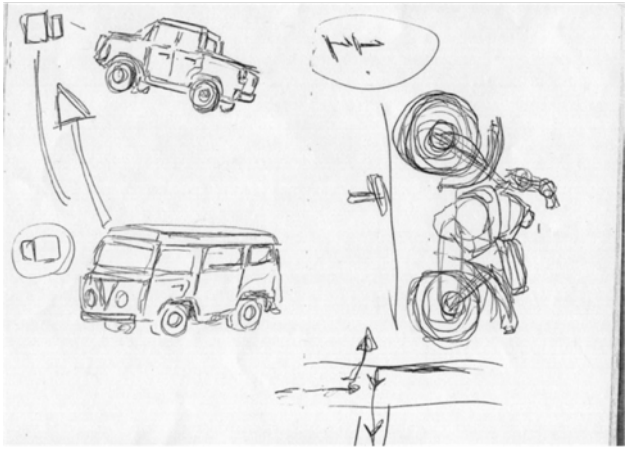
Number Line



Communicative Drawing



VERIFY:
Make sure that you really understand

- Summarize slowly and clearly what you think the person is trying to say… "so let me make sure I understand…"
- Add gestures or write key words, if necessary

P: Partner Training

Aphasia Institute
www.aphasia.ca

E: Education & Resources

"Why didn't anyone ever explain aphasia to me in a way I could understand?"

E: Education & Resources

- **How would you typically find out about a medical condition that you have?**
  e.g. Hecht-Scott syndrome
- **What resources are available to you?**
- **How would you find out about a medical condition if you had aphasia?**

CONTINUED

E: Education & Resources

Family Members and Friends

- Could you create a handout?
  - Information on aphasia and stroke
  - Books—First hand accounts
  - Websites
  - Community Resources
    - Caregiver organizations
    - American Stroke Association (American Heart Assoc. local chapters)

CONTINUED

E: Education & Resources

Businesses and Organizations

- Could you raise awareness of Aphasia and teach companies to be more aphasia friendly?
  - Information on aphasia and stroke
  - Aphasia Friendly Business program—NAA
  - Emergency Responder Program—NAA and La Trobe University

CONTINUED

E: Education & Resources

People with Aphasia

- Could you provide/create Aphasia Friendly Materials?
  - Information on aphasia and stroke
    - Aphasia Institute--Life is Larger than Aphasia
    - Aphasia Institute--What is Aphasia?
    - Aphasia business cards: "I have aphasia"
  - Books—First hand accounts
    - National Braille and Talking Books library
  - Community Resources
    - Medic Alert bracelet
    - Emergency response system or cell phone

CONTINUED

E: Education & Resources

People with Aphasia (con.)

- To create Aphasia Friendly Materials:
  - Collections of pictographs
    - ParticiPics--Aphasia Institute: www.aphasia.ca
  - Website An example of making information Aphasia Friendly:
    - Aphasia Center of California: www.aphasiacenter.org

A&E: Education & Resources

Aphasia Center of California

Website

www.aphasiacenter.org

- Learn about aphasia page Overview-can choose
- "Aphasia Friendly" format

E: Education & Resources

A Sample of other Websites:

- National Aphasia Association
  - www.aphasia.org
- What is Aphasia? Booklet
  - www.aphasia.ca
- Life is Larger than Aphasia
  - www.aphasia.ca
- Aphasia Friendly Webpages (button to toggle)
  - www.aphasiacenter.org

E: Education & Resources

- Aphasia Hope Foundation
  - www.aphasiahope.org
- Aphasia United
  - www.aphasiaunited.org
- Aphasia Access
  - www.aphasiaaccess.org
- La Trobe University "Build Your Own Aphasia Talk"
  - https://www.latrobe.edu.au/aphasia-lab/resources

A great need for advocacy:

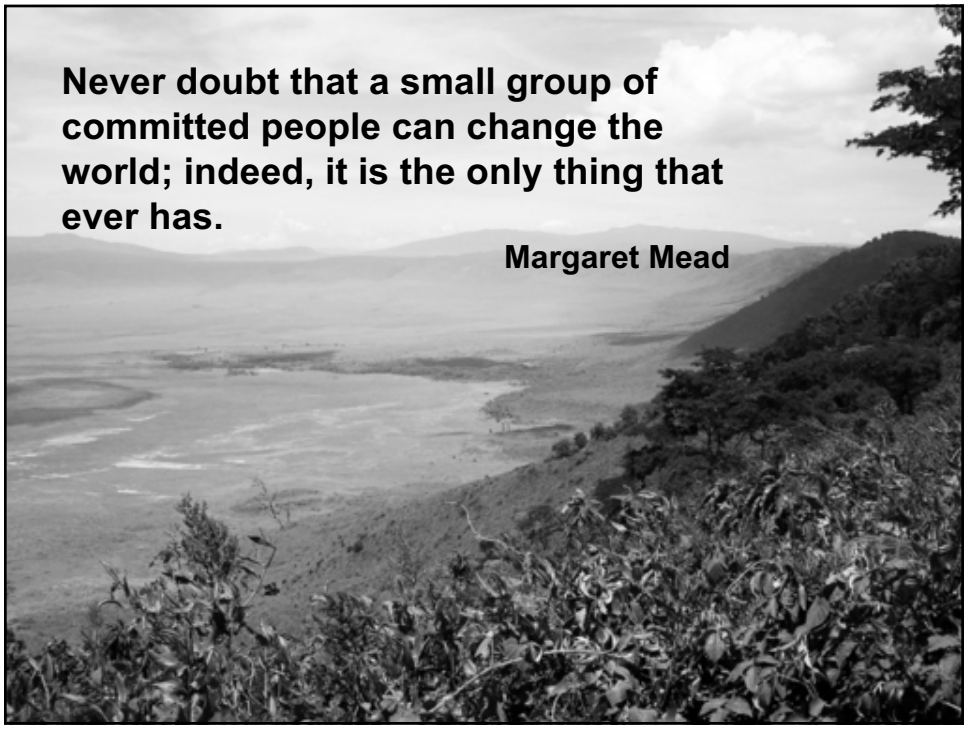
Lack of awareness has great impact

(Elman, Ogar & Elman, 2000; Simmons-Mackie et al, 2002, etc)

- Isolation of individuals with aphasia
- Less authorized treatment
- Less research funding

Need for targeted media and political campaign!

CONTINUED

Some closing thoughts:

- **Social and life participation approaches focus on reestablishing:**
  - Desired activities
  - Desired social contacts
- **Speech-language pathologists should focus on optimizing communication skills and improving quality of life**
  - Within meaningful life contexts
  - Using individual's perspective
- **Remember C.A.P.E. categories/checklist!**
  - **C = Connecting People**
  - **A = AAC**
  - **P = Partner Training**
  - **E = Education & Resources**