

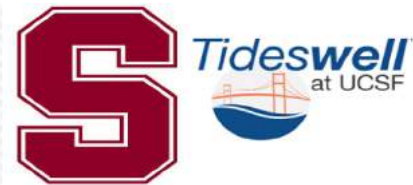


# Advancing inclusion and social justice in aphasia care: Three things you can do

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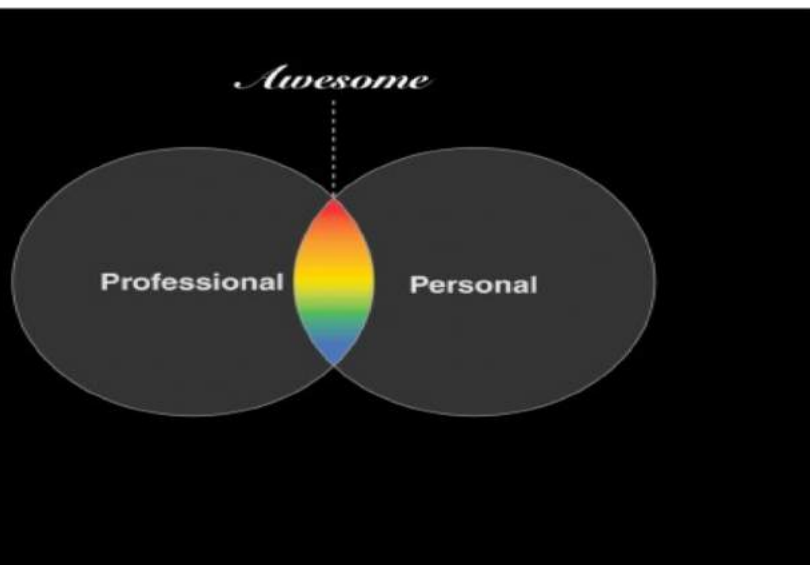
# Disclosures



- Reduced Registration as AA Invited Speaker
- Funding from CSU Chancellor's Office, ASHA, TCWF, El Camino Healthcare District, and the West Foundation
- Board/committee work on ASHA's SIG 14, MIB, ASHA Policy documents
- Non-financial relationship with apps Speakaboo and SmartAp

# 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**

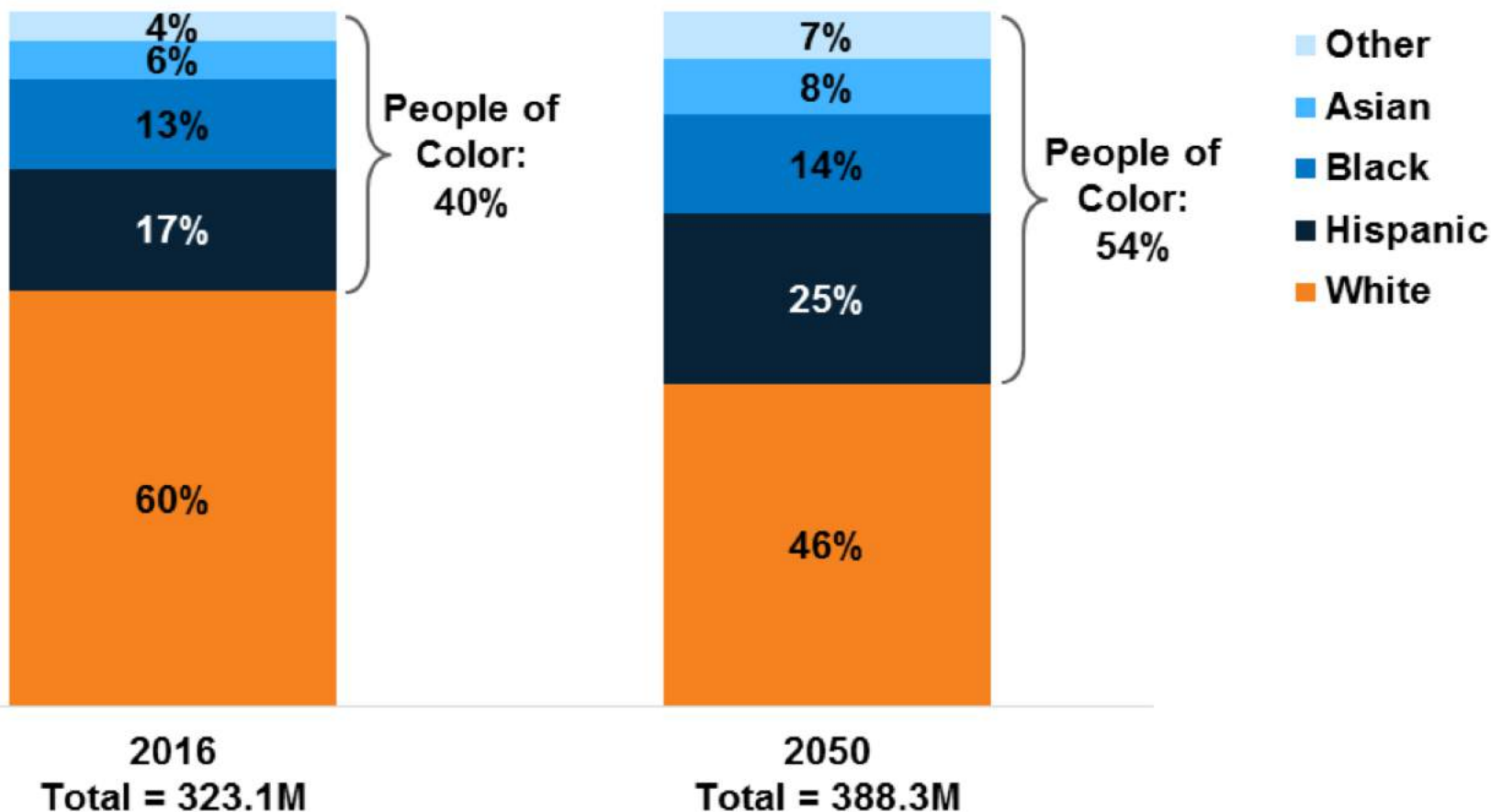
## YOUNG CHILDREN AND OLDER PEOPLE AS A PERCENTAGE OF GLOBAL POPULATION



Source: United Nations Department of Economic and Social Affairs, Population Division. *World Population Prospects. The 2004 Revision*. New York: United Nations, 2005.

Figure 2

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



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.

