APHASIA ROUNDTABLES



SUPPORTING MENTAL HEALTH AND APHASIA SERVICES IN MICHIGAN

Katie A. Strong, Ph.D, Becca Johnson, Kait Moses, M.A., Robin Pollens, M.S. MSHA Conference, East Lansing MI, March 24, 2022

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Speaker Disclosures

Katie Strong – *Financial* – Salary from Central Michigan University, Grant funding from Project BRIDGE, Complementary conference registration. *Nonfinancial* – facilitator Lansing Area Aphasia Support Group, Aphasia Access Affiliate, Virtual Connections for Aphasia Volunteer.

Becca Johnson - *Financial* - Conference registration paid by Project BRIDGE. *Nonfinancial* - Aphasia advocate, Lansing Area Aphasia Support Group member.

Kait Moses - *Financial* - Salary University of Michigan Aphasia Program, Conference and lodging accommodations paid for by Project BRIDGE. *Nonfinancial* - Aphasia Access Affiliate.

Robin Pollens - Financial disclosures - Salary Western Michigan University, Conference and lodging accommodations paid for by Project BRIDGE. Nonfinancial - Aphasia Access Affiliate.

Learning Outcomes

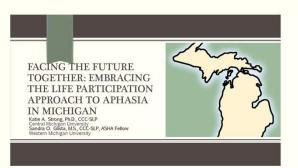
- 1. List 3 programs within Michigan providing specialized aphasia services
- 2. Identify resources for local groups within Michigan and other online resources for individuals impacted by aphasia
- 3. Participate in collaborative brainstorm on identifying further needs or plans with particular emphasis on mental health services for people living with aphasia

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History of Aphasia Roundtables at MSHA

2017 – Strong and Glista hosted a discussion at MSHA to begin to share resources

2017 questions that we posed for discussion

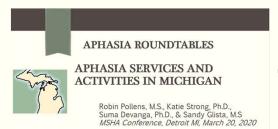


Questions????

- 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?
- 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?

History of Aphasia Roundtables at MSHA

2020 – Pollens, Devanga, Strong, and Glista planned to continue the discussion



Conference canceled due to pandemic

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Bringing us to today...

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AGENDA



Question:

Are there actions we can take individually and/or collectively to improve opportunities for greater life participation for people with aphasia and their families in our communities and in our state?

Stating the problem



Let's Talk Surveying services for people with aphasia in Michigan

Providing resources to support program planning



Let's Talk Visioning in our own communities



Let's Talk Visioning in Michigan

Questions prompting this presentation



My client with aphasia needs mental health support. Do you know any providers?

My husband has PPA. Do you know where we should go to get help?

My aunt speaks Arabic and has aphasia. Is there someone who can help her?

This patient's insurance allows a very limited number of visits. How can he get more therapy?



"Divorce"

What do people with aphasia want?

Worrall et al. (2011)

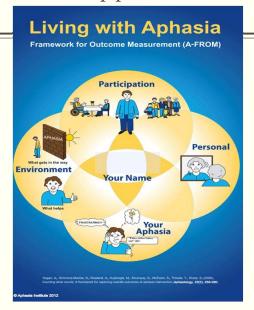
to return to their pre-stroke life and to communicate not only their basic needs but also their opinions

- •more speech therapy;
- •information about aphasia, stroke, & available services;
- •dignity and respect;
- •engagement in social, leisure, and work activities;
- •to help others;
- •greater autonomy.

