*ECHO: Journal of the National Black Association for Speech-Language and Hearing* is an international e-journal concerning communication and communication disorders within and among the social, cultural and linguistically diverse populations, with an emphasis on those populations who are underserved.



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### About the Executive Editor

**Robert Mayo, PhD**, *ECHO*'s, Executive Editor, is a professor in the Department of Communication Sciences and Disorders at The University of North Carolina at Greensboro. Dr. Mayo has served as Managing Editor for ECHO and as an editorial reviewer for journals published by the American Speech-Language-Hearing Association such as the Journal of Speech-Language-Hearing Research and Language, Speech, and Hearing Services in Schools. Dr. Mayo has published and presented papers in his primary areas of scholarly interest: Fluency Disorders, Craniofacial Anomalies, and Public Perceptions of Communication Disorders and Differences. E-mail address: <u>r\_mayo@uncg.edu</u>.

### About the Managing Editor

**Ronald Jones, PhD**, *ECHO's* Managing Editor, is a professor in the Department of English and Foreign Languages at Norfolk State University, Norfolk, Virginia. Dr. Jones has served as Editor (of Letters) for the former ASHA magazine and is the Founding Editor for Resound))), NBASLH's e-newsletter. Dr. Jones served as Chair of the Board for the National Black Association for Speech-Language and Hearing (2006-2008), and has been Managing Editor for ECHO for all but two of the past 10 years. Dr. Jones has published and presented papers in his primary areas of scholarly interest: Auditory Processing Disorders. E-mail address: rjones@nsu.edu.

### Contributing Editors

The following individuals served as reviewers or otherwise contributed, editorially, to this issue of the Journal. We thank them for their contributions to ECHO (any omissions were certainly unintentional):

### Ronald Jones Robert Mayo

### About the Journal

*ECHO: Journal of the National Black Association for Speech-Language and Hearing* is a peer-reviewed, refereed journal that welcomes submissions concerning communication and communication disorders from practitioners, researchers or scholars that comprise diverse racial and ethnic backgrounds, as well as academic orientations.

*ECHO* welcomes submissions from professionals or scholars interested in communication breakdown and/or communication disorders in the context of the social, cultural and linguistic diversity within and among countries around the world.

ECHO is especially focused on those populations where diagnostic and intervention services are limited and/or

are often provided services which are not culturally appropriate. It is expected that scholars in those areas could include, but not limited to, speech-language pathology, audiology, psychology, linguistics and sociology. Articles can cover any aspect of child or adult language communication and swallowing, including prevention, screening, assessment, intervention and environmental modifications. Special issues of *ECHO* concerning a specific topic may also be suggested by an author or through the initiation of the editors.

### Guidelines for Authors

Topics accepted for publication in ECHO could include, but is not limited to, the following:

- Communication breakdowns among persons due to culture, age, race, background, education, or social status
- Use of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) framework to describe communication use and disorders among the world's populations.
- Communication disorders in underserved or marginized populations around the world
- Service delivery frameworks for countries' minority populations, including those who are minorities for a variety of reasons including race, religion, or primary language spoken.
- Dialectical differences and their effects on communication among populations
- Evidence base practice research with culturally and linguistic diverse populations
- Provision of communication services in low income/resource countries
- Provision of communication services in middle income/resource countries
- Provision of communication services to immigrant and/or refuge populations
- Effects of poverty on communication development and the provision of services
- Education/training issues in serving diverse populations
- Ethical issues in serving diverse populations
- Role of religion in views of communication disability and its effect on service delivery

Submissions may include:

- research papers using quantitative or qualitative methodology
- description of clinical programs
- theoretical discussion papers
- scientifically conducted program evaluations demonstrating
  clinical forums

- works using disability frameworks or models effectiveness of clinical protocols
- critical clinical literature reviews
- case studies
- tutorials
- letters to the editor.

### Manuscript Submissions

All manuscripts should be accompanied by a cover letter (e-mail) in which the corresponding author:

- Requests that the manuscript be considered for publication;
- Affirms that the manuscript has not been published previously, including in an electronic form;
- Affirms that the manuscript is not currently submitted elsewhere;
- Affirms that all applicable research adheres to the basic ethical considerations for the protection of human or animal participants in research;
- Notes the presence or absence of a dual commitment;

- Affirms that permission has been obtained to include any copyrighted material in the paper; and
- Supplies his or her business address, phone and fax numbers, and e-mail address.

All manuscripts must be submitted electronically and should follow the style and preparation presented in the Publication Manual of the American Psychological Association (Sixth Edition, 2010); see Journal for exceptions to APA style) Particular attention should be paid to the citing of references, both in the text and on the reference page. Manuscript submissions and inquiries should be addressed to: <a href="https://www.nbaslh.org">nbaslh@nbaslh.org</a>.

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### Sponsoring Organization

National Black Association for Speech-Language and Hearing, PO Box 779, Pennsville, NJ 08070, 877-936-6235 (phone & fax), <u>nbaslh@nbaslh.org</u> (email), <u>www.nbaslh.org</u> (website)

Periodically, *ECHO*, *The Journal of the National Black Association for Speech-Language and Hearing*, reports on the progress of research-scholars and practitioners who are addressing issues that relate to health disparity. Most welcomed are articles that explore underlying causes of health inequity and which describe interventions that have been undertaken to eliminate health disparities across the communication disorders.

This issue of ECHO contains a range of articles on issues that impact the delivery of speech-language diagnostic and therapeutic services delivered by speech-language pathologists and audiologists to racial and ethnic and/or socially diverse populations.

