

Language Disorders in Adults Grand Rounds: Life Participation Approaches to Aphasia

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Selected References

- Bernstein-Ellis, E. and Elman, R. (1999). Group communication treatment for individuals with aphasia: The Aphasia Center of California approach. In R. Elman (Ed.). Group treatment for neurogenic communication disorders: The expert clinician's approach. pp. 47-56. Woburn, MA: Butterworth-Heinemann. <www.bh.com>
- Elman, R. (1998). Memories of the 'plateau': Health care changes provide an opportunity to redefine aphasia treatment and discharge. Aphasiology, 12(3), 227-231.
- Elman, R. (Ed.). (1999a). Group treatment of neurogenic communication disorders: The expert clinician's approach. Woburn, MA: Butterworth-Heinemann <www.bh.com>.
- Elman, R. (1999b). Practicing outside the box. Asha, 41(6), 38-42.
- Elman, R. (1999c). Aphasia group treatment at the Aphasia Center of California. Gerontology Special Interest Division 15 Newsletter, 4(1), 20-24. Rockville: American Speech-Language-Hearing Association.
- Elman, R. (1999d). Long-term care approaches to aphasia treatment and management. In R. Elman (Ed.). ASHA Special Interest Division 2 Newsletter: Neurophysiology and Neurogenic Speech and Language Disorders, 9 (5), 15-17.
- Elman, R. (In press). Working with groups: Neurogenic communication disorders and the managed care challenge. [Videotape.] Rockville, MD: American Speech-Language Hearing Association.
- Elman, R., and Bernstein-Ellis, E. (1995). What is functional? American Journal of Speech-Language Pathology, 4(4), 115-117.
- Elman, R. and Bernstein-Ellis, E. (1999a). The efficacy of group communication treatment in adults with chronic aphasia. Journal of Speech, Language, and Hearing Research, 42, 411-419.
- Elman, R. and Bernstein-Ellis, E. (1999b). Psychosocial aspects of group communication treatment: Preliminary findings. Seminars in Speech & Language, 20(1) 65-72.
- Elman, R., Ogar, J., and Elman, S. (2000). Aphasia: Awareness, advocacy, and activism. Aphasiology, 14(5/6), 455-459.
- Ewing, S. (1999). Group process, group dynamics, and group techniques with neurogenic communication disorders. In R. Elman (Ed.). Group treatment for neurogenic communication disorders: The expert clinician's approach. pp. 9-16. Woburn, MA: Butterworth-Heinemann. <www.bh.com>
- LPAA Project Group (2000). Life participation approach to aphasia: A statement of values for the future. ASHA Leader, 5(3). 4-6. <www.asha.org/publications/ashalinks.htm>

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LIFE PARTICIPATION APPROACH TO APHASIA: AN OVERVIEW

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Introduction

Life Participation Approach to Aphasia* (LPAA, 2000) is 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.

World Health Organization "Components of Health" (ICIDH-2)

The Body Level

- Integrity of body structures (e.g. brain)
- Integrity of body functions (e.g. language processing)
- Problem at this level is an **impairment** (e.g. anomia, alexia).

Individual Level

- Ability to perform tasks or activities in a uniform environment (e.g. functional tasks, activities of daily living)
- Assessed in comparison to an accepted population standard
- Problem at this level is an **activity limitation** (e.g. difficulty talking on the phone, difficulty reading the newspaper).

The Societal Level

- The nature and extent of a person's involvement in life situations - what an individual actually does within his/her relevant social context (e.g. practice law, attend Rotary Club).
- This level captures the "personal experience" of aphasia
- Problem at this level is a **participation restriction** (e.g. no longer reads for pleasure, has quit attending Rotary).

These three levels of health conditions should not be interpreted as a "linear" model. Although the levels interact and interrelate, they should not be viewed as "sequential" levels of intervention.

Core Components 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.

The explicit goal is enhancement of life participation

- A Life Participation Approach focuses directly on life participation. There is no expectation that decreased impairment or increased functional skill will automatically enhance participation & well-being at the societal level.
- Although therapy might include activities at the "body" and "individual" levels, these must explicitly bridge to defined life participation goals.

Recipients of services: All those affected by aphasia are entitled to service

- Basic assumption that life with aphasia affects and is affected by those "around" the person with aphasia.
- The "entourage" can create an enabling or disabling environment and helps determine the quality of life for all those affected.
- A few examples of services for those "other than" the person with aphasia:
 - Training others how to support and facilitate communication (e.g. Kagan & Gailey, 1993; Lyon et al 1997)
 - Counseling regarding communication, life participation, and how to live life to the fullest with aphasia (e.g. Holland, 1999; Ireland & Wooten, 1996)
 - Support groups & advocacy programs (e.g. Byng et al, 2000)
 - Couples therapy –work on communication and relationship together (e.g. Boles, 1998)
 - Group training in supported communication (e.g. training work colleagues, training health care practitioners)

Both personal and environmental factors are targets of intervention

- Personal (internal) factors pertain to physical, psychological and emotional changes that accompany aphasia (e.g. mental, bodily, linguistic, motor, behavioral and/or sensory impairments). For example, language impairment associated with processing deficits or hemiplegia might be personal obstacles.
- Environmental (external) factors refer to physical and social structures of the outside world that facilitate or obstruct involvement in daily life.
- Physical factors (e.g. architecture, geography, climate, temporal factors, visual or auditory conditions)
- Social factors (e.g. beliefs/attitudes of society, political systems government, corporate rules or systems, economic factors, education/knowledge of aphasia, partners to support communication).
- Factors range from disabling (barriers to participation) to enabling (facilitate participation).
- Intervention in LPAA aims to reduce barriers and build facilitators/supports to participation.

Documentation: Measures of success include documented life changes

- LPAA calls for the use of outcome measures that assess quality of life and degree of life participation.

- o Increased participation in activities or roles of choice
- o Enhanced social connections
- o Improved feelings/attitudes (e.g. well being, purpose in life).
- o Possible outcome measures
 - o Quality of Life & well-being measures (see Hirsh & Holland, 2000)
 - o Satisfaction measures (e.g. Lyon, 1998; Lyon et al, 1997)
 - o Participation measures (e.g. Communicative Profiling System, Simmons-Mackie & Damico, in press)

VI. Availability of services as needed at all stages of aphasia.

- Recognition of the chronicity of aphasia.
- Service availability based on "life needs" versus medical needs.
- Limitations of health care system!!!
 - o Alternative service delivery systems
 - o Shift in philosophy of funding
 - o Advocacy, advocacy, advocacy

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Selected References

- Boles, L. (1998). Conducting Conversation: A Case Study Using the Spouse in Aphasia Treatment. ASHA SID 2 Newsletter: Neurophysiology and Neurogenic Speech and Language Disorders, 24-31.
- Byng, S., & Pound, C. & Parr, S. (2000). Living with aphasia: A framework for therapy interventions. I. Papathanasiou (Ed), Acquired neurological communication disorders: A clinical perspective . London: Whurr.
- Elman, R. (1999). Group treatment of neurogenic communication disorders: The expert clinicians approach. Woburn, MA: Butterworth-Heinemann.
- Elman, R. & Bernstein-Ellis, E. (1995). What is Functional? American Journal of Speech-Language Pathology, 4, 115-117.
- Fougeyrollas, P., Cloutier, R., Bergeron, H., Cote, J, Cote, M., and St. Michel, G. (1997). Revision of the Quebec Classification: Handicap creation process. Lac St-Charles, Quebec: International Network on the Handicap Creation Process.
- Hirsch, F. & Holland, A. (2000). Beyond activity: Measuring participation in society and quality of life. . In L. Worrall & C. Frattali, (Eds). Neurogenic communication disorders: A functional approach (pages 35-54). NY: Thieme.
- Holland, A. (1999). Counseling adults with neurogenic communication disorders. [Videotape]. ASHA (Producer) Rockville, Maryland: American Speech-Language-Hearing Association.
- Ireland, C. & Wootten, G. (1996). Time to talk: counseling for people with dysphasia. Disability and Rehabilitation, 18(11), 585-591.
- Kagan, A. (1995). Family perspectives from three aphasia centers in Ontario, Canada. Topics in Stroke Rehabilitation, 2(3), 33-52.
- Kagan, A., & Gailey, G. (1993). Functional is not enough: Training conversation partners in aphasia. In A. Holland, & M. Forbes (Eds), Aphasia treatment: World perspectives (pp. 199-226). San Diego, CA: Singular.

LPAA Project Group (2000) Life Participation Approach to Aphasia: A statement of values for the future. The ASHA Leader, 5, 4-6.

Lyon, J. G. (1998). Treating Real-Life Functionality in a Couple Coping With Severe Aphasia . In N. Helm-Estabrooks & A. Holland (Eds), Approaches to the Treatment of Aphasia (pp. 203-239). San Diego: Singular.

Lyon, J. G., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S., & Blanc, M. (1997). Communication partners: enhancing participation in life and communication for adults with aphasia in natural settings. Aphasiology, 11(7), 693-708.

Muller, D. (1999). Managing psychosocial adjustment to aphasia. Seminars in Speech and Language, 20(1), 85-92.

Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). Talking about aphasia. Buckingham, UK: Open University Press.

Rogers, M. A., Alarcon, N. B., & Olswang, L. B. (1999). Aphasia Management Considered in the Context of the WHO Model of Disablements. Physical Medicine and Rehabilitation Clinics of North America on Stroke . Philadelphia: W.B. Sanders Co.

Sarno, M. T. (1993). Aphasia rehabilitation: psychosocial and ethical considerations. Aphasiology, 7(4), 321-334.

Simmons-Mackie, N. (in press) A social approach to intervention in aphasia. In R. Chapey (Ed.) Language intervention strategies in aphasia. 4th edition. Baltimore: Williams & Wilkins.

Simmons-Mackie, N. (2000). Social approaches to management of aphasia. In L. Worrall & C. Frattali, (Eds). Neurogenic communication disorders: A functional approach (pages 162-188). NY: Thieme.

Simmons-Mackie, N., & Damico, J. S. (1996). Accounting for handicaps in aphasia: Communicative assessment from an authentic social perspective. Disability and Rehabilitation, 18(11), 540-549.

Simmons-Mackie, N. & Damico, J. S. (in press). Intervention Outcomes: A Clinical Application of Qualitative Methods. Topics in Language Disorders.

World Health Organization (October, 2000). ICDH-2 Prefinal Draft. Geneva, Switzerland, WHO.