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https://www.aphasia.ca/shop/personal-a-from/



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Bridges to the Community (Pollens & Glista, 2006)



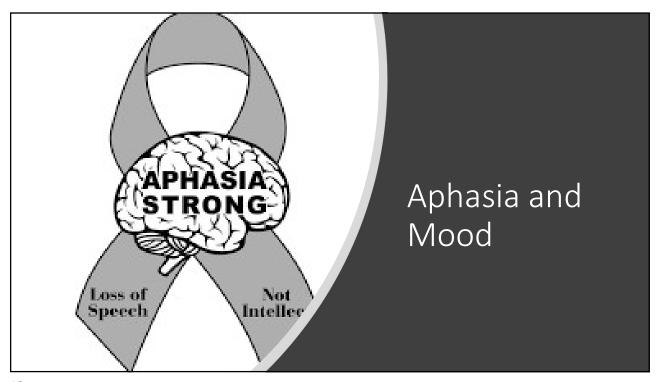
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Recommendations: Call to Action (Simmons-Mackie, 2018)

- 1. Launch a strategic program to build **knowledge and awareness of aphasia**
- 2. Improve services for family members or caregivers.
- 3. Improve **communication access in health care** and the wider community.
- 4. Connect across organizations to **identify** *best available resources* suitable for aphasia.
- 5. Promote inter-professional programs designed to **prevent social isolation**
- 6. Improve **services for people with aphasia** (including attention to **depression**).

Podcast link

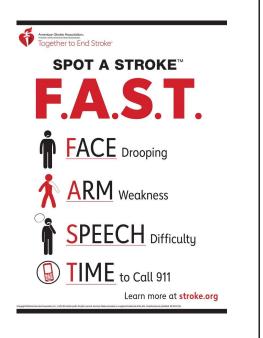


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Stroke

- Stroke is the fifth leading cause of death in the United States and the leading cause of serious long-term disability.
- Every year, more than 795,000 people in the United States have a stroke.
- Stroke is the most common cause of aphasia.
- About 1/3 of strokes result in aphasia.

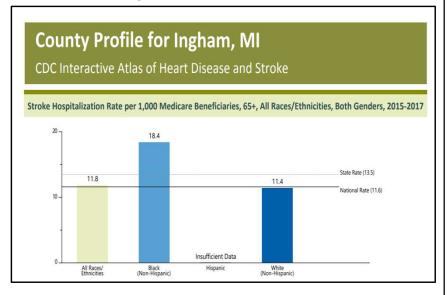
(American Heart Association & National Aphasia Association)



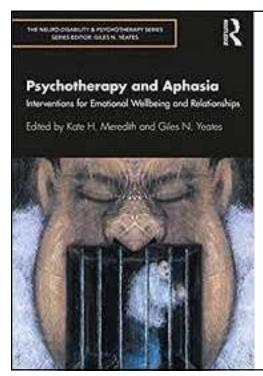
Stroke in Ingham County

- In 2015-2017, approximately 11,800 people in Ingham County were hospitalized from a stroke.
- Meaning that about 4,000 people acquired aphasia.

Centers for Disease Control and Prevention https://nccd.cdc.gov/DHDSPAtlas/?state=County



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Aphasia impacts mood and causes depression.

- 1/3 of adults with aphasia report significant depression
- Depression can increase over time
 - 3 months after stroke 11% report depression
 - 12 months after stroke 33% report depression
- Emotional problems often persist over time

The bottom line is depression is underdiagnosed

people with aphasia

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in

Aphasia affects more than the person who has it.

- Family members, friends, and others close to people with aphasia also struggle with changes in mood and depression due to
 - Loss
 - Changes in roles
 - Stress of caregiving



Why this is important to me

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Before my stroke

- I had ADHD (attention deficit hyperactive disorder).
- I took medication (Celexa) for anxiety.
- I went to therapy to talk about me and my emotional health.

After my stroke

- I have aphasia.
- I still have ADHD.
- I still have anxiety.
- I have depression.
- I am NOT taking any medication for my ADHD or anxiety but do take medication for seizures and stroke.
- I am NOT talking to anyone about my emotional health.
- I want to see a counselor, but my aphasia gets in the way.

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Let's talk:
Does any of
this
resonate
with you?

What is your experience?

Did you ever talk to a counselor **before** your stroke/ aphasia?

Have you ever wanted to talk to a counselor <u>after</u> your stroke/aphasia?

Different ways of managing stress

- Talk (psychotherapy)
 - Psychology
 - Social Work
 - Psychiatry
- Medicine
- Alternative methods
 - Massage
 - Acupuncture
 - Support groups
 - Etc.