Ellis and company, for example, explore the complex range of factors that contribute to issues of disparity and health-related outcomes within speech-language pathology.

Wright-Harp addresses the changing demographics of the U.S. and the growing demand for SLPs to be both clinically and culturally competent.

Jones provides information about differing means by which people become health literate. She also addresses the role of health care professionals who have direct contact with patients and caregivers.

Martinez also addresses issues related to health literacy but as it impacts the health status of individuals and their communities.

Wright-Harp and Payne introduce strategies that SLPs can use to design and implement treatment protocols to individuals from diverse backgrounds.

Holt and Ellis explore issues relating to the delivery of SLP services to pediatric populations and factors that may contribute to limited access to services, uneven quality of service and clinical outcomes.

And finally, Mayo and Mayo provide an operational definition of communication wellness for use by communication sciences and disorders (CSD) professionals. They introduce a rationale for developing and promoting communication wellness activities in individuals and communities of color.

It is hoped that the articles in this special issue of ECHO will spark an interest among its readers to pay greater attention to procedures and practices that could negatively impact the delivery of speech, language and hearing services, particularly, to racial and ethnic minority populations. It is also hoped that further research in this area will provide greater insight into racial disparities in health, in general, and lead to the development of approaches that effectively reduce and eliminate health inequities overall.

Ronald Jones, Ph.D. Managing Editor

### THE MULTIDIMENSIONAL NATURE OF DISPARITIES IN HEALTH-RELATED OUTCOMES: CONTRIBUTIONS OF PATIENTS, PROVIDERS AND HEALTH SYSTEMS

Charles Ellis, Ph.D. East Carolina University Greenville, NC

**Robert Mayo, Ph.D.** University of North Carolina at Greensboro Greensboro, NC

Carolyn M. Mayo, Ph.D. Communications Research Evaluation and Wellness Specialists, LLC Burlington, NC

> Yolanda F. Holt, Ph.D. East Carolina University Greenville, NC

#### ABSTRACT

Significant and longstanding racial disparities in health outcomes have been consistently reported in the United States. Reports have shown that racial disparities exist in clinical outcomes that are attributed to limited access to care due to a paucity of healthcare generalists and specialists, especially in economically depressed urban and rural communities. Additionally the quality of services rendered by healthcare providers who are insensitive to the culture, language and health beliefs of their patients may be a major contributing factor to the underutilization of health care service by these patients. Although significant discussion has occurred about racial disparities in the profession of Speech-Language Pathology (SLP), to date, few data-driven studies have been produced that document such disparities or examine the presence of or to what extent the proposed disparities may affect clinical outcomes or access/utilization/quality measures. The purpose of this paper is to introduce and briefly explore the issue of disparities in health-related outcomes within SLP with a special focus on the impact of racial/ethnic health disparities. Specifically, we review the complex range of factors that potentially contribute to such disparities and offer an action plan that incorporates key elements to address those disparities.

KEY WORDS: Health disparities, communication disorders, service access and utilization, cultural competence

### THE MULTIDIMENSIONAL NATURE OF DISPARITIES IN HEALTH-RELATED OUTCOMES: CONTRIBUTIONS OF PATIENTS, PROVIDERS AND HEALTH SYSTEMS

### Charles Ellis, Ph.D.

East Carolina University Greenville, NC

**Robert Mayo, Ph.D.** University of North Carolina at Greensboro Greensboro, NC

**Carolyn M. Mayo, Ph.D.** Communications Research Evaluation and Wellness Specialists, LLC Burlington, NC

### Yolanda F. Holt, Ph.D.

East Carolina University Greenville, NC

#### **INTRODUCTION**

ealth outcomes are the end point of the receipt of healthcare or measures of healthcare activities that include: a) whether the disease or condition gets better or worse, b) the cost of care and c) patient satisfaction with the care received (Burns & Grove, 2007; Foundation for Health Services Research, 1994). Substantial concerns exist regarding health outcomes in the U.S. because of the aging U.S. population and the expected disabling health conditions associated with an older population (Ortman, Velkoff & Hogan, 2014). Consequently, health outcomes research has emerged as a key topic of discussion for local, state and national government entities, health sciences educators, researchers and lay people. In the context of dramatic and historic healthcare reform (i.e., The Patient Protection and Affordable Care Act and the Health Care and Education Reconciliation Act aka: Obamacare, enacted into law in 2010), understanding the nation's health and related outcomes has become a universal topic for discussion and debate.

Similarly, significant concerns exist because of observed disparities in health outcomes research, particularly between U.S. racial/ethnic minorities and majority population groups. According to the U.S. Centers for Disease Control and Prevention (CDC) disparity or gaps in health outcomes exists between segments (racial/ethnic groups) of the U.S. population (CDC, 2013). Unfortunately in health outcomes research, the term "disparity" has not been consistently used to characterize specific types of disparities such as: disparities in access, disparities in referral for services, disparities in service utilization disparities in clinical or outcomes. Consequently, the current literature includes an assortment or variety of definitions or descriptors about the meaning of the term 'health disparities'. Stated differently, each conceptualization of the term's meaning brings its own unique perspective. Additionally a major limitation of existing definitions is that they fail to distinguish the type or nature of disparities in outcome differences between populations. Therefore, achieving clarity regarding disparities in access, referral for services, service utilization or clinical outcomes will be a major key to understanding the complex nature of disparities. Going forward, the focus of this paper will primarily emphasize racial disparities. In doing so, we recognize and acknowledge that a range of other sociodemographic factors (e.g., socioeconomic status, rural/urban residence, and educational level) are directly intertwined with race.

