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

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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

Life Participation Approach to Aphasia

A Statement of Values for the Future

*http://www.asha.org/public/speech/disorders/LPAA/

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.

Disclosures

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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
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

Taking 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 mobile phone
- 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)

National Aphasia Association

- What is Aphasia
  - Definitions
  - FAQ
  - Aphasia Quiz
  - 2016 Awareness Report
- Find Support
  - Find affiliates
  - Support for people with aphasia, caregivers, & professionals
  - Aphasia ID card download
  - Aphasia Bill of Rights
  - Caregiver Bill of Rights
- Stories & News
  - Stories and blog posts
  - Aphasia in the news
Aphasia Access

- [http://www.aphasiaaccess.org/](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

Aphasia Institute [www.aphasia.ca](http://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/](http://www.aphasia.ca/cahsp/)

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

- [Collaborative Goal Writing Project](https://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals)
- 4-pronged method (Haley, Richardson, Jacks, & de Riesthal (2015))

Collaborative Goal Planning

- [http://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals](http://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals)
- [http://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals](http://www.med.unc.edu/ahs/sphs/card/resources/aphasia-goals)
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=mH0SsC9ug9Q

Participation in Action

Aphasia Tones
https://www.youtube.com/watch?v=IIFcMmVzuiM

Aphasia Journeys
https://www.youtube.com/watch?v=ZXL4CD0M7ik

Voices of Hope for Aphasia
https://www.youtube.com/channel/UCM-HZSJbebxpJM4xrbA

Social Media - FaceBook

- Pages
  - Aphasia Access
  - Aphasia Recovery Connection
  - National Aphasia Association
  - Aphasia United
  - Aphasia The Movie
  - Aphasia Coalition
  - University of Michigan Aphasia Program
  - Aphasia Community Friendship Center
  - The list goes on and on!

- Groups
  - Living Successfully with Aphasia
  - WMU Aphasia Campers and Friends
  - Aphasia Recovery Connection
  - Aphasia Friends Worldwide
  - The list goes on and on!

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
- Taught each other iPhone games which promoted spelling
- Laughed and told jokes that they chose and read orally
- Created written directions to navigate a phone app and search for apartments

Client Choice

- Needed access to public transportation system
- Wanted to volunteer as a community board member
- Needed new apartment
- Generated & rehearsed verbal scripts to reserve the ride
- Listened to narratives (TED), took notes, asked 3 questions
- Created written directions to navigate a phone app and search for apartments

Content responds to need

3. THREE CLINICAL INTERVENTIONS OCCURRING IN MICHIGAN THAT INCORPORATE LPAA

University Based Teaching Clinic
Community Based Support Group
Client Choice

Content is flexible and problem solves to meet life participation (Pollens, 2016)
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
- People with aphasia and caregivers
- Monthly meetings (90 minutes)
- Agenda
  - Topics and open discussion
  - Guest speakers
- Community aphasia education

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

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

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."

Email Group
- Supporting personal factors
- Reducing participation barriers
- Reducing environmental barriers
- Reducing impairment barriers

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


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?

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LIVING SUCCESSFULLY WITH APHASIA IN MICHIGAN


Scope of Practice Domains

Collaboration, Counseling, Prevention & Wellness, Screening, Assessment, Treatment, Population & Systems

Questions????

• 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?
• 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?

References


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