

Tools for Aphasia Advocacy, Community Outreach and Education: National Initiatives and Personal Perspectives

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Course Outline

- Aphasia-Facts/Incidence/Communication Strategies
- Life Participation Approach to Aphasia (LPAA)
- NAA Resources/Programs/Services
- Aphasia Education /Awareness/Advocacy Strategies
- Groups and Support Systems-Rationale and Programming
- Living Successfully with Aphasia
- Discussion and Questions

What is Aphasia?

- Aphasia is an acquired communication/language disorder, usually caused by stroke, head injury, migraines, brain tumor or neurological conditions.
- Aphasia impairs a person's ability to speak, process language, and sometimes understand others.
- Most people with aphasia experience difficulty reading and writing.
- Aphasia does NOT affect intelligence.

What causes Aphasia?

- Stroke is the most common cause (25-40% of stroke survivors acquire aphasia)
- Head injuries, brain tumors, migraines, and neurological conditions are other causes.
- About 1/3 of severe head injured persons have aphasia

What Causes Aphasia?

- Aphasia can also result from Frontotemporal Degeneration, Corticobasal Degeneration and other neurodegenerative disorders referred to as "Primary Progressive Aphasia" (PPA)

Types of PPA

- Semantic PPA- can't understand words or recognize familiar people/objects
- Agrammatic PPA (Progressive Nonfluent Aphasia)-omits words that link nouns and verbs, i.e., to, from, the; difficulty swallowing; movement symptoms; eventually may no longer speak

Types of PPA

- Logopenic PPA-trouble finding the words in conversation but can understand words and sentences; hesitations/pauses in speech
- Those with PPA may experience behavioral changes as disease progresses

Aphasia Facts

- Over 1 million Americans struggle with the devastation of aphasia.
- There are over 200,000 new cases each year; the numbers are expected to rise as the population ages.
- Aphasia is more common than cerebral palsy, muscular dystrophy or spinal cord injuries, yet most people have never heard of it.

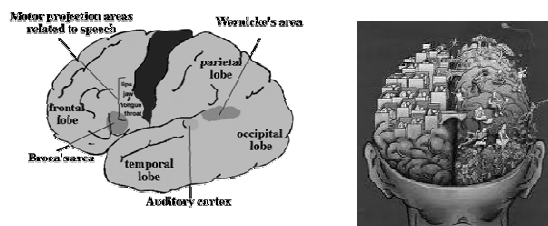
Aphasia Facts

- Lack of awareness and information is as devastating as disorder
- People with aphasia are at a disadvantage in today's health care system where the ability to access resources is closely tied to the ability to advocate for oneself

Aphasia Facts

- Can be acquired by all ages, race, genders, nationalities
- Many are prone to depression due to feelings of social isolation.
- Aphasia can co-occur with other speech disorders- apraxia , dysarthria
- Onset is usually sudden
- 10% have Primary Progressive Aphasia (PPA) which is a FTD

The Brain



Other Key Definitions

- **Agnosia**-impaired understanding of the meaning of certain stimuli. People can see, feel, and hear stimuli but cannot understand their meaning.
-Auditory, Auditory Verbal, Visual, and Tactile
- **Alexia** -loss of previously acquired reading skills due to recent brain damage
- **Agraphia** -loss or impairment of normally acquired writing skills.
- **Acalculia**-loss or impairment of math/number skills

Aphasia in the US (2006)

Figure 3. Regional Distribution of Aphasia among All Patients to Discharge in 2006



| | Northeast | South | Midwest | West |
|--|------------|-------------|------------|------------|
| 2006 Population | 54,741,350 | 106,502,222 | 96,217,736 | 69,355,643 |
| Number of patients with stroke | 176,899 | 376,222 | 217,934 | 159,559 |
| Number of patients with aphasia | 19,034 | 35,732 | 29,415 | 24,254 |
| Percentage of stroke patients with aphasia | 10.7% | 9.4% | 13.4% | 15.1% |
| Percentage of regional population with aphasia | 0.0003 | 0.0003 | 0.0004 | 0.0003 |

Common Misconceptions:

People with aphasia are:

- Psychologically ill
- Mentally retarded
- Under the influence of drugs/alcohol
- Hard of hearing/deaf
- Confused
- Unwilling to try
- Elderly

Deficits of Communication Characteristic of Aphasia

- Impaired verbal expression
- Impaired auditory comprehension
- Presence of paraphasias
- Perseveration
- Agrammatism, or grammatical errors
- Nonfluent speech or nonmeaningful fluent speech

Deficits of Communication Characteristic of Aphasia

- Impaired prosodic features of speech
- Difficulty repeating words, phrases, and/or sentences
- Problems with naming and word finding (anomia)
- Impaired reading ability
- Impaired writing ability (possibly confounded by loss of use of dominant hand due to hemiparesis)
- Pragmatic deficits
- In bilingual clients, unequal impairment between the two languages

People with aphasia find it difficult:

- take part in a conversation
- talk in a group or noisy environment
- read a book or magazine or road sign
- understand or tell jokes
- follow the television or radio
- write a letter or fill in a form
- use a telephone
- use numbers and money
- say their own name or the names of their family
- express their immediate needs or ideas or words
- go out

www.ukconnect.org

Friends and Family have a Difficult Time with:

- slowing down speech
- resist finishing sentences
- adapt the way they communicate
- keep the conversation going
- understand what a person is saying
- know what to do

www.ukconnect.org

Communication Tips

- Have the person's attention before you speak.
- Minimize or eliminate background noise if possible (Sirens, TV, radio, other people).
- Keep your own voice at a normal level.
- Keep communication simple, but adult.
- Confirm that you are communicating successfully with "yes" and "no" questions.
- Repeat statements or directions when necessary

Communication Tips-cont'd

- Give them time to speak, resist the urge to finish sentences or offer words.
- Communicate with drawings, gestures, writing and facial expressions.

