

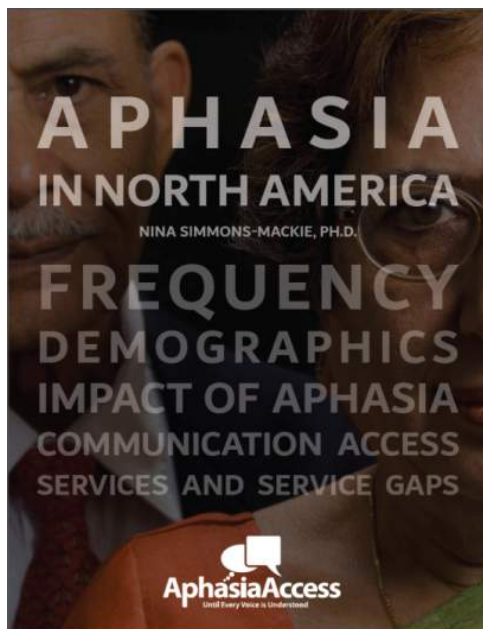
The State of Aphasia: What Next?

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Aphasia in North America: A Call to Action



- The “State of Aphasia” report was published in 2018 as an advocacy tool and resource
- It provides 125 pages of data on key advocacy topics and over 600 references
- But, the report is not the ‘end’ goal
- The goal is to address critical recommendations and move the field of aphasia forward



The State of Aphasia: Moving from Data to Recommendations



The Plan

To begin the process of addressing recommendations

- I will review each of 10 key topics & recommendations
- You jot down ideas & suggestions
- Each table discusses “assigned” recommendation
- Representative from each table presents summary of their discussion

Frequency of Aphasia



**When you
report *frequency
of aphasia*, what
statistics do you
use?**

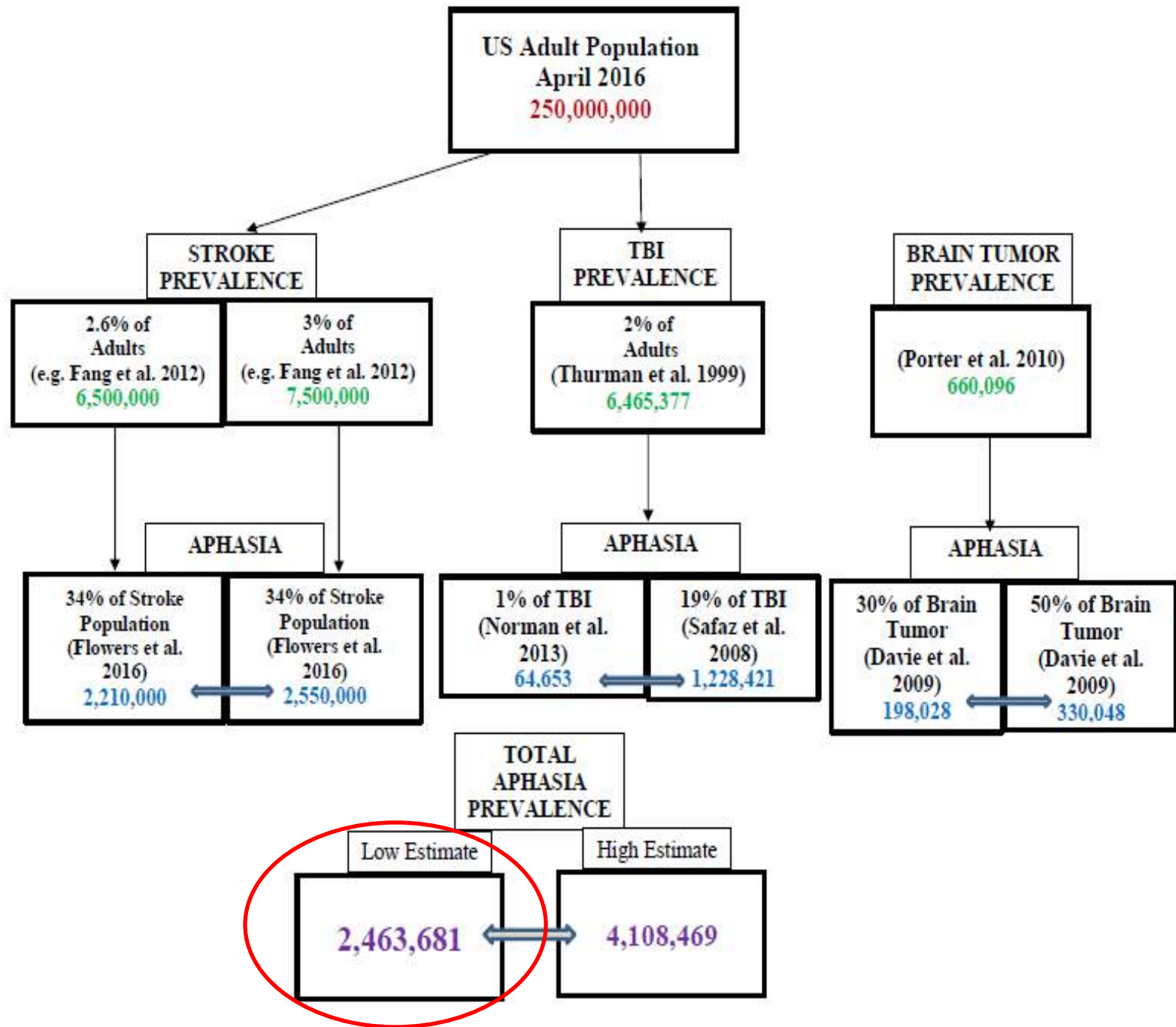


Frequency of Aphasia

- **The NIDCD reports on their website that “about 1 million people in the United States currently have aphasia” (estimates extrapolated from stroke data)**
- **ASHA cites the 1 million prevalence estimate of the NIDCD**
- **The National Aphasia Association website uses 2 million as a prevalence estimate (no data source cited)**
- **The American Stroke Association gives no frequency statistics for aphasia**

