

Aphasia and Life PARTICIPATION:
Our Role as Speech-Language Pathologists

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Disclosures



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and

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Disclosure

I am receiving an honorarium from
Indiana Speech and Hearing Association
Thank you

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Disclosure


Volunteer member of:

Aphasia Access
Education & Research Committee:
Academic Curricula Work Group

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Acknowledgement

- Sandra Glista, M.A., CCC-SLP – collaborator since 2002
Aphasia Communication Enhancement (ACE) Program



- ACE clinical supervisors
Marie Koss-Ryan, M.A., CCC-SLP
Elizabeth Nagler, M.S., CCC-SLP

–WMU speech-language pathology graduate students 2002 to the present

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Learning Objectives

- Name 3 values of the “Life Participation Approach to Aphasia”
- Name 2 roles of the SLP beyond ‘therapist’ in LPAA
- Write an example of an impairment based goal supporting a participation goal.
- Name three strategies or resources SLPs can use to determine participation goals.

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Aphasia

- Talking
- Listening
- Reading
- Writing

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If you had aphasia...
what would you miss?

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If I had aphasia, what would I miss

- .
- .
- .
- .
- .
- .
- .

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Participation

>the state of being related to a larger whole

>The action of taking part in something

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Swiss cheese, lettuce, & mayo
NO tomato

Number 3



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LPAA – the essence

- Collaborating on real-life goals of people affected by aphasia
- Focusing on re-engagement in life activities

http://www.aphasia.ca/wp-content/uploads/2011/06/LPAA_AI.pdf
Chapey, Duchan, Elman, Garcia, Kagan, Lyon, and Simmons-Mackie
Life Participation Approach to Aphasia

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LPAA
“philosophy and model of service delivery”

Not a treatment **TECHNIQUE**
(Script training, Semantic Feature Analysis, ORLA, CART, Written Choice, Response Elaboration Treatment, Augmentative Communication Aids, Supported Conversation Techniques)

WMU ACE Program: Treatment techniques may be used to develop the ability to achieve the Participation goal.

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LPAA VALUES

- Explicit goal is enhancement of life participation
- Services are available to all affected by aphasia
- Success is measured by documented life changes
- Services are available as needed at all stages

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In LPAA, SLP clinician roles are expanded beyond the role of ‘therapist’
ehttp://www.aphasia.ca/wp-content/uploads/2011/06/LPAA_AI.pdf

```

    graph TD
      CP[Communication Partner]
      PS[Problem Solver]
      C[Coach]
      SP[Support Person]
      T[Therapist]
      CP --- PS
      C --- SP
      T --- C
      T --- SP
  
```

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```

    graph TD
      CP[Communication Partner] --- C[Conversations]
      C --- LG[Life Goals]
      C --- CONC[Concerns]
      C --- BTP[Barriers to Participation]
  
```

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```

    graph TD
      C[Coach] --> GO[Overcome challenges to engaging in activities]
      PS[Problem Solver] --> GO
      SP[Support Person] --> GO
  
```

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Caring Circle

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ACE Program

*Aphasia Communication Enhancement
(ACE) Program*

*Western Michigan University
Unified Clinics*

10:00 – 2:00 Tues. and Thurs.

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Relationship Centered Care

- (1) Relationships in health care ought to include the personhood of the participants,
- (2) Affect and emotion are important components of these relationships,
- (3) All health care relationships occur in the context of reciprocal influence, and
- (4) The formation and maintenance of genuine relationships in health care is morally valuable
(Beach, Inui, Relationship-Centered Care Research Network, 2006)

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Opening Day Initial Session

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WHO-ICF

Impairments--problems in body function or structure
Activity --the execution of a task or action.
Participation -- involvement in a life situation.
Participation --problems an individual may experience in life situations.
Environmental Factors --physical, social and attitudinal
Personal Factors -- gender, age, coping styles, education

<http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1>
<http://www.who.int/classifications/icf/icfchecklist.pdf?ua=1>

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What people with aphasia want (goals)

- **People with aphasia and family:** activity and participation goals were a high priority
(Worrall, et al, 2011)
- **SLP goals:** addressed language impairments
- **PwA goals:** Improve communication....and... return to valued activities (hobbies, returning to work, to travel).
(Rhode,Townley-O'Neill, et al, 2012)

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“I want to learn to email to connect with family”.

(Pollens & Glista, 2008)

```

    graph TD
      A[EMAIL GROUP] --> B[Reducing Impairment Barriers]
      B --> C[Supporting Personal Factors]
      C --> D[Reducing Environmental Barriers]
      D --> E[Reducing Participation Barriers]
      E --> A
    
```

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Email

	Impairment	Participation	Personal Factors	Environmental
Barriers				
Goals				
Outcomes				
(Pollens & Glista, 2007)				

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HOSPITAL

- Menu

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Clinic (outpatient)

	Impairment	Participation
Goal	Oral read 3-5 word primary sentences with 80% accuracy	Oral read a children's story to her young children.
Method	ORLA	Individually with SLP, then with family

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Home Care

- RET phrases
- Script doctor
- Short Term Goal
- Long Term Goal

Reading

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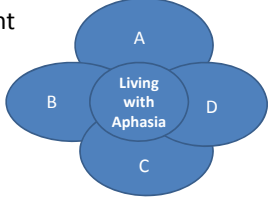
Telepractice

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A-FROM

Kagan & Simmons-Mackie, 2007


- A - Participation
- B - Environment
- C - Language
- D - Personal



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Identity

- *This is where I can take time to say what I mean and people listen*
- *When I come to ACE... I am respected.*



Narratives (Hinkley)
Identity (Shadden)

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Living successfully with aphasia during the first year post-stroke: a longitudinal qualitative study

“...one overarching theme: actively moving forward.