"It's Still Me!" Video



Metacognitive Processes Important to Treatment Outcomes

- Self-awareness and Insight
- Motivation
- Self-monitoring
- Self-initiation
- Goal-oriented Behavior

Neural Plasticity

- The adaptive capacity of the Central Nervous System
- The mechanism by which the brain encodes experiences and learns new behaviors
- The mechanism by which the damaged brain "relearns" lost behavior in response to rehabilitation

Kleim & Jones 2008

Experience-Dependent Plasticity

- **"The ability of the nervous system to wire and rewire itself in response to lasting changes in experience has become known as experience-dependent plasticity."**



Experience can increase or decrease the synaptic gain of a particular sensory pathway in the cortex

Principles of Experience-Dependent Neural Plasticity (Kleim & Jones, 2008)

1. Use It or Lose It
2. Use It and Improve It
3. Specificity
4. Repetition Matters
5. Intensity matters
6. Time Matters
7. Salience Matters
8. Age Matters
9. Transference
10. Interference

Life Participation Approach to Aphasia (LPAA)

- General philosophy and model of service delivery
- Focuses on re-engagement in life by strengthening daily participation in activities of choice
- Places the life concerns of those affected by aphasia at the center of all decision making

The Life Participation Approach to Aphasia: Statement of Values*

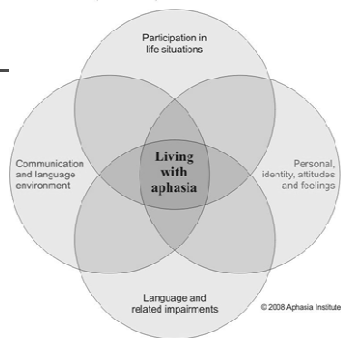
"LPAA places the life concerns of those affected by aphasia at the center of all decision making; it empowers the consumer to select and participate in the recovery process, and to collaborate on the design of interventions that aim for a more rapid return to active life."

*LPAA Project Group Statement, ASHA Leader 2/15/00

The LPAA Project Group-Roberta Chapey, Judith Duchan, Roberta J. Elman, Linda J. Garcia, Aura Kagan, Jon Lyon and Nina-Simmons-Mackie

<http://www.asha.org/public/speech/disorders/LPAA.htm>

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



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

Core values of LPAA

- Explicit goal is enhancement of life participation
- All those affected by aphasia are entitled to service
- Measures of success include documented life enhancement changes
- Both personal and environmental factors are targets of intervention
- Emphasis is on availability of services as needed at all stages of aphasia

Domains

- Language and Related Impairments Domain
Auditory comprehension (e.g. pointing to pictures named); Reading (e.g. matching a written word to a picture); Speaking (e.g. word finding, sentence formulation) and Writing (e.g. writing the names of objects)
- Communication and Language Environment Domain
Aspects of external context that might facilitate or impede language, communication or participation of PWA such as: Physical environment (signage, lighting, written supports); Social environment (attitudes of people, skills of partners); Political environment (policies supporting participation)

Domains

- The Participation Domain
Life roles (e.g. mother, teacher); Responsibilities (e.g. managing finances, performing a job); Relationships (e.g. engaging in conversation, making friends); Activities of Choice (e.g. leisure and recreation, community participation) and Tasks engaged in by an individual e.g. writing letters, cashing a check
- Personal Factors/Identity Domain
Factors such as age, gender, culture but expands the ICF domain to include internal factors that vary as a consequence of aphasia such as confidence and personal identity
- Living with Aphasia Domain
Dynamic interaction of multiple life domains; captures elements of quality of life (how satisfied someone is with their life)

Supported Conversation for Adults with Aphasia (SCA™)

- Communicating with people who know more than they can say
 - Ensures accurate exchange of opinions, information and feelings
 - Developed in Ontario by the Aphasia Institute in Canada
- www.aphasia.ca

Goals of Supported Conversation

The Conversation Partner can:

- **Acknowledge** the **competence** of the adult with aphasia
- Help the adult with aphasia to **reveal** his or her **competence**

Goals for healthcare professionals:

- Increase communicative access to your services
- Increase the efficiency and effectiveness of your service

Acknowledging Competence

Indirectly:

- Tone of voice (sounding natural and not patronizing)
- Respect
- Choosing adult or complex topics to discuss
- Integrating supports (techniques) into natural talk

Directly:

- "I know that you know"
- Explicitly attributing breakdowns to your own limitations as communicator (often using humor)
- Deal openly with situations in which you have to communicate with a partner

Revealing Competence

Techniques to **get** and **give** accurate information

- In
- Out
- Verify

CONVERSATION= two or more people (not one-sided!)

It is an EXCHANGE of information!

IN- Is Your Message Clear?

- Use short, simple sentences and expressive voice
- Use gestures that person can easily understand
- Write key words/main ideas (e.g. "pain" in bold print)
- Use pictures-focus on one at a time
- Eliminate distractions
- Observe person for comprehension

Helping to Get the Message **OUT**

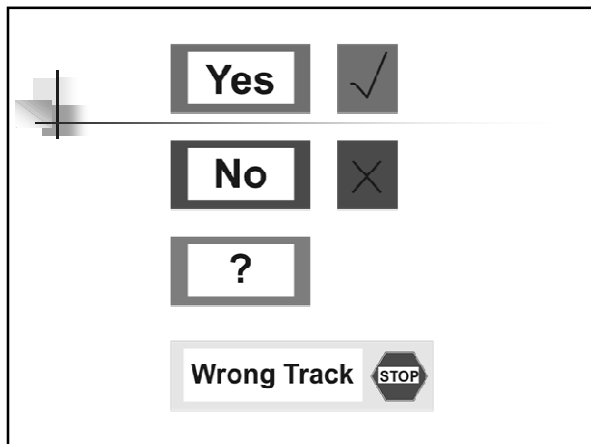
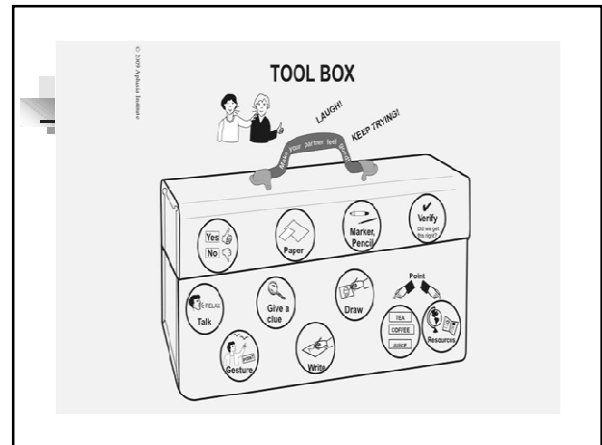
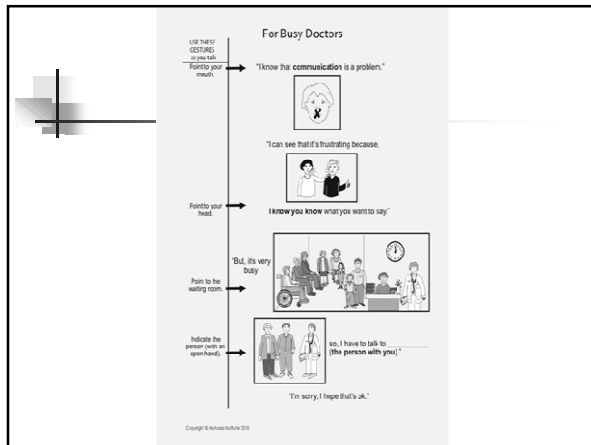
- Give sufficient time to respond
- Ask "yes/no" questions
- Ask one thing at a time
- Ask for clues by gesturing or pointing to objects, pictures and written key words (e.g. "can you show me...?")
- Go from general to specific