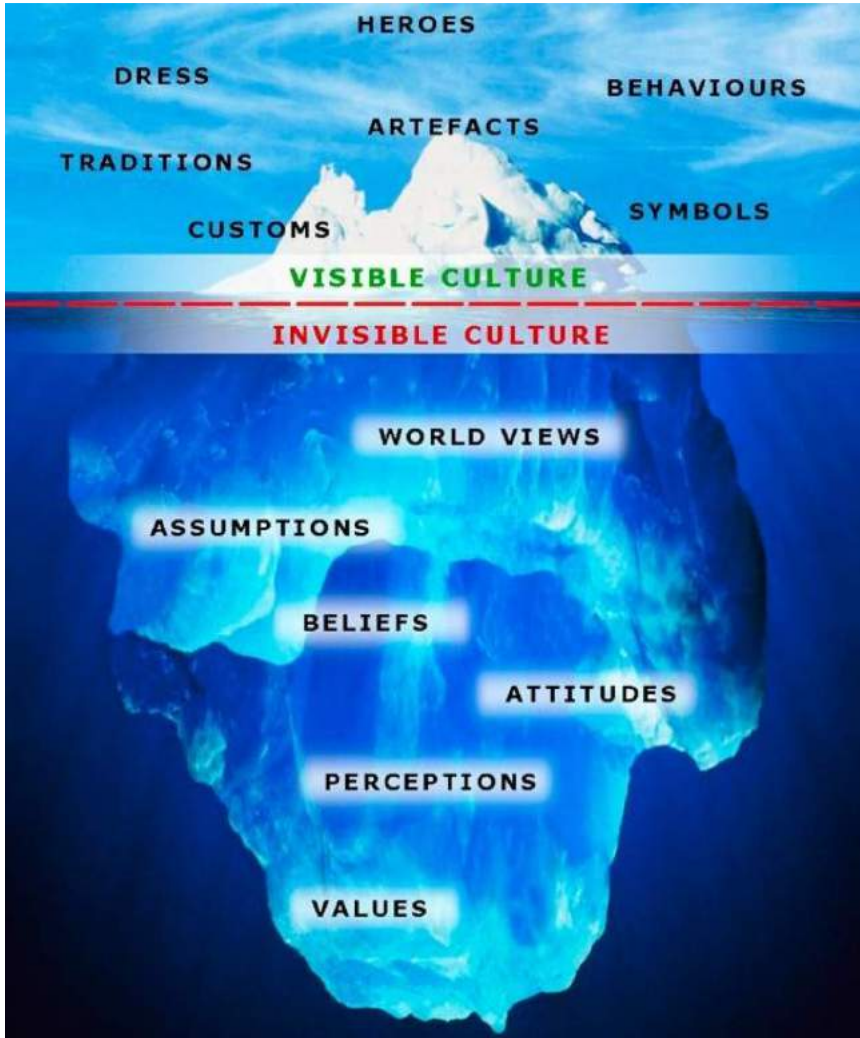
SOURCE: U.S. Census Bureau, 2017 National Population Projections, Projections of Race and Hispanic Origin, 2017-2060. Available at: <https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html>.



# Consider This

- 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)

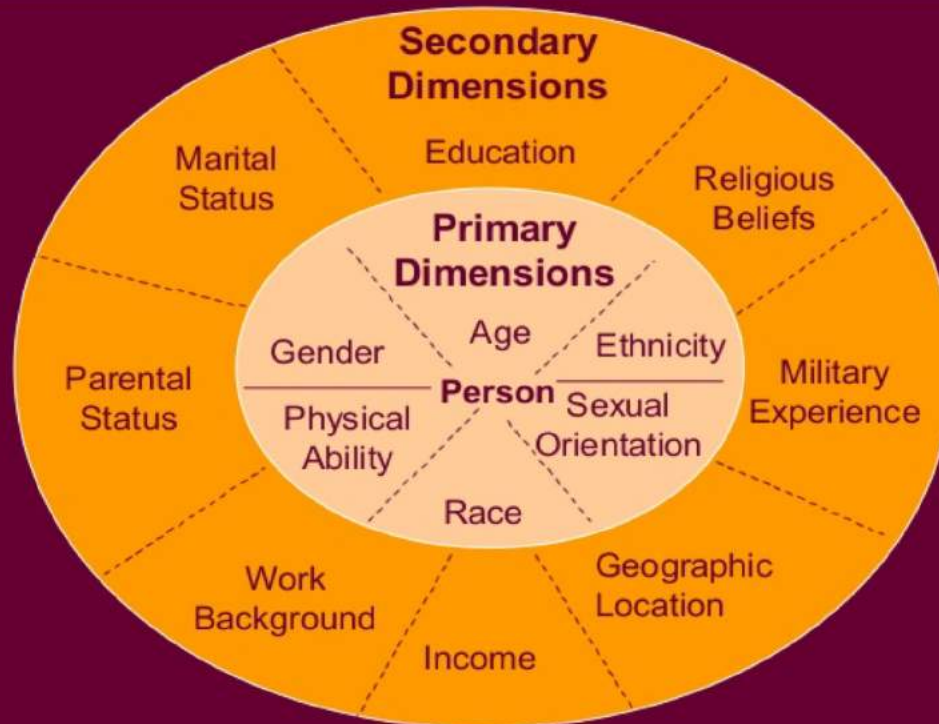
Be leaders that facilitate change and transformation through these stories

# Diversity is multidimensional

## Dimensions of Diversity

### Primary Dimensions

Inborn difference -  
Have an impact throughout one's life



### Secondary Dimensions

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>

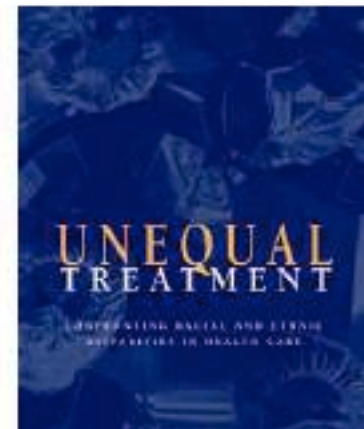


March 2002

# INSTITUTE OF MEDICINE

*Shaping the Future for Health*

**UNEQUAL TREATMENT:  
WHAT HEALTHCARE PROVIDERS NEED TO KNOW  
ABOUT RACIAL AND ETHNIC DISPARITIES IN HEALTH-  
CARE**



# What factors lead to health disparities?

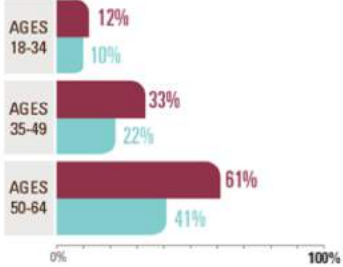
- Common themes
  - Culture
  - Language (language barriers)
  - Health literacy
  - Geography (e.g., rural areas)
  - Socio-economics
  - Gender
  - Religion
  - Access to healthcare
- [IOM, 2003](#): Bias, prejudice, and stereotyping by providers also contributes to these disparities.
- Consensus is that persistent health disparities are reflections of long-standing discrimination or exclusion.



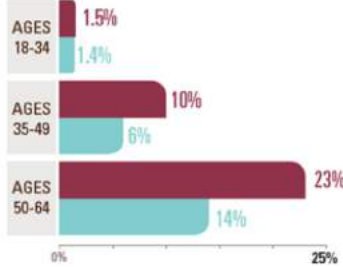
# Stroke-related disparities

- 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](#)

## High Blood Pressure



## Diabetes



## Stroke



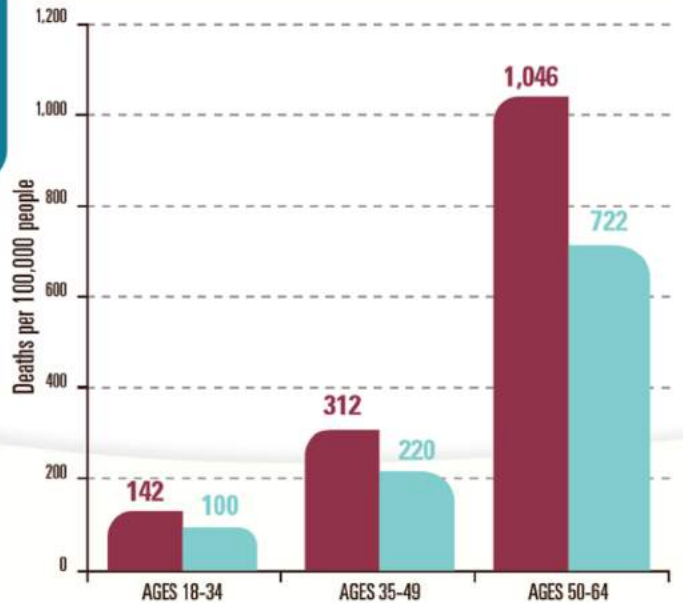
African American White

African Americans and whites include Hispanic and non-Hispanic origin.

SOURCE: Behavioral Risk Factor Surveillance System, 2015.

[www.cdc.gov/vitalsigns/aah\\_ealth](http://www.cdc.gov/vitalsigns/aah_ealth)

African Americans are more likely to die at early ages from all causes.



SOURCE: US Vital Statistics, 2015.

