

MSHA Conference 2023

Friday, March 24th

8:30-9:30am

Allison Mezo, SLP
Kate Leckie



Disclosures

Allison Mezo works for Hope Network Neuro Rehabilitation and Western Michigan University.

Kate is a co-presenter and has given full permission for everything we will be sharing today.



Young Adults with Aphasia: Supporting Psychosocial Wellbeing with person Relationship-Centered Care

Allison Mezo, SLP
Kate Leckie

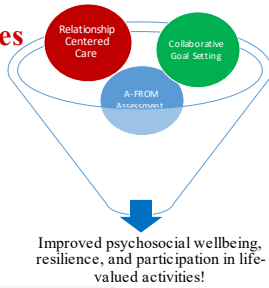


Reflection Points

- Can psychosocial wellbeing be influenced by relationship-centered care?
- What life events happen in young adulthood (ages ~18-40)?
- To what extent might young persons with aphasia require different assessment and treatment goals than older adults with aphasia?

Learner Outcomes

- Understand relationship-centered care for psychosocial wellbeing;
- You will meet a young adult with aphasia;
- How A-FROM assessment and goal setting can lead to improved outcomes;
- Learn strategies and resources to implement new skills into your clinical practice



RESILIENCE

Models of Care

Life Participation Approach to Aphasia (LPAA)

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

Chapey et al., 2000
Kagan & Simmons-Mackie, 2007

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Models of Care

Participation in Life Events

Communication and Language Performance

Language and Symbolic Expression

Transactivity: Acquisition and Use

Linking with Aphasia

Kagan et al. 2007
Kagan & Simmons-Mackie, 2013

Photo from <https://www.aphasia.ca/>

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Learner Outcome #1:

Understand relationship-centered care (RCC) for supporting psychosocial wellbeing(PWB)

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Defining

Relationship-centered care (RCC) is an appreciation of how relationships can influence health care experiences and outcomes. It is founded upon 4 principles:
(1) that relationships in health care should 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.

Psychosocial well-being (PWB) refers to psychological, social, and subjective components which influence the overall functionality in life.

Beach and Inui, 2006
Yobas et al., 2021



RCC definition expands to aphasia:

- Therapists and patients bring dimensions of themselves as **people** into the relationship.
- The notion of “**detached concern**” of the SLP is challenged.
- The SLP is affected by the PWA in the same manner as the client is affected by the SLP.
- Through genuine relationships, SLPs can generate the interest and investment needed to serve others and to be renewed from that service.

Worrall et al., 2010 p. 279



But how do SLPs support psychosocial well-being?

1. Prioritize relationships;
2. Find a rope team;
3. Begin with the end in mind;
4. Practice SMARTER therapy;
5. Leave no person behind;
6. Look behind the mask, and
7. Find a voice. ¹

"Strong therapeutic relationships enable client engagement... reduces depression." ²

"...ineffective communication and lack of connection with our clients can limit engagement, promote withdrawal, and ultimately diminish treatment response!" ³

1: Worrall, 2019
2: Cohen-Schneider et al., 2020
3: Street et al., 2009; Williams et al., 2021



What elements benefit a RCC approach?

- Listening to the client’s “whole self”
- Having considerations around self-disclosure
- Dealing with biases
- Recognizing and surfacing clients’ identities
- Fostering hope

Cohen-Schneider et al., 2020



Young adults with aphasia

- Strokes in young adults are reported as being uncommon, comprising 10%–15% of all stroke patients
- Approximately one third of stroke patients present with aphasia

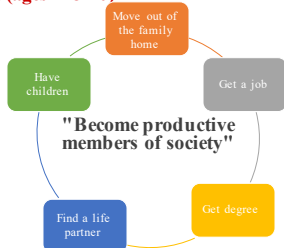
800,000 strokes in US per year and 658,000 of those people live
 10–15% = 65,800–98,700 young people in US per year who have a stroke

young adults with aphasia in the US (per year)
~21,000-33,000

Simmons-Mackie, 2018
Cde.gov
Sungjoo, 2022



Young adulthood (ages ~18-40)