VERIFY: Have you Checked to Make Sure you are Understood?

- Summarize slowly and clearly what you think the person is trying to say (e.g. "so let me make sure I understand")
- Add gesture or written key words as necessary
- Reflect, Expand, Summarize

Goals to a Social Approach:

1. Help the PWA reengage in life by giving them opportunities to reenter larger communities, and personally relevant activities
2. Supportive environment
3. Client takes an active role: empowering
4. **Minimize** declines in relationships, give access to prior roles/identities, prevent exclusion and seclusion
5. Improve quality of life by unmasking competences: improve communication through SCA!



Practical Considerations: Using LPAA

- Assessment: Look at how the PWA does with support-look at competencies
- Treatment: Facilitate the achievement of life goals
- Work on making the PWA's environment more "aphasia-friendly"
- Look at all those that are affected by aphasia as legitimate targets for intervention (family, friends) and educate
- Expand your role as a clinician: coaching and support to help the PWA reengage
- Document quality of life and life participation changes

Chapey, R. et al. (2008) Life Participation Approach to Aphasia: A Statement of Values for the Future. In *Language Intervention Strategies in Aphasia and Related Neurocommunication Disorders*, 5th Edition, R. Chapey (ed), pp. 279-289.

Ways to Measure Participation and Social Outcomes

- ICF: International Classification of Functioning, Disability and Health (World Health Organization, 2001)
- Quality of Communication Life Scale
- CADL-2: Communication Activities of Daily Living (Holland et al.)
- CETI: Communicative Effectiveness Index : Measure for Caregivers
- A-FROM: Living with Aphasia: Framework for outcome measurement (Kagan et al, 2007)
 - Impairment
 - Environment
 - Participation
 - Personal Factors
- ALA: Assessment for Living with Aphasia

National Aphasia Association (NAA)

NAA is a consumer-focused, not-for-profit organization that was founded in 1987 as the first national organization dedicated to advocating for persons with aphasia and their families. Resources include:

- **The Aphasia Quiz** on www.aphasia.org
- **NAA Hotline (800-922-4622)** helps over 4,000 families a year.
- **NAA National Registry** links to over 440 aphasia US support groups.
- **NAA State Representative Network of over 220 volunteers**

NAA Mission

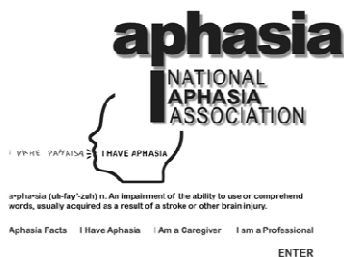
The Mission of the NAA is to Promote Universal Awareness and Understanding of Aphasia and Provide Support to All Persons With Aphasia, Their Families and Caregivers.

NAA Resources

- **www.aphasia.org** receives over 30,000 hits per month, potentially helping over 200,000 families a year.

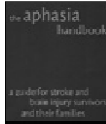


New Website Landing Page <http://www.devaphasia.dreamhosters.com/home>



NAA Resources

- **The Aphasia Handbook: A Guide for Stroke and Brain Injury Survivors and Their Families** -- with its simple, illustrated design and practical, non-technical content – this award-winning, internationally acclaimed book is a user-friendly, easy-to-understand resource.



NAA Resources

- **Aphasia Bill of Rights** adopted in 2006, available on www.aphasia.org
- **National Aphasia Awareness Month** in June
- **E-News Bulletin**

aphasia THE NATIONAL APHASIA ASSOCIATION

APHASIA BILL OF RIGHTS

WHEREAS:

Aphasia is a condition, usually acquired as a result of stroke or other brain injury, which impairs the ability to use or comprehend words, but does not affect intelligence and...
As a result of their difficulty communicating, people with aphasia may experience great frustration and isolation in their daily lives, which is often made worse by the lack of information that they receive about their condition, and...
"National Aphasia Month" has been proclaimed by the health care system without regard to...
people with aphasia that the communication advantages as other patients do not and...
people with aphasia have the same fundamental rights as other members of society including the right to the pursuit of happiness and a full and positive quality of life.

NOW THEREFORE do we, the members of the National Aphasia Association (NAA), vote unanimously to approve the following Bill of Rights:

People with aphasia have the right to:

1. Be told the scope as it is determined, preferably by a qualified speech-language pathologist (SLP), both orally and in writing, that they have "aphasia" and have an understanding of the nature of aphasia.
2. Be provided, upon release from the hospital, with written documentation that "aphasia" is part of their diagnosis.
3. Be told, both orally and in writing, that there are treatment options available to them, including National Certified Stroke to care centers, as well as national organizations, such as the National Aphasia Association (NAA).
4. Have access to volunteer interpreters by the nearest national organization, by a qualified speech-language pathologist (SLP).
5. Give their informed consent or assent or refusal to participate in research.
6. Exercise their controlling rights over signage and health care facilities and related communication and services to suit their needs.
7. Have access to information in their most functional language through a qualified professional, either through written or verbal communication, and access to a variety of written and oral communication aids, including a language reference from their local area to be used when necessary.

NAA | 200 Bennett Ave | Suite 102 | New York, NY 10001 | 200924142 | www.naa.org

Caregiver's Bill of Rights (author unknown)

I have the right to take care of myself. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.

I have the right to maintain facets of my own life that do not include the person I care for just as I would if he or she were healthy. I know that I do everything that I reasonably can do for this person and I have the right to do some things just for myself.