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How do mental health providers feel about aphasia and mental health services?

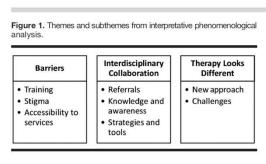
Research Article

How Do You Do Talk Therapy With Someone Who Can't Talk? Perspectives From Mental Health Providers on Delivering Services to Individuals With Aphasia

Katie A. Strong* and Jenna Randolph**

Katie A. Strong* and Jenna Randolph**

Furpose: Aphasis is considered with depression and privately provider with pro



Programs Emerging from Around the World

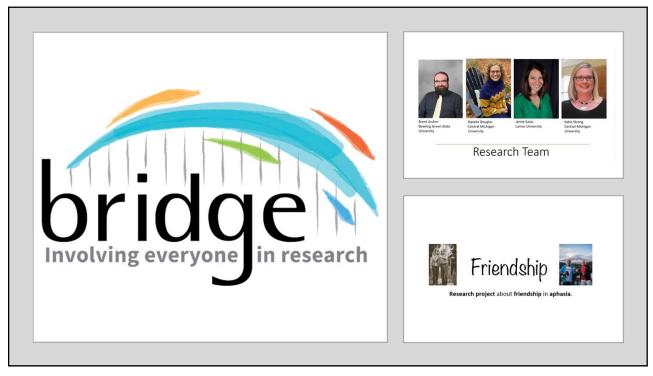
United Kingdom

- SOFIA Project led by Dr. Sarah Northcott Solution Focused Brief Therapy
- https://blogs.city.ac.uk/sofia/results/
- SUPERB Trial Dr. Katarina Hilari Adjustment with aphasia after stroke Peer befriending https://www.city.ac.uk/news-and-events/news/2021/03/peer-befriending-may-help-people-with-aphasia

Australia

- Aphasia ASK Project led by Dr. Brooke Ryan
- https://www.latrobe.edu.au/research/centres/health/aphasia/research/optimising

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We feel there is a gap in services in Michigan for people with aphasia accessing mental health services.

What can we do about this?

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Starts with today's conversation

- Building a team
- Project BRIDGE stakeholders
 - People with aphasia
 - Care partners
 - Speech-language pathologists
 - Mental health providers
 - Primary care physicians
 - Researchers
- www.projectbridge.online



If you are interested in continuing the conversation

- We're starting a team to address the gap of mental health services for people with aphasia in Michigan.
- Contact Katie and Becca ston4ka@cmich.edu

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SURVEY ACCESS AND SUPPORT FOR PEOPLE WITH APHASIA IN MICHIGAN



- •What do aphasia services look like in Michigan across the continuum of care?
- How does a person with aphasia navigate transitions between different venues of care?

(Simmons-Mackie, 2018, *Aphasia in North* America, p. 20)

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National Aphasia Association Michigan Affiliates/2019

National Aphasia Association Nitrod Front National Total Association Nitrod Front Indian Mariette (ALCHIDAN) Indian Mariette (ALCHIDAN)

22 total listings

- 6 emails undeliverable
 - 2 no responses
 - 2 people listed twice
- 1 person mentioned PPA
- 2 required multiple phone calls to reach the correct person

• 13 cities: Alma, Ann Arbor, Bay City, Brownstone, East Lansing, Grand Rapids, Harrison Township, Mt. Pleasant, Kalamazoo, Royal Oak, Sterling Heights, W. Bloomfield, Wyoming

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Activity One

Introduce yourself

What services or activities are available for people with aphasia and their families in your facility, community, or university?

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WHAT RESOURCES CAN SUPPORT

PROGRAM PLANNING?