Frequency of Aphasia

- Aphasia Access has reported (for over a year) a *conservative* estimate of approximately 2.5 million people living with aphasia in the United States
- References and extrapolations are presented in the “State of Aphasia” publication
- These data were checked by an epidemiologist as suitable “estimates”



Frequency of Aphasia

- **Why are critical organizations NOT using updated estimates of prevalence?**



More About Frequency



Example of “Research” Sources: % of Aphasia in Stroke

	Medical Diagnosis	Setting	Time Post onset	Sample Size	Assessment	Reference
24%	Ischemic Stroke	Follow-up	3 months post onset	7219	Screening with NIHSS*	Ali et al. 2015
26%	Ischemic Stroke	Follow-up	3 months post onset	106	Western Aphasia Battery	Kauhanen et al. 1999
28%	Stroke	Acute hospital	Acute	8848	Physician	Bersano et al. 2009
29%	Ischemic Stroke	Rehab.	Within first month of stroke	80	SLP clinical assessment	Kong et al. 2000
30%	Stroke	Acute stroke unit	Admission	3207	Varied	Dickey et al. 2010
30%	1 st Ischemic Stroke	Hospital, rehab., physician report	Varied	269	Varied	Engelter et al. 2006
30%	Ischemic Stroke	Stroke Center	Acute	221	Varied	Flowers et al. 2013
35%	Stroke	Acute stroke unit	Discharge	3207	Varied	Dickey et al. 2010
24%	Ischemic Stroke	Hospital	Admission	2983	Physician or nurse assessment	Guyomard et al. 2009
42%	Ischemic Stroke	Hospital	Acute	177	Boston Diagnostic Aphasia Exam	Kadovic et al. 2012
42%	Stroke	Hospital admission	Chronic	141	Western Aphasia Battery	Paolucci et al. 2001
45%	Ischemic Stroke	Hospital	Early post stroke	8904	Screening with NIHSS*	Ali et al. 2015
50%	Stroke	Rehab.	Chronic	262	Screening / Aachen Aph. Test	Gialanella et al. 2011
Median 30%	Stroke	Hospital	Acute	Meta-analysis of articles	Varied	Flowers et al. 2016
Median 34%	Stroke	Rehab & Community	Chronic	Meta-analysis of articles	Varied	Flowers et al. 2016

*NIHSS = National Institutes of Health Stroke Scale (<http://www.nihstrokescale.org/>)

Frequency of Aphasia in Stroke

- **Range = 24% to 50% of stroke survivors presented with aphasia**
- **More recent studies**
 - 14% (Ellis et al. 2018)
 - 42% (Mitchell et al. 2018)

Frequency of Aphasia in Stroke

- Reason for wide range across studies
 - Samples vary in:
 - time post onset
 - stroke type
 - sample size
 - setting (e.g. hospital admission, acute, rehab.)
 - sources (e.g. Medicare stats, chart reviews)
 - Assessments vary from crude screenings to full evaluations
 - Studies derive from different countries



What percentage do we use to validly reflect frequency of aphasia among stroke survivors?



Frequency of Aphasia

- **Another issue: aphasia prevalence data are restricted to people who have had a stroke**
- **Extrapolated data do not address other etiologies of aphasia**

Such as:

- **Focal Brain Tumor**
- **Focal Traumatic Brain Injury**
- **By estimating aphasia frequencies associated with other etiologies the overall prevalence increases markedly**



**And This is
Important
Because???**

Frequency of Aphasia

- Most aphasia stats around the world that draw only from *stroke data* create an underestimate!
- Use of different statistics by different people or organizations creates confusion
- Funders and policy makers often look at prevalence and incidence to guide funding and resource needs
- Limited attention to aphasia in other etiologies means that frequency, outcomes & interventions for these etiologies are largely ignored

CALL TO ACTION

Recommendation #1

Address discrepancies in reported frequency of aphasia!

- How can we coordinate the data reported across organizations (e.g. NAA, NIDCD, ASHA)
- Is there a way to collect valid data on aphasia more systematically within and across countries?
- How do we systematically collect data on various etiologies of aphasia?

Awareness of Aphasia



Surveying the Public re. Awareness

- 20 public surveys on aphasia awareness and knowledge have been published
- Awareness is defined as “having heard the word” aphasia
- Knowledge: know something such as “it is due to a stroke” or “it is a language disorder”
 - very low standard to be considered to have “basic knowledge”

Surveying the Public Regarding Awareness

- **New Zealand (McCann et al., 2013)**
 - 11% awareness of aphasia
 - 1.5% basic knowledge of aphasia
- **Ontario, Canada (Patterson et al., 2015)**
 - 32% awareness of aphasia
 - 5.7% basic knowledge of aphasia
- **The Balkan States (Vukovic et al., 2017)**
 - 24.8% awareness of aphasia
 - 4.8% basic knowledge of aphasia
- **England (Code et al. 2002)**
 - 13.7% awareness of aphasia
 - 5.1% basic knowledge of aphasia

Surveying the Public re. Awareness

2002 public survey in USA (Simmons-Mackie et al.)

