Serving the Needs of Individuals with Moderate-Severe Aphasia

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Serving the Needs of Individuals with Moderate-Severe Aphasia

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With Special Appreciation

• The work of many colleagues including Margaret Rogers, PhD, Lesley Olswang, PhD, & Pat Dowden, PhD

• Graduate Clinicians in the UW Dept of Speech & Hearing Sciences

• Our patients and their communication partners
Areas We’ll Focus On

• Emphasizing the power of communication interaction
• Exploring assessment of multiple modalities of communication to identify relative strengths
• Designing a treatment plan that:
  – Advocates for enhanced quality of life for the individual with aphasia and their communication partners
  – Strives to reveal the competency of the individual with moderate to severe aphasia

Key Definitions for Our Discussion

• **Aphasia** “is an *acquired communication disorder* that impairs a person’s ability to process language, but does not affect intelligence. Aphasia impairs the ability to speak and understand others, and most people with aphasia experience difficulty reading and writing.” (NAA 2013)

• **Augmentative & Alternative Communication** is “An area of clinical practice that attempts to *compensate* either temporarily or permanently for the impairment and disability patterns of individuals with severe receptive and expressive communication disorders” (Beukelman & Mirenda, 2005)

• **Multi-Modality Communication** is “the individual’s *full communication capabilities*, including any residual speech or vocalizations, gestures, sign, and aided communication.” (ASHA 1991)
Incidence of Stroke & Aphasia

- Stroke is a leading cause of death in the United States behind heart disease and all forms of cancer combined.
  - Approximately 795,000 people in the U.S. have a new or recurrent stroke each year.
  - Stroke kills approximately 133,000 Americans each year. There are more than 6 million stroke survivors living in the United States. Men make up about 2,500,000 of survivors and women make up 3,900,000. About one-third have mild impairments, another third are moderately impaired and the remainder are severely impaired.

  American Heart Association. Heart Disease and Stroke Statistics 2011 Update At-a-Glance
  http://www.americanheart.org/presenter.jhtml?identifier=3003999

- It is estimated that there are approximately 80,000 new cases of aphasia per year in the United States (National Stroke Association, 2008).
- The National Institute of Neurological Disorders and Stroke (NINDS) estimates approximately 1 million people, or 1 in 250 in the United States today, suffer from aphasia (NINDS, n.d.).

  National Aphasia Association (June 2013)

Our Responsibility

The task of the Speech-Language Pathologist in aphasia rehabilitation becomes “primarily one of helping the patient and his or her intimates adjust to the alterations and limitations imposed by the disability”

  Dr. Martha Taylor-Sarno, 1991
Guiding Framework

*Life Participation Approaches to Aphasia (LPAA*, 2000)*

“a consumer-driven service delivery philosophy that focuses on maximizing re-engagement in life for all those affected by aphasia. LPAA can serve as an "umbrella" or guiding philosophy that unites a variety of approaches around the globe. The philosophy of LPAA provides a framework for assessment and intervention, research and advocacy efforts in the field of aphasia.”


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Core Elements of LPAA

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

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Guiding Framework


- “An ICF adaptation designed to organize people’s thinking regarding intervention and outcomes in aphasia.” Simmons-Mackie 2013
- Built upon the components of:
  - Language and Related Processing
  - Participation
  - Personal Factors and Identity
  - The Environment with its barriers and facilitators
- Focusing on the outcomes of intervention that make a difference in the everyday experiences of individuals with aphasia and their families

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The Participation Model

*Beukelman & Mirenda, 2013*

- Framework reference for our dynamic assessment
- Comprehensive model which demonstrates revised W.H.O. principles
- Emphasizes functional participation requirements in activities of daily life
- Facilitates designing an intervention plan

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The Participation Model - Principles

- Multi-phased assessment
- Importance of consensus building
- Identifying participation patterns and communication needs
- Assessing opportunity barriers
- Assessing access barriers
- Planning and implementing interventions for today and tomorrow
- Evaluating intervention effectiveness

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What We Know

- Communication is markedly disrupted
- For many individuals, spoken communication may no longer be a successful primary mode of communication
- For the individual and their family, the hope will be for spoken communication to return
- For the clinician, the course of support may be full of obstacles and challenges

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What We Need to Remember

- Interpersonal human communication is a critical tool in life adjustment for people of all ages & backgrounds
  - linking us with our world, promoting our well-being, and serving as a regulator of an individual’s behavior
- Adjustment in life depends, in part, on being able to use communication resources effectively
  - This does not guarantee that everyone has a foundation of effective communication skills
- Revealing the competency of the individual with moderate to severe aphasia requires:
  - Partnership among the individual with aphasia and their communication partners

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OUR GOAL

“Keeping our patients in the game of life!”

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Disrupted Communication

The Individual with Moderate to Severe Aphasia presents with a disruption of language, involving multiple modalities, as well as concomitant issues

Communication
- Input:
  - Auditory
  - Visual
- Output:
  - Verbal
  - Written
  - Gesture
  - Drawing

Concomitant challenges
- Motor and Sensory skills
  - Speech
  - Extremities
- Cognition
- Pragmatics
- Vision
- Hearing

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Individuals & Families Living with Aphasia

- Experience a sudden disruption of the family system
- Face an increase in life stressors
- Assume unsolicited changes in roles and responsibilities
- Report changes in psychosocial well-being and a gradual alteration in social and support networks
  .......and an overall diminished quality of life (QOL)

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What is “Quality of Life”?  