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Some resources for planning services for people living with aphasia

- Needs assessment
 - Surveys
 - Interviews / Focus Groups
 - Products
- Professional Aphasia Associations
- Aphasia Support Groups
- Networks of aphasia services (state-level models)
- Research

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Needs Assessment: Survey examples

Survey SLPs about their community aphasia groups

Rose M. & Attard M. C. (2015). Practices and challenges in community aphasia groups in Australia: Results of a national survey. *International Journal of Speech-Language Pathology,* 17, 241–251. Survey is linked here. <u>iasl_a_1010582_sm2282.zip</u>

Do you currently offer community aphasia group services for people with aphasia?

IF YOU ANSWERED "NO", COULD YOU TELL US WHY YOU DO NOT PROVIDE THIS SERVICE? Providing detail

IF YOU ANSWERED 'NO', COULD YOU TELL US WHY YOU DO NOT PROVIDE THIS SERVICE? Providing detail will help us understand some of the possible challenges/restrictions you may be facing, and the nature of your services. After you provide your answer there are no further questions for you in this survey. Thank you for your vital contribution.

Needs Assessment: Interviews and Focus Groups

Ask all stakeholders about issues personal to them

Morris, K., Ferguson, A., & Worrall, L. (2014) A qualitative study of legal and social justice needs for people with aphasia, International Journal of Speech-Language Pathology, 16(6), 541-551. DOI: 10.3109/17549507.2013.855260

Health and financial and consumer situations were most frequently identified in the data. Additionally, there were a number of situations found specifically relating to people with aphasia involving their signatures and credit card use. Instances of discrimination and abuse were also identified, and, although infrequent, these issues point to the profound impact of aphasia on the ability to complain and, hence, to ensure rights to care are upheld.

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Needs Assessment: Communication

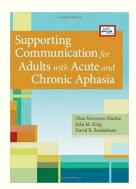
WHAT WOULD YOU LIKE TO TALK ABOUT DURING CONVERSATIONS?

List:

- Funny stories about your children
- Your adventures as a young child/growing up
- Dating and getting married
- Being in the military Your worst jobs
- Your most important job/career
- □ Moving or traveling
- Hobbies or unique interests
- □ Family history/ancestry/genealogy
- Local events Current events
- Sports
- □ Politics/the economy/the government
- □ Weather
- □ Favorite meals/restaurants
- □ My house/home town/things to fix
- My stroke and/or other medical issues

APHASIA NEEDS ASSESSMENT

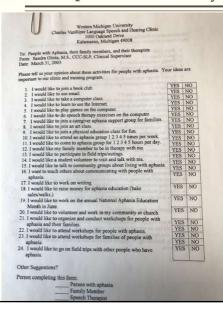
(©) 1997, revised 2006, Garrett, K & Beukelman, D.



Simmons-Mackie, N., King, J., Beukelman, D. (2013). Supporting Communication for Adults with Acute and Chronic Aphasia. Baltimore: MD: Paul H. Brookes.

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Example: WMU ACE Program needs assessment for people with aphasia and family members (Glista & Pollens, 2003)



- Most preferred activity: Field Trips and outings with people with aphasia
- Attend an aphasia group, twice a week, for 2 hours each day.
- Physical education class
- Student volunteers visiting
- Working on writing skills
- Fund-raising for aphasia education
- Attending workshops for people with aphasia

*Implemented

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Needs Assessment: Focus Group

Aphasia Communication Enhancement (ACE) Program WMU 2019

What else could be helpful for people with aphasia in Michigan?

Family Members (TPO 9 months to 17 years); 6

counties

- Educate other Professionals about Aphasia: eye doctor, bank, police, PT, OT
- "I certainly wish more restaurants had picture menus"
- Inform others about this type of program (ACE)
- Learn about durable power of attorney, etc.

The Seven Habits of Highly Effective Aphasia Therapists as reported by people living aphasia

- Prioritize relationships
- · Begin with the end in mind,
- Look behind the mask

Give them a voice

Worrall, L. (2019) The seven habits of highly effective aphasia therapists: The perspective of people living with aphasia. *International Journal of Speech-Language Pathology, 21*(5), p. 445

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"OUTCOMES"

https://pubmed.ncbi.nlm.nih.gov/30303810/

A core outcome set for aphasia treatment research:

The ROMA consensus statement

In addition to Language

"Satisfaction and Impact of Treatment"

Devanga, S. R., Pollens, R., Koss-Ryan, M., Nagler, E., & Ruffini, C, (2022). Measuring patient-reported satisfaction/impact of treatment and care-partners' perceptions of a university aphasia clinic (will present at IARC in June).