- 13.6% awareness of aphasia
- 5.4% basic knowledge of aphasia

14 years later!!!

2016 public survey in USA (NAA)

- 15.5% awareness of aphasia
- 8.8% basic knowledge of aphasia

Surveying the Public re. Awareness

2002 public survey in England (Code et al.)

- 13.7% awareness of aphasia
- 5.1% basic knowledge of aphasia

16 Years Later!!!

2018 public survey in England (Hill et al.)

- 34% awareness of aphasia
- 5% basic knowledge of aphasia

Awareness of Aphasia

- In England there were increases in “awareness”
- **BUT, simply having heard the word aphasia is not sufficient!**
 - “It’s the same as Alzheimer’s”
 - “Aphasia is a skin disorder”
 - “Some sort of mystical creature”
 - “A form of pre-leukemia”
 - “Would that be a half a facial?”

Aphasia Awareness

Does it matter?



Impact of Aphasia Awareness

Lack of public & political knowledge of a disorder or disability has major consequences -

- Influences the level of financial support for services and research (Bojorquez, 1998; Simmons-Mackie et al. 2002)
- Associated with inappropriate referral for services and inadequate management (NAMI, 1995)
- Reduces public acceptance of people with aphasia (Elman et al. 2000)
- Impacts social relationships and reintegration into the community and workplace (Elman et al. 2000)
- Reduces access to community, health care and government services
- Inhibits access to information and resources by people living with aphasia (Hinckley et al. 2013)

Surveying the Public re. Awareness



Enough already!!!

We have demonstrated repeatedly that the public is not knowledgeable about aphasia
AND that awareness is important....

Let's DO SOMETHING!!!

CALL TO ACTION

Recommendation #2

Improve public awareness and knowledge of aphasia

- Requires a systematic and collaborative inter-organizational strategy
- Requires understanding of what ‘catches the attention’ of the public

Funding for Aphasia Services



World Health Organization Mandate

“Parties [governments] should undertake to ensure people with disabilities are able to access health-related rehabilitation ...to enable ... full inclusion and participation in all aspects of life” (WHO, 2013)



International Best Practice Guidelines

- **People with aphasia should be offered intensive individualized aphasia therapy designed to have a meaningful impact on communication and life**
- **People with aphasia benefit from intervention in both acute and chronic phases of recovery**
 - www.aphasiaunited.org

Funding

- “Health Financing” is one of 6 building blocks of the WHO (2011) “framework for action” to improve health services
- However, “stroke rehabilitation remains underfunded relative to the scope of the challenge in Western societies” (Conroy et al. 2009)
- This problem is magnified when we consider the impact of communication disability on the lives of people with aphasia and family members

- **42% of stroke patients were not referred for rehabilitation after acute care (compared to an earlier non-referral rate of 31%) (Winstein et al., 2016; Gage et al., 2009)**
- **Only 32% of Medicare funded stroke patients were referred to home health services (Mozaffarian et al. 2016)**
- **Only 31% of stroke survivors were referred for outpatient rehabilitation - much lower than expected (Roger et al. 2011)**
- **In the Veterans Administration system only 30% of people with aphasia received speech pathology services (Winans-Mitrik et al. 2014)**
- **Even after referral, most funding sources in developed countries limit the duration of therapy and number of sessions**

Insufficient Funding

- **Lengths of stay in acute hospital are short**
 - USA Median length of stay for ischemic stroke = 4 days (Winstein et al. 2016)
 - Canada median length of stay for stroke = 7 days (Canadian Stroke Network, 2011)
- **Aphasia is often not the priority during acute care and even into rehabilitation stays**

What happens in the hospital?

- **Swallowing takes precedence in acute settings**
 - 77% of assessments are for swallowing
 - 24% are for language (ASHA, 2016)
- **Dysphagia was the main caseload for**
 - 89% of clinicians in acute settings
 - 78% of clinicians in residential settings (Rose et al., 2014)

What happens over the longer term?

- Aphasia is considered a chronic condition with ongoing needs over the long term
- There is substantial evidence supporting therapy for chronic aphasia (Allen et al. 2012)
- A study investigating long term community services, found that gains in meaningful activity for people with stroke took \geq *one year* to achieve (Mayo et al. 2015)
- However, there is minimal funding for services in chronic aphasia
- Most funding is available during the first weeks or months after the onset of aphasia

What happens over the longer term?

- **Service delivery models for chronic aphasia?**
 - University clinics
 - Aphasia Centers
 - Intensive Comprehensive Aphasia Programs
- **Highly varied availability of these services**
- **Minimal increase in number of Aphasia Center survey responses from 2010 to 2016**
 - Although new centers had opened, several prior centers had closed; minimal net increase?
- **Funding & sustainability remain barriers for chronic delivery models**

- **Consequences of inadequate rehabilitation and long term support:**

- Increased medical incidents
- Hospital readmissions
- Higher levels of care
- Higher financial costs
- Increased distress for person with aphasia and family

CALL TO ACTION

Recommendation #3

Increase sustainable funding sources for aphasia services

- Is a Political Action Committee or similar a viable goal?
- Are there alternative funding sources that are sustainable?
- Should aphasia advocates work with other long term disability groups?
- Should services be reconfigured to give better care within funding constraints?