## Access to Speech-Language Pathology Services for African-American Clients with Aphasia: A Qualitative Study

2014

*Nidhi Mahendra*

Department of Communication Sciences and Disorders, California State University East Bay Hayward, CA

*Julianne Spicer*

Center for Student Research, California State University East Bay Hayward, CA

# What works to reduce disparities

- Team-based care (e.g. Bell, Lopez, Mahendra et al., 2016; Hagge, Nouredine 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>

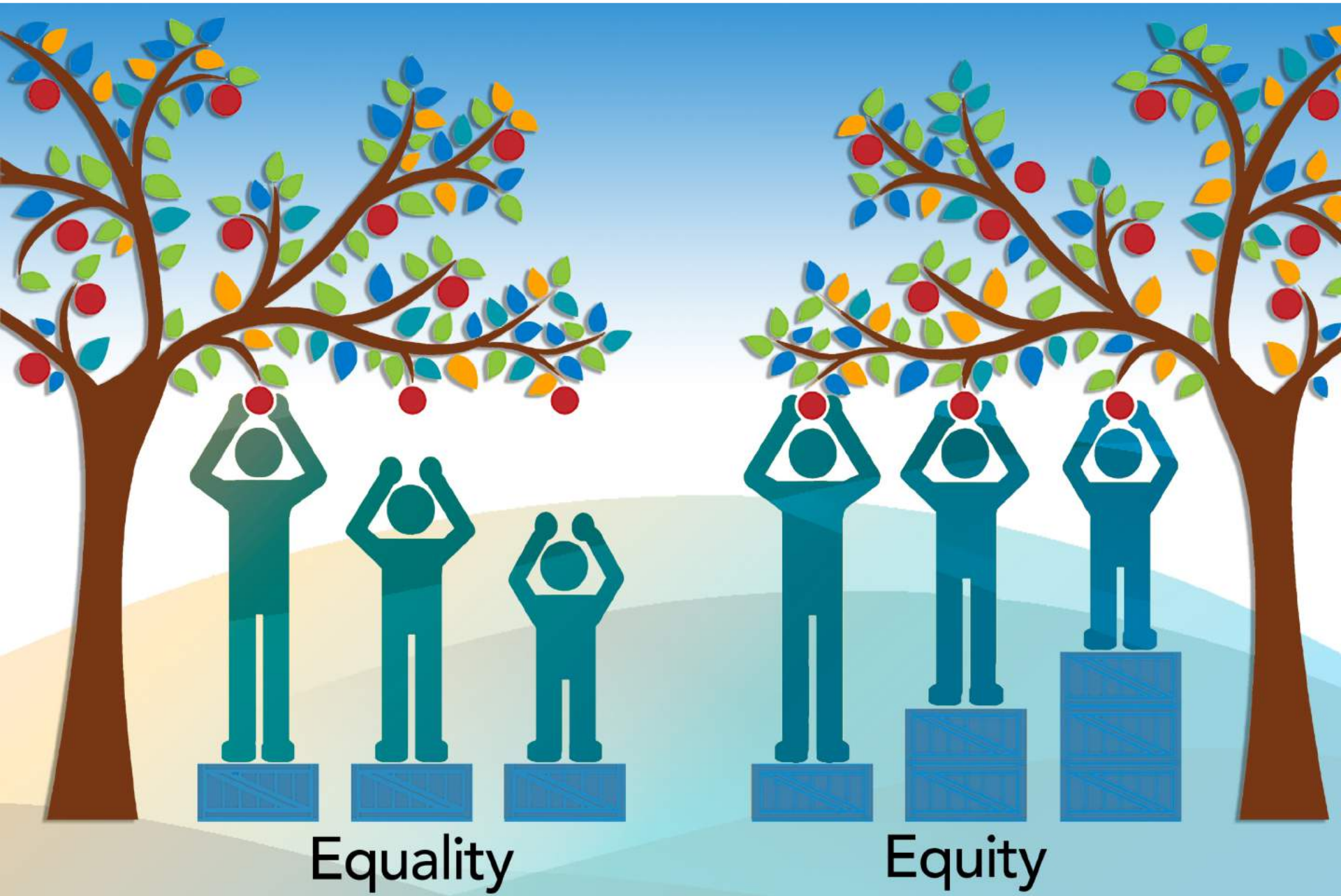
# Health Equity and Aphasia Care

- 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

# Health inequalities



How do we serve these clients who are at a disadvantage?



Equality

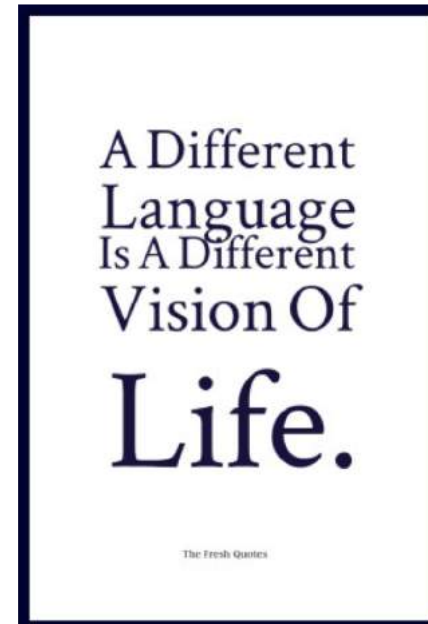
Equity



**CBC Health Brain Trust –  
Kelly Report**



# Thinking about language barriers that many clients face



Federico Fellini

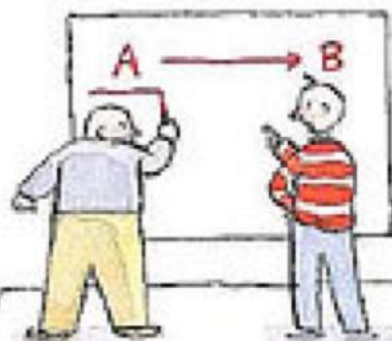
# What is language?

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

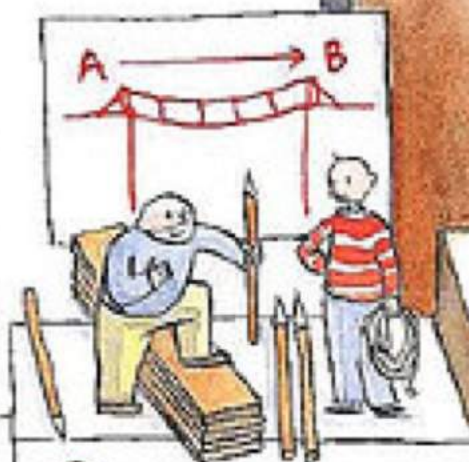
Language is the accumulation of shared meaning - of common ground.



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



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



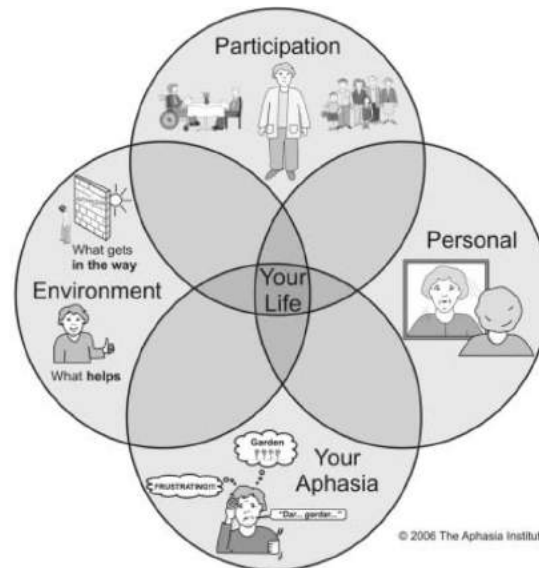
**3 Collaboration**  
Thinking, planning,  
making decisions.