(Lally & Valentine-French, 2018)



Meet Kate

Our young adult with aphasia




About me

- 23 years old
- Parchment
- Graduated from high school in 2017
- Occupation: paraprofessional at Parchment Community Schools
- Big family
- Lots of friends
- Lots of hobbies - softball, dancing, concerts, traveling
- Personality: stubborn, funny, caring



Timeline

- 3-19-2021
- Stroke, TBI, hemiplegia, aphasia
- Borgess
- Mary Free Bed

Timeline

- I discharged home from Mary Free Bed in May 2021
- Started at Hope Network on June 1st, 2021

Adjustment home was HARD
 My identity was stolen from me

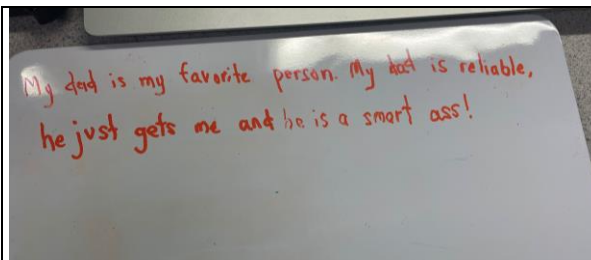


My goals

Gain back my independence

1. Move into my newhouse
2. Return to driving
3. Return to college, finish my degree!
4. Return to work





Therapy, therapy, and more therapy



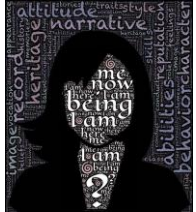
Neuropsychological testing.....

Back to college and work I go!



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 significant issue in rehabilitation
- Communication is essential to identity negotiation



Simmons-Mackie, 2018

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Aphasia and Identity

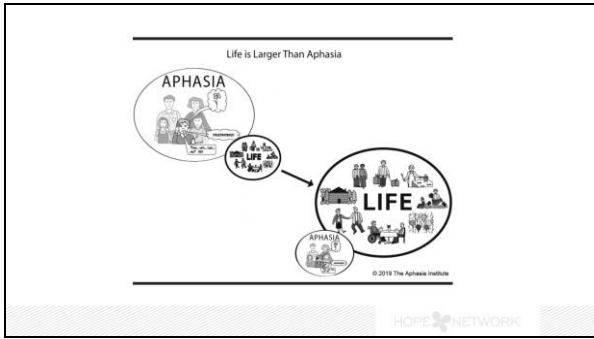
“When asked to describe herself a woman with aphasia explained
 Me . . . nothing . . . nothing.
 Before a teacher . . . now,
 I don't know . . . what.
 What?”

(Simmons-Mackie & Danico, 2001, p. 11)

- Aphasia can have a devastating impact on self-esteem and identity
- The send of '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

Simmons-Mackie, 2018

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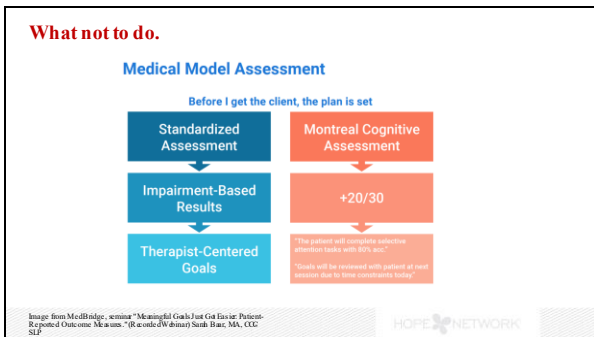


Learner Outcome #2:

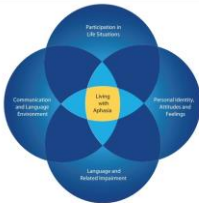
A-FROM assessment and goal setting can lead to improved outcomes

(with a vignette from Kate and Allison on collaborative goal setting)

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Many options to support assessment from an A-FROM lens.