Services for Aphasia



Services for Aphasia

- **Multiple aphasia service domains need improvement**
- **Focusing on 2 critical areas related to health and life quality:**
 - Mood & depression
 - Participation in activities & life situations

Aphasia and Depression

I get very depressed, very emotional. It's hard – yeah I find that really hard.”

(Hudson et al. in preparation)



Do you address depression in your aphasia practice?



Aphasia and Depression

- **93% of stroke survivors with aphasia versus 50% of stroke survivors without aphasia experienced high psychological distress at 3 months post onset (Hilari, 2011; Hilari et al. 2010)**
- **65% to 70% of people with aphasia experienced depression at 3 months post onset (Hudson et al. in preparation; Kauhanen et al. 2000)**
- **Depression early post onset tends to persist at 6 months (Thomas & Lincoln, 2008)**
- **The frequency of MAJOR depression increased from 11% at 3 months to 33% at 12 months for people with aphasia (Kauhanen et al. 2000)**

Does Depression Matter?

- **Depression is associated with:**
 - Decreased quality of life (Jaracz et al. 2002)
 - Poorer overall health (Menefee, 2001; Sapolsky, 1998)
 - Lower functional outcomes (Donnellan et al. 2010)
 - Poorer physical and cognitive recovery (Morris et al. 1992)
 - Higher health care costs (Kutlubaev & Hackett, 2014)
 - Longer hospitalizations (Cushman et al. 1988)
 - Increased mortality (House et al. 2001)
- **Psychosocial factors such as mood were the highest predictors of living well with aphasia in the 1st year post onset (Worrall et al. 2017)**

Risk Factors

- **Depression and anxiety are significant risk factors for stroke** (Henderson et al., 2013; Lambiase et al., 2014; Pan et al., 2011)
 - Depression = 2-fold heightened odds of stroke (Jackson & Mishra, 2013)
 - Depression = 34% higher risk for development of subsequent stroke (Dong et al., 2012)

What's the Message?

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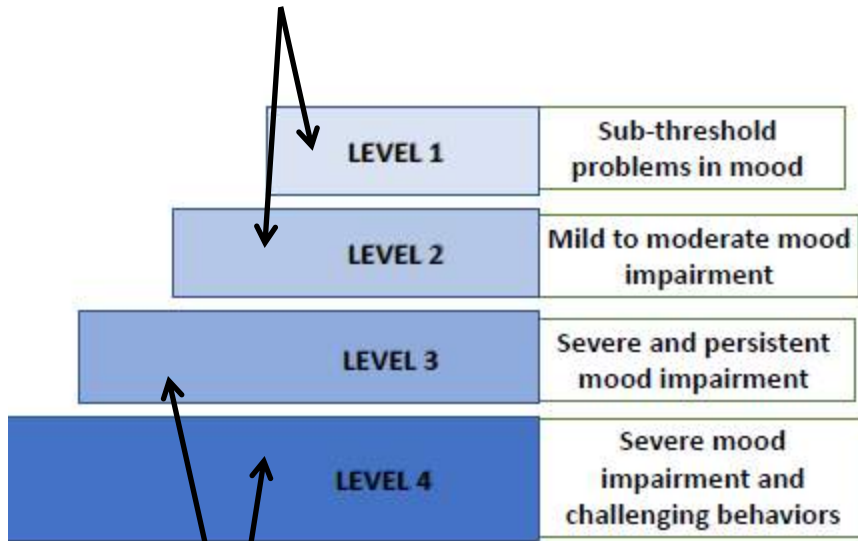


The Message

- **SLPs should be involved in identifying anxiety and depression in patients**
 - Screening and assessment tools are available (e.g. Stroke Aphasic Depression Questionnaire)
- **SLPs should address counseling needs at an appropriate level of a stepped care hierarchy**

Role of SLP in Mood Issues

Management of mood addressed in SLP services via a “stepped care model” (e.g. Baker et al. 2017; Kneebone, 2016)



Refer to mental health professional

Level 1

- Routine assessment of mood (e.g. SADQ, HADS, VAMS)
- Psychological information provision
- Psychosocial Support (e.g. aphasia groups. Support groups)
- Caregiver training (e.g. to learn communication support, enablement strategies)
- Participation & patient centered services in a community setting (Hoen et al. 1997; vanderGaag et al. 2005)
- Prevention strategies (e.g. Worrall et al. 2016 – ASK program)
- Counseling integrated into communication therapy (e.g. Holland & Nelson, 2013)

Levels 1 & 2

- Goal setting (shifting to a focus on the future; use of Goal Attainment Scaling for participation oriented goals to track progress e.g. Brock et al. 2009)
- Problem solving & Positive Psychology (e.g. identifying positive traits – to replace negative thinking e.g. Holland, 2007)
- Self-efficacy or self-management programs (e.g. Jones et al. 2009)
- Participation-based intervention (e.g. aphasia choir, Tamplin et al. 2013; theatre program, Cherney et al. 2011)