I have the right to get angry, be depressed, and express difficult feelings occasionally.

Caregiver's Bill of Rights (author unknown)

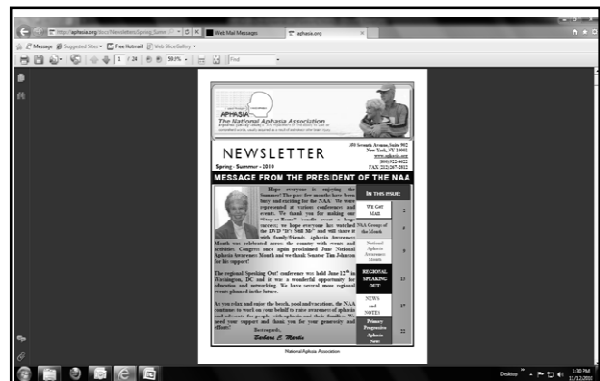
I have the right to reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt or anger.

I have the right to receive consideration, affection, forgiveness, and acceptance for what I do for my loved one as I offer these attributes in return.

I have the right to take pride in what I am accomplishing and to applaud the courage it has taken to meet the needs of my loved one.

I have the right to protect my individuality and my right to make a life for myself that will sustain me in times when my loved one no longer needs my full-time help.

I have the right to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.



Quarterly Newsletter

**June is
National Aphasia Awareness Month**

Is Your Business Aphasia Friendly?

My Restaurant is... My Pharmacy is...
My Bank is...

Aphasia affects talking, understanding, reading and writing. Aphasia is typically caused by stroke, head injury, brain tumor or neurological disease. Aphasia can occur in people of any age. Over 1,000,000 Americans live with aphasia every day.

Thanks to: Snyder Center For Aphasia Life Enhancement
www.snydercenter.com

LEARN HOW TO MAKE YOUR BUSINESS APHASIA FRIENDLY!

Contact:
National Aphasia Association
230 Seventh Avenue Suite 902
New York, NY 10001
(800) 922-4622
(212) 587-2814
www.aphasia.org

Business Survey

Aphasia Friendly Business Survey:

| Facility | Before Training | | | After Training | | |
|--|-----------------|------|----|----------------|------|----|
| | Yes | Some | No | Yes | Some | No |
| Clean | | | | | | |
| Door easy to open | | | | | | |
| Good lighting | | | | | | |
| Space to walk, or use wheelchair | | | | | | |
| Hours with announcements | | | | | | |
| Easy to hear toll-free number or address | | | | | | |
| Customer Service | | | | | | |
| Friendly | | | | | | |
| Responsive | | | | | | |
| Patience | | | | | | |
| Speak slowly | | | | | | |
| Repeat when needed | | | | | | |
| Clear directions | | | | | | |
| Use paper & pencil | | | | | | |
| Use pictures, pictures | | | | | | |
| Use gestures | | | | | | |
| Use written questions | | | | | | |
| Understandable signage | | | | | | |
| Willing to learn | | | | | | |
| Barriers | | | | | | |
| Door easy to open | | | | | | |
| Restroom wheelchair accessible | | | | | | |
| Smooth floors | | | | | | |
| Grab bars both sides | | | | | | |

Easy to get soap
Easy to use
Overall safe

Aphasia Friendly Business Survey:

| Written Materials | Before Training | | | After Training | | |
|-----------------------|-----------------|------|----|----------------|------|----|
| | Yes | Some | No | Yes | Some | No |
| Signs and Displays | | | | | | |
| Written menus | | | | | | |
| Easy to read | | | | | | |
| Picture | | | | | | |
| List of clear choices | | | | | | |
| Signatures for checks | | | | | | |
| Receipt provided | | | | | | |

Comments:

Printed (complete survey)

Supportive Materials

ATM Bank
Pictorial Guide To Banking

RESTAURANT HOLLOW
Pictorial Menu

RESTAURANT HOLLOW
Pictorial Menu

Color Chart
Black, Brown, Blue, Red, Silver, White

Certified Aphasia Friendly

APHASIA + Awareness + Communication Tools = Aphasia Friendly Business

APHASIA Friendly Business Campaign

Working with businesses to expand services to people with disabilities through:

- Awareness &
- Supportive Communication Tools

ACTION PLAN

Engage

- Visit local businesses and share information about aphasia with business owners and staff

Survey

- Employee knowledge of aphasia and ways to facilitate communication
- Accessibility of restrooms
- Accessibility of reading material (such as signs, menus, or instructions)

Invite

- Business representatives to your center, clinic, office to learn more about aphasia and participate in raising or support communication

Recommend

- Provide examples of resources that will make the products/services more accessible to people with aphasia, for example icons, menus, or symbols to accompany written signs

Implement

- Involve people with aphasia, families, volunteers in creating materials specifically designed for each business to make their specific products and services accessible.

Recognize

- Award businesses that implement changes by posting their efforts on your website, Facebook page, create newsletters
- Award outstanding businesses with an "Aphasia Friendly Business" decal

MY STROKE. ? ? ?

100 Days From Severe Aphasia To Speaking, Reading and Writing
By EVELYN F. WINSTON, Ph.D.

A chronology of the monthly activities, feelings and thoughts after my stroke and the assistance I received from professionals, loved ones and supporters.

Aphasia Advocacy and Outreach



I have aphasia (uh 'fay' zhu) a communication impairment.
 My intelligence is intact, I am not drunk or mentally unstable.

Please Take Time To Communicate

I have aphasia (uh 'fay' zhu) a communication impairment.

My intelligence is intact, I am not drunk or mentally unstable.

How You Can Help

Give me time to communicate.
 Speak simply and clearly to me.
 Do not shout. It does not help.
 Ask yes/no questions.

(Check those that apply)

- Speaking takes a little more time.
- Speaking is very difficult.
- Understanding speech is difficult.
- Use simple sentences.
- Writing key words helps.
- Numbers are difficult for me.



Current and Future Initiatives

- Multicultural Task Force (MTF)
- Aphasia Awareness Training for Emergency Responders
- Annual Regional Conferences
- Institutional Affiliates
- PPA Survey
- Needs Assessment

<http://survey.constantcontact.com/survey/a074hxb9aygqtp7mw0/a01h4qu096a05/questions>

Current and Future Initiatives

- Increased Outreach and Visibility
- Revised Information Packet/Resources
- Aphasia Friendly Businesses
- "I Am The Voice of Aphasia" Videos
- Public Awareness of Aphasia Survey
- Joint Funding/Collaboration
- Legal Advocacy
- The After Words Project
- ????