### In Search of a Definition of Health Disparities

How one defines 'health disparities' has important implications for health policy and practice and in the equitable apportioning of healthcare services. A review of commonly used definitions of health disparity/disparities in the United States as shown in Table 1, suggests that definitions can spring from a populations model frame of reference (e.g., AHRQ, 2006), be perceived through a socioeconomic lens (e.g., Healthy People 2020), or emanate from a social justice model (e.g., WHO definition by Dahlgren & Whitehead, 1991; Braverman, Kumanyika, Fielding, LaVeist, et al. 2011), wherein the focus is on those differences which society has a role in creating, and therefore has the greatest potential to ameliorate (Dehlendorf, Bryant, Huddleston, Jacoby, & Fujimoto, 2010). Specific definitions may also be favored by government funding agencies that seek to target certain disorders or conditions for reduction, elimination or focused research.

### Table 1. Definitions of Health Disparity.

Definition	Source of Definition
"Differences in disease risk, incidence, prevalence, morbidity and other adverse conditions, such as unequal access to quality health care, that exist among specific population groups in the United States."	Smedley, Stith, & Nelson (2003)
"Any differences among populations that are statistically significant and differ from the reference group by at least 10 percent."	Agency for Healthcare Research and Quality (2006)
"racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention."	Institute of Medicine (Stith & Nelson. 2002)
"differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and	World Health Organization (Dahlgren & Whitehead,
unjust."	1991)
"a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion."	Healthy People 2020 (USDHHS, 2010)
"Health disparities are systematic, plausibly avoidable health differences adversely affecting socially disadvantaged groups. They may reflect social disadvantage, although a causal link need not be demonstrated. Differences among groups in their levels of social advantage or disadvantage, which can be thought of as where groups rank in social hierarchies, are indicated by measures reflecting the extent of wealth, political or economic influence, prestige, respect, or social acceptance of different population groups."	Braverman, Kumanyika, Fielding, LaVeist, et al. (2011)

### Patient Contributors to Disparities in Health Outcomes

Disparities, whether by race or other sociodemographic characteristics are multidimensional in causality rather than being attributable to a single cultural, environmental. genetically inherited or lifestyle factor. Still, patients tend to engage in personal health-related decision-making that also contribute to health outcomes. For example, healthcare utilization patterns among minorities are known to be associated with beliefs about health and past experiences, particularly discrimination, when seeking out healthcare (Harris, Fleming & Harris, 2012). There is evidence in the general health outcomes literature that health systems themselves can negatively influence patient utilization patterns due to poor understanding of cultural beliefs, provider biases about health-seeking behaviors among minorities, provider interpersonal behaviors and provider professional decision making (Meyers, 2008). Consequently, the differential patterns of healthcare utilization that exists among racial/ethnic minorities may be influenced largely by attitudes and beliefs, value systems, priorities related to healthcareseeking behaviors and the groups' social, educational, cultural, and economic circumstances even when they are insured (Van Ryn & Fu, 2003).

An emerging literature also suggests that some differential healthcare utilization behaviors are influenced by factors that are not as obvious. Data from the Centers for Disease Control and Prevention suggests that when considering only adults with a usual source of care, Hispanics and African Americans are more likely to delay or go without necessary care more often than Whites (Centers for Disease Control and Prevention, 2010). Similar patterns exist in how racial/ethnic minorities manage the health of their children regardless of whether they have a source of care or insurance. Weitzman, Byrd and Auinger (1999) found that middle class African American children whose parents had health insurance. received healthcare from difference sources and experienced different patterns of healthcare utilization than White children. A more recent study by Ashiabi (2013) showed that at comparable levels of access to care, Whites are more likely to use both preventive and curative care (Ashibi, 2013). Therefore, it is tenable that some observed disparities in healthcare utilization patterns are related to beliefs and attitudes about how to care for one's personal health and well-being, as well as negative or at best, reserved precautionary attitudes toward utilizing existing healthcare systems. It remains unclear, however, if such behaviors contribute to disparities in health-related outcomes.

A third key and related issue is racial/ethnic differences in perceptions of the need for care. Perceptions of need can be confounded by the perceived level of difficulty the person is experiencing in terms of delays or timeliness in obtaining care and problems encountered when care is desired. Perception of need issues can be interpreted by healthcare professionals as a barrier to access and the primary reason that some minorities decide the barriers of access to care are too great to overcome. The impacts of these factors on members of minority communities who choose not to access care are not clearly defined, clearly understood or easily quantifiable and are therefore difficult to study. Little is known about how patient beliefs and attitudes and perception of need impacts service utilization in the field of Speech-Language Pathology (SLP). Therefore, it is unclear if disparities in beliefs or perception of need and consequently utilization patterns are contributors to disparities in outcomes in the field of SLP as little if any data exist about this issue in the field SLP.

