



**FACING THE FUTURE TOGETHER:
EMBRACING THE LIFE
PARTICIPATION APPROACH TO
APHASIA IN MICHIGAN**

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Disclosures

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Learning Outcomes

1. Learn essential elements of Life Participation Approach to Aphasia (LPAA)
2. Learn of online resources available to support clinicians in incorporating LPAA into your clinical work with persons with aphasia
3. Learn about 3 current clinical interventions occurring in Michigan that incorporate LPAA

1. ESSENTIAL ELEMENTS OF LIFE PARTICIPATION APPROACH TO APHASIA (LPAA)

ASHA

- <http://www.asha.org/public/speech/disorders/LPAA/>



AMERICAN
SPEECH-LANGUAGE-
HEARING
ASSOCIATION



Life Participation Approach to Aphasia

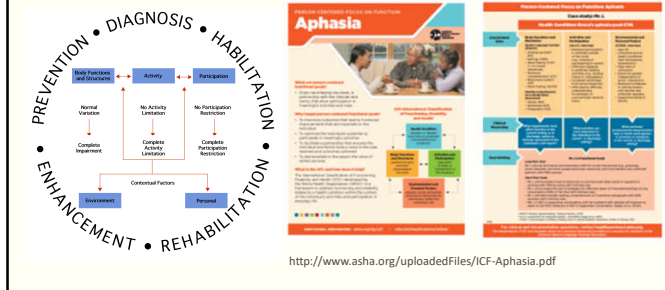
<http://www.asha.org/public/speech/disorders/lpaa/>

A Statement of Values for the Future

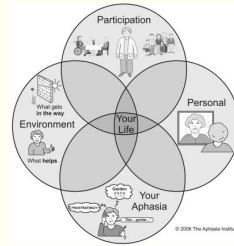
by the LPAA Project Group (in alphabetical order: Roberta Chapey, Judith F. Duchan, Roberta J. Elman, Linda J. Garcia, Aura Kagan, Jon Lyon, and Nina Simmons Mackie)

- The "life participation approach to aphasia" (LPAA) is a consumer-driven service-delivery approach that supports individuals with aphasia and others affected by it in achieving their immediate and longer term life goals (note that "approach" refers here to a general philosophy and model of service delivery, rather than to a specific clinical approach). LPAA calls for a broadening and refocusing of clinical practice and research on the consequences of aphasia. It focuses on re-engagement in life, beginning with initial assessment and intervention, and continuing, after hospital discharge, until the consumer no longer elects to have communication support.
- LPAA places the life concerns of those affected by aphasia at the center of all decision making. It empowers the consumer to select and participate in the recovery process and to collaborate on the design of interventions that aim for a more rapid return to active life. These interventions thus have the potential to reduce the consequences of disease and injury that contribute to long-term health costs.

WHO and ASHA



Essential Elements to LPAA and the A-FROM (Kagen et al., 2008)



What do people with aphasia want?

Providing Platforms for LPAA assessment & intervention Worrall, L. et al. (2011)

to return to their pre-stroke life and to communicate not only their basic needs but also their opinions

- information about aphasia, stroke, and available services;
- more speech therapy;
- dignity and respect;
- engagement in social, leisure, and work activities;
- to regain their physical health;
- to help others;
- greater autonomy

Using Educational Counseling for Dynamic Assessment (Pollens & Glista, 2016)

Strategy to determine participation goal	Participation Goal ICF	Identified Barriers	Associated Impairment Goals	Participation Outcomes
Life Mapping (Strydom & Harbord, 2007)	• Live independently in own apartment • Plan personal budget independently #8700 Economic self-sufficiency	• Limited income • Impaired comprehension of written language • Impaired complex problem solving BDAM Severity Level 3	• Comprehend written language using text-reader software • Select and enter personal budget vocabulary into software • Execute multi-step tasks accurately	• Moved into apartment and is living independently • Developed personal budget
Relationship Centered Care (Houch & Ismail, 2006)	• Serve on transportation board as a service consumer #9500 Political life and citizenship #9600 Using transportation #9500 Employment	• Impaired understanding and expression of complex language/communication • Impaired written language • Inability to drive due to disability BDAM Severity Level 4	• Understand and express complex language/communication • Write a sentence personal statement for application • Learn to fill out forms, and complete and submit forms accurately	• Submitted formal application to serve on the community transportation advisory board for application
Counseling (Lanning helps to translate into action, counseling Houlahan & Nelson, 2013)	• Present testimony about recovery #9800 Religion and spirituality	• Impaired spoken and written language expression • Impaired reading BDAM Severity Level 4	• Summarize written illness narrative • Oral read chosen multifaceted words accurately	• Oral read personal testimony at church

Strong, K. A. (2015). Co-construction of personal narratives in supporting identity in adults with aphasia: The 'My Story' project. American Speech-Language Hearing Association Annual Convention, Denver, CO.