MTF Accomplishments

- Creation of MTF web page
- Recruitment of multicultural state representatives
- Fostering the creation of multicultural support groups
- Newsletter articles on multicultural topics
- Translation of NAA brochure into Spanish, Greek, Chinese, Tamil, Portuguese, Hebrew, Korean, Russian, French and Arabic
- Revision of NAA Mission and Bill of Rights

MTF Accomplishments

- Created subcommittees for Language Bank and Outreach Plan
- Received ASHA Multicultural Project Grant for *Sigo Siendo Yo!* Aphasia Film Project for Hispanic Persons with Aphasia



MTF Accomplishments

- Collaboration with related organizations and outreach to international aphasia community

http://issuu.com/latinoneworkmagazine/docs/april_2010
<http://issuu.com/latinoneworkmagazine/docs/marchissue>



Annual Regional Conferences

- Expanding successful Speaking Out! conference format to offer more frequent, regional meetings
- Retain unique features of Speaking Out! in a one day conference
- Serve a wider community; eliminate physical and financial constraints

Annual Regional Conferences

- Conduct Needs Assessment
- Create Manual as a template
- Standard components of each conference
- 1st held in October 2009 in Tulsa, Oklahoma
- June 12, 2010 in Washington, DC
- June 26, 2011 in Chicago, IL
- Ramp up over next 5 years

Regional Speaking Out Conference



Annual Regional Conferences 2012-NAA 25th Anniversary

- Pittsburgh, PA- July 28, 2012
- Atlanta, GA
- Orlando, FL-May 27, 2012
- Las Vegas, NV-June 29, 2012
- Oklahoma City,OK
- Madison, WI -2013

Collaborative Efforts to Empower People with Aphasia

- Collaboration between two Regional Community Aphasia Programs
 - Stroke Comeback Center
 - The Snyder Center for Aphasia Life Enhancement (SCALE)
- To highlight members using technology to facilitate communication

Presentation Themes- Five Key Points

1. Get back your life
2. Everyone should be able to get help
3. Success = a better life
4. You and your world should be included
5. You should get help at all stages of your recovery (in the hospital, at home and in the community)

Empowering Others to Live Well with Aphasia

- Process- Topic Selection
 - Members from both centers determined points to share
 - Small groups met to generate themes using the acronym "EMPOWER"
 - Center members conferenced by SKYPE to plan
 - SCALE members created video of their personal messages
 - Members from both centers volunteered to share their personal stories

Empowering Others to Live Well with Aphasia

- Process- Message Delivery
 - Members were supported in formulating their stories
 - Members practiced their speeches with volunteers and with each other via Skype
 - Some members used technology to deliver their speeches
 - Members who were unable to attend the conference sent video recordings

Video Assisted Speech Technology



VAST is an innovative application of video technology to facilitate and improve communication abilities for individuals with apraxia and nonfluent aphasia. The simultaneous combination of visual and auditory cues allows these individuals to produce speech for live scripted communication and for therapeutic practice. Developed at the Stroke Comeback Center. Visit www.speakinmotion.com for further information.

Presentation Themes- EMPOWER

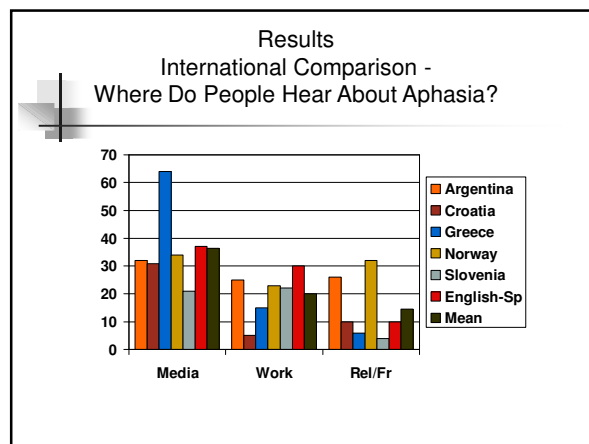
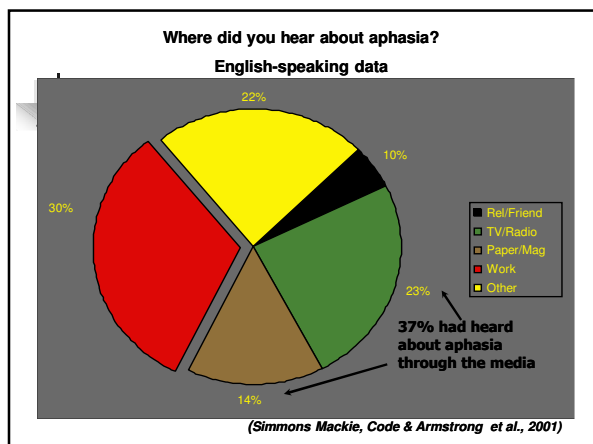
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M
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R

Engage yourself in everyday activities
Make new friends, community and relationships
Practice, practice, and be positive
Other ways of doing things
Working on new interests, teach others
Exercise and recreation
Religion

Increasing Awareness & Knowledge of Aphasia

Improving understanding of the public awareness of aphasia in different cultures and communities is particularly relevant for:

- Efforts to improve and extend services
- Efforts to increase research support and
- To encourage improved social inclusion of aphasic people



Conclusions and Implications

- We found significant variability in knowledge of aphasia between the countries surveyed.
- As with previous studies, this appears to provide further evidence of differences in levels of awareness of aphasia in different cultures, though our survey method has in-built reliability issues. Our combined sample is larger than previous surveys.
- Variation in awareness may be related to local media impact, regional variations in incidence/prevalence of aphasia and socio-economic and educational variations *and cultural differences in attitude to disability*. Such information is vital for targeting awareness raising.