Level 2

- Modified Cognitive-Behavioral Therapy (e.g. Kneebone, 2016; Thomas et al. 2013 – delivered by an ‘assistant psychologist’ after training by SLP)
- Behavioral Activation (e.g. Kneebone, 2016 – supporting and time-tabling pleasant or enjoyable activities)
- Relaxation training (e.g. Golding et al. 2016; Kneebone et al. 2014)
- Biographic-narrative treatment (Corsten, et al. 2015)
- Aphasia group (e.g. Brumfitt & Sheeran, 1997)

Role of SLP in Mood Issues

- In other words we can target typical causes of depression in people with aphasia (these can be addressed by SLP & team)
 - social isolation & loneliness
 - lack of participation in meaningful activities
 - unskilled communication partners
- Create Interprofessional programs designed to prevent depression

Services for Aphasia



Mood & depression

Participation in Life

**How do you
include
participation in
aphasia
management?**



Impact on Participation

“Jean was very reluctant to leave the house, even to go on an outing with her husband. He felt she was frightened and expressed his own frustration at being cooped up” (Parr, 2007)

Impact on Participation

- **People with aphasia participate in fewer activities after onset**
 - Boden- Albala et al. 2005
 - Dalemans, 2010
 - Hilari et al. 2011
- **Pastimes tend to consist of sedentary and lonely activities (e.g. watching television)** (Winstein et al. 2016)

Does Participation Matter?

- **Participation in valued activities is associated with:**
 - Living well with aphasia (Brown et al. 2010, 2011, 2012; Grohn et al. 2012, 2014)
 - Higher quality of life (Dijkers et al. 2000; Eadie et al. 2006; Mayo et al. 2014; Robison et al. 2009)
 - Better overall health (Winstein et al. 2016)
- **Lack of meaningful participation is associated with depression** (Ahern & Hendryx, 2008; Angeleri et al. 1993)

Is Participation Assessed?

- **However, limited attention is given to participation outcomes (Canada et al. 2016)**
- **Assessments continue to emphasize language and impairment outcomes**
 - In a survey of top rehab facilities only 23% of SLPs report assessing participation outcomes
 - However no reported measures were participation-oriented (e.g. ratings of communication ability) (Simmons-Mackie, 2016)

Is Participation a Goal?

Three (3) studies of goals in aphasia management showed very minimal attention to participation

- **O'Brien (2014):** only 6% of goals across 41 patients with aphasia were considered related to participation.
- **Torrence et al. (2016):** only 8% of surveyed SLP goals referenced participation
- **Haley et al. (2017):** only 5% of over 1,000 goals “deposited” in an online goal bank were categorized as “Communication Participation”

Is Participation a Goal?

- **Treatments largely focus on impairment and basic “functional” activities** (Canada et al, 2016; Laliberte et al. 2016; Simmons-Mackie, 2016; Torrence et al. 2016)
- **A survey of SLPs in North America** (Simmons-Mackie, 2016)
 - 13% of inpatient treatment time involved participation-oriented intervention
 - 15% of outpatient treatment time involved participation-oriented intervention

Barriers to Addressing Participation

- Medical model culture of health care environment
- Lack of formal tests for participation outcomes
- Lack of treatment protocols or activities for this approach
- Difficulty getting ‘outside’ of the clinic to more authentic settings
- Funding limited to “medical necessity”
- Time limitations & productivity requirements

CALL TO ACTION

Recommendation #4

Implement improved services for people with aphasia including

- Management of mood & depression
- Attention to participation in life activities & situations

Social Relationships

**How do you
address
friendship in
your aphasia
practice?**



Impact on Social Relationships

“Ronald ...refused to attend social functions and withdrew from favored pursuits. Carol his wife described their lives as *barren and depressing*”



Impact on Social Relationships

Aphasia is associated with reduced social contacts and social networks

- Code, 2003
- Cruice, Worrall & Hickson, 2006
- Cruice, Worrall, Hickson & Murison, 2003
- Davidson et al. 2008
- Gialanella et al. 2011; Hilari & Northcott, 2006
- Vickers, 2010

Friendships

- **Loss of friends is a widespread consequence of aphasia**
 - Astrom et al. 1992
 - Brown et al. 2013
 - Ford et al. 2017
 - Hilari & Northcott, 2006
 - Lee et al. 2015
 - Parr et al. 1997
 - Northcott & Hilari, 2011
 - Northcott, Marshall & Hilari, 2016
- **People with aphasia are significantly lonelier than nonaphasic controls (Ross et al. 2008)**

Impact on Friendships

- **One study of 83 people with aphasia found** (Hilari & Northcott, 2006)
 - 64% had less contact with friends
 - 30% could not name a single close friend

Friendship Matters!

- **A higher frequency of contacts with friends and higher # of friends are related to:**
 - Better health (Van der Horst & Coffe, 2012)
 - Greater life satisfaction & well-being (Astrom et al. 1993)
 - Higher quality of life (Hilari & Northcott, 2006)
- **Over time having few friends or social contacts outside the house**
 - is associated with loneliness and social isolation (World Health Organization report, 2003)
 - is the strongest predictor of depression (Astrom et al. 1993)

Friendship Matters!

- **Social isolation and loneliness are associated with:**
 - Lower general well-being (WHO, 2003)
 - Higher incidence of physical illness (Alpass & Neville, 2003)
 - Higher rates of depression (Alpass & Neville, 2003; Astrom, Adolfsson & Asplund, 1993; Cacioppo et al. 2006)
 - Higher level of disability (Lund, Milsson & Aylund 2010)
 - Higher rates of premature death (Shiovitz & Avalon, 2010; Steptoe et al. 2013)
 - Greater cognitive decline (James et al. 2011)
 - Higher health care costs (Andersen & Newman, 2005)

- **Social isolation and loneliness increase the probability of disease or death by 200 to 500% (Ornish, 1998)**
- **Reduced social relationships is a risk factor similar to obesity or alcohol abuse and equivalent to smoking up to 15 cigarettes a day (Holt-Lundstad & Smith, 2012)**



The Message?

