

**Aphasia and Identity: The Storytelling Journey**

MSHA 2025

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- Clinical educator at Western Michigan University and coordinator of the Aphasia Communication Enhancement (ACE) Program
- Member of the MSHA Healthcare Committee
- Disclosures: paid WMU and Hope Network employee

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**My (incredible) Colleagues**

**Peggy**  
**Nikki**  
**Megan**  
**Kate**  
Micah, Kiley

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### Objectives and Agenda

- Understand**  
•Understand the impact of storytelling on identity, confidence, and communication for individuals with aphasia.
- Learn**  
•Learn directly from women with aphasia about their experiences, challenges, and the role of storytelling in their journeys.
- Gain**  
•Gain practical tools and strategies to facilitate storytelling interventions that align with the Life Participation Approach to Aphasia (LPAA) and Living with Aphasia: Framework for Outcome Measurement (A-FROM) treatment models.

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### Pre-Reflection Questions for Attendees

Does storytelling play a role in helping individuals with aphasia reclaim their identity?

How might a storytelling align with the principles of LPAA and A-FROM?

How could you integrate storytelling into your own practice?

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### Aphasia and Identity

- Aphasia can have a devastating impact on self-esteem and identity
- 'Who I was' no longer reconciles with 'who I am now' for many people with aphasia
- The reactions of others can significantly impact sense of self and self-esteem

“ When asked to describe herself a woman with aphasia explained 'Me . . . nothing . . . nothing. Before a teacher . . . now, I don't know . . . what. What?' ”

(Simmons-Mackie & Duncan, 2001, p. 31)

Simmons-Mackie, 2018

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**Why Does Identity Matter?**

- **Strong or robust identity** is associated with **well-being** and a **higher quality of life**
- **Positive sense of self** helps people **overcome barriers** and **take communicative risks**, in turn this *enables* **social relationships, participation and communication practice**
- **Attention to identity renegotiation** should be a target in rehabilitation
- Communication is *essential* to identity negotiation

Simmons-Mackie, 2018

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**Aphasia and Confidence**

- PWA's communicative **confidence** **influences** **life participation**
- **Fear of judgement**, leading to **social withdrawal**

• Research shows that personal storytelling helps individuals process their experiences, find meaning, and build confidence (Strong & Shadden, 2020).

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**Why Storytelling Matters in Aphasia Therapy**

- **Personal narratives**, particularly concerning stroke and aphasia, **significantly influence how one's life story is perceived**.
- These narratives help individuals **articulate the impact** of their experience, **guiding personal acceptance** and **meaning-making**.
- Writing about meaningful life events **encourages** participants to **address conflicts** and **find resolution**.

Strong & Shadden, 2020

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**Why Storytelling Matters in Aphasia Therapy**

- Many clinicians continue to struggle to support their clients in domains *beyond language impairment*.
  - Social co-construction involves a **collaborative** act where communication is essential for story creation.
  - The **relationship** between the client and the clinician **facilitates meaningful narrative exchanges**.
  - A study found that 80% of SLPs believe they play a role in supporting identity reconstruction after aphasia onset; 28% address identity indirectly in treatment, 35% incorporate personal narratives.
  - Highlights a gap between perceived role and actual therapy practices.

O'Bryan & Strong, 2024  
Strong & Shadden, 2020  
Strong & Nelson, 2012

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**Outcomes of Narrative-Based Storytelling**

- Improved communication confidence
- Identity reconstruction and psychosocial well-being
- Engagement in social participation
- Functional communication gains support for care partners
- Positive reception in group and individual therapy

O'Bryan & Strong, 2024

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**LPAA and Narrative Identity**

- **LPAA = Life Participation Approach to Aphasia**
  - Focuses on **meaningful life engagement**.
  - **Clients drive therapy goals** based on what matters to them.
  - **Narrative identity** helps people integrate their past, present, and future.
  - **SLPs support this process** by helping clients tell their stories.

