Advancing inclusion and social justice in aphasia care: Three things you can do

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Why me? Why not me?

• Life in 3 countries; Multilingual, multiliterate experience (learning/losing/teaching languages).

• Perspectives as an international student, researcher, multilingual SLP, professor, and in leadership.
Clinical trails

Masonic Homes of California
Objectives

I hope that you will be able to think deeply about:

1. Health disparities and identify known disparities in stroke and aphasia

2. Concepts of health equity and social justice

3. Three (maybe more) things you can do to ensure no community is left behind in aphasia care
Demographic Perspectives
YOUNG CHILDREN AND OLDER PEOPLE AS A PERCENTAGE OF GLOBAL POPULATION

Figure 2

Distribution of U.S. Population by Race/Ethnicity, 2016 and 2050

2016
Total = 323.1M

- White: 60%
- Black: 13%
- Hispanic: 4%
- Asian: 6%
- Other: 4%

People of Color: 40%

2050
Total = 388.3M

- White: 46%
- Black: 14%
- Hispanic: 25%
- Asian: 8%
- Other: 7%

People of Color: 54%

NOTE: All racial groups are non-Hispanic. Other includes Native Hawaiians and Pacific Islanders, Native Americans/Alaska Natives, and individuals with two or more races. Data do not include residents of Puerto Rico, Guam, the U.S. Virgin Islands, or the Northern Mariana Islands.

• Older adults > 85 years are our fastest growing population segment. (PRB, 2018)

• Nearly 80% of the U.S. population lives in urban areas.

• Asians are the fastest growing ethnic group in the U.S.
  – Chinese
  – Filipino
  – Asian-Indian

• 14% of the US population lives in poverty; 6% in deep poverty (US Census Bureau, 2017)

• Shortage of qualified SLPs, even greater shortage of bilingual and bicultural SLPs. (ASHA, 2013)
Culture: Much more to it than meets the eye

Impossible to know everything about all cultures

Hall, 1976
Yet we can:

Better understand the layers of someone’s identity

Ask questions that unfold stories

Listen to these stories (the identities, biographical narratives therein)

Be leaders that facilitate change and transformation through these stories
Diversity is multidimensional

Dimensions of Diversity

Primary Dimensions
- Inborn difference
- Have an impact throughout one's life

Secondary Dimensions
- Education
- Religious Beliefs
- Military Experience

Person
- Gender
- Physical Ability
- Ethnicity
- Sexual Orientation
- Race

Work Background
- Geographic Location
- Income

Parental Status
- Marital Status

Acquired or changed throughout one's lifetime
Have less impact – still impact self definition
Health is freedom

• According to a liberation health perspective, health is freedom. Keeler, 2013

• By extension, access to health care also is freedom.

• Healthcare or Health services leadership then has to be an act of facilitating health, wellness and access to services.
What is a health disparity?

Differences in the health status of different groups of people

• A *preventable* difference in the burden of disease, injury, violence, or other opportunities to achieve optimal health that is experienced by a minority population.

  **CDC, 2015**

• Such health differences are often closely linked with social, economic and/or environmental disadvantage.

  [https://www.healthypeople.gov/2020](https://www.healthypeople.gov/2020)
UNEQUAL TREATMENT:
WHAT HEALTHCARE PROVIDERS NEED TO KNOW ABOUT RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE
What factors lead to health disparities?

• Common themes
  – Culture
  – Language (language barriers)
  – Health literacy
  – Geography (e.g., rural areas)
  – Socio-economics
  – Gender
  – Religion
  – Access to healthcare

• IOM, 2003: Bias, prejudice, and stereotyping by providers also contributes to these disparities.

• Consensus is that persistent health disparities are reflections of long-standing discrimination or exclusion.
Stroke-related disparities

• Higher rates of stroke occurrence in the “stroke belt”. Cushman et al., 2008; Howard, 1999

• Clear disparities in stroke incidence, prevalence and mortality in young- and middle aged African Americans (AA) below age 65. Kisella et al, 2004

• AA and Latinos: Significantly higher risk for hemorrhagic strokes than Whites. Wetmore et al., 2014

• AA had the highest mortality across stroke types for all ethnic minorities (incl. deaths among children). Stansbury et al., 2005

• Risk of stroke death among AA is 4 x higher than non-Hispanic Whites for ages 35-54, 3 x higher at 55-64yrs, 2x higher at 65-74 yrs. NINDS, 2002

• AA, AI/AN, and Hispanic persons: Pervasive prevalence of stroke risk factors including HTN, diabetes, ventricular hypertrophy and smoking history (for AA), and metabolic syndrome and diabetes for Latinos. Cruz-Flores et al., 2011
What works to reduce disparities

• Team-based care (e.g. Bell, Lopez, Mahendra et al., 2016; Hagge, Noureddine et al., 2018)

• Multifaceted programs (e.g., like Silverman’s TAP)

• Cultural targeting (e.g., Alzheimer’s Association)

• Assistance with patient navigation (e.g. Aphasia United Best Practice Recommendations for Aphasia)

• Interactive education (e.g. Hinckley’s workshops- I have aphasia – Now what?)

• Ethnographic research
Thinking about Health Equity

Attainment of the highest level of health for all people

https://www.healthypeople.gov/2020
Health Equity and Aphasia Care

• Are we designing a future with equitable access for all people with regard to:

  – Client recruitment
  – Community outreach
  – Reporting race/ethnicity and language data
  – Access to least-biased assessment techniques
  – Access to long-term aphasia rehabilitation
How do we serve these clients who are at a disadvantage?

NHS, Scotland - 2017
Equality

Equity

NW Health Unit, Canada
Thinking about language barriers that many clients face
**What is language?**

Language is more than just communication, it is the primary method by which we do things together.