**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.

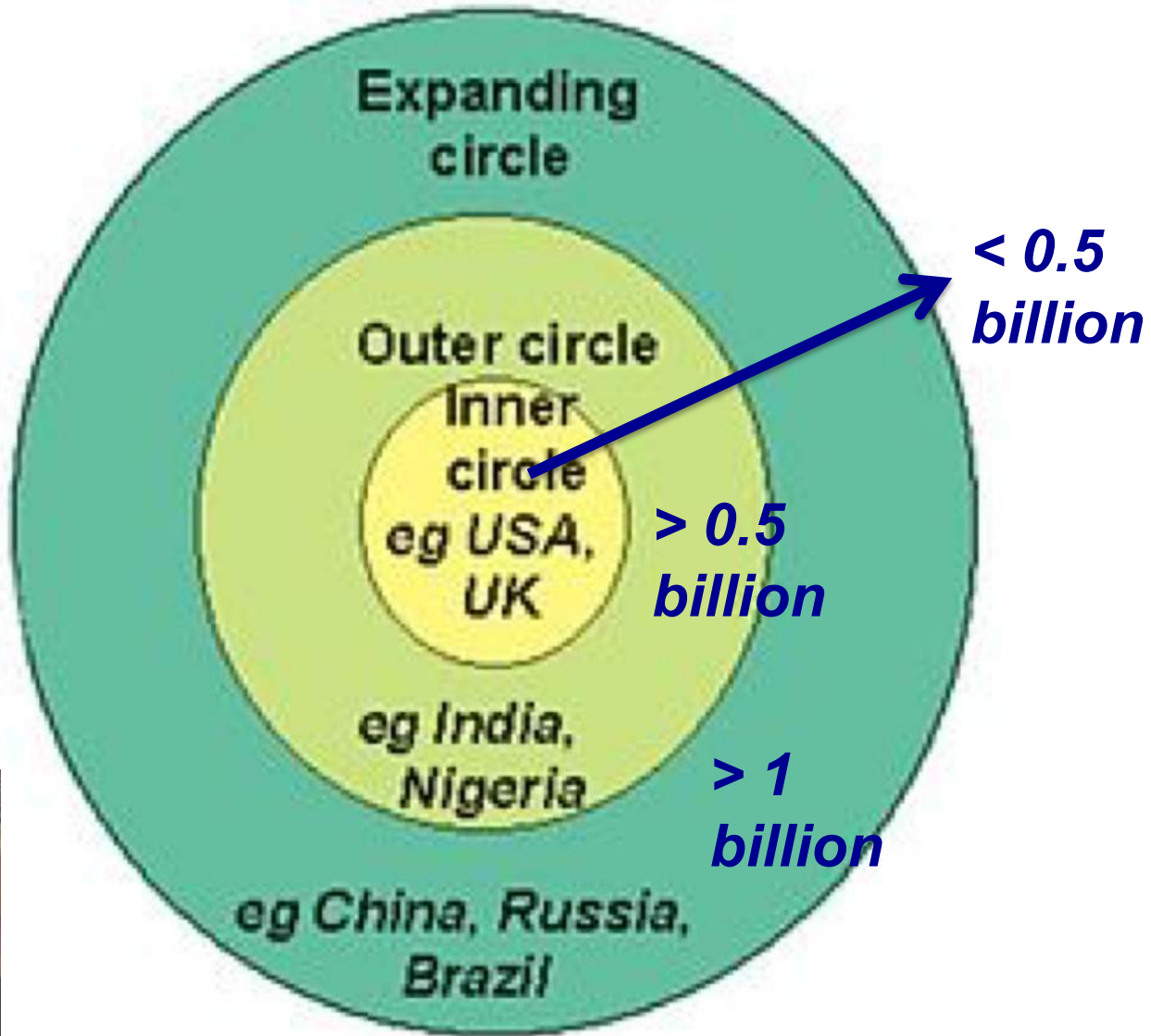
> 350 languages spoken in the United States.

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



# 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

Communicative  
access

Identity

Narrative  
practice

Relationship-  
centered care



# Social Justice and Advocacy



Social justice is the equal access to opportunity, privilege, and wealth in a society

# Advocacy....

❑ Advocacy is the intentional ***application of knowledge, skills and resources to effect systemic changes.***

*Hearne, 2008*

❑ Dearth of health professionals competent in advocacy and policy development. *Institute of Medicine, 2003*

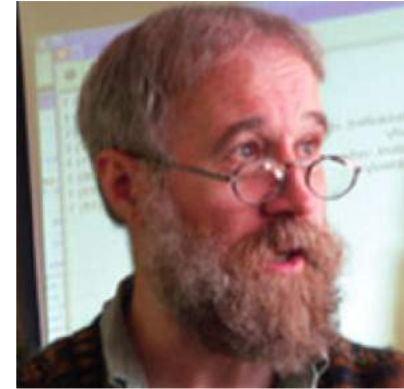
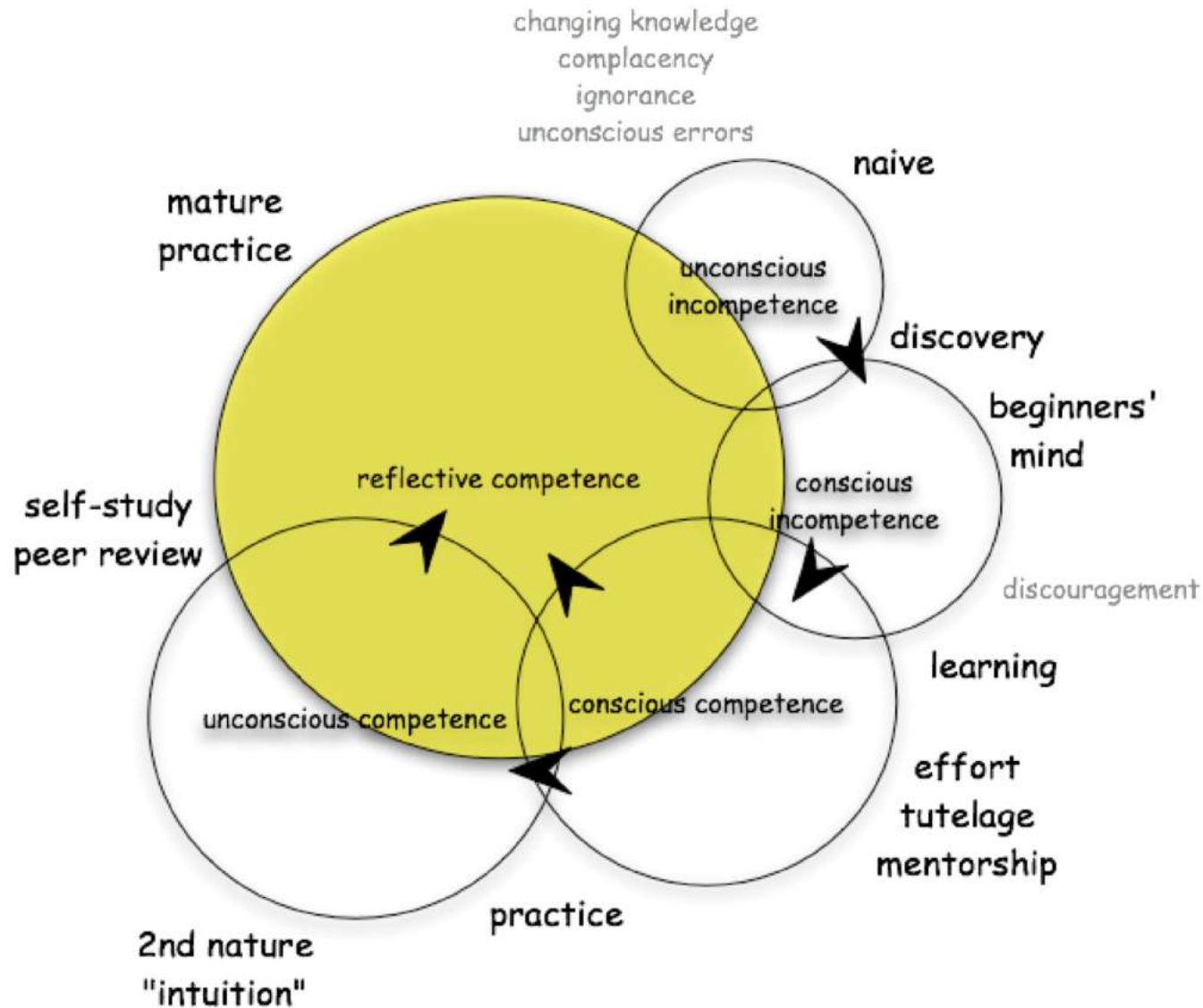
# Tied to Cultural Competence