- Formal vs informal
- Assessment for Living with Aphasia (ALA)
- Motivational and ethnographic interviewing
- Needs assessments
- Behavioral observations
- Questionnaires and PROMs
- Caregiver interviewing
- Referral to other professionals

Kinga A., Simonee Mackie, H. Stewart, A. Hahn, M. Sharma, C. McEwen, S. Truesdell, & P. S. (2015). Creating a new vision of assessment for working with the realities of aphasia intervention. Aphasiology, 29(3), 258-280.

Goal Setting

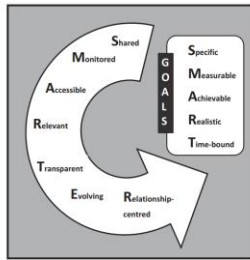


Figure 1. The SMARTER goal setting framework.

Herschet al., 2012

Use this tool to talk about your life

Participation
 Activities, Relationships, Roles and responsibilities, Conversations

Personal
 Aphasia and why you are, The future, Your own of yourself, Your feelings

Environment
 Services, systems and policies, Attitudes of others to you and the aphasia, Help with communication and conversation

Aphasia
 Talking, Writing, Understanding and listening, Reading

Kate's A-FROM for goal setting, September 2021

Participation	Personal
Finish Bachelor's degree Maintain employment as a paraprofessional Keep up in conversations Be prepared for oral presentations	Struggle with aphasia. "I feel stupid." "I can do this, I can do that!" Sometimes positive and sometimes not "Figuring out who I am and what I want to do with my life."
Environment	Aphasia
Navigating college systems Letters of accommodations Using voice-to-text and text-to-voice Attitude of instructors to me and my aphasia	Accommodations: Finding the words to say is hard Reading long textbooks makes me tired I've been getting down my thoughts on paper.

**Additional goal setting tools compliment
RCC/A-FROM frameworks**

- Goal Mapping
- Goal Attainment Scaling (GAS)
- Self-Anchored Rating Scales (SARS)

Here's an example

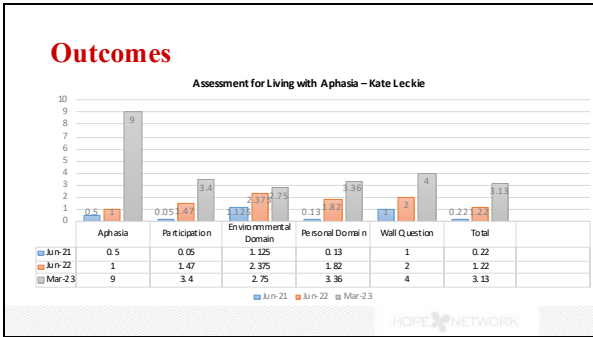
A vignette.

Treatment

Response Elaboration Training oral speaking ---> written via use of **dictation** function on Google Docs.

Script Training, saved in Google Docs for copy/paste

- Disability officer, to discuss accommodation paperwork
- To professors for asking questions
- For responses in Discussion Posts
- To support beginning, middle, and end paragraph transitions for expository and narrative essays



Outcomes

Kate is graduating with her Bachelor's Degree in May 2023!

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Practicing relationship-centered care positively supports psychosocial wellbeing, which has the power to positively impact outcomes.

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Outcome #3: Resources to explore and implement within your clinical practice to be relationship-centered

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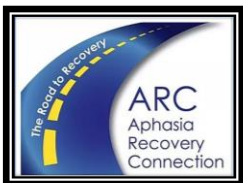


Support Group Finders

- American Heart Association
 - <https://www.stroke.org/en/stroke-support-group-finder>
- National Aphasia Association
 - www.aphasia.org

ACTION STEP: You can also REGISTER your own support groups on these websites.