Targeting *Where* and to *Whom*

- **'Service providers'...**
 - 'service encounters' in pubs/restaurants, shops, churches, cinemas, public transport, community venues
 - TV/Radio, newspapers/magazines
- **Professionals...**
 - health & social services, residential homes, hospitals, conversation partner training, lobbying & advocacy with 'purse holders'
- **Family & Friends...**
 - conversation partner training, relatives' workshops, family counseling

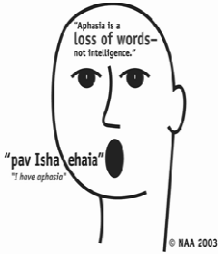
Increasing Public Awareness

- Use the word "aphasia" to describe aphasia
- Encourage and support PWA, family and friends in promoting public awareness
- Participate in public awareness campaigns- June is National Aphasia Awareness Month
- Bombard the media
- Look for public venues to educate
- Involve students in aphasia advocacy
- Influence public policy and legislation

Aphasia Awareness Training for Emergency Service Providers

- Grant received from Christopher and Dana Reeve Foundation to initially fund project
- Training of Police Officers, Firefighters and EMTs in NY, NJ and CT
- Distribution and recognition of Aphasia Sticker
- Go National!

RECOGNIZE THE DECAL



- Windshield/Window Decal
 - Part of a National Campaign
 - Place decal for vehicle in the left rear passenger side of car
 - At home place at front and back entrance

Contact: National Aphasia Association
(800) 922-4622 www.aphasia.org

Social Networking/Blogs

MKCREATIVEBlog



Groups, State Reps, Programs/Centers



Reversing the trend... Connecting with the Community

What we know...

- Greater than 70% of individuals with aphasia are unable to return to work.
- 70% of individuals with aphasia felt that people avoid contact with them because of their difficulty with communication.
- 90% of individuals with aphasia are socially isolated!



So what will it take?

- "It takes a village" ...
- Awareness / Understanding / Training
- Confidence on behalf of the PWA (Person with Aphasia) and all potential Communicative Partners!
- Bridges to successfully re-engage... or perhaps...never dis-engage!

Abilities

- What "CAN" the PWA do?
- Strength based assessment and treatment planning.
- Consider the journey...not the destination!



Barriers → Bridges



*We recognize the challenges of returning to vocational, avocational, and recreational life for the individual with aphasia are **MULTIDIMENSIONAL** and require more than support, encouragement and desire... it requires = a **hierarchy!***

- Individualized Hierarchies for each LPAA goal
- Addresses Communicative Confidence
- Can generalize from one goal to another because of success

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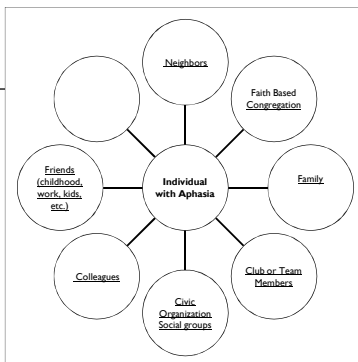
...the village...*your* community!



Ask yourself how many communities you belong to...

- "I belong to _____"
- Access to communities
- Strength in numbers
- Evening out the playing field: the bi-lingual advantage...if everyone "speaks Aphasia"

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What is a Communication Support Team?

A Communication Support Team®, or CST, is a trained group of volunteers, selected by the Person With Aphasia and their family members. The Team can be made up of friends, neighbors, members of a church or social group ... models Care Teams that many faith based organizations have been using for years!

What kind of activities can the CST do with the Person With Aphasia?

The LPAA (Life Participation Approach to Aphasia) states that any activity in which communication is a barrier to the full enjoyment of that activity, is appropriate for support and intervention.



Who does the training?

A Speech / Language Pathologist familiar with the Individual's Communicative Strengths, Opportunities and Interests

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Queens College-NSSLHA Bake Sale



The Adler Aphasia Center in Maywood, NJ

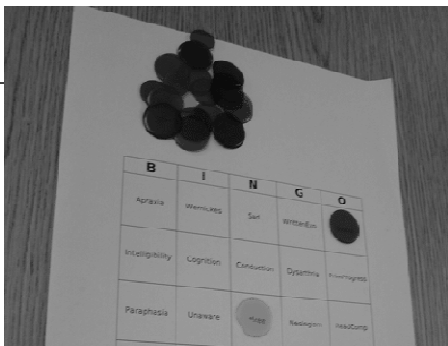


The Aphasia Center of West Texas



HealthSouth MountainView in Morganstown, WV

- As a fundraiser for our Aphasia Club, area restaurants and affiliated companies donated gift cards that we used for Aphasia Bingo. Staff paid to play at lunch time. The cards were designed with Aphasia Terminology and emotional words that express how our members with Aphasia describe their feelings. Throughout the course of the game, we would define some of the words or talk about those emotions and how staff can better communicate and support individuals with Aphasia. -Mary Burleson, Coordinator



M.A.G.I.C. in Iowa City, IA

"To follow up on the theme of ARTS (Aphasia Recovery Through the Senses), we decided to create a "paper quilt". During our first meeting of the summer, each participant contributed a square symbolizing what their aphasia recovery has meant to them. Some of the images are more symbolic, some are literal. Some of our participants just wanted to portray a feeling of contentment and enjoyment. We posted the finished squares in a quilt pattern on the bulletin board in the lobby of the Wendell Johnson Speech and Hearing Center, where they will remain until the end of the summer."
-Jean Gordon, Facilitator
M.A.G.I.C. (Modalities Aphasia Group - Improving Communication)

M.A.G.I.C. in Iowa City, IA



SCALE-Snyder Center for Aphasia Life Enhancement in Baltimore, MD

SCALE members participated in Annual Baltimore Herb Festival. They manned tables With educational information on aphasia. Flowers and vegetable plants grown by horticulture program were featured for purchase



Aphasia is not a plant.....
But what is it?

Aphasia Awareness in the News

Special Supplement Section in The Washington Times about Aphasia Awareness Month.

<http://www.print2webcorp.com/news/washingtontimes/AphasiaAwareness/20090611/p1.asp>

- Congresswoman Gabby Giffords Interview

WINGS SOARS!
Jan Maxwell and director John Doyle deliver A TREMENDOUS THEATRICAL HEADRUSH!
DON'T MISS THE "MUST-SEE" PERFORMANCE OF THE SEASON!
NOW THROUGH NOVEMBER 21 UNLY!

"TRULY TRANSCENDENT!"
"Jan Maxwell delivers a standout, TOP-OF-FORM PERFORMANCE!"
"A TRULY MEMORABLE THEATER EXPERIENCE!"