“...the importance of participants taking positive actions in order to promote living successfully with aphasia across time.”

Grohn, Worrall, Simmons-Mackie, Hudson (2014)

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Life changes! New goals emerge

New Participation Goal	Treatment
<ul style="list-style-type: none"> • Needed access to public transportation system • Wanted to volunteer as a community board member • Needed new apartment 	<ul style="list-style-type: none"> • Rehearsed verbal scripts to reserve the ride • Listened to narratives (TED), took notes, asked 2 questions • Created written directions to navigate a phone app and search for apartments

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Barriers?

Wallace (2010) –reassess IWA periodically to identify authentic interests in life participation

However, SLPs in U.S., Canada and Australia described barriers to addressing participation goals.

(Torrence, Baylor, Yorkston, and Spencer, 2016) (Laliberte, Gauvreau, & Dorze, 2016) (Verna, Davidson, & Rose, 2009).

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How do we find out client’s Participation Goal?

How do we listen so we can truly hear what clients and families want?

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Beginning with the End

(Kagan & Simmons-Mackie 2007)

Wants to talk with grandchild on the phone

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"10 strategies" (Pollens & Glista, 2016)

Strategy to determine participation goal	Participation Goal ICF	Identified Barriers	Associated Impairment Goals	Participation Outcomes
Life Mapping (Strydum & Herbst, 2007)	<ul style="list-style-type: none"> Live independently in own apartment Plan personal budget independently d9302 Economic self sufficiency 	<ul style="list-style-type: none"> Limited income Impaired comprehension of written language Impaired complex problem solving BDAE Severity Level 3 	<ul style="list-style-type: none"> Comprehend written language using text-reader software Select and enter personal budget vocabulary into software Execute multi-step tasks accurately 	<ul style="list-style-type: none"> Moved into apartment and is living independently Developed personal budget
Relationship Centered Care (Beach & Innui, 2006)	<ul style="list-style-type: none"> Serve on transportation board as a service consumer d950 Political life and citizenship d460 Using transportation H436 Employment 	<ul style="list-style-type: none"> Impaired understanding and expression of complex language/conversation Impaired written language Inability to drive due to disability BDAE Severity Level 4 	<ul style="list-style-type: none"> Listen to TED talk, state opinion, and formulate a related question Write 3 sentence personal statement for application 	<ul style="list-style-type: none"> Submitted formal application to serve on the community transportation advisory board
Counseling <i>Listening helps to translate into action / coaching</i> (Holland & Nelson, 2013)	<ul style="list-style-type: none"> Present testimony about recovery d930 Religion and spirituality 	<ul style="list-style-type: none"> Impaired spoken and written language expression Impaired oral reading BDAE Severity Level 4 	<ul style="list-style-type: none"> Generate written illness narrative Oral read chosen multisyllabic words accurately 	<ul style="list-style-type: none"> Oral read personal testimony at church

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Strategy to determine participation goal	Counseling <i>Listening helps to translate into action /coaching</i> (Holland & Nelson, 2013)
Participation Goal & WHO-ICF	Present testimony about recovery <i>d930 Religion and spirituality</i>
Identified Barriers	<ul style="list-style-type: none"> Impaired written language expression Impaired oral reading
Associated Impairment Goals	<ul style="list-style-type: none"> Generate written illness narrative Oral read chosen multisyllabic words accurately
Participation Outcomes	Oral read personal testimony at church

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Example Resources




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L!V cards



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Client Choice

Please rate these			
 Do you want to teach other people about aphasia?	Not at all	Maybe	Very much
 Do you want to use the internet and talk about what you find out?	Not at all	Maybe	Very much
 Do you want to improve your spelling and writing of sentences?	Not at all	Maybe	Very much

(Glista & Pollens, 2016)


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Example Community


"Recreation Day"


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Community Resources



Book Club





• Providing companionship, engage in activities
<http://www.archindy.org/cc/indianapolis/programs-seniors.html>

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Book Club and Art Museum goals and outcomes

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Nature



Meijer Gardens,
Grand Rapids Michigan

(Hendrick, 2017)
TAPRoots: How a LPAA Garden Club is impacting the community
TAProotsblog.org

The IMA Gardens and Greenhouse,
Indianapolis



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Advocacy

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Individual

LPAA roles...

- Support Person
- Conversation Partner

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Systems

<https://www.nps.gov/yose/planyourvisit/upload/aphasia-guide.pdf>

**A Visual Guide to Visiting Yosemite Valley
APHASIA FRIENDLY**

Ellen Bernstein-Ellis - California State U. - East Bay

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Communities

(Silverman & Greenspan, 2017)
Benefits of Hub & Spoke

- Transportation simplified - groups meet close to home
- Local friendships
- Community re-entry – meet in familiar spaces, e.g., libraries, houses of worship, etc.
- Connection with larger aphasia community (e.g., Skype)
- Care partner meet concurrently

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Aphasia Access

<http://www.aphasiaaccess.org/>

We need to facilitate the rebuilding of a meaningful life despite aphasia
We need to instill hope and optimism

Kagan, Aura, Aphasia Access video

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Our roles

Communication Partner	Problem Solver	
Coach	Support Person	Therapist

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