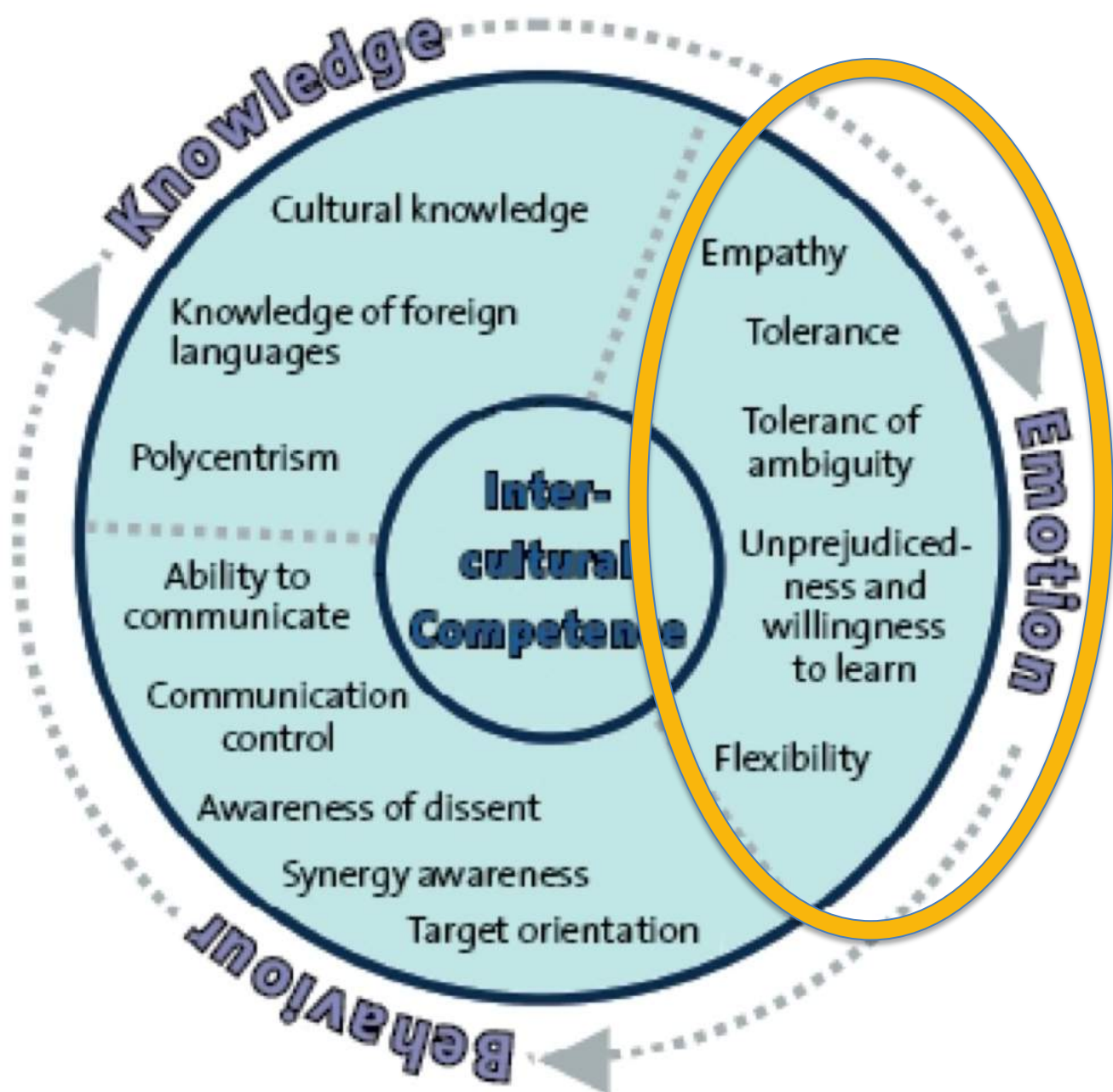
A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enable effective work in cross-cultural situations.

*Source: **National CLAS Standards in Health Care** (2001). U.S. Department of Health and Human Service, Office of Minority Health.*

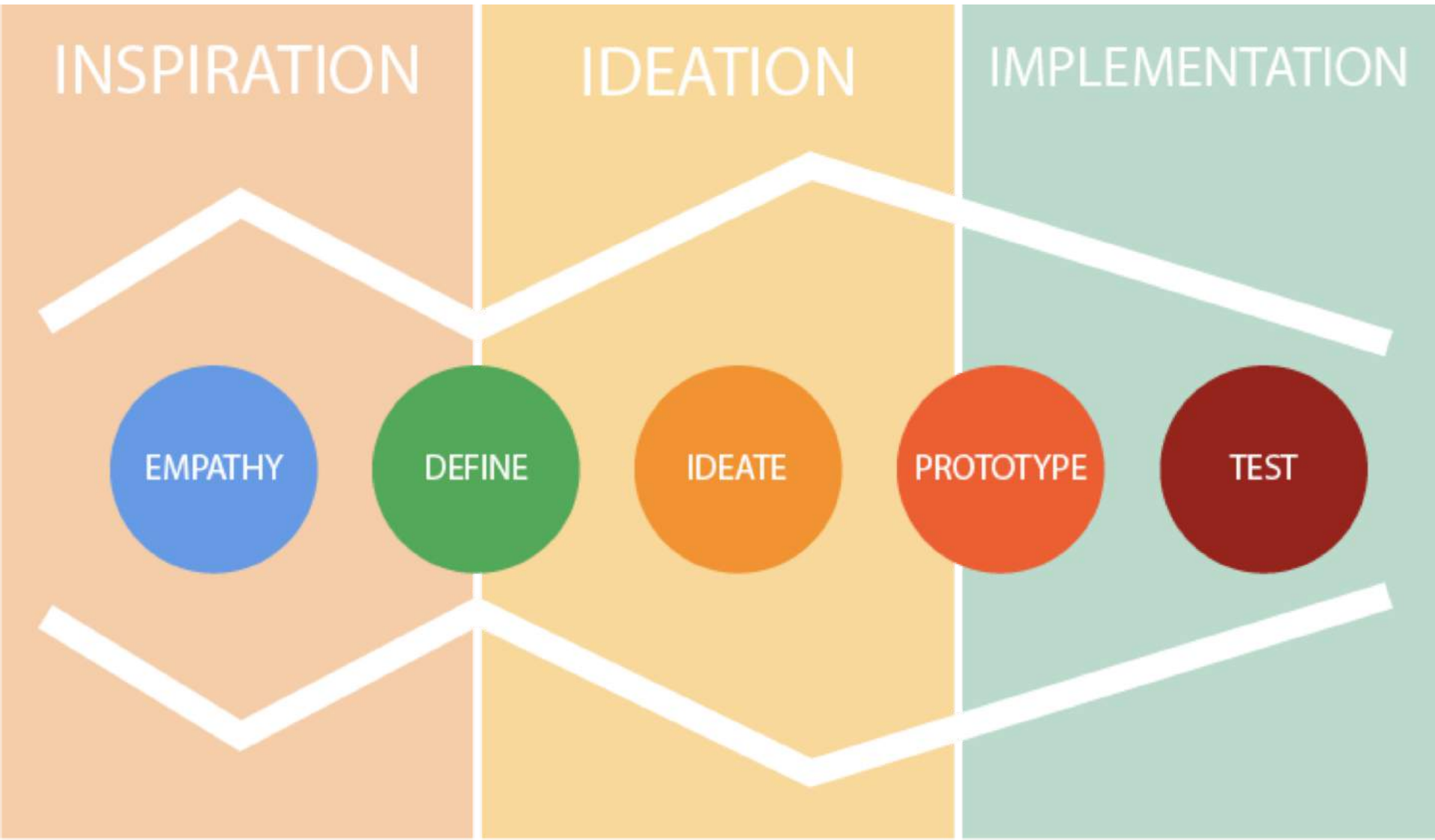
got competence?

