Aphasia Community Education and Advocacy:
Speaking Out! and Beyond

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

Sharon Antonucci, Ph.D. CCC-SLP
New York University
Department of Communicative Sciences and Disorders

Melodie Dregansky
DaZy Aphasia Centre University of Toledo
ASHA 2009
New Orleans, LA

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 Resources

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


NAA Resources

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

Aphasia ID Card

People with Aphasia are encouraged to carry a card identifying themselves.

How you Can Help
Give me time to communicate
Speak simply and directly to me.
Do not shout. It does not help.
As yes/no questions.

Please Take Time To Communicate
I have aphasia (uh fay’zhuh) a communication impairment.
My intelligence is intact.
I am not drunk, retarded, or mentally unstable.
Aphasia ID Card

(Check those that apply)

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

Aphasia Facts

- Aphasia is an impairment of a person’s ability to process language, but does not affect intelligence. The causes are stroke, head injury, brain tumor or neurological conditions.
- Aphasia will impair ability to speak and understand others and most people with Aphasia experience difficulty reading and writing.

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

Current and Future NAA Initiatives

- Multicultural Task Force (MTF)
- Aphasia Awareness Training for Emergency Responders
- Revision of Aphasia Community Group (ACG) Manual
- Annual Regional Conferences
- Videoconferencing Project

Multicultural Task Force (MTF)

- Formed in September 2007
- Members reflect various settings; variety of languages/cultural experiences and expertise
- Monthly conference calls
MTF Accomplishments

- Creation of MTF web page
- Recruitment of multicultural state representatives
- Fostering the creation of multicultural support groups
- Press release on MTF and issues

MTF Accomplishments

- 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

- Application and consideration for grants
- Collaboration with related organizations and outreach to international aphasia community
Aphasia Awareness Training for Emergency Service Providers

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

Windshield / Window sticker

- Part of national campaign
- Place sticker for vehicle in the left rear passenger side of car
- For home place at front or rear entrance

Revision of ACG Manual

- Original manual printed in 1995 as part of NIDRR grant project
- Emphasized value of ACGs since the NAA was established
- Insufficient number to meet needs
- Need for ACGs has become more urgent in the last decade
Revision of ACG Manual
- Survey sent in February 2009 to selected ACG facilitators
- 35 responses received
- Information used to update manual
- Peer review of manual
- Manual posted to website

Videoconferencing Project
- Use of webcams to facilitate participation in ACGs
- Multi-state collaboration
- Creation of Best Practices Manual
- Funding through grants

More NAA Initiatives
- Animated Educational Video
- Increased Visibility and Outreach
- Information Packet Revisions
- Website Survey/Updates
- Night Sky
Speaking Out! History

- Held every other year since 1998
  - 1998-Chicago
  - 2000-Michigan
  - 2002-Washington, DC
  - 2004-Tampa, FL
  - 2006-Boston, MA
  - 2008-NYC

Speaking Out! Features

- Unique structure
- PWA, caregivers and professionals attend and interact together—hallmark
- Networking opportunity
- Empowerment of PWA
- Student training component
- Co-Sponsorship

Speaking Out 2008!

- National Aphasia Association
- Co-sponsorship:
  New York University
  Steinhardt School of Culture, Education, & Human Development
  Department of Communicative Sciences and Disorders
Based on successes at Speaking Out! 2006 in Boston...

- **Taking it to the streets: Aphasia community and advocacy**
  - Presented at ASHA Convention 2006
  - Authors
    - Laura J. Glufling-Tham, MS, CCC/SLP  Emerson College
    - Jerome Kaplan, MA, CCC/SLP Boston University
    - Marjorie Nicholas, Ph.D., CCC/SLP  MGH Institute of Health Professions
    - Therese O'Neil-Pirozzi, Sc.D., CCC/SLP  Northeastern University

Aphasia Advocacy and Participation

Aphasia-Friendly Presentation

- Individuals with aphasia
  - Provided in handout form for visual reference and to take home

- As a model for students

What?

- Conference for
  - People with aphasia and their families
  - Healthcare professionals
  - Students
- Speakers and Topics
  - People with aphasia, “Living well with aphasia”
  - Professionals
People with Aphasia

- Introduction and Training for Office of Special Programs Staff
- Contribution of artwork for display / auction
- Banquet entertainment

Introducing the speakers

- We’ll practice with you beforehand

People with Aphasia: Introducing the Speakers

- Persons with aphasia collaborating with masters students
- Encouraged to use whatever communication strategies were most useful
  - Collaborative ‘scripting’
    - Scaffolding introduction: Personal & speaker information included
    - Follow-up practice sessions as requested
    - Recording for home practice
    - Presence at the session(s)
- Additional supported conversation strategies
  - iPhone
  - Visual display for audience
Student volunteer participation

- Onsite support
  - Aphasia friendly maps
    - In programs
    - Posted at venue
  - Pair of undergraduate students

Program

- Based on feedback from previous conferences
  - Keynote address from people with aphasia
  - Repeated session on treatment techniques
  - Progressive language impairments
- Additional highlights
  - Neurology panel
  - Bilingual aphasia
  - Conversations with couples
  - "Living well" perspective
Feedback
- Who provided feedback?
  - Survivors 18%
  - Co-survivors 7%
  - Professionals 75%
- Overall response
  - Pleased to have attended >63%
  - Would attend again  >59%
- Logistics
  - Student volunteers vital
  - Continue develop ‘aphasia-friendly’ presentations
- Expense
- Program
  - Informative & Interesting >50%
  - Even more gearing toward persons with aphasia
  - Even more on specific treatment techniques