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<https://www.aphasiarecoveryconnection.org/>

- 10,000+ members
- Group members can:
 - Meet others with aphasia and their caregivers & families
 - Help new group friends stay in touch
 - Learn the latest information about aphasia
 - Help each other through difficult times
- Vibrant Facebook Group Communities
 - Persons with Aphasia
 - Caregivers




VIRTUAL CONNECTIONS

Aphasia Recovery Connection & Lingraphica


- **FREE Online Meetups for Families Living with Aphasia**
- Sessions facilitated by speech-language pathologists, music therapists, and aphasia experts.
- Join sessions to meet others, share ideas, and practice your communication skills.
- End the isolation, sign up for your favorite sessions today

<https://devices.aphasia.com/virtual-connections>



Young Survivors Under 40


Sunday, February 26 @ 12:30 pm EDT



This session is for **YOUNG SURVIVORS, AGES 18-40 ONLY.** Join other young people with aphasia for fun group activities and lots of conversation! Sessions will be encouraged to help guide the topic of conversation and engage with each other.


Rebuilding Identity

Thursday, March 16 @ 1:30 pm EDT



Join **Shirley Gonzalez's** Kathy Fowler and Flannery O'Hall, stroke survivors with aphasia to discuss identity and emotional health. During this 4 week group, we will talk about the emotional journey of living with aphasia and how to rebuild identity in the face of it. The group will start on **Thursday NOVEMBER 10th** and conclude on **MARCH 23th**, meeting every other week.

Space is limited to 20 participants



Training Videos

Communication Access: Fundamental Techniques Video Series

- Adjusting Your Talking
- Using Writing and Graphics
- Using Gestures and Body Language
- Strategies for Adult Care
- Strategies for Outpatient and Community Programs
- Strategies for Rehabilitation

<https://www.aphasiaaccess.org/videos/>
<https://aphasiaaccess.org/>

"Transforming services and environments so people with aphasia can participate more fully in life"

Podcasts

A few featuring psychosocial issues

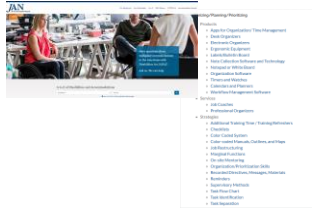
- Episode 95 with Jasvinder Sekhon
- Episode 78 with Michelle Gravier & others
- Episode 69 with Michael Biel
- Episode 67 with Janet Patterson
- Episode 64 with Sarah Northcott
- Episode 46 Carol Dow-Richards
- Episode 38 Robyn O'Halloran
- Episode 35 Deborah Hersh
- Episode 34 Ian Kneebone
- Episode 23 Linda Worrall
- Episode 9 Audrey Holland
- Episode 5 Barbara Shadden

Websites



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Learn more in thousands of professional focused speech therapy videos: Evidence, Evidence, Evidence, Assessment, Goals, Reports, and more designed for real speech therapy.



Reflection Points

- Can you describe the link between psychosocial wellbeing (PWB) and relationship centered care(RCC)?
- What life events happen in young adulthood (ages ~18-40)?
- To what extent might young persons with aphasia require different assessment and treatment goals than older adults with aphasia?



Learner Outcomes (revisited)

- Relationship centered care is the foundation for psychosocial wellbeing;
- A-FROM assessment and goal setting can lead to improved outcomes,
- Learner have strategies and resources to implement new skills into their clinical practice

****Check out the poster sessions to see another real-life example!**

(29) Interwoven Aphasia Goals that Impact Environment, Participation, Impairment, and Identity





References

Bauer, S. (2019, November 22). Person-centred approach to assessment of aphasia. Retrieved October 10, 2022, from <https://www.hope-network.org/aphasia-person-centred-approach-to-assessment/>