- **Management of aphasia should go beyond language impairment to assess & improve social engagement**



Solutions?

Directly target social relationships in aphasia management, such as:

- Reconfigure goals to include social engagement

Example of Reconfiguring Goals

“JB will write 5 sentences to describe pictures”

Versus

“JB will write an email to a friend, consisting of 5 sentences to describe photos of her birthday party”



Solutions?

- **Directly target social relationships in aphasia management:**
 - Buddy Systems (e.g. Jon Lyon's work)
 - Pair people with aphasia to accomplish a task or participate in an activity
 - Use coaching & aphasia therapy to make sure they have the communication skills required
 - Volunteer Mentors

Solutions?

- **Directly targeting social relationships in aphasia management**
 - Befriending programs
 - Re-CONNECT (<https://www.cscic.org/info/our-projects/re-connect/>)
 - Research: Supporting Wellbeing through Peer Befriending (SUPERB) (Hilari et al. at City Uni in London)

Solutions?

Directly target social relationships in aphasia management:

– Social Network Intervention

- Identify the person's existing social network
- Identify “potential” extensions to social network e.g. “former” friends
- Include the “friend” in dyad oriented communication partner training or buddy approach

Aphasia Groups

- Conversation group
- Computer or technology group
- Community connection group
- Writing group
- Book club
- Games group
- Art group
- Advocacy group
- Theatre or drama group
- Sports group
- Debate group



Solutions?

- **Use social media as the context for therapy**
 - Email for writing practice
 - Face time or Skype for speaking
 - Facebook or other social media
- Aphasia Recovery Connection www.aphasia-connect.org: uses videoconferencing to help people with aphasia meet and talk to each other

Solutions?

- **Drawing from the large literature on effective methods of addressing social isolation in the elderly** (e.g. Gardiner, Geldenhuys & Gott, 2018)
 - Social facilitation approaches
 - Leisure/skill development
 - Group psychological approaches
 - Animal interventions

CALL TO ACTION

Recommendation #5

**Develop & implement
services to prevent social
isolation in aphasia**

Family and Caregivers





What Family Services Do You Offer?

- Education & information provision?
- Counseling?
- Sign posting to other services?
- Communication Partner Training?
 - “Full on” evidence-based partner training program?
 - Listing “do’s and don’ts” or giving suggestions

Impact of Aphasia: The Family

“Edgar was so happy to be going home; the staff were all congratulating him. But I was terrified...all I could think was “Oh my God...what now?”

(Wife of man with aphasia)

Impact of Aphasia: The Family

- **Close family members experience changes in:**
 - Relationships (Denman, 1998; Michallet et al. 2001, 2003; Zemva, 1999)
 - Health & well-being (Grawburg et al. 2014; Natturland, 2010)
 - Employment (Salonen, 1995)
 - Roles & responsibilities (Christensen & Anderson, 1989; Denman, 1998)
 - Participation in social life (Herrmann et al. 1995)
 - Emotional well-being (Christensen & Anderson, 1989)
 - Marital satisfaction (Williams & Freer, 1986)

Impact of Aphasia: The Family

- **Changes in family member functioning is consistent with the concept of “third-party disability”**
(Grawburg et al. 2013; 2014)
- **Third-party disability is the negative functional impact of a person’s health condition on their family or caregivers**

Family Services

- **Best practice guidelines recommend that family members should be included at all stages of aphasia rehabilitation including:**
 - Receiving information
 - Having their own needs for support met
 - Getting trained to communicate with the person with aphasia
- **Families should be referred to resources such as respite, medical or counseling services**
- **Inclusion is NOT simply sitting in on therapy sessions**

(Hebert et al. 2015; Hilton et al. 2014; Simmons-Mackie et al. 2016; Winstein et al. 2016; www.aphasiapathway.com.au)

Do Families Get What They Need?

**Apparently
Not!**



Family Services

- **Family member services are limited** (Halle, Le Dorze & Mingant, 2014)
- **Across 41 patients with aphasia, only 3 out of 137 goals mentioned family** (O'Brien, 2014)
- **In interviews, SLPs rarely reported goals for family members** (Sherratt et al. 2011)
- **Resources and models for family specific services are extremely limited** (Levack et al. 2009)

Family Services

- **Rehabilitation services tend to focus almost exclusively on the person with aphasia (not the caregiver/family)** (Cameron et al. 2013; Halle & Le Dorze 2014; Howe et al. 2012)
 - Family education is typically “about” the person with aphasia
 - Families rarely receive services for their own needs

Family Services: Information Needs

Information needs of families are not being met

- Avent et al. 2005
- Denman, 1998
- Halle & LeDorze, 2014
- Halle, LeDorze & Mingant, 2014
- Hilton et al. 2014
- Le Dorze & Brassard 1995
- LeDorze & Signori, 2010
- Paul & Sanders 2010
- Smith et al., 2008
- Worrall et al. 2011