### Provider Contributors to Disparities in Health-Related Outcomes

It is important to note that patient behaviors do not contribute to healthcare utilization disparities in isolation. Evidence of prejudice and bias exists among health care providers yet many do not recognize prejudice in their behaviors (Institute of Medicine, 2003; 2004). Provider stereotyping and poor patient-provider communication can play key roles in observed racial disparities in outcomes (Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006). Racial minority patients are less likely to engage in treatment plans when seen by White healthcare Similarly, lack of engagement and poor providers. communication with providers can lead to greater mistrust and in turn greater refusal to engage in preventive or non-emergency care (Kilbourne et al., 2006). Consequently, providers must be sensitive to cultural differences when there is a lack of concordance between the race of the patient and the provider. Providers must also empower patients to be active participants in their care and engage in a process of negotiation between patient and provider to identify the best course of

treatment (Bocanegra & Gany, 2004). To be clear, as Smedley (2007) notes, many nonminority health professionals are supremely skilled and sensitive clinicians who provide excellent care and achieve excellent outcomes for the minority clients/patients that they serve. However, the factors that make a client/patient and healthcare provider "click" as a team are varied, with some outcomes importantly based on personality, shared trust, communication styles, race, culture, ethnicity, and other outcomes related to additional or difficult-to-define factors (Smedley, 2007). In summary, a range of patient sociodemographic characteristics can influence provider's perceptions and attitudes towards patients when managing their health (Institute of Medicine, 2003).

### Health System Contributors to Disparities in Health-Related Outcomes

Provider issues also do not operate independently. Providers operate within healthcare systems that have organizational characteristics that result in disparities in the receipt of preventive care (Kilbourne et al., 2006). Historically, these same healthcare systems have had negative reputations among minority patients primarily due to documented past discriminatory practices such as the Tuskegee Syphilis Study (Jones, 1993; Alsan & Wanmaker, 2016) and the cloning of Henrietta Lacks' cancer cells (aka: HeLa cells) without permission (Skloot, 2010) that have and continue to be used in scientific experiments to cure or minimize the effects of countless diseases, In fact, when it comes to understanding the detrimental effects that racial attitudes and practices have had, and continue to have on the health status of patients of color and, ultimately, the creation and enactment of national health policies, the U.S. healthcare system has a historical "blind spot" (Jones, 1993).

Factors such as location and accessibility of health care facilities, lack of readily available and safe public transportation and comprehensive diagnostic, intervention and preventive healthcare services can play a key role in the choice of patients either using or not using healthcare systems. These causative factors contribute to disparities in service utilization and subsequent negative clinical outcomes for populations of color. Further, the underrepresentation of minority practitioners in the health and allied health workforce is an additional contributing factor to health disparities. While the percentage of the U.S. population is comprised of 26.7 percent racial minorities and 16.3 percent ethnic minority i.e., Hispanics (U.S. Census Bureau, 2015), in the profession of speechlanguage pathology, only 7.5 percent of American Speech-Language-Hearing Association (ASHA)-certified SLPs are racial minorities and 4.7 percent are Hispanic (Council of Academic Programs in Communication Sciences and Disorders & ASHA, 2015). Moreover, 60 percent of existing bilingual SLPs are White and of non-Hispanic background (ASHA, 2014).

Evidence suggests that having a diverse health care workforce improves health outcomes among racial/ethnic minority groups. Patients are more likely to report greater patient-provider communication, enhanced educational experiences and overall satisfaction when there is racial or ethnic concordance between the patient and provider (Smedley, Butler & Bristow, 2004). In reality, when given a choice, patients from all racial/ethnic backgrounds report that they prefer receiving health care services from members of their own racial/ethnic and/or cultural-linguistic background. Additional benefits for increasing the number of racial/ethnic minority providers is that they are more likely to set up (establish) their practices in underrepresented communities and serve as role models and mentors for current and future generations of health care practitioners (U.S. Department of Health and Human Services, 2006). In turn, the minority provider's presence gives more choices and options to patients of color and often leads to patients reporting more positive health outcomes as they interact with healthcare service delivery (Smedley, Butler & Bristow, 2004).

In summary, increased diversity within healthcare systems can lead to improved health outcomes particularly as increased racial/ethnic and language concordance translates into improved access to and satisfaction with services in underserved communities (U.S. Department of Health and Human Services, 2006).

### Disparities in Access and Utilization of Communication Healthcare Services

Significant interest has emerged in the study of disparities in the field of Speech-Language Pathology (SLP) and Audiology. Although racial disparities have received significant discussion in the field, there have been very few data-driven, peer reviewed published studies that have examined issues related to disparities in 1) access to care, 2) SLP service utilization or 3) clinical outcomes in the adult patient literature. In a 2008 review titled

"Racial-Ethnic Differences in Utilization of Post-Stroke Rehabilitation Services: A Systematic Review", Ellis and colleagues found only two published studies related to service utilization that emphasized racial disparities in the field of SLP and associated with adult post-stroke care (Ellis, Breland & Egede, 2008). In both studies, Whites were more likely to utilize SLP services for stroke-related care when compared to African Americans. Likewise, Wallace and Freeman (1991) reported that African under-utilize Americans urban speech-language pathology clinics and often opt out of services before their completion, citing barriers to accessibility and cost as primary reasons for discontinuing of services before maximum intervention benefits or goals are obtained. Research in a related field (otolaryngology) offers specific evidence of racial disparities in the utilization of non-surgical approaches for larynx cancer. Hou, Daly, Lee, Farwell, Luu and Chen (2012) examined data from the Surveillance Epidemiology and End Results (SEER) database to explore racial disparities in the use of larynx preservation treatment among over 3,800 patients using multivariate logistic analyses and controlling for age, sex, year of diagnosis, stage, and surgical site found that African Americans were less likely to receive larynx preservation treatment than Whites, Hispanics and Asians (Odds ratio [OR] = 0.78; 95% CI, 0.63-0.96; p=.02). These finding are of concern because positive outcomes have been observed in larvnx preservation surgeries and specific underlying causes of the disparities are not clear. Yet traditional explanations for racial disparities (minority patients may decline services, financial barriers, health insurance and tradition) were raised as potential contributors although no clear evidence to support these claims were offered.