# Taylor's 5 stage model *(Taylor, 2007; 4-stage model attributed to Robinson, 1974; Broadwell; 1969)*





# Design Thinking (DT): 5 phases



what can



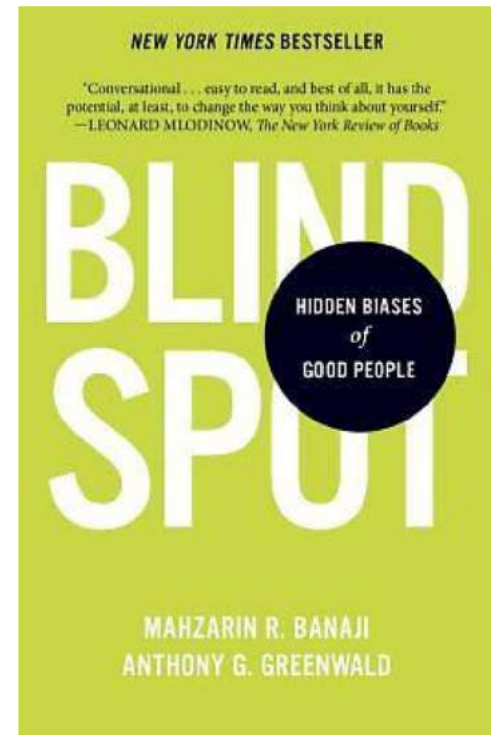
person do?

# 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

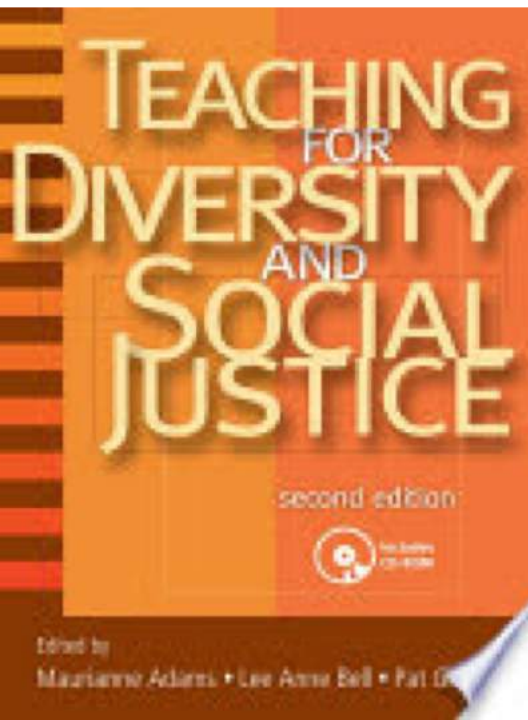
*(Tervalon & Murray-Garcia, 1998)*

- 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

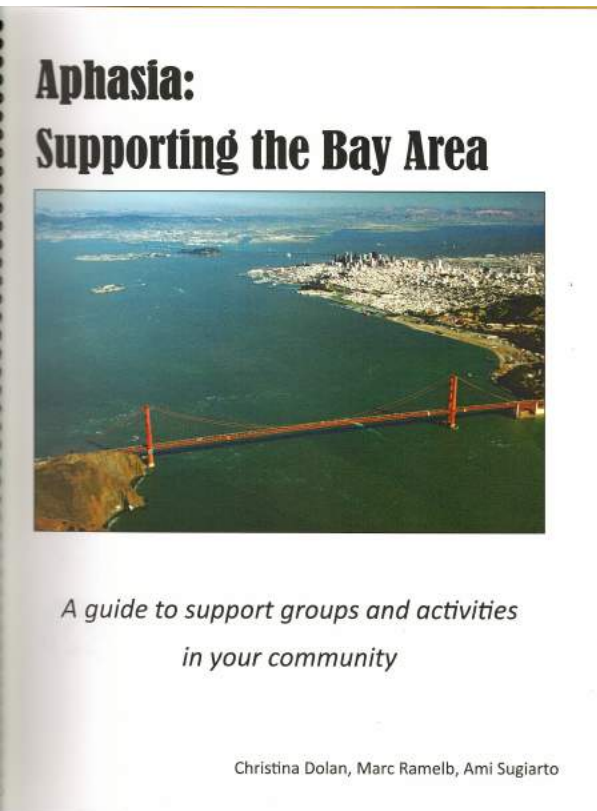
- In the classroom
- In the clinic
- In research and advocacy



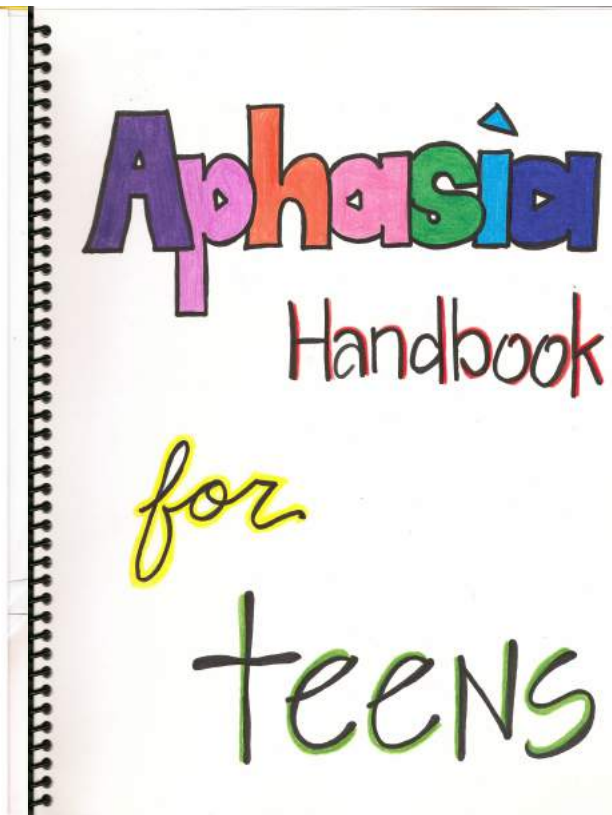
# 5. Reimagine curriculum

- 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

# My Dad and Aphasia



I love my Dad, he's the best dad in the world!



One day, he fell down and had to go to the hospital. The doctor said he had a stroke.



When he came home, the right side of his body wasn't moving, and he couldn't do things like he used to.



A blood vessel was damaged and hurt part of his brain.



My dad has aphasia. He doesn't understand me like he used to, and he doesn't talk when we go out. He also gets frustrated a lot.



He goes to speech therapy...His Speech-Language Pathologist helps him find other ways to tell us what he's thinking.

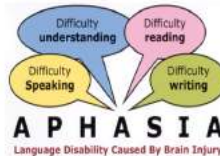
La afasia es un trastorno a consecuencia de un derrame cerebral o daño cerebral, y le afecta a la persona en su capacidad para expresar o entender lenguaje, incluso leer y escribir.