Family Services: Communication Partner Training

Family communication training needs are not being met

- Chang et al. 2018
- Elman, Cohen & Silverman, 2016
- Simmons-Mackie & Elman, 2014

The lack of communication training for family members is a substantial and astonishing gap in aphasia services

Family Services

- **SLPs report barriers to providing services to family such as:**
 - Rehab is about the person with aphasia
 - Insufficient time & resources
 - Funding is specific to the person with aphasia
 - Lack of family member “availability”
 - Not a “legitimate professional role”
 - Lack of training in relevant areas (e.g. communication partner training, counseling)

(Denman, 1998; Halle & Le Dorze 2014; Howe et al. 2012; Johansson, Carlsson & Sonnander, 2011; Law et al. 2010)

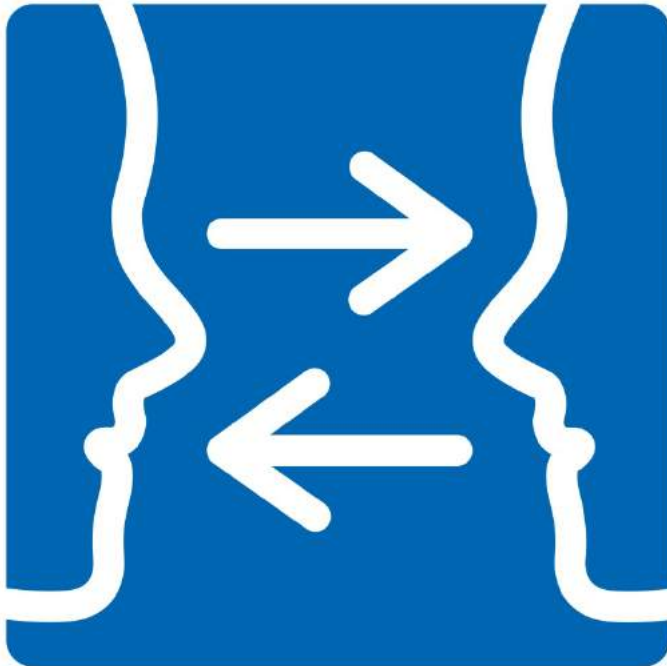
CALL TO ACTION

Recommendation #6

Improve services for family members & caregivers

- Are there creative ways to deliver these services (e.g. e-learning, groups)?
- Are there ways to collaborate with other professionals or team members to make sure families receive aphasia related services?
- How do we make sure family needs are met?

Communication Access



- **“Having the means, supports and opportunities to communicate effectively, meaningfully, accurately and authentically in order to get equal uncompromised access to goods and services” (Collier et al. 2012, p. 207)**
 - **Health care**
 - **Community**
 - **Government Services**
 - **Education**

Communication Access in Health Care

Successful patient-provider communication correlates positively with

- patient safety
- patient satisfaction
- positive health outcomes
- adherence to recommended treatment
- self-management of disease
- lower costs

- Blackstone, 2016



Communication Access in Health Care

- **There is ample evidence that communication can be improved by implementing relevant communication supports for people with aphasia** (e.g. Simmons-Mackie, King & Beukelman, 2013)
- **Projects have succeeded in integrating communication supports for aphasia into a variety of health care settings** (Jensen et al. 2015; Horton et al. 2016; Simmons-Mackie et al. 2007; Sorin-Peters, McGilton & Rochon 2010; McGilton et al. 2011)

Communication Access in Health Care

- **Other vulnerable populations also profit by communication support measures** (Bourgeois et al. 2004; Bourgeois, 2016; Burgio et al. 2001; Hoerster et al, 2001;)
 - 21% of the US Census respondents spoke a language other than English
 - Over 25 million people in the US have limited English proficiency
 - Over 5 million Americans are living with Alzheimer's disease
 - Almost 14 million Americans will have Alzheimer's by 2050
 - People with developmental disabilities may benefit from communication support
- **The number of people's lives that would be enhanced by implementing communication supports in health care and community is staggering**



However

- **People with communication disabilities report low levels of satisfaction with their health care** (Asplund et al, 2009; Hoffman et al. 2005)
- **People with aphasia and families report negative health care experiences, largely due to communication issues** (e.g. Hemsley et al. 2013; Simmons-Mackie et al. in preparation)

Communication Access in Health Care

“I know they meant well but I was completely overwhelmed. It was talk, talk, talk and I couldn’t make sense of it and I couldn’t ask questions”

(patient hospital experience, from Kagan, 2017)



Let's Dig Deeper into Communication Access



Communication in Health Care

- **Medical error is the 3rd leading cause of preventable death in the US**
- **50 to 70% of adverse hospital events are preventable**
- **60 to 70% of adverse events are attributable to poor communication**
- **Two thirds of studies examining fall risk identified communication disability as contributing to falls**
- **18.3 million medical visits would not be needed if good patient-provider communication occurred**

Communication Access in Health Care

In a US survey of “top rated” rehabilitation facilities (Simmons-Mackie, 2016):

- 85% had no written policy regarding patient-provider communication
- 85% did not include patient-provider communication in quality improvement programs or audits
- 62% reported no mandatory staff training in methods of communicating with people with communication disorders
- Approximately 50% reported no use of adapted or aphasia-friendly written materials

Communication Access in Health Care

What is the status of patient-provider communication in your health care system?



Aint it a shame!



Too marvelous for words!

Solutions?