Similarly, several data-based studies of disparities in SLP service utilization currently exist. Benedict (2006) examined use of and unmet needs for therapeutic and supportive services among 3,400 school-age children with functional limitations using data from the Disability Supplement to the U.S. National Health Interview Survey. Therapy services in the study included: audiology, occupational, physical, and speech therapy. Regardless of therapy service type, children with public insurance were two to three times more likely to use services than children with private or no insurance. In addition, Non-Hispanic White children were more likely to use services beyond the school services (OR = 1.30, 95% CI 0.79-2.13) than non-Hispanic Black children although the findings did not reach statistical significance. In a second study using the National Survey of Children's Health. including more than 102,000 children age 0-17, Flores and Tomany-Korman (2008) found disparities in incidence of medical and dental condition as well as both access to and utilization of medical services. Regarding speech disorders, Flores and Tomany-Korman also reported that African American children had a higher percentage of speech disorders (5.1%) compared to Whites (3.2%), Hispanics (3.5%; p=.0002). African American children (6.9%) also had a greater need for or were receiving special therapy (i.e., speech, occupational or physical) than White children (6.3%) and Latino children (5.7%). However, they were less likely than Native American children (11.2%) and those classified as multiracial (7.2%) to need or receive the same services (p=0.004).

With regard to disparities in hearing healthcare among older Americans, Nieman, Marrone, Szanton, Thorpe and Lin (2016) analyzed nationally representative, crosssectional data from 1,544 older adults  $\geq$ 70 years (1,165 White, 227 African American, 152 Hispanic American) with audiometry and hearing care data from the 2005-2006 and 2009-2010 National Health and Nutritional Examination Surveys. After adjusting for age and speech frequency pure tone average, African Americans (OR = 1.68, vs. Whites) and those with greater education (OR =1.63,  $\geq$ college vs. <high school; p=.05) were more likely to report having undergone recent hearing testing. However, based on a multivariate analysis, African Americans were less likely than Whites to use hearing aids despite being more likely to have had recent hearing testing. The findings suggest that racial/ethnic and socioeconomic disparities exist in hearing healthcare and represent critical areas for research and intervention.

Table 2 provides a summary of published studies of communication-related disorders disparities with foci in three areas---prevalence of speech disorders, access to services, and receipt of services. These studies underscore that barriers that prevent the complete utilization of speech-language and hearing services by all persons can affect functional recovery, quality of life, and the ability to re-integrate into home and work (Payne, 2011; Wright-Harp, Mayo, Martinez, Payne, & Lemmon, 2012; 2013).

Table 2. Published Studies of Communication-Related Disorders Disparities with Foci on Prevalence of Speech Disorders, Access to Services, and/or Receipt of Services. Implications of Findings of these Studies are Highlighted in Bold.

Authors, Objective and Study Focus	<b>Results and Conclusions (in bold)</b>
Flores & Lin (2013):	Prevalence of speech disorders was greater among Native Americans and African Americans.
To identify racial/ethnic disparities in medical and oral health, access to care, and use of services in US children, and determine whether these disparities have changed over time using 2003 & 2007 National Surveys of Children's Health.	<ul> <li>In multivariate models, greater odds of speech disorders were observed in African American versus white children.</li> <li>Urgent policy solutions are needed to eliminate these disparities, including collecting racial/ethnic and language data on all patients, monitoring and publicly disclosing disparities data annually, providing health-insurance coverage and medical and dental homes for all children,</li> </ul>
Focus: Prevalence/Receipt of Services	• Disparities should made part of the national healthcare quality discussion, ensuring all children receive needed pediatric specialty care, and more research and innovative solutions.
Flores & Tomany-Korman, (2008): To examine racial/ethnic disparities in medical and oral health, access to care, and use of services in a national	<ul> <li>Prevalence of speech problems was greater among Native Americans and African Americans.</li> <li>In multivariate models, greater odds of speech problems were observed in African American versus white children.</li> </ul>
sample using 2003-2004 National Survey of Children's Health.	• Reduction and elimination of racial/ethnic disparities in children may require (a) more comprehensive data collection, analyses, and monitoring of disparities in all of the major racial/ethnic groups and multiracial children; (b) improvements in access to care and reducing
Focus: Prevalence	unmet needs; and (c) targeted community-based interventions.
Montes & Halterman (2011): Comparison of the reported receipt of family-centered care between parents of white and black children with	<ul> <li>Among children with special health care needs but no ASD, more white parents than black parents reported receiving family-centered care.</li> <li>Among parents with a child with ASD, being black was associated with lower reporting of family-</li> </ul>
autism spectrum disorders (ASD) and to disentangle the associations of race and ASD on different aspects of	<ul> <li>Families with children with ASD are less likely to receive family-centered care.</li> </ul>
family-centered care.	• Families with black children with ASD are less likely to receive critical aspects of family-centered care than families of white children with ASD.
Focus: Access/Receipt of Services	• Targeted efforts are needed to improve family-centered care for parents with a child with ASD, and particularly for black families.
Hou et al. (2012):	• Blacks were significantly less likely to undergo larynx preservation therapy than Whites, Hispanics,
To identify potential racial disparities in the use of voice preservation therapy (i.e., radiation therapy with	<ul> <li>and Asians.</li> <li>Pronounced racial disparities exist in the use of larynx preservation therapy for locally</li> </ul>
concurrent chemotherapy) as the initial treatment for	• Fromounced racial disparities exist in the use of farying preservation therapy for locally advanced laryngeal cancer.
locally advanced laryngeal cancer	<ul> <li>While acknowledging that socioeconomic and non-ethnicity related variable have the potential to confound observations, future research should focus on identifying and eliminating barriers</li> </ul>
Focus: Receipt of Services	