WINGS

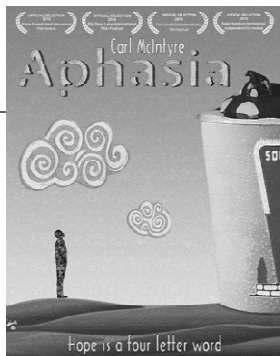
BY ARTHUR KOPIK DIRECTED BY JOHN DOYLE

Arthur Kopik's "Tough" immortal Jay, WINGS, is a journey through the eyes of Emily Ellison, a 1920s singer/actress who discovers her life's purpose in a battle of love, hope, and self-discovery, proving that even when her mental will fails her, her divine/angelic spirit proves unaffable.

See about WINGS with our National Aphasia Association discount!

\$39
Use code FF39

ONLINE | 23T.COM
BY PHONE | Cal (212) 246-4422
IN PERSON | 305 West 43rd Street (East side of 8th Ave)



NIGHT SKY

NIGHT SKY
A PLAY
BY
SUSAN
YANKOWITZ
DIRECTED
BY
DANIELLA
TOPOL



Not Voiceless Dance Project

- Created and choreographed by CTRS
- Based on writings/interviews with PWA
- Sections performed in July 2012
- Collaborating with Amalgamate Dance Company in NYC to create other aphasia related dance pieces



Why Are Groups Needed?

- NAA Priority-Development of a National Directory of Aphasia Community Groups
- Majority of individuals with aphasia and families:
- Lack opportunities for socialization and support
 - Unaware of resources
 - Become socially isolated

Why Are Groups Needed?

- Insurance coverage for speech therapy limited
- Few can afford to pay privately
- ACGs are low cost option
- Comfortable environment to "practice"
- Research demonstrates that speech can continue to improve years after reaching a "plateau"

Beyond the Plateau...

Wepman, JM, 1953, JSHD

"Aphasic patients left to their own devices tend to plateau in the resolution of their language deficits.

With this plateauing comes the development of a whole series of so called secondary reactions to their condition. Accepting their disability usually means a withdrawal from the social environment. Anxiety and depression become increasing problems.

A sense of worthlessness, feelings of futility and an over-all attitude of insecurity becomes pervasive. In sheltered environments they tend to become overly dependent, invalidated and infantilized.

Beyond the Plateau...

Wepman, JM, 1953, JSHD (cont)
"Therapy that is supportive as well as instructive is the only way in which these patients can again regain a wholesome self-concept which permits them to function in society as whole people. They must be stimulated to action. Their physiological readiness must be utilized. Their motivational levels must be understood and constructively used."

Beyond the Plateau...

With apologies to Audrey Holland, Holland, A (2011...in person)
"Wepman said...when a PWA "plateaus" they should find another therapist...it is the clinician that plateaus, not the PWA."

Beyond the Plateau...

Most aphasia TX studies are done with people with "chronic aphasia" to remove the impact of spontaneous recovery...

So why are we telling people they will have 1 year to recover???

Value of Aphasia Center Participation

- Increase in Aphasia Centers in past 2 decades (Elman, 2010)
- Most employ "social approach" and at least some group TX/conversation TX (Elman, 2007)
- Enhance identity /adjustment (Simmons Mackie and Elman, 2010)

Value of Aphasia Centers Participation (Elman, 2007, 1999)

Some Benefits of Conversation TX:

- ❑ Conversation groups promote interaction among members
 - Turn-taking
 - Initiation
- ❑ Provides different communication partners and more typical/natural communication task
- ❑ May foster transfer of gains and generalization (complexity theory)
- ❑ Reduce isolation caused by aphasia

Value of Aphasia Centers Participation (Elman, 2007, 1999)

Benefits of Conversation/Group TX:

- Supportive environment improves psychosocial function (Elman and Bernstein-Ellis, 1999)
- Help PWA establish new positive identity; (Simons-Mackie, 2008; Elman, 2007)
- Narrative helps with adjustment to post-stroke changes (Shadden & Hagstrom, 2007)

Value of Aphasia Centers Participation (Elman, 2007, 1999)

Benefits Group TX:

- Aphasia Group TX are effective (Wertz et al., 1981; Elman and Bernstein-Ellis, 1999; Elman, 2007)
- Provide opportunities for *interactional* (interpersonal content) and *transactional* (factual content) uses of language (Elman, 2005; Simmons-Mackie 2001)
- Cost-effective (Wertz et al., 1981; Elman and Bernstein-Ellis, 1999; Elman, 2007)

Value of Aphasia Centers Participation (Simmons-Mackie et al., APM&R, 2010)

Communication Partner Training in Aphasia: A Systematic Review.

"Communication partner training is effective in improving communication activities and/or participation of the communication partner and is probably effective in improving communication activities and/or participation of persons with chronic aphasia..."

What do Groups Do?

- Empower
- Combat social isolation and friendship
- Promote conversation
- Build Optimism
- Provide setting to learn new things
- Move person out of "patient" role

Getting Started-Needs Assessment

1. Who should be served by the group?
2. How will potential members be identified?
3. What areas of focus best meet the needs of group?
4. How will emerging interests be accommodated?

Needs Assessment, cont'd.

5. Who are the group facilitators? Expertise?
6. Who will take over if facilitator (s) is away?
7. Are there volunteers to assist?
8. What must volunteers know? Training?
9. Is there need for an advisory board? If so, composition, size?

Needs Assessment, cont'd.

10. Are there sub-groups within potential membership?
11. Will there be group goals and/or rules?
12. How will various communication modalities i.e. drawing, gesture, writing, be incorporated?
13. Is there a space that can be regularly scheduled?

Needs Assessment, cont'd.

14. What transportation is available?
15. What will be the group funding source?
16. How often should the group meet and for what length of time?
17. How will ongoing group development take place?
18. How will feedback be solicited and used?

Recommendations

- Helpful to start with small group that wants group to succeed
- "Acknowledge competence" then trust it
- Provide venues for participants to tell/retell their stories
- Help people with aphasia find ways to advocate for themselves
- Group should be a safe place where judgment is suspended

More Recommendations

- Establish leadership within group and delegate
- Create cohesion amongst the group
- Create structure within the group so members can work toward achievable goals
- Be interactive and incorporate meaningful activities
- Get people interested and involved in educating others

What is the Group Focus?



What is the Group Focus?

Peer Support



What is the Group Focus?

- Enhancing communication, confidence and supported conversation
- Emphasizing personal narratives
- Sharing opinions
- Education and Advocacy
- Nonverbal communication skills
- Listening skills
- Caregiver support
- Etc, etc.