It’s a level of needs satisfaction that is  
- our ability to engage in enjoyable activities  
- our psychosocial well-being and self-esteem  
- our ability to find meaning in life and contentment  

Can be assessed indirectly through measurement tools completed by  
- Self-report (the individual with aphasia)  
- Partner report (spouse, family, friends)  

Using Instruments such as  
- Structured interview  
- Questionnaire  
- Forced choice format  
- Scaled tools  

Measuring QOL  

- Personal Histories and Inventories  
  - Individual with communication impairment  
  - Partners  
- Tool examples:  
  - Visual Analog Scales (basic continuum) or Pictorial Representations (e.g., Blobbi People)  
  - Quality of Life assessments  
    - Stroke and Aphasia Quality of Life Scale -39 (SAQOL - Hilari, et.al., 2003)  
    - ASHA Quality of Communication Life Scale (QCL - Paul, et.al, 2004)  
  - Affect or Mood tests/scales  
  - Specific population tools: Aphasia Needs Assessment by Garrett & Beukelman, 1997 and revised 2006
Visual Analog Scale

1 2 3 4 5 6 7 8 9 10

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“Blobbi People”

Pound et al., 1999

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Our Services Need to...

- Recognize the communication strengths and challenges of the individual
- Identify strategies and abilities of the individual that unmask and reveal their competency
- Identify their communication partners (significant others, family, non-family)
- Specifically target communication support skills of their partner(s)
- Identify opportunities for communication and life participation

A Foundation for Assessment & Intervention

“Supported Communication” which focuses on three components:

- Multi-modality communication
- Dyad interaction
- Social opportunities

(Alarcon and Rogers, 2007)
Dynamic Assessment

- **Output Modalities:**
  - Spoken language
  - Gesture (literal or representational; static and dynamic...)
  - Writing (partial to complete; letter, #, word...)
  - Drawing (static and dynamic; single and multiple event...)

- **Input Modalities:**
  - Auditory comprehension
  - Visual attention, scanning, visual comprehension

Pound, et. al., 1999

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Communication Output
Observations

• Communication modes
  – Spoken language → to vocalizations
  – Gestures and use of natural props
  – Drawing – on target & approximations
  – Writing - partial and/or whole word
• Access to paper, markers, analog/visual scales...
• The Multimodal Communication Screening Task for Persons with Aphasia (Garret & Lasker 2005)

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Drawing Assessment Protocol

• First Assessment
  ➢ Simple to complex objects
    • Beginning at 1 part and moving to multiple part objects
    • Auditory vs. Aud/Visual Recall stimulus
  ➢ People
    • Man and Woman
    • Auditory vs. Auditory/Visual Recall stimulus
  ➢ Action
    • Man or Woman “doing _______”
    • Auditory vs. Auditory/Visual Recall stimulus

• Second Assessment
  ➢ Drawing familiar places and people
    • From different perspectives
  ➢ Clarifying pictures using enlargement of a key area for detail
  ➢ Drawing actions and sequenced actions
    • Immediate recall
    • Single event and multiple step events
  ➢ Conveying personal events and/or experience

*Note: Review the work of Jon Lyon, Ph.D., for additional drawing references and resources
Drawing Samples
“Revealing competency”

First Assessment

Auditory request: “draw a spoon”
Note: 1<sup>st</sup> drew a fork and self-corrected

Draw a Man
Draw a Woman
Note: readily differentiated

Leading to Meaningful Communication

Second Assessment: Conveying Single event actions – from immediate recall.

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Dynamic Assessment: A Deeper View

- Communication Partner’s assessment of modalities
- Observations in the clinical environment and across settings (via verbal report, video, partner log)
- Partner communication questionnaires and inventory
- Discourse & behavioral analysis of the Individual and their Communication Partners via a conversation dyad analysis
Assessment & Interaction of the Communication Partner

- Dyad Conversation Protocol Rogers & Alarcon 2007; King et.al. 2007
  - Approximate 7 minute conversation
  - Couple chosen topic – if possible
  - Paper and writing tools available (but not cued)
- Communication Support Rating Scale Alarcon & Rogers 2007
  - Qualitatively assess the partner’s interaction
  - Observing the Communication partner as speaker and listener
  - Focusing on Supportive and Non-supportive behaviors of the partner
- Identifying target behaviors for treatment and providing baseline and probe data

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Measurable Treatment Objectives

- To increase the quality of communication in the dyad
- To increase the use of supportive communication behaviors by the communication partner
- To decrease the use of non-supportive communication behaviors by the communication partner

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Stages of Partner Treatment

• Educating the Communication Partner (CP)
  ➢ Help CP understand and accept nature and severity of disorder, including areas of strength and weakness
  ➢ As part of the educational process, the CP’s own communication needs and style must be assessed -- valuable information for guiding intervention

• Teaching the Communication Partner strategies to enhance communication exchanges

Keep In Mind.....

The Communication Partner:
• May have high expectations for speech to return
• May expect a level of pre-morbid independence
• May have a strong uncertainty and/or uncomfortableness with AAC; or feel that AAC will fix the communication problem
• May focus on the message exchange
• May have a history of unrewarded social interactions
• May need an adult learning style approach
Treatment Essentials

- Individual with aphasia AND Communication Partner in the treatment room
- Hands on and experiential
- Gradual introduction of change
  - Start with what is going well; move to what needs to be improved upon or changed
- Customized, yet use established resources
- Reflective, supportive, and a safe learning environment
- Small steps, building on tangible successes

Building Successful Communication

- Personalized and dynamic tools developed by clinician and partners for the individual and partners
- Support materials created for the person with aphasia and their communication partners
- Providing partners with information and hands-on experience
- Family reaching out to other communication partners – “each one teach one”
“We must remember that human communication sciences and disorders is a discipline dedicated to improving the quality of life of persons with communication disorders”
(Carol Fratelli 1992)

“Stroke recovery can last a lifetime”
National Stroke Association – Explaining Stroke 101

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References


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