	to the use of laryngeal preservation for all medically suitable patients, with a particular focus on black patients with state IV disease.
Fridriksson et al. (2005): To examine speech-language pathology and audiology services after stroke Focus: Access/Receipt of Services	<ul> <li>Regardless of race/ethnicity, patients residing in urban metropolitan centers tend to have better access to and utilization of SLP and Audiology rehabilitative services than patients living in rural settings.</li> <li>Rural-based rehabilitation centers may need to make concerted efforts to recruit and retain SLP and Audiology personnel to serve their patient populations</li> </ul>
Hsia et al. (2011): To determine whether race was associated with tissue plasminogen activator (tPA) treatment for ischemic stroke in a predominantly African American urban population. Focus: Receipt of Services	<ul> <li>Of 1044 patients with ischemic stroke, 74% were African American, 19% were non-Hispanic white, and 5% received intravenous tPA (a 'clot-busting' drug shown to improve clinical outcome in acute ischemic stroke).</li> <li>African Americans were one-third less likely than whites to receive intravenous tPA.</li> <li>However, African Americans were also less likely than whites to present within three hours of symptom onset and also significantly less likely to be <i>tPA eligible</i>.</li> <li>Those African Americans who presented within three hours were almost half as likely to be treated with tPA than whites.</li> <li>The treatment rate for tPA eligible patients was similar for African Americans and whites.</li> <li>In a predominantly African American urban environment, African Americans were significantly less likely to be treated with intravenous tPA due to contraindications to treatment, delayed presentation, and stroke severity</li> <li>Effective interventions designed to increase treatment in this population need to focus on culturally relevant education programs designed to address barriers specific to this population.</li> </ul>
Jones (2009): To identify factors that might account for the reported disparity in the acquisition of information and the utilization of hearing rehabilitative services and related healthcare technologies, particularly, by racial and ethnic minority U.S. populations. <b>Focus: Access/Receipt of Services</b>	<ul> <li>257 completed surveys distributed nationally to parents/guardians of deaf or hard of hearing children (White 73.9%, African American 12.8%, Latino 7.4%, Asian 3.9%, Native American .39%, and 1.5% other).</li> <li>Parents with moderate to high incomes, regardless of their race or ethnicity, tended to have broader knowledge of the nature of hearing rehabilitation services, and acquire such services and hearing technologies at a greater rate than that of parents with lower incomes.</li> <li>The unavailability of hearing healthcare services in minority communities and high costs associated with hearing aids and cochlear implants were reported as the major reasons why disparities exist, among minorities</li> <li>Socioeconomic issues rather than race or ethnicity appear to be a more discernable factor to account for hearing healthcare disparities among minorities in general.</li> </ul>

### Cultural and Linguistic Competency in Service Provision

As noted above, the lack of diversity among healthcare providers is believed to contribute indirectly to health disparities and that having a diverse workforce is associated with improved outcomes among racial/ethnic minority groups. Moreover, lack of cultural and linguistic competence and sensitivity among healthcare professionals has been associated with the perpetuation of health disparities (e.g., Geiger, 2001; Johnson, Saha, Arbelaez, Beach, & Cooper, 2004). Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations (ASHA, 2013). Culturally competent care is defined as care that respects diversity in the patient population and cultural factors that can affect health and healthcare, such as language, communication styles, beliefs, attitudes, and behaviors.

The federal government, through the development of the Office of Minority Health (OMH) of the U.S. Department of Health and Human Services (USDHHS), has sought to offer resources that health practitioners such as speechlanguage pathologists can use to develop cultural competence. Among these resources is the National Standards for Culturally and Linguistically Appropriate Services in Health and Healthcare (aka: National CLAS Standards) created by OMH (USDHHDS, Office of Minority Health, 2016). The National CLAS Standards are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations to provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs. Since its creation in 2000, 20 states have either initiated legislative activity or enacted legislation on cultural competence training and state-sponsored National CLAS Standards implementation activities (USDHHDS, Office of Minority Health, 2016).

Speech-language pathologists seeking to develop cultural competence should also be aware that the implementation of clinical research and community health education and service outreach agendas are also foci of the federal government through nationwide minority health initiatives launched at the National Institutes of Health (aka: NIH) and the Centers for Disease Control and Prevention (aka: CDC). Specifically, established in 2010 as integral part of NIH, the mission of the National Institute of Minority Health and Health Disparities or NIMHD is 'to coordinate, conduct, and support research that improves minority health and eliminates health disparities' (NIMHD, 2016). The NIMHD carries out its

mission by 1) conducting research on biological and nonbiological markers to gain an understanding of minority health and underlying causes of health disparities; 2) engaging in research capacity building by supporting the training and career development of scholars from health disparate and/or underrepresented populations in the science and medical fields as well as institutional and organizational capacity building for purposes of conducting minority health scientific research; 3) developing educational outreach and health literacy information and dissemination programs within health disparate communities and to providers that service these communities; and 4) integrating research, research capacity-building, and outreach to foster collaborations and partnerships among distinct disciplines and areas that all play an integral role in improving minority health and eliminating health disparities. The NIMHD is primarily a funding source to support the four above-stated objectives.