Using Community Resources for Participation Assessment (Pollens & Glista, 2016)

Strategy to determine participation goal	Participation Goal ICF	Identified Barriers	Associated Impairment Goals	Participation Outcomes
ACE Program Groups Client Choice Client Organizations	• Join Aphasia Advocacy Group • Teach public about aphasia #8400 Human Rights • Read and discuss "Reading Together" book selection from the public library #9200 Recreation & Leisure	• Anomia • Impaired spoken language discourse BDAM Severity Level 3 • Impaired understanding of language • Impaired spoken language • Limited mobility BDAM Severity Level 3	• Co-create key word narrative outline • Engaged public in lobby • Discussed & distributed aphasia resource materials • Listen to audio book in an accessible format independently • Express opinions via multi-modality communication • Attended community lecture communication	• Engaged public in lobby • Discussed & distributed aphasia resource materials • Attended community lecture communication
Disability Resource Network	• Resume bowling for fun #9200 Sports	• Impaired spoken and written language comprehension & expression • Minimal family/social support • Limited transportation access BDAM Severity Level 3	• Demonstrate use of supported communication techniques to facilitate communication between her and senior companion • Joined Disability Network Bowling League with Senior Companion • Rated high enjoyment	• Resumed bowling for fun with senior companion • Joined Disability Network Bowling League with Senior Companion • Rated high enjoyment
Inter-Professional Team Art, Nursing, CIE, Art, Music, SLP & Low Vision Therapies	• Enroll in art lessons #9200 Recreation & Leisure	• No access to supported art class • Impaired comprehension & expression BDAM Severity Level 2	• Write single words or draw to communicate choices and opinions • Use written choice in Art Therapy • Created handprints and etching art objects related to life interests	• Enrolled in art lessons • Created handprints and etching art objects related to life interests

Using Dedicated Products for Participation Assessment (Pollens & Glista, 2016)

Strategy to determine participation goal	Participation Goal ICF	Identified Barriers	Associated Impairment Goals	Participation Outcomes
Create Social Activity List (in Wood & Hickson, 2003)	• Increase reading time • Read & understand daily news #9200 Recreation & Leisure #9500 Political life & citizenship	• Impaired comprehension of written language • Lack of awareness of accessible news formats BDAM Severity Level 2	• Identify and apply 3 strategies for increased reading comprehension of multi-paragraph information • Sample internet news providers and choose most suitable media	• Read news on a daily basis • Discussed the news in ACE Conversation Group
LV Cards (in Wood & Hickson, 2003)	• Go to the museum with ACE Group members #9200 Arts & Culture #9200 Socializing	• Impaired understanding and expression of spoken language • Lack of communication accommodations in public museum BDAM Severity Level 1	• Teach museum discounts to promote spoken language comprehension by using conversation and hearing support • Express opinions using written choice	• Attended art museum tour with peers • Discussed opinions with peers
ACE Participation Survey (Pollens & Glista, 2008)	• Vote in national election #9500 Political life & citizenship	• Impaired understanding of written language BDAM Severity Level 2	• Increase understanding of complex information by simultaneously listening to and reading content	• Voted

Crosswalk of participation self-report measure for aphasia to the ICF: What content is being measured? Brandenburg, C. et al. (2015)



- What constitutes a participation item?
- What ICF category correlates with participation?
- Is there a shared definition or operationalization of participation?
- How is participation measured? What is measured?
- Can a consensus be formed in defining and measuring participation?



Participation Needs Assessment

LIV Cards



Assessment for Living with Aphasia



Talking Mats



LPAA to meet communication need (Simmons-Mackie & Buekelman, 2013)

In Acute Care

- Use nurse call button
- Ask for help
- Answer questions regarding condition
- Understand information regarding condition
- Greet family and visitors
- Select menu options
- Make a complaint
- Ask about the future

In Rehab

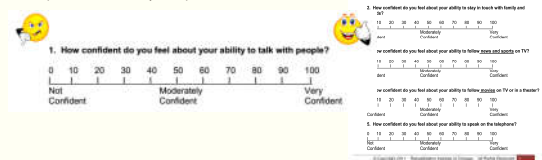
- Answer autobiographical questions
- Give or refuse consent for procedure
- Collaborate on goals
- Follow instructions
- Understand safety precautions
- Follow a daily schedule
- Make a complaint
- Understand discharge options
- Participate in discharge decisions

At Home

- Communicate needs for all activities
- Give instructions
- Make request to caregivers
- Use calendar
- Manage medications
- Answer phone, make calls
- Use mail/e-mail
- Read bills, manage finances
- Make appointments
- Make lists, do shopping
- Manage transportation