**Participation** is an integral focus of services to people with aphasia and is **considered best practice**

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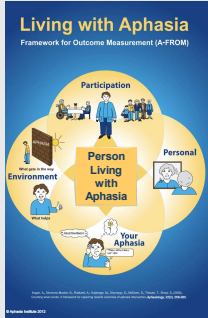
### The A-FROM Framework & Identity in Aphasia

**A-FROM** (*Living with Aphasia: Framework for Outcome Measurement*)

Highlights **four key domains** of aphasia impact:

1. **Personal Identity, Attitudes, and Feelings** (Rebuilding self through storytelling)
2. **Participation in Life Situations** (Sharing narratives to reconnect with others)
3. **Language and Related Impairments** (Using language to express identity)
4. **Communication Environment** (Creating a supportive space for storytelling)

Kagan et al., 2008



The diagram shows a central yellow circle labeled 'Person Living with Aphasia'. Surrounding it are four quadrants: 'Participation' (top), 'Personal' (right), 'Your Aphasia' (bottom), and 'Communication Environment' (left). Each quadrant contains small icons representing the respective domain.

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### How SLPs Facilitate Narrative Identity

- **Share their life stories** in meaningful ways.
- **Reframe their aphasia experience** into a story that fosters growth.
- **Engage in personal storytelling** to strengthen confidence, communication, and identity.

Strong & Shadden, 2020

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### Panel Interview: Using the A-FROM Model to Ask Questions About Identity

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Please introduce yourself. Tell us **your name, where you're from** and about your **injury** (e.g., stroke, brain injury)

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**Life Before Aphasia**



1. Please share a little **about your life** before aphasia? What were your **hobbies, work, or daily routines**?
2. How would you **describe your communication skills** and **interactions** with others **before your aphasia**?
3. What are some things **you loved doing** that have been more **difficult** or **impossible** since having aphasia?

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**A-FROM Domain: Impairment (Specific communication challenges)**



1. What has been the **hardest part** of **communicating with aphasia**?
2. Are there **specific words, phrases, or responses** you find especially **difficult** to communicate now?
3. Have any **devices** or **strategies** helped you communicate? How have you learned to **compensate** for your **communication difficulties**?
4. Can you **share a time** when you **felt proud** of how you were able to communicate, even with aphasia?

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**A-FROM Domain: Participation (How aphasia affects life activities and social involvement)**



1. How has your aphasia impacted your ability to participate in family events or celebrations?
2. What activities or hobbies have you been able to return to since your aphasia?
3. How has aphasia impacted your ability to work?
4. Are there new activities or groups you've joined as part of your recovery?

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**A-FROM Domain: Environment (How people and surroundings support or hinder participation)**



1. How have family and friends supported you in your recovery?
2. Have there been any experiences when you felt unsupported or misunderstood by those around you?
3. Can you describe a time when someone made communication easier for you?
4. What have you learned about how society (in general) treats people with communication difficulties? Any specific experiences you're willing to share?

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**A-FROM Domain: Personal Factors (Feelings, attitudes, and emotional responses)**



1. Can you talk about an experience where you felt judged or rushed by others around you to communicate, and how did that make you feel?
2. What has been the most emotionally challenging part of living with aphasia?
3. Have you noticed any changes in your confidence or self-identity living with aphasia?
4. What personal beliefs or attitudes have helped you stay motivated (or made it harder) during your journey?
5. Is there something you've learned about yourself through this journey?

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**Hopes and Dreams for the Future**



1. What would you say is your **biggest dream** right now?
2. Is there something you've been **practicing in therapy** that you're **excited to improve**?
3. If there's **one thing** you could **accomplish in the next year**, what would it be?

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**What SLPs and Other Therapists Should Know About Living with Aphasia**



1. What can SLPs do to make their clients feel **heard, understood, confident, and hopeful**?
2. Are there ways that SLPs can better **involve family members** in therapy?
3. If you could **change one thing** about speech therapy, what would it be?
4. What do you wish SLPs understood about how **aphasia affects everyday life**?