- **Consider creative methods of integrating partner training into health care systems?**
- **Draw on the implementation literature to help change health care systems?**
- **Recruit other organizations to press for mandates?**
- **Create a national aphasia awareness campaign targeting communication access in health care?**
- **Etc.**



CALL TO ACTION

Recommendation #7

**Improve communication
access in health care and the
wider community**

The Big Picture: It's About Quality Care

**Monitoring the
quality of our
services**

???



Monitoring the Quality of Aphasia Services

- **Patients with stroke induced aphasia incur higher health care costs than those without aphasia** (Ellis et al. 2012; Kagan et al. 2018)
- **Outcomes for people with aphasia are poorer than outcomes for stroke without aphasia** (Flowers et al. 2016; Gialanella et al. 2011; Wade et al. 1986)
- **Aphasia is associated with higher rates of hospital readmission than stroke without aphasia** (Bersano et al. 2009)



Monitoring the Quality of Aphasia Services

- **People with communication disabilities are 6x more likely to have costly or adverse medical incidents** (e.g. Bartlett et al. 2008)
- **Poorly coordinated discharge plans resulted in 29% of patients being readmitted** (Nahab et al. 2012)
- **The list of consequences of inadequate care goes on and on.....**

Monitoring the Quality of Aphasia Services

- **Monitoring aphasia services could reduce consequences of inadequate care**
- **Promoting quality services can take a variety of forms such as:**
 - Management protocols
 - Conformance with Best Practice Guidelines
 - Discharge checklists
 - Audits

Monitoring Quality of Services

- Programs for continuous quality improvement (QI) are integral aspects of health care systems (WHO, 2014)
- This involves collecting targeted data to monitor care
- Online manuals describe the process of creating QI criteria
- However, communication disability is rarely considered in QI criteria

Monitoring the Quality of Aphasia Services

- *US Agency for Healthcare Research and Quality (AHRQ)* provide priorities for health care quality
- These should be applied as key elements of quality aphasia services

Priorities of the US Agency for Healthcare Research and Quality

- Priority 1: Making care safer by reducing harm caused in the delivery of care
- Priority 2: Ensuring that each person and family are engaged in care
- Priority 3: Promoting effective communication and care coordination
- Priority 5: Working with communities to promote wide use of best practices to enable healthy living
- Priority 6: Making quality care more affordable for individuals, families, employers, and governments by developing new healthcare delivery models

Monitoring Aphasia Services

- **What are the key indicators of quality care in aphasia?**
- **How can we apply current QI concepts**
 - Co-design of programs
 - Patient partnering in quality assessment
 - Stakeholder engagement
 - Auditing beyond #s of patients, #s of diagnoses, etc.
 - Outcome, Process and Content measures



CALL TO ACTION

Recommendation #8

Identify & implement mechanisms to track key features of aphasia services for QI

- Suggested audit criteria?
- Discharge checklists?
- Monitoring patient experience?
- Engaging stakeholders?



Research & Aphasia

Research Gaps Reported at 2015 Aphasia Access Summit

**Insufficient high quality research evidence regarding
the impact of:**

- Impairment treatment on participation
- Participation /socially oriented interventions across ICF domains
- Aphasia Centers across ICF domains
- Environmental modifications & support resources
- Interventions for psychosocial adjustment and mood



Progress to Date?

- **No high quality research publications addressing “big questions” re. life participation interventions**
- **Gaps from 2015 remain**
- **Why?**
 - Not enough time since 2015?
 - Complexity of the research questions /design?
 - Lack of researcher capacity in the gap areas?
 - Lack of sufficient or relevant outcome measures?
 - Lack of adequate funding sources for this type research?

Are major granting agencies addressing the gaps?



- **National Institutes of Health funding for aphasia research in 2018 = \$36,000,000** (compared to \$148 million for Cannabinoid research)
- **A perusal of 2017 funded projects suggested that 2 out of 98 projects had some relationship to participation, conversation or similar**

Moving The Research Agenda Forward

- **Are we clear on our research priorities?**
 - What are the key questions?
 - What do people with aphasia want?
- **Can we involve people with aphasia as research partners?** (resources available... Pearl, 2014; Pearl & Cruice, 2017)
- **Can we develop better North American collaborations, such as:**
 - Centers for Research Excellence in Aphasia in Australia
 - Collaboration of Aphasia Trialists in EU

CALL TO ACTION

Recommendation #9

Increase research to determine “what works” to ameliorate the impact of aphasia on life participation and QOL

Creating Change

- **Change will require a concerted effort across organizations and key stakeholders**
- **Funding and resources are limited**
- **We must come together and act now to transform the lives of people with aphasia**



BUT

- **Organizations tend to ‘go it alone’**
 - Fear of being overshadowed by partners
 - Fear of losing funding
 - Not enough time/people to develop partnerships
- **Organizations and stakeholders often don’t know what others are doing**
- **Many organizations waste time by duplicating efforts**

Solutions?

- **Create alliances across organizations**
 - Identify relevant organizations & individuals
 - Identify a process for creating alliances
 - **Capacity building**
 - Ensure that related organizations understand aphasia & needs of people living with aphasia
 - Ensure that missions and workings of allies are understood by all parties
- **Look beyond aphasia and stroke organizations**

CALL TO ACTION

Recommendation #10

Collaborate across organizations and systems to recruit “best available resources” for aphasia and other communication disabilities





Much to do!

Depressing?



NO

Opportunity!!



**Where to
from
here?**