Communication Confidence Rating Scale for Aphasia (Cherney & Babbitt, 2011)

- Self-assessment outcome tool to target the domains of personal identity, attitudes and feelings
- Potential barometer of the health of identity (Babbitt & Cherney 2010)



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2. ONLINE RESOURCES FOR INCORPORATING LPAA INTO CLINICAL PRACTICE

National Aphasia Association



- What is Aphasia
 - Definitions
 - FAQs
 - Aphasia Quiz
 - 2016 Awareness Report

Find Support

- Find affiliates
- Support for people with aphasia, caregivers, & professionals
- Aphasia ID card download
- Aphasia Bill of Rights
- Caregivers Bill of Rights

Stories & News

- Stories and blog posts
- Aphasia in the news



AphasiaAccess

- <http://www.aphasiaaccess.org/>
- Mission...
 - Aphasia Access: Growing a network of healthcare, business, and community leaders to advance lifelong communication access for people with aphasia.
- Aphasia Access service providers and researchers believe that:
 - people with aphasia should have access to services that not only improve language and communication, but also help them participate in life's interactions and activities
 - professionals who serve those with aphasia must strive to create environments people with aphasia can successfully navigate
 - professionals who serve those with aphasia deserve practical strategies, ongoing support, and a network of peers.
- Began in 2014



AphasiaAccess Training 'Landing Page'



- Members only (or for fee)
 - Webinar Series
 - On-Demand Webinars (members only)
- Public Access (free)
 - On-Demand Video
 - 9 free videos
 - LPAA 101 series
 - LPAA 101 in Action series
 - Podcasts
 - 30-45 minute interviews with LPAA experts

Aphasia Institute

www.aphasia.ca

Free Resources

- FAQs and information about aphasia
- Personal stories
- Hearing Screening (next page)

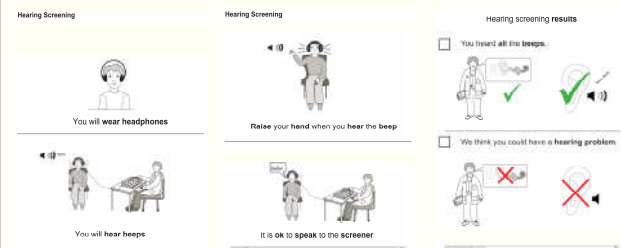


Products for purchase

- Knowledge Exchange – online speaker series featuring world renowned speakers talking about LPAA topics
- ParticiPics
- Assessment Tools
- Numerous products on communication enhancement and aphasia

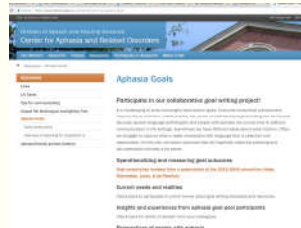
Aphasia Institute - Communicatively Accessible Hearing Screening Protocol

<http://www.aphasia.ca/cahsp/>



Center for Aphasia and Related Disorders (Haley, K.)

- Collaborative Goal Writing Project
 - We share resources that will hopefully make the planning and documentation process a bit easier.
 - Goal construction handout from 2015 ASHA presentation
- <https://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals/aphasia-goals>



Collaborative Goal Planning 4-pronged method

(Haley, Richardson, Jacks, & de Riesthal (2015))



<https://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals/overview-of-planning-for-outpatient-tx/view>

Aphasia Friendly Guidelines

- Stroke Association – stroke.org.uk
- 32 page manual for making information more accessible for people with aphasia



The Five Steps

There are Five Steps to follow

- Step 1: A short message
- Step 2: Clear sentences
- Step 3: Easy words
- Step 4: Good layout
- Step 5: Make a set



<https://www.youtube.com/watch?v=hTh86NoQh7Q>

Participation in Action



Talk to me (SCALE empowerment series)
<https://www.youtube.com/channel/UCd3H8eEK0acCMU8570WSKGA>

Aphasia Tones

<https://www.youtube.com/watch?v=llFcMmVzuIM>



Voices of Hope for Aphasia
<https://www.youtube.com/channel/UCM-HZ5IbebpjM4xrBalyA>



Adler Center Newsletter
https://www.youtube.com/watch?v=pgBMuzZ_xU4



Aphasia Journeys (RIC & ITA)
<https://www.youtube.com/watch?v=ZXL4CD0M7ik>

Social Media - FaceBook

- Pages
 - AphasiaAccess
 - Aphasia Recovery Connection
 - Speaking of Aphasia
 - National Aphasia Association
 - Aphasia United
 - Aphasia The Movie
 - Aphasia Institute
 - University of Michigan Aphasia Program
 - Aphasia Community Friendship Center
 - The list goes on and on!*
- Groups
 - Living Successfully with Aphasia
 - ARC Aphasia Caregivers and Friends
 - Aphasia Recovery Connection
 - Aphasia Choirs Go Global
 - The list goes on and on!*



3. THREE CLINICAL INTERVENTIONS OCCURRING IN MICHIGAN THAT INCORPORATE LPAA

University Based Teaching Clinic
Community Based Support Group
Client Choice

University-Based Teaching Clinic WMU's ACE Program



For example.....