Outcomes and Lessons Learned
- Successful Event
- Expense
- Planning: time and coordination
- Reach a wider audience
- Travel is difficult for PWA
- Need increased frequency
- Enlist even more volunteers

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 scheduled for October 2009 in Toledo, Ohio
- Ramp up over next 5 years

Needs Assessment
Dear __________,

In order for the NAA to address the many problems facing those who acquire aphasia, the following needs assessment has been geared toward the person with aphasia (PWA) and caregiver(s). If you have received this survey and you do not fit into these categories, we ask that you please click the “forward” button below and send it on to those you know who are PWA and/or caregivers.

The small amount of time that you take to fill out this survey will help the NAA tremendously by allowing us to hear how we can better serve you all. Your participation is confidential and answers are anonymous. Thank you in advance for participating in this survey. We appreciate your time and effort.

Needs Assessment
- Electronic
- 22 questions
- Yes/no; multiple choice
- Icons
- Room for comments
- PWA and caregivers
**Results of Needs Assessment**

**Regional Conference-Toledo**

Mid-West Aphasia Conference

...this region has a long history of Aphasia Conferences

- Madison, Wisconsin 2005
- Chicago, IL 2006
- Minneapolis, MN 2007 –At this meeting it was decided to hold this meeting every other year opposite Speaking Out (odd years)
- Toledo, Ohio 2009

**Speaking Out @ the Mid-West Aphasia Conference**

- **Fall 2007**: It was decided that the next Mid-West Conference would be in Toledo, Ohio

- **Summer 2008**: National Aphasia Association joined forces with the DaZy Aphasia Centre to bring the first regional conference to life

- **Winter 2009**: University of Toledo joined the effort to help with ASHA’s CEU’s and venue for Professional Day preceding the main conference
Ideas for an Aphasia Friendly Conference

**Problem**
1. Persons with Aphasia have a great deal of trouble participating in a large group
2. Active listening can be impaired, when content and length are arduous

**Solution**
1. Conversational Cafes* (Living Successfully with Aphasia, conference in Toronto in Sept 2007)
2. No lengthy speakers

Ideas, continued

**Problem**
3. PWA want to be heard
4. Physical environment needs to very handicap friendly

**Solution**
1. Facilitated small group interaction*
2. Hotel that was all inclusive, with many areas for networking
*graduate students paired with PWA

Lessons Learned......

- Present Economic Environment effects both attendees and vendors
- Keep costs down
  - 1 day Only  
  - No entertainment, banquet etc  
  - More local vendors...less travel
  - Earlier registration with possibly a reduced rate
Lessons Learned......

- Seek sponsorship to underwrite costs
- More diverse committees
- Engage local resources
- Piggy back on another local event i.e., state speech and hearing convention
- Direct networking to get attendees

2010 Regional Events

June 12, 2010
National Rehabilitation Hospital
Washington, DC

October 2010
Tulsa, Oklahoma

Carondolet Aphasia Program in Tucson, AZ

“The members of the advocacy group in the Carondolet Aphasia Program in Tucson, AZ, sent a letter to a local news station about National Aphasia Awareness Month. We were thrilled to be invited for a live interview! ”

Fabiane M. Hirsch, Ph.D., CCC-SLP
Program Lead
The Aphasia Conversation Connection in Clayton, MO

"The St. Louis Post Dispatch featured one of the Aphasia Conversation Connection group members, Bill Sanford, in the Health and Fitness section for Aphasia Awareness Month. Here's the link:

"Stroke Survivor Talks the Talk"

We have received over a dozen inquiries about aphasia and our programs including a new one that is starting, the Community Aphasia Club at Village North. Bill's story has been an inspiration to many people who have aphasia and their family members."

-Fran Tucker, Ph.D., CCC-SLP
Coordinator, Aphasia Conversation Connection

The Good Shepherd Aphasia Support Group in Allentown, PA

- held a Bake Sale for the NAA and also wrote to all of their local hospitals for a dress down day to raise more money to donate and put up signs around their community about National Aphasia Month!!

-Meghan Kline, Group Facilitator
The Adler Aphasia Center in Maywood, NJ

The Aphasia Center of West Texas

"celebrated National Aphasia Awareness Month with: Four educational newspaper articles, an Open House at its new location with Center members and volunteers conducting tours (approx. 100 attended), public service announcements on a local television station, and 75 car magnets proudly displayed on vehicles in West Texas!"

-Kathryn Shelley, Executive Director

www.aphasiawtx.org

The Aphasia Center of West Texas
HealthSouth MountainView in Morganstown, WV

"...celebrated Aphasia Awareness month by kicking off the Speech Department's goal to train ALL clinical staff in "Supportive Conversation for Adults with Aphasia" techniques by December 2009. Training was begun with 22 staff members. We also had a display board posted with these techniques outside of our cafeteria for all to view.

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
Aphasia Awareness in the News

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


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.
**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

**Next Steps**
- Advocacy Strategies
- Fundraising Strategies
- Community Outreach Initiatives
- What you can do
- Collaborative efforts
- Wish List....

**National Aphasia Association**