Paralleling the initiatives of the NIMHD, the Center for Disease Control and Prevention (CDC) was mandated by the U.S. Congress and the Executive Branch of government to create the Office of Minority Health and Health Equity (OMHHE). The mission of OMHHE is to 'advance health equity and women's health issues across the nation through CDC's science and programs, and increase CDC's capacity to leverage its diverse workforce and engage stakeholders toward this end'. With respect to health disparities, the stated goal of the OMHHE is to 'decrease health disparities, address social determinants of health, and promote access to high quality preventive health care' (Centers for Disease Control and Prevention, 2016). The OMHHE represents a direct, community-based, grassroots approach by agents of the federal government to eliminate health disparities and promote health equity among all individuals within the U.S. borders and beyond. Essentially, the intent of this office is to empower people and health care providers within communities to identify, differentiate and minimize or eliminate the effects of diseases and disorders on patients both individually and collectively within their community structures. Community-driven project funding resources are also available through the OMHHE as well as CDC in general. Finally, this organization promotes health care leadership among students (especially those involved in public health training and education programs), use of and training of community-lay health care workers, the promotion of health literacy and translational research for public consumption and also acts as a funding source for community based projects involving access, utilization and attitudes of patients toward the health care enterprise or industry.

With regard to cultural competence education for future speech-language pathologists and audiologists,

communication sciences and disorders graduate programs accredited by the Council on Academic Accreditation (CAA) in Audiology and Speech-Language Pathology of the American Speech-Language-Hearing Association are responsible for providing students-in-training coursework and clinical experiences, to promote the depth and breadth of knowledge and experiences to achieve cultural competency (ASHA, 2016). The two main cultural competency education approaches often implemented in graduate speech-language pathology programs include (a) the use of stand-alone courses that promote cultural competence education or (b) the integration of cultural competence into existing courses within a program's curriculum. However, it should be noted that the cultural competence of graduate SLP students might be underdeveloped when there is not a clear, systematic mission by faculty members to embrace and incorporate diversity issues into training programs (Kohnert, 2013).

### Implications for Communication Disorders Specialists

Research has demonstrated that racial and ethnic minorities, in particular, tend to have poorer health outcomes, more chronic disease, and higher mortality than the White majority population (LaVeist, 2005). These issues exist in the profession of speech-language pathology with racial and ethnic minorities and lowincome non-minorities for example, being at greater risk for the precursors leading to stroke and the resultant disabilities of aphasia, motor speech impairments and swallowing disorders (dysphagia). While our profession has made tremendous advances in developing evidencebased treatments for neurogenic communication and related disorders, lack of access to these rehabilitation modalities by specific populations and the question of whether these treatments are culturally appropriate remain problematic. Moreover, in some instances, even when access to rehabilitation services is available, the lack of cultural competency among caregivers may compromise service outcomes (Payne, 2011). Further compounding the matter of health disparities among racially and ethnically diverse populations is the insidious interaction between epidemiologic data, language differences and access-resource barriers. For example, while the prevalence of Autism Spectrum Disorder has been reported as lower among Hispanic children compared to non-Hispanic White and African American youngsters, more recent studies suggest that the gap may be closing. In fact, rather than these patterns reflecting true differences, they are more likely the result of language barriers, lack of access to services, and public

health insurance coverage (Boyle, Boulet, Schieve, Cohen et al. 2011).

Currently, one in four young adults, or 17.9 million Americans, speaks a language other than English at home. That proportion is higher still in New York, New Jersey, Texas, New Mexico and Nevada (where it is about one in three) but is highest in California where it is almost one in two (U.S. Census Bureau, 2015). The U.S. Census Bureau projects that, by 2044, more than half of all Americans will belong to a minority group (any group other than non-Hispanic White alone) and by 2060, nearly one in five of the nation's total population is projected to be foreign born. Based on these data and, as previously stated, the fact that the majority of practicing SLPs are White and monolingual, it is clear that cultural competence in service delivery and increasing the racial and ethnic diversity of the speech-language pathology and audiology workforce are more and more important to eliminate long-standing disparities in the health status of people of diverse racial, ethnic, and cultural backgrounds; improve the quality of services and health outcomes; and meet legislative, regulatory, and accreditation mandates (ASHA, 2013).

### RECOMMENDATIONS

We conclude by providing the following list of recommendations, enumerated below, that are designed to undergird and reinforce existing information on this topic while also serving as a guide to foster future patient and evaluation. programmatic assessment. program development and research. We present these recommendations as a beginning point for discussion in the hope that researchers, and health education scholars will 'take up arms' to initiate and add to the scholarly literature and effective program development and implementation surrounding these topics. Having set this premise, it is recommended that subsequent scholarly endeavors address these topics:

- 1. Systematic research should be conducted to extend our understanding beyond informal discussions or anecdotal evidence of racial/ethnic disparities in SLP.
- 2. A theoretical framework for the study of racial disparities needs to be adopted to drive programmatic research that will ensure consistent terminology and outcomes used to determine the true impact of health disparities. Otherwise, a long list of descriptive, non-databased studies will emerge that will not advance the research through the stages outlined by Kilbourne, Switzer, Hyman, Crowley-Matoka, and Fine (2006). Such theoretically-driven approaches will culminate

with studies designed to develop, implement and evaluate interventions to reduce or eliminate disparities.

- 3. Although the focus of our paper is on racial/ethnic disparities, future research should also emphasize residence (rural vs urban) and socioeconomic contributors to healthcare access issues and resulting clinical outcomes.
- 4. Researchers should be encouraged to look beyond the traditional explanation of limited "access to care" to other contributors at the patient, provider and system levels.
- 5. Disparity issues must emphasize three points of concern 'access to care', 'service utilization and quality' and 'clinical outcomes'. Evidence from these areas will help unravel how racial/ethnic disparities and other factors mentioned previously contribute to clinical outcomes and perceptions of quality in speech-language pathology.