- Prepared & delivered a presentation about aphasia for our university police officers
- Authored articles for a newsletter
- Used non-verbal augmentative aids to discuss hobbies
- Taught each other iPhone games which promoted spelling
- Laughed and told jokes that they chose and read orally
- Used games as a context for producing descriptive cues
- Discussed coping strategies for living with aphasia
- Held aphasia education workshops for students, family, community members

Content is flexible and problem solves to meet life participation (Pollens, 2016)

Client Choice	Content responds to need
<ul style="list-style-type: none"> Needed access to public transportation system 	<ul style="list-style-type: none"> Generated & rehearsed verbal scripts to reserve the ride
<ul style="list-style-type: none"> Wanted to volunteer as a community board member 	<ul style="list-style-type: none"> Listened to narratives (TED), took notes, asked 2 questions
<ul style="list-style-type: none"> Needed new apartment 	<ul style="list-style-type: none"> Created written directions to navigate a phone app and search for apartments

Community Based Support Groups Lansing Area Aphasia Support Group

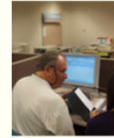
- Established in 2004 by 3 local SLPs
- Membership of about 40 families and providers
 - Typically 5-15 in attendance
 - People with aphasia and caregivers
- Monthly meetings (90 minutes)
- Agenda
 - Topics and open discussion
 - Guest speakers
- Community aphasia education



Group members and CMU graduate students share lunch after coming to class and teaching about life with aphasia

Client Choice Charles Van Riper Language, Speech, and Hearing Clinic

"I want to learn to email to connect with family."



STARTING A CONVERSATION ABOUT WHAT CAN WE DO IN MICHIGAN

Examples from other countries

Aphasia United

- Best practice recommendations
- Aphasia Friendly best practice recommendations



<http://www.aphasiaunited.org/about-us/>

Australian Aphasia Rehabilitation Pathway



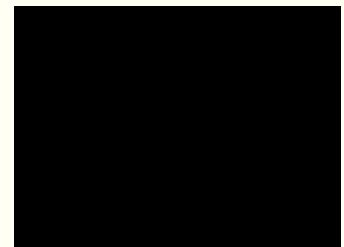
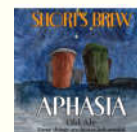
The Pathway

- Receiving the right referrals
- Optimising initial contact
- Setting goals & measuring outcomes
- Assessing
- Providing intervention
- Enhancing the communicative environment
- Enhancing personal factors
- Planning for transitions

<http://www.aphasiapathway.com.au/>

MSHA's Aphasia Advocacy Project

- http://www.michiganspeechhearing.org/aphasia_advocacy_project.php
- Website Resources and links to other resources
- Two Videos on What Exactly is Aphasia
 - 2-minute
 - 6-minute



What do people with aphasia want?

Providing Platforms for LPAA assessment & intervention
Worrall, L. et al. (2011)

to return to their pre-stroke life and to communicate not only their basic needs but also their opinions

- information about aphasia, stroke, and available services;
- more speech therapy;
- dignity and respect;
- engagement in social, leisure, and work activities;
- to regain their physical health;
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LIVING SUCCESSFULLY WITH APHASIA IN MICHIGAN

Who? How? What? Where? When?

Scope of Practice Domains
Collaboration, Counseling, Prevention & Wellness,
Screening, Assessment, Treatment, Population & Systems

Questions????

- | | |
|---|--|
| <ul style="list-style-type: none"> ▪ In Michigan, what do people with aphasia want? ▪ What are the needs of people with aphasia in your town? People with aphasia whom you serve? ▪ Do caregivers and family members of people with aphasia have unmet needs? ▪ What resources are available to caregivers and family members? ▪ Will collaboration across the state improve access and opportunities for people with aphasia? | <ul style="list-style-type: none"> ▪ How can people with aphasia be linked to innovative opportunities? ▪ Can access to communication and communication opportunities increase? ▪ What barriers exist to communication access for people with aphasia who live in Michigan? ▪ Can successful programs used in other states and communities be replicated in our state and our communities? ▪ Can client choice become a viable alternative? |
|---|--|

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