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Goal operationalized: Aphasia Education and Advocacy Team Trained all 200 Ingham County Sheriff's Employees in 2021





Resources: Participation Needs Assessment

L!V Cards







Assessment for Living with Aphasia







Talking Mats



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Resources: Beginning a Support Group



American Stroke Association.

A division of the American Heart Association.



Opening the door to a brighter tomorrow

Home

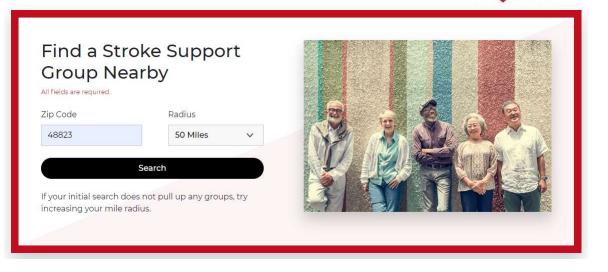
- ASA Successful Stroke Support Groups
- Support Group Leader Resources
- ASA Register your Stroke Support Group
- Groups that work. Stroke Comeback Center

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https://www.stroke.org/en/stroke-support-group-finder



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Resources: Conducting telepractice groups

SIG 18 Telepractice

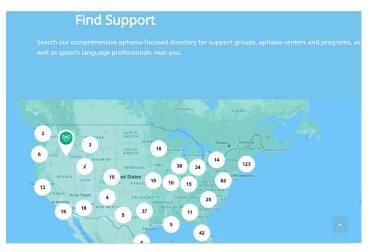
Detailed report of small telepractice aphasia group including group plan, management, and outcome data.

Walker, J., Price, K., & Watson, J. (2018). Promoting Social Connections in a Synchronous Telepractice, Aphasia Communication Group. *Perspectives* (January) , American Speech-Language-Hearing Association. https://doi.org/10.1044/persp3.SIG18.32

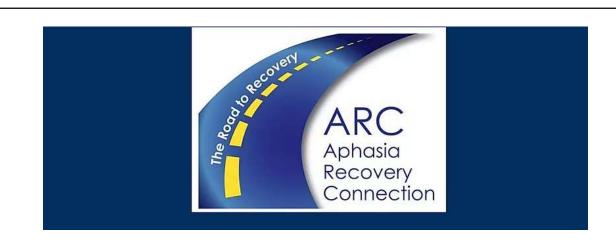
Aphasia Support Groups



- www.aphasia.org
- Support Group Finder
- Also a place where existing groups can register their group for others to fine.
- Professionals can become affiliates and list information about their services



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Online Aphasia Communities

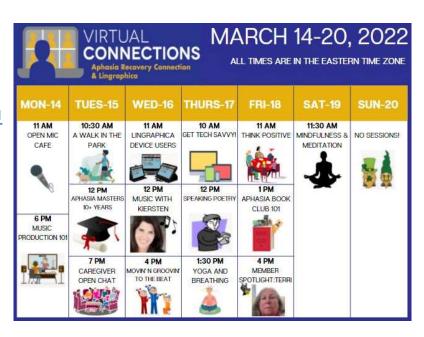
https://www.aphasiarecoveryconnection.org/

- 10,000+ members in ARC
- 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



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Weekly offerings
https://www.apha
sia.com/virtual-connections-info/



Resources: Professional Associations



Resources for planning and program development



Aphasia Group Activities

View Samples and Log In





Road map link

Anhasia Conversat



Aphasia Conversations Podcasts



Listen and Learn

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Resources: Networks of Aphasia Services (State-level models)



Triangle Aphasia Project

North Carolina

Hub & Spoke model



Minnesota Connect Aphasia Now

https://mncan.org/

& Julia Halvorson podcast

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Resources: Aphasia and PPA Treatment Research at Western Michigan University

Neurogenic Communication Intervention Lab

- Bridging the clinical-functional gap in managing acquired neurogenic communication disorders
- Research on interventions that help individuals with aphasia and other neurogenic communication disorders to communicate in everyday life.
- ACE Program is analyzing outcome measures for university-based aphasia services.