### CONCLUSIONS

We provided definitions of health disparities emanating from a populations model framework, a socioeconomic perspective, and a social justice model. We introduced and explored the issue of disparities in health-related outcomes within speech-language pathology with a special focus on the impact of racial/ethnic health disparities. Specifically, we reviewed the complex range of factors that potentially contribute to such disparities and offered an action plan that incorporates key elements to address those disparities. Researchers are encouraged to assess the multilevel determinants of communication health and healthcare disparities, including individual, provider, and system factors, to better understand the root (Kilbourne causes of disparities et al. 2006). Theoretically-driven research studies of potential and actual communication healthcare disparities are crucial to understanding this issue, thereby allowing for policy development and judicious deployment of resources designed to eliminate these inequities wherever they exist.

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### **ABOUT THE AUTHORS:**

**Charles Ellis, Ph.D., CCC-SLP**, is an Associate Professor in the Department of Communication Sciences and Disorders and Director of the Communication Equity and Outcomes Laboratory at East Carolina University. His research focuses on service utilization, cost analyses and outcome disparities among individuals with neurologically-based disorders of communication.

**Robert Mayo, Ph.D., CCC-SLP**, is a Professor in the Department of Communication Sciences and Disorders at The University of North Carolina at Greensboro. His areas of interest and research include fluency disorders, craniofacial anomalies, public perceptions of communication disorders and differences, and exploring disparities in access to communication healthcare services.

**Carolyn M. Mayo, Ph.D., CCC-SLP**, is Chief Executive Officer of Communications Research Evaluation and Wellness Specialists, LLC. Her areas of interest and research include evaluation of higher education health systems and organizations, personnel preparation, communication wellness and adult neurogenic communication disorders.

**Yolanda F. Holt, Ph.D., CCC-SLP**, is an Assistant Professor in the Department of Communication Sciences and Disorders at East Carolina University. Her research interests focus on dialect variation in African American English and Southern American English, sociophonetics, speech production and speech perception.

### CULTURAL COMPETENCE IN ASSESSMENT OF CULTURALLY AND LINGUISTICALLY DIVERSE POPULATIONS

Wilhelmina Wright-Harp, Ph.D. Howard University Washington, D.C.

#### ABSTRACT

Culturally appropriate and unbiased assessment of individuals from diverse populations is a longstanding issue that has had a major impact on the effective delivery of services in the fields of speech-language pathology and audiology. Professionals are directed to offer clinically competent services, but according to whose value system? The World Health Organization (WHO) has recognized in its International Classification of Functioning, Disability and Health (ICF, WHO, 2001) that environmental factors including aspects of culture, language, race, and ethnicity directly influence the ability of individuals with impairments of body structure and function to participate in life activities. Therefore, understanding and appreciating the influence of these factors is critical if we are to utilize best practice assessment approaches when evaluating individuals from culturally and linguistically diverse (CLD) populations. The purpose of this article is fourfold: 1) to address the changing demographics of the U.S. and growing demand for SLPs to be both clinically and culturally competent in the assessment of CLD populations; 2) to discuss factors to consider in the assessment of CLD populations; 3) to present types of test bias and its negative impact on differential diagnosis of diverse populations; and 4) to offer alternative approaches to standardized tests for assessment. Although the focus, of this article is on the delivery of services by professionals in the fields of communication sciences and disorders to adults with neurogenic and communication disorders from diverse populations, the issues addressed related to cultural competency are relevant to all health professionals.

**KEY WORDS:** Evidence-based assessment, test bias, cultural competency, culturally and linguistically diverse populations

### CULTURAL COMPETENCE IN ASSESSMENT OF CULTURALLY AND LINGUISTICALLY DIVERSE POPULATIONS

Wilhelmina Wright-Harp, Ph.D.

Howard University Washington, D.C.

### **INTRODUCTION**

A ssessment may be defined as "the process of making a judgment or forming an opinion, after considering something or someone carefully" MacMillian (2015). If we are to provide culturally competent assessment, a key to this process is the careful consideration of the influence of cross-cultural differences in communication styles, views toward health, illness, and disability; the nature and prevalence of communication disorders; and language differences that affect the diagnostic evaluation process (Wyatt, 2002).

Culturally appropriate and unbiased assessment of individuals from diverse populations is a longstanding issue that has had a major impact on the effective delivery of services in the fields of speech-language pathology and audiology (Taylor, K. Payne, 1983; Seymour, Bland-Stewart & Green, 1998; Vaughn-Cooke, 1986; J. Payne, 1995, 2013, 2014; Stockman, 1996, 2000; Battle, 1998, 2015; Konert, Kennedy, Glae, Kan & Carney, 2003; Wallace, 1997; Oualls, 2002, 2015; Reveron, 1998;Wright-Harp, 2013, 2014, 2015, Wyatt, 2002, 2015). As professionals involved in the assessment and treatment of diverse populations, we must be cognizant of our attitudes within the context of serving populations from diverse cultures. Moreover, to be clinically and culturally competent (ASHA, 2004, 2014; Payne, J. & Wright-Harp, 2014, Wright-Harp, 2015), we must be aware of the projected changes in the diversity of our caseloads and knowledgeable of the impact that culture, environment and language have on the assessment process. The issue is even more compounded by the fact that professionals in the field of communication sciences and disorders (CSD) are expected to adhere to a code of ethics that includes demonstration of cultural competence (ASHