APHASIA ADVOCACY: TOOLS FOR COMMUNITY OUTREACH, EDUCATION, & INCREASED AWARENESS

Ellayne S. Ganzfried, M.S. CCC-SLP
ASHA Fellow
Executive Director
National Aphasia Association
ISHA-April 4, 2014

Relevant Financial and Non-Financial Interest Disclosures

- Expenses and honorarium have been provided for this presentation
- Presenter is employed by the National Aphasia Association and will be describing programs and services.

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)
- PPA is a clinical dementia syndrome caused by neurodegenerative disease
- www.nia.nih.gov/alphimers
- www.theaftd.org

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

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 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

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

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
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

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](http://www.aphasia.org)
- NAA Hotline (800-922-4622) helps over 4,000 families a year.
- [NAA National Registry](http://www.aphasia.org) links to over 440 aphasia US support groups.
- [NAA Affiliate Network](http://www.aphasia.org)

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](http://www.aphasia.org) Receives over 13,000 unique visits each month

Aphasia Bill of Rights adopted in 2006
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 as 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.

Aphasia Advocacy and Outreach

NAA Affiliate Goals

- To create a network of individuals and institutions committed to the mission of the NAA
- To further the NAA mission of aphasia advocacy by creating a consistent, collective voice
- To provide a means of sharing information and collaborating

Expectations

- Maintain knowledge level both about issues surrounding aphasia and the NAA
- Share appropriate information with the network of affiliates
- Advocate for PWA and the NAA whenever appropriate and possible
- Represent the NAA at local aphasia-related functions when requested
- Assist with Aphasia Awareness programs during the month of June

Benefits

- A prestigious listing on the NAA web site
- Access to the community of affiliates for communicative and networking purposes
- An “Affiliates Only” page on the website that links to items that others cannot access
- Discounts on NAA merchandise and conferences/webinars
- Opportunity for institutions to fulfill their proof of community outreach/service
- Annual affiliate event at ASHA and/or other regional conferences
- Annual supply of brochures and ID cards at no charge
- June Aphasia Awareness Month materials
Social Networking/Blogs

Current and Future Initiatives

- Multicultural Task Force (MTF)
- Aphasia Awareness Training for Emergency Responders
- Aphasia Friendly Business Program
- Regional Speaking Out Conferences
- Institutional / Individual Affiliates
- Public Awareness Survey
  [http://www.aphasia.org/content/other-aphasia-awareness-information](http://www.aphasia.org/content/other-aphasia-awareness-information)

Multicultural Task Force (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, Vietnamese, Malaysian, German and Arabic, Polish
- Received ASHA Multicultural Project Grant for Sigo Siendo Yo! Aphasia Film Project for Hispanic Persons with Aphasia

Legal Advocacy

"I Am the Voice of Aphasia"

[http://aphasiacorner.com/blog/?s=ruby+mcdonough](http://aphasiacorner.com/blog/?s=ruby+mcdonough)

[Aphasia Awareness Training for Emergency Service Providers](http://www.youtube.com/user/NationalAphasiaAssoc)

Aphasia Awareness Training for Emergency Service Providers

- Grant received from Christopher and Dana Reeve Foundation to fund project
- 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
Overall Goals

- Recognize signs of aphasia
- Recognize Aphasia Awareness Sticker/Decal
- Communicate Better and Respond More Effectively to people with aphasia

Training Objectives

Participants will be able to:
1. Describe aphasia
2. Identify the person who has aphasia
3. Utilize communication strategies to make encounters with persons who have aphasia less stressful and more productive
4. Be prepared to manage common contact situations with people who have aphasia

Components of Training Program

- Recognize the Decal
- What is Aphasia?
- What Causes Aphasia?
- Aphasia Facts
- Types of Aphasia/Etiology
- How to Communicate with Someone with Aphasia?
- Videos
- Aphasia encounters and what to look for?
- Personal perspectives
- What you can do?
- Resources?

Sample Training Package

- Template for Letter of Inquiry
- PowerPoint presentation
- Aphasia Quiz-pre/post
- NAA brochure/ ID card
- Aphasia Awareness Sticker
- Aphasia Education for Emergency Personnel DVD
- "It's Still Me!" DVD
- Evaluation Form

Accomplishments

- Inquiries and training begun in more than 25 states including NY, NJ, CT, MA, ME, NH, TX, OH, KY, MI, FL, MD, NC, NE, PA, OR, GA, CO, IL and OK
- 450 Trainers from NYPD trained and charged with bringing program to more than 25,000 police officers and personnel
- Aphasia Awareness is subject of doctoral dissertation and masters thesis

Accomplishments

- Articles written for Latino NY magazine in March/April 2010: [link](http://issuu.com/latinonewyorkmagazine/docs/april_2010)
- Article written and published to UPI by Amy Hasselkus, SLP at ASHA, pursuing Masters degree in Health Communications: [link](http://www.upi.com/Features/Public_Health/Diseases_Conditions/2009/11/24/Training-emergency-responders-about-aphasia/125909003707362/)
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

Presentation Themes - EMPOWER

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

Video-Assisted Speech Technology

- VAST: close-up video of mouth movements
- Simultaneous combination of visual & auditory cues
- VAST Samples:
  - VAST Keyword: individual phonemes & words
  - Building Speech: basic wants and needs, words and phrases
    - Compound words, word triplets, linking phrases and paired intelligibility phrases
  - VAST Songs: common songs
- Custom Recording Service: can send a personal message or speech and then will record
- www.speakinmotion.com

Awareness is key!
Increasing Knowledge and Awareness 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 people with aphasia


Where did you hear about aphasia?

(Simmons Mackie, Code & Armstrong et al., 2001)

Increasing Public Awareness

- Use the word "APHASIA" to describe aphasia
- Encourage and support PWA, family and friends in promoting public awareness
- June is National Aphasia Awareness Month

Results
International Comparison - Where Do People Hear About Aphasia?

Increasing Awareness, cont’d

- Bombard the media
- Look for public venues to educate
- Involve students in aphasia advocacy
- Influence public policy and legislation

Social Networking/Blogs

@NatAphasiaAssoc

May not be reproduced without permission
Who needs to partner and why?
• Consumers
• Professionals
• Clinicians
• Researchers
• Policy makers
• Funding sources

Strong Consumer Voice is needed to achieve outcomes
Clinicians need to support PWA/families
Connected to Consumer organizations
Research needs to be relevant
Funding is outcome driven

What can we achieve through partnership?
• Increase Public Awareness
• Leadership and Media Training
• Increased Funding
• Consistent Messaging
• Peer Mentoring
• Empowering PWA/Families
• Changes in Legislation
• Best Practices/Consistent Outcomes

Consumer Focused Mission/Objectives
- Universal awareness and understanding of aphasia
- Resources/services/programs/support for PWA and their families
- Education
- Outreach
- Advocacy

Needs of Consumers/Professionals They are the SAME!
Agreement on WHAT information they would like
Top 5 topics:
1. How to Keep Improving
2. Communication Strategies
3. Aphasia Therapy Techniques
4. Coping Strategies
5. Strategies for Caregivers

Agreement on HOW they want to receive information
1. Written Information
2. Webinars/teleseminars
3. Conferences

They also agree on EASE OF ACCESS rating it “Somewhat difficult to find” information

Common Themes
Availability of Resources
- Difficulty locating resources
- Need for support groups
- Funding issues
- Need for increased public awareness

Barriers to Finding Information
- Overwhelmed
- Health care providers have limited knowledge
- Aphasia
- Need for increased public awareness

Consumer/Professional Challenges
- Mutual lack of awareness
- Time constraints
- Financial resources
- Perceived competition
- Inconsistent messaging
- Conflicting agendas i.e. research, information
- Continuum of Care

Ganzfried, E & Hinckley, J. (2012) the persistent needs of people living with aphasia: results of a national survey
Strategies for Success

- Capacity Building: Where are the PWA?
- Infuse Advocacy, Outreach and Education into training curriculum
- Develop consumer leadership/empowerment
- Connect professionals and consumers i.e., Speaking Out conference
- Consumer voice needs to be infused into professional organizations
- Partner on awareness activities/ media attention
- Peer mentoring
- Educate Health Professionals

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!

...the village... your community!

- “I belong to ________”
- Access to communities
- Strength in numbers
- Even evening out the playing field: the bi-lingual advantage... if everyone "speaks Aphasia"

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!

Who does the training?
A Speech / Language Pathologist familiar with the Individual’s Communicative Strengths, Opportunities and Interests

The Goal...

- Advocacy
- Self-Determination
- Awareness
- Belief
- Support
- Active engagement
- Empowerment
Why Are Groups Needed?

"I get a "psychic boost" when we come together in our group. I get inspired."  
*Aphasia Community Group Member*

"We need to feel welcome to visit people and we do not. Even several family members make us feel as outsiders. We have no visitors... and lead very lonely lives."  
*Person with aphasia*

Why Are Groups Needed?

"I think I could have been spared a lot of unnecessary emotional strain had I had some kind of support system."

*Person with aphasia*

"Everything is so different since my husband had his stroke and acquired aphasia. Going to the group helps me see how other people are coping, and I'm relieved to know that other people have made it through these problems."  
*Spouse of person with aphasia*

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
- 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"

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

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, invalidized 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...

Kleim J., and Jones, T (JSLHR, 2008)

Principles of Experience-dependent Neuroplasticity...

“It is hypothesized that the plasticity brought about through repetition represents the instantiation of skill within neural circuitry, making the acquired behavior resistant to decay in the absence of training (Monfils et al., 2005).”

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-Eliss, 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...”

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

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)

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


Ways to Measure Participation and Social Outcomes

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

Questions We Avoid

- How is your recovery going?
- What’s on your mind lately?
- What’s been important to you lately?
- What are you hoping will improve right now?
- What aren’t you doing now that you would like to do?
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

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 in the Comics
Lynn Johnston—“For Better or For Worse”

Garry Trudeau
“Doonesbury” strip from 2/18/2008: Toggle has come back from Iraq with some serious brain damage, and the classic symptoms of Broca’s aphasia.
Tom Batiuk—“Funky Winkerbean”

Group Activities
- Music and movement activities
- Mind/Body
- Computer
- Current events discussion
- Games
- Guest speakers/performers
- Pen Pals
- Watch films followed by discussion

Group Activities
- Book Clubs
- Practice ordering food, giving directions, taking phone messages
- Mock Court
- Literature
- Cooking
- Store/Gift shop
- Theatre/Drama

Groups/Programs
- University Based
- Hospital Rehab Based
- Community Based
- Aphasia Centers/ LPAA
- Intensive Comprehensive Aphasia Programs

Online Groups
- Aphasia Toolbox
  (724) 494-2534
  information@aphasiatoolbox.com
  www.aphasiatoolbox.com
- Aphasia Recovery Connection
  https://www.facebook.com/groups/Aphasia.Recovery.Connection

Aphasia Camp Manitou-Eau Claire, WI
Aphasia Film Forum

These materials consist of a variety of helpful tools for therapists, and partners of people with aphasia to use before, during, and after watching movies. In this way, people with aphasia can have a more enjoyable experience and be supported in a relevant conversation about the movie afterward. Each packet also includes a set of clinical practice exercises that are optional, but may be used in conjunction with the movie packet. Currently, we are offering a variety of film packets.

http://www.speakingofaphasia.com/productsnew.html

Museum of Modern Art (MOMA)

- Aphasia training for museum staff
- Multi-part program
- Pre-visit
- Visit museum
- Post-visit


http://dx.doi.org/10.1080/08893675.2011.625208
What You Can Do

- Contact the National Aphasia Association and obtain aphasia ID cards/stickers and distribute them to the community
- Learn about Research Opportunities
- Become an NAA Affiliate
- Start an Aphasia Community Group
- Train Emergency Responders/Businesses
- Educate the community and each other
- 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

For More Information

National Aphasia Association
350 Seventh Avenue-Suite 902
New York, NY 10001
(212) 267-2814
(212) 267-2812 (fax)
(800) 922-4622
www.aphasia.org
ganzfried@aphasia.org

For More Information

Ellayne Ganzfried, M.S., CCC-SLP
Executive Director
ganzfried@aphasia.org

Amy Hsiao
Information/Administrative Coordinator
coble@aphasia.org

Stephen Symbolik
Project Coordinator
symbolik@aphasia.org