Individuals and families with aphasia, TBI or PPA may contact Suma Devanga, PhD <u>suma.devanga@wmich.edu</u>

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Resources: University of Michigan Aphasia Program (UMAP)

Intensive Comprehensive Aphasia Program (ICAP)

- Providing intensive therapy, focusing on reengagement in life and care partner programming for families living with aphasia.
- Bonding & peer support are a huge benefit of participating in an ICAP
- Interdisciplinary team approach (SLPs, Neuropsychologist, Social Worker-led groups)





More information at www.AphasiaHelp.com or call (734) 764 8440

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Resources: UMAP



Hells, the person seeking services has a part of the person seeking services and person seeking services are personal services.

Please review the information below-before provision of services.

Name of person with application (PVA)

Will there be exceed a similar services below the personal services.

Has the PPAN necessary physical deficits the major impact services? TES NO Does the PPAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that may impact services? TES NO Does the PVAN have any prisend deficit that the prisend deficit that the prisend of the pvan deficit that the prisend deficit that the pvan prisend deficit that the prisend deficit that the pvan prisend deficit that the pvan deficit that th

Aphasia FAQ for Health Services

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https://mari.umich.edu/wp-content/uploads/UMAP-Resources-Aphasia-Community-and-Treatment-Referrals.pdf

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Resources: Aphasia & TBI Research at Central Michigan University

Strong Story Lab

- Aim 1: Explore storytelling methods to create tools for clinicians to use with people who have aphasia & TBI in reconstructing their identity and moving forward with a successful life.
- Aim 2: Create a community to support students in engaging in research centered around LPAA, qualitative research methods, narrative co-construction, and identity.
- Recent projects Photovoice- using photos to express what life is like living with aphasia
- Currently running
 Aphasia This is Our World
 Storytelling, to Support Identity with Virtual Connections
- Contact: Katie Strong, Ph.D., CCC-SLP stron4ka@cmich.edu



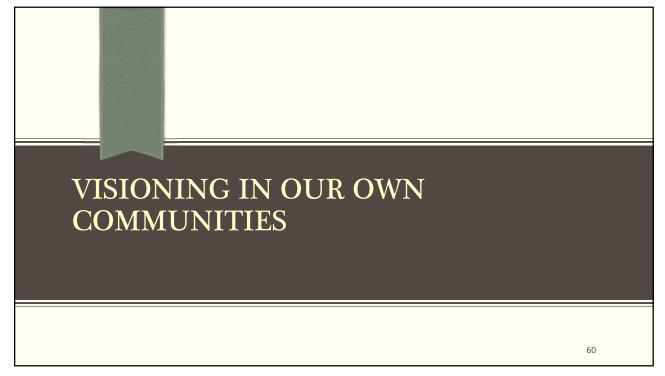






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Activity Two Visioning in our own communities

- 1. Where are the **gaps** in service delivery for people with aphasia in your community?
- 2. What are your ideas for your community/facility?
- 3. What is **one small change** you can make to service delivery in your community?

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VISIONING FOR OUR STATE

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Activity Three Let's Talk Visioning in Our State

Call to Action, Simmons-Mackie, 2018



- 1. Improve services for people with aphasia (including attention to depression).
- 2. Improve services for family members or caregivers.
- 3. Improve communication access in health care and in the community.
- 4. Connect across organizations to identify best available resources for aphasia.

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Live Google Document for transcribers?? Say out loud/discussion?

- Improve services for people with aphasia (including attention to depression).
- Improve services for family members or caregivers.
- Connect across organizations to identify best available resources for aphasia.
- Improve communication access in health care and in the community.
- OTHER!

References

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