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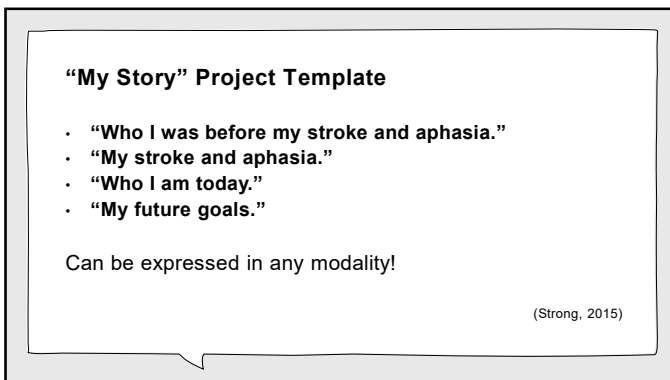
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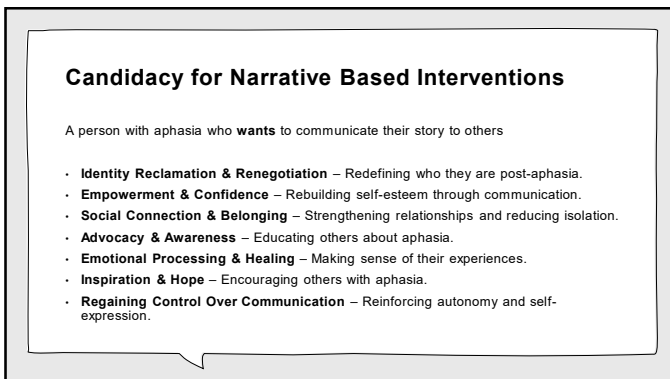
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**Where And With Whom Someone With Aphasia Could Share Their Story**

<p><b>With Family &amp; Friends</b></p> <ul style="list-style-type: none"> <li>• Family gatherings</li> <li>• One-on-one conversations</li> <li>• Writing letters or cards</li> </ul>	<p><b>Through Technology &amp; Media</b></p> <ul style="list-style-type: none"> <li>• Social media posts</li> <li>• Personal blogs or vlogs</li> <li>• Podcasts or audio stories</li> </ul>
<p><b>In Community Groups &amp; Social Settings</b></p> <ul style="list-style-type: none"> <li>• Book clubs</li> <li>• Religious or spiritual communities</li> <li>• Support groups for aphasia or brain injury</li> </ul>	<p><b>Public Speaking &amp; Advocacy</b></p> <ul style="list-style-type: none"> <li>• Aphasia awareness events</li> <li>• Hospitals or rehabilitation centers</li> <li>• University guest speaker</li> </ul>
<p><b>At Work or Professional Settings</b></p> <ul style="list-style-type: none"> <li>• Speaking to colleagues</li> <li>• Advocacy &amp; awareness events</li> <li>• Writing a blog or newsletter entry</li> </ul>	<p><b>Creative &amp; Alternative Expression</b></p> <ul style="list-style-type: none"> <li>• Art or music therapy groups</li> <li>• Writing a memoir or book</li> </ul>

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**Therapy Goal Examples**



**Long-Term Goal (A-FROM, Participation in Life Situations):**  
 -The client will create and share a personal narrative with others (e.g., family, friends, healthcare providers) who are important in their life.

**Short-Term Goal (A-FROM, Personal Identity, Attitudes, and Feelings):**  
 -The client will convey aspects of their former life, stroke event, and goals for the future to construct a story to share with people who are important in their life.

**Short-Term Goal (A-FROM, Communication and Language Environment):**  
 -The client will use supports such as projected slides with a written script and a mouse to highlight key words they are expressing during the verbal sharing of their personal narrative, increasing accessibility of their verbal message to the audience.

**Short-Term Goal (A-FROM, Language and Related Impairments):**  
 -The client will produce key words verbally during the sharing of their story using written cues, slow rate of speech, phonemic cues, and other supports as needed.

(O'Bryan & Strong, 2024)

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**Summary and Key Takeaways**

**LPAA + A-FROM + Storytelling = A Holistic Approach to Aphasia Therapy**

- Storytelling fosters identity, participation, and engagement
- Co-constructing stories is a skilled, billable intervention with measurable outcomes.
- SLPs are not just therapists; they are facilitators of life stories.
- SLPs play a crucial role in co-constructing stories to restore identity.

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**Post-Reflection Questions for Attendees**

Does storytelling play a role in helping individuals with aphasia reclaim their identity?

How might a storytelling align with the principles of LPAA and A-FROM?

How could you integrate storytelling into your own practice?

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**Thank you!**

**Check out the WMU ACE Program!**



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