Chapman, R., Ditchikoff, J. F., Brown, R. J., Davis, L. J., Kagan, A., Lynn, J. G., & Simmons-Mackie, N. (2008). User-participation approach to aphasia: A statement of value for the future. *The ASHA Gazette*, 53, 4-9. <https://www.asha.org/pubs/prof/gazette/0708080409/>

Cohen-Schneider, R., Cross, M. T., McGill, D. M., Tellewa, A. M., & Abumars, A. P. (2020). Spotlight on the clinician in the life participation approach to aphasia: Reintegrating the person into the center. *Journal of Aphasia Disorders*, 50, 114-149. <https://doi.org/10.1080/00216887.2020.1815270>

Cooper, M., & The Katz Q. (2018). Clinician 'views and practicality' of life participation approach to aphasia rehabilitation. *Aphasiology*, 33(1), 123-134. <https://doi.org/10.1080/02643758.2018.1516270>

Hersh, D., Shemelt, S., Howe, T., Wornell, L., Davidson, B., & Ferguson, A. (2020). An analysis of the 'goal' in aphasia rehabilitation. *Aphasiology*, 28, 57-154. DOI: 10.1080/02643758.2020.1815270

Hersh, D., Wornell, L., Howe, T., Shemelt, S., Davidson, B. (2012). SMARTER goals in aphasia rehabilitation. *Aphasiology*, 26, 220-233. DOI: 10.1080/02643758.2012.64032

Hanning, Peterson, R., & Nech, H. (2022). Characteristics of Resilience in Poststroke Aphasia. *Topical Disorders*, Vol. 4#No. 3, 28-29. <https://www.hope-network.org/publications/>

Kagan, A., & Simmons-Mackie, N. (2021). Engaging with the self: Clinician experience in remote intervention with life participation approach. *Topics in Language Disorders*, 21(6), 309-317. <https://doi.org/10.1097/TLD.0000000000000463>

Kagan, A., & Simmons-Mackie, N. (2021). From a participatory approach to a life participation approach: A review of the literature. *Journal of Aphasia Disorders*, 51, 1-14. <https://doi.org/10.1080/00216887.2021.1915270>

Kagan, A., Simmons-Mackie, N., Rowland, A., Hahnberg, M., Shumway, E., McEwen, S., Theats, T., & Sharp, S. (2008). Counting the costs: A framework for capturing real life outcomes of aphasia intervention. *Aphasiology*, 22(12), 1459-1480. <https://doi.org/10.1080/02643758.2008.304519>

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References

Lally, M., & Vohs, R. D. (2016). *Living Well: A Psychology of Positive Living*. Oxford: Oxford University Press.

Lewis, M., Segal, K., Heise, G., Conroy, P., and Semel, L. (2018). Speech-based language clinical perspective of the person with aphasia: A review of the literature. *International Journal of Language & Communication Disorders*, 53, 282-297. <https://doi.org/10.1080/13682839.2018.1484444>

Simmons-Mackie, N. (2018). Aphasia in North America: Response to the impact of aphasia on communication services and research. *Aphasia Awareness*. <https://www.asha.org/pubs/prof/aw/1801180101/>

Wornell, L., Davidson, B., Hersh, D., Ferguson, A., Howe, T., & Shemelt, S. (2020). The evidence for relationship-centered aphasia rehabilitation. *Journal of Functional Research in Communication Disorders*, 1(1), 27-30.

Wornell, L., Shemelt, S., Ragan, T., Howe, T., Hersh, D., Ferguson, A., Davidson, B. (2011). What people with aphasia want: Their goals and goals for ICF. *APHASIOLOGY*, 25, 3, 309-322. DOI: 10.1080/02643758.2011.59880

Yokoy, P., Vongpradith, N., Ramon, D. O., et al. *Evaluating the relationship among user, resilience and psychological wellbeing among young adults: A structural equation modeling approach*. *BMJ Open*, 2022, 11(1), 20210222. <https://doi.org/10.1136/bmjopen-2021-022222>

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