National Institutes of Health  
(Institutos Nacionales de la Salud)



Nombre: \_\_\_\_\_

Dirección: \_\_\_\_\_



**A P H A S I A**  
Language Disability Caused By Brain Injury

# Tengo afasia

*Mahendra, Hayes, Selepec, 2013*

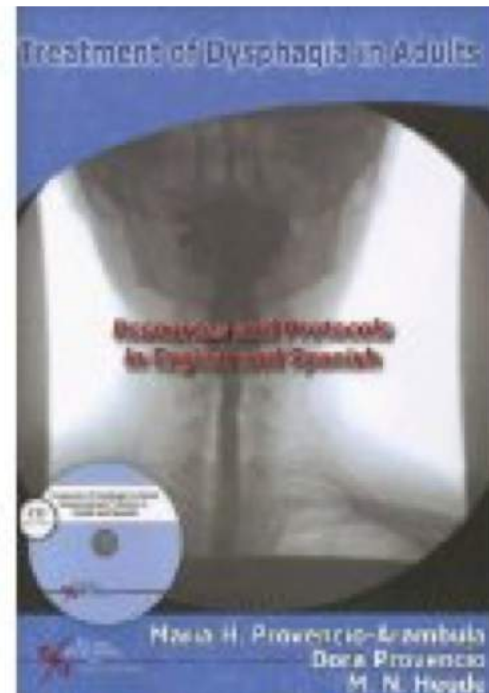
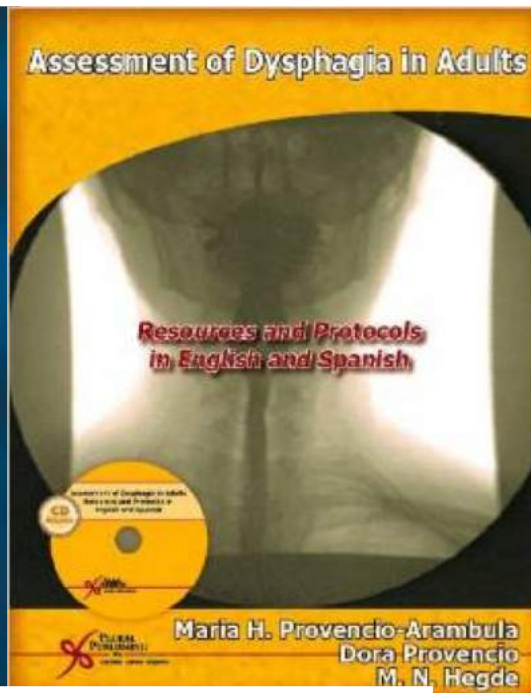
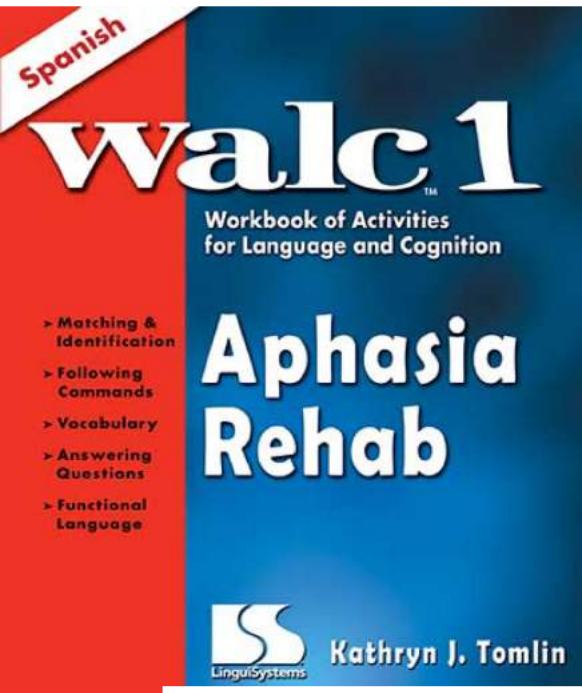
## 6. Let's raise the bar in the clinic, every day, the LPAA way



# 7. Nurture heritage languages

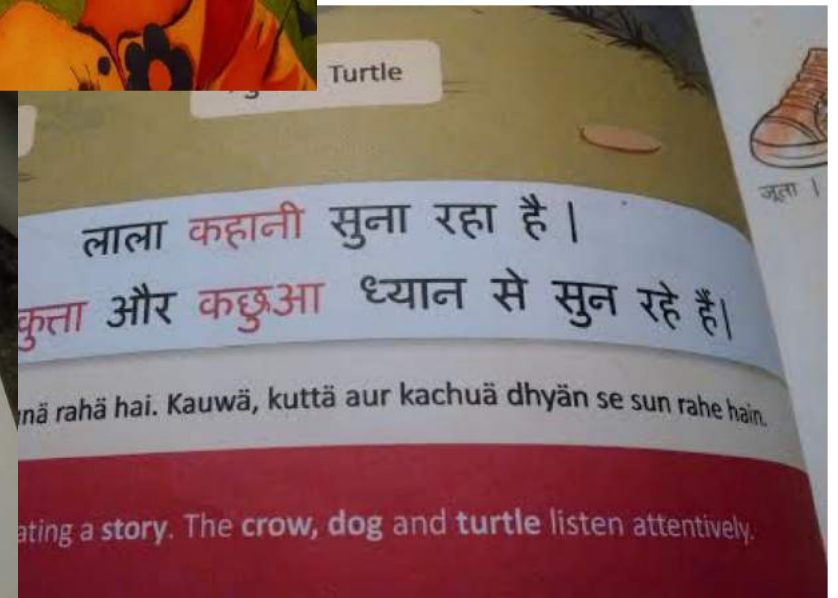
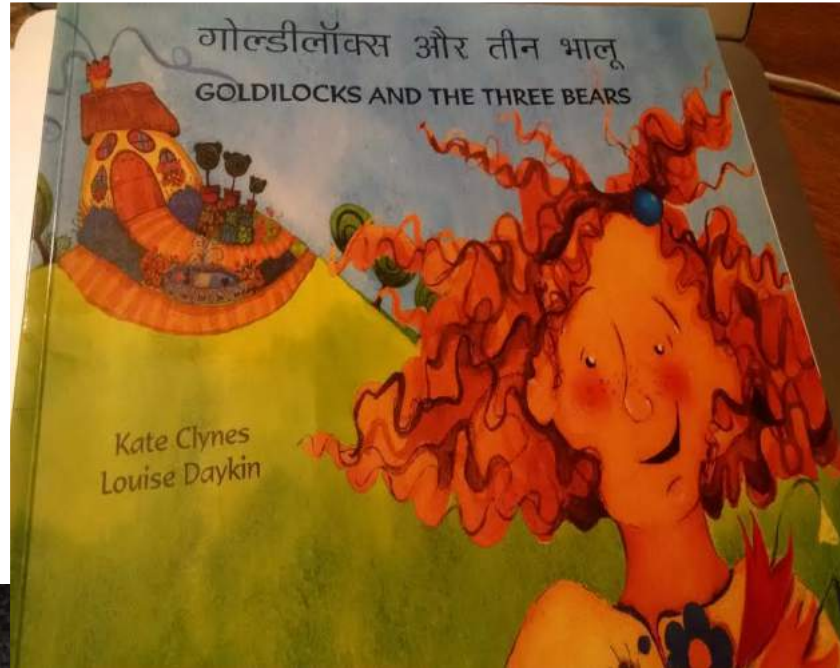
- Minimally, let's obtain a rich language and social history for every client.
- Consistently find out about client's family history, their social networks.
- Learn about how they use/receive their languages (e.g. texting, What's App, prayer circles, TV shows, radio)
- Transform the everyday clinic culture 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