Group Activities

- Music and movement activities
- Sharing news of family/friends
- Flash cards with themed questions
- Current events discussion
- Holiday luncheons/birthday celebrations
- Guest speakers/performers
- Pen Pals
- Watch films followed by discussion

Group Activities

- Category Story
- Practice ordering food, giving directions, taking phone messages
- Mock Court
- Educate students/provide inservices
- Cooking
- Store/Gift shop
- Theatre/Drama

Games

- Board Games-
cranium, pictionary
- Bingo
- Interactive Games
- Crossword Puzzles
- Name that Tune
- Jeopardy
- Bowling



Computer Group Activities

- **Using special effects and animations**
- **Expression about their interests**
- **Creating a personal slide show**
- **Filming funny skits (written and spontaneous to view on computer)**
- **Teaching basic computer skills**

Computer Group Benefits

- **Facilitating new learning (directions , vocabulary related to technology)**
- **Engaging in a fun social activity**
- **Encouraging creativity**
- **Stimulating word finding skills**
- **Independence**

Computer Group Video

- Love life to the fullest video
- Computer Group video (skits and jokes)- Start -9:00

Literature Group Activities

- **Selecting interesting literature to read as a group (poetry , short stories, plays, novels)**
- **Utilize reading skills**
- **Discuss literature**
- **Act out segments of a play**

Literature Group Benefits

- **Discussing literature**
- **Facilitate recall of information about authors and playwrights**
- **Enhance inferencing skills**
- **Stimulate memory skills**
- **Expand knowledge base**
- **Assist with word finding through discussion**
- **Promoting a real world, social activity**

Music Group Activities

- **Reading about a composer/singer-classical , popular, Broadway**
- **Recalling information about music**
- **Singing/ humming familiar melodies**
- **Discussing a singer, composer, musician**

Music Group Benefits

- **Stimulate right brain activity**
- **Facilitates word finding**
- **Stimulates cognitive skills- (eg recalling information about the selected music, word recall through a familiar melody)**
- **Involves reading skills about the music selection & lyrics**
- **Provides a normalizing activity & socially gratifying**

Mind/Body Group Activities

- **Relaxation techniques presented through creative channels- visualization, music , meditation,**
- **Gentle yoga and stretching**
- **Discussion before/after group about feelings, pain, body changes, etc.**

Mind/Body Group Benefits

- **Relaxation/use of music to relax**
- **Creative visualization to enhance meditation and promote relaxing**
- **Expressing feelings about their body**
- **Facilitating word finding**
- **Participating in an activity that is social and fun**

Mind/Body Group Video

- Aphasia and the Arts CD

Outcomes /Value of Using Arts with PWA

- Empowers
- Participation regardless of severity, physical impairment, previous experience
- Collaborate, coach and support
- Encourages spontaneous communication

Outcomes/Value, cont'd

- Discover new talent
- Learn a new skill
- Return to valued and meaningful activity
- Gains in linguistic, psycho-social, emotional and recreational skills

University/College Based

- University of Arizona
- Cal State-East Bay
- Boston University
- Western Michigan University
- Kean College- NJ
- University of Washington
- **The Aphasia House**-University of Central Florida
- CW Post- Brookville,NY
- Duquesne University-PA
- UNC –Chapel Hill
- DaZy Aphasia Centre- University of Toledo
- MGH Aphasia Center-Boston
- Aphasia Center of Acadiana-University of Louisiana/Lafayette

Hospital/Rehab Based

- Rehabilitation Institute of Chicago
- St Joseph's Carondelet Hospital-Tucson
- Moss Rehabilitation Center-Philadelphia
- National Rehabilitation Hospital –D.C.
- Luther-Midelfort-Mayo Health System-WI
- Gaylord Hospital, CT
- Center for Aphasia & Related Disorders-CA

Residential/ Intensive Treatment Programs

University of Michigan
www.aphasiahelp.com

Dalhousie University, inteRACT
(spring and summer only)
www.aphasiaaction.com

PIRATE-The Program for Intensive Residential Aphasia Treatment & Education
www.pittsburgh.va.gov/PIRATE/index.asp

North Memorial Medical Center- MN
<http://northmemorial.com/strokeCenter/speechPrg.cfm>

Rehabilitation Institute of Chicago <http://aphasiatherapy.org/>

Aphasia Centers/ LPAA Approach

Aphasia Institute-Toronto
www.aphasia.ca

Aphasia Center of California-Oakland
www.aphasiacenter.org

Adler Aphasia Center-Maywood, NJ
www.adleraphasiacenter.org

Aphasia Center of West Texas -Midland, TX
www.aphasiawtx.org

Speaking of Aphasia-Montclair, NJ
www.speakingofaphasia.com

Aphasia Community Friendship Center-Ann Arbor, MI
www.aphasiacentermi.org

Aphasia Center/LPAA Approach

Stroke Comeback Center-Vienna, VA
www.strokecomebackcenter.org

Snyder Center for Aphasia Life Enhancement
www.scalebaltimore.org

HARC-Houston Aphasia Recovery Center
www.harcx.org

Austin Speech Labs
www.austinspeechlabs.com

Steps Forward, LLC-St. Petersburg, FL
<http://stepstherapy.net/>

Triangle Aphasia Project-Raleigh, NC
www.aphasiaproject.org

Online Groups

- **Aphasia Toolbox**
Pittsburgh, PA 15212
(724) 494-2534
information@aphasiatoolbox.com
www.aphasiatoolbox.com

Personal Perspectives

- Rachel's story

Local Initiatives

- identify gaps in the state
- Create resource book / updates
- Link websites ... include map
- Consider joint funding opportunities
- Lending libraries
- Graduate education and presentations
- Eliminate any perception of territorialism

What You Can Do

- Contact the National Aphasia Association and obtain aphasia ID cards/ stickers and distribute them to the community
- Become an NAA Affiliate
- Train Emergency Responders/Businesses
- Educate the community and each other
- Start aphasia group/program
- Fundraising events
- Collaborate

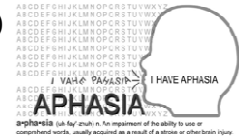
At the end of the day...

- "It's about believing so strongly in people that their awareness of your belief in them causes them to rise to new heights of individual growth and achievement." Ron Willingham from The People Principle



National Aphasia Association

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