Language is the accumulation of shared meaning - of common ground.

1. **Communication**
   - One-way communication. Message sent.

2. **Conversation**
   - Two-way communication. Both sides feel understood.

3. **Collaboration**
   - Thinking, planning, making decisions.

4. **Co-creation**
   - Joint activity, making, doing.
“If culture were a house, language is the key to the front door and to all the rooms inside.”
Bilingualism in the U.S.

20% (55.4 million) of all Americans speak a language other than English at home (US Census Bureau, 2010).

Over 51 million (18% of the population) know and use English fluently or are bilingual.

> 350 languages spoken in the United States.

Bilingualism: Typically not promoted or nurtured as a stable and enduring element of American society. Most fluent bilingual children become English-dominant or monolingual in English (Wong-Fillmore, 2000; Yu, 2016).
World Englishes
Kachru, 1992; Crystal, 2007

- Expanding circle
- Outer circle
  - Inner circle
    - eg USA, UK
  - eg India, Nigeria
  - eg China, Russia, Brazil

- < 0.5 billion
- > 0.5 billion
- > 1 billion
Issues for our Bilingual Clients

• Documented language attrition/loss/death of non-English languages.  
  Datta, 2012; Nickels, 2019; Sharma, 2006

• Lack of appreciation for what comes bundled with our clients’ language/s.

• Language mismatch between clinician and monolingual clients, LEP clients, or bilingual clients.

• Limited access to resources/information/materials and trained interpreters in many heritage languages.  
  Barr & Wanat, 2004; Chen, Youdelman & Brooks, 2007; Mahendra & Spicer, 2014

• Scant research on encounters of multilingual clients with SLPs and impressions of those encounters.  
  Mahendra, 2012; Mahendra & Spicer, 2014
Other Issues

- Limited consideration of benefits of therapy in non-English languages for children (Kay-Raining Bird et al., 2005; Yu, 2013; Yu, 2016) and for adults (Ansaldo & Saidi, 2014; Centeno, 2016; Kiran et al., 2013; Nickels, 2019).

- Limited avenues to provide therapy in non-English languages, and because this end result is not always possible, often clients do not receive assessments of speech/language/cognition in a preferred language.
Language rights intersect with core values of LPAA practitioners

Functional Communication

Identity

Narrative practice

Communicative access

Relationship-centered care

afasia  aphasia ἁφασία afázie aphasia afasi αφασία 失语症 حبسة كلامية बोली बंद होना
Social Justice and Advocacy

Social justice is the equal access to opportunity, privilege, and wealth in a society.
Advocacy is the intentional application of knowledge, skills and resources to effect systemic changes. 

*Dearth of health professionals competent in advocacy and policy development.*

Institute of Medicine, 2003
Tied to Cultural Competence

A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enable effective work in cross-cultural situations.

Taylor’s 5 stage model  

(Taylor, 2007; 4-stage model attributed to Robinson, 1974; Broadwell; 1969)
Design Thinking (DT): 5 phases

- Inspiration
- Define
- Ideate
- Prototype
- Test
what can ONE person do?
1. You first: Reflect on your personal and professional journey

- What’s your story?
- Have you shared your story?
- What are the layers of your identity?
- What biases lie hidden within you?

Bertsch & Beckendorf, 2018

Banaji & Greenwald, 2016
2. Commit to Cultural humility

(Tervalon & Murray-Garcia, 1998)

- Engage in lifelong inquiry and critical self-reflection
- Recognize and challenge power imbalances
- Create institutional accountability
- Create cultural safety for our clients
- You know about aphasia. Yet who knows about a community or a community-engaged method so you can provide more inclusive services?
4. Harness your superpower as an SLP and LPAA practitioner

• In the classroom
• In the clinic
• In research and advocacy
5. Reimagine curriculum

• Invest in a social justice foundation for students (and future providers)
• Incorporate content on health disparities into course on neurogenic communication disorders
• Expose students to service learning, international exchange, therapy abroad, advocacy assignments, and Design Thinking activities
• Advocate for increasing our linguistic capital as a profession
Show-n-tell from the teaching trenches

Dolan, Ramelb, Sugiarto, 2016

Angeles et al., 2016

Attiyeh et al., 2015
La afasia es un trastorno a consecuencia de un derrame cerebral o daño cerebral, y le afecta a la persona en su capacidad para expresar o entender lenguaje, incluso leer y escribir.

National Institutes of Health
(Institutos Nacionales de la Salud)

Nombre: 
Dirección: 

Tengo afasia

Mahendra, Hayes, Selepec, 2013
6. Let’s raise the bar in the clinic, every day, the LPAA way
7. Nurture heritage languages

• Minimally, let’s obtain a rich language and social history for every client.
• Consistently find out about client’s family history, their social networks.
• Learn about how they use/receive their languages (e.g. texting, What’s App, prayer circles, TV shows, radio)
• Transform the everyday clinic culture for how to do at least *some* assessment in a dominant non-English language
There are materials we can use....
Dual language materials
Technology and apps underutilized

BAT Android App - Free

MOCA Test App

Speech with Milo – Interactive Story Book

Pictello

Interactive Story Book App – In 5 languages

SPEAKABOO APP

http://www.speakabo.io
Access to interpreters
8. Examine research as an opportunity to promote equity

• Phenomenological research: Goal of such research is to describe ‘lived experience’ of a phenomenon
• Chance to ‘construct’ clinical knowledge that includes and is enriched by a client’s experience and meanings’ *(Greenfield & Jensen, 2010)*
• Engage in international research collaborations
• Interprofessional research with anthropologists, sociologists, linguists, disability studies, and ethnic studies experts
What are three things you can do, where you are, right now?
Thank you!

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