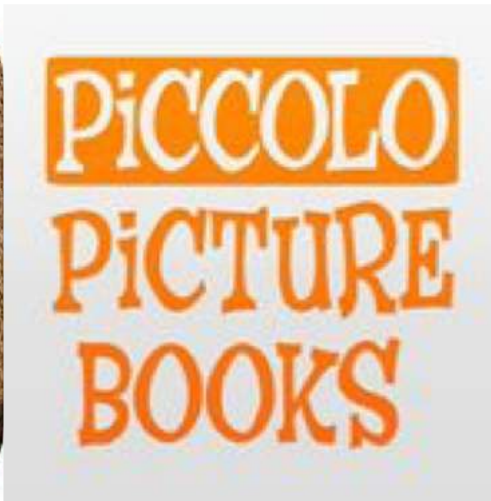


*MOCA Test App*

*BAT Android App - Free*



*Speech with Milo –  
Interactive Story Book*



**SPEAKABOO  
APP**

<http://www.speakaboo.io>

*Pictello*

*Interactive Story Book App – In 5  
languages*

# Access to interpreters



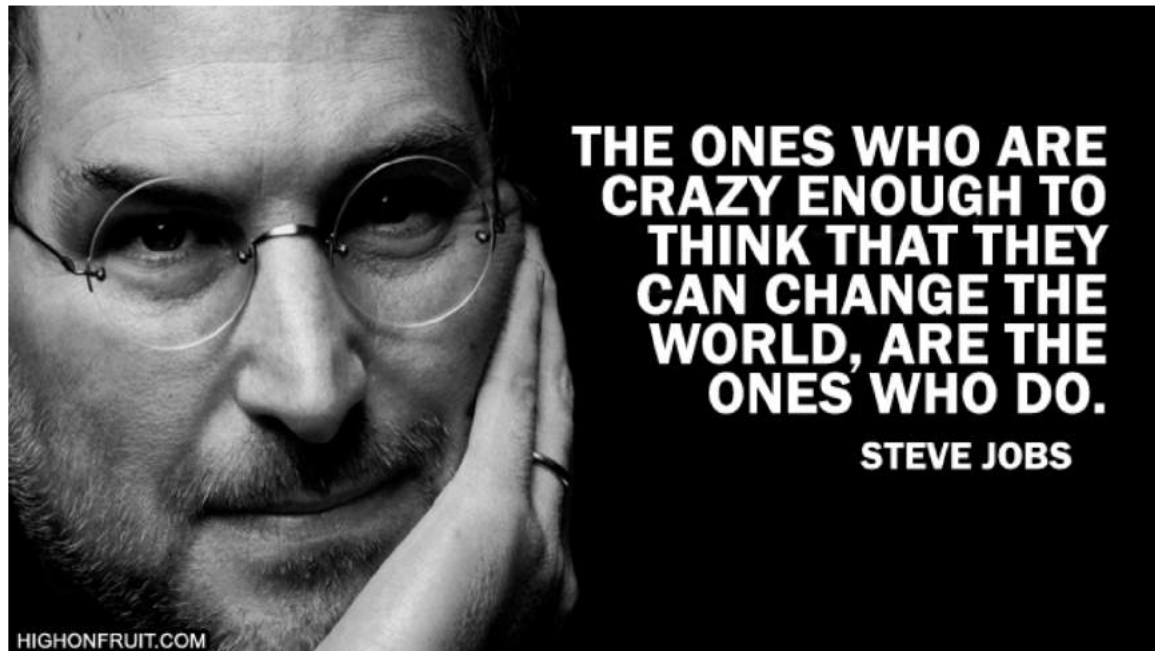
LANGUAGE 411™

Translation & Interpretation On Call

## 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



**THE ONES WHO ARE  
CRAZY ENOUGH TO  
THINK THAT THEY  
CAN CHANGE THE  
WORLD, ARE THE  
ONES WHO DO.**

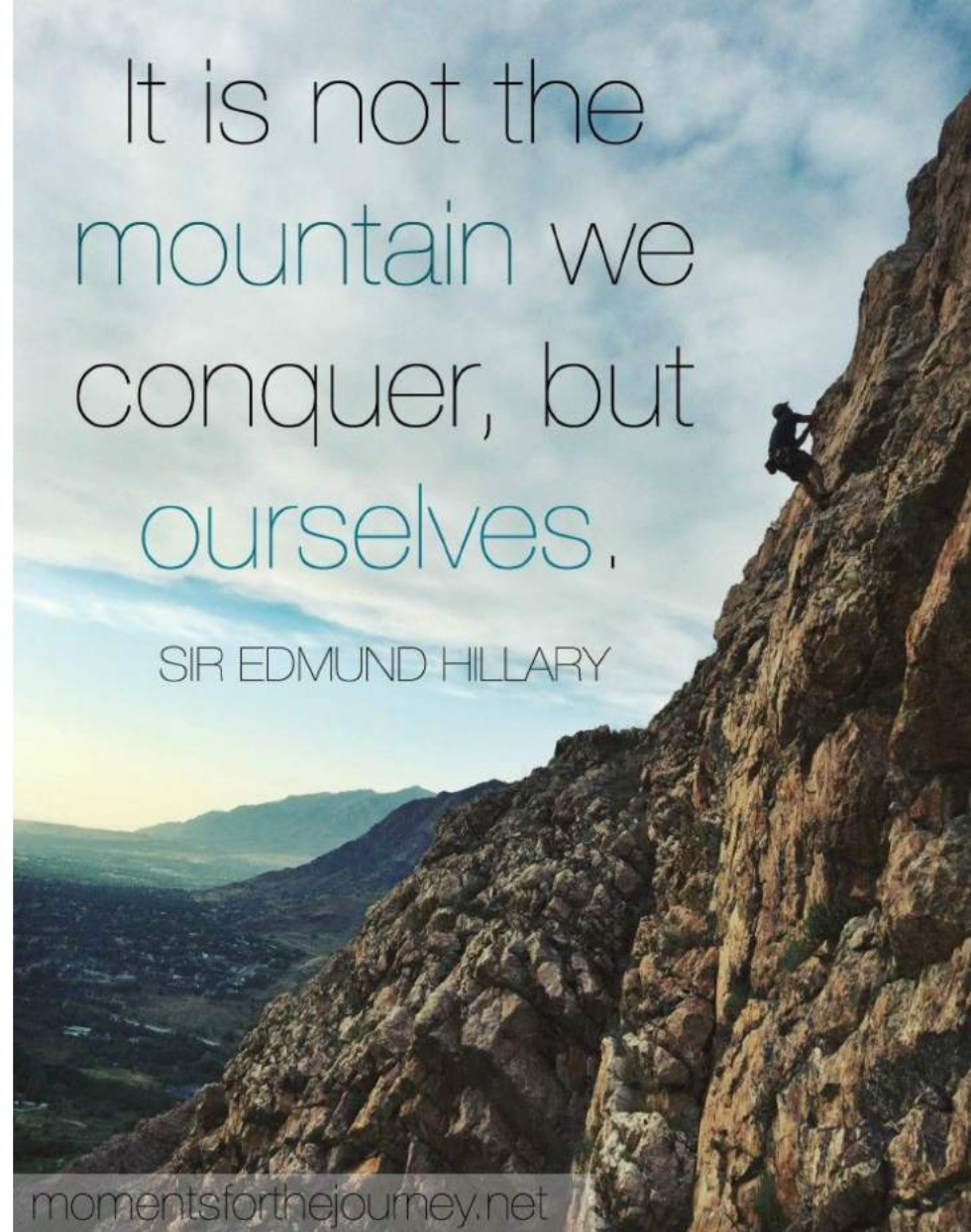
**STEVE JOBS**

HIGHONFRUIT.COM

**What are three things you can do, where you are, right now?**

# Thank you!

- Kathryn Bayles (UA)
- Audrey Holland (UA)
- Elena Plante (UA)
- Prathibha Karanth (India)
- Jan Avent (CA)
- Janet Patterson (CA)
- Ellen Bernstein-Ellis (CA)
- Dianne Rush Woods (CA)
- Michael Kimbarow (CA)
- Lilly Cheng (CA)
- Vicki Deal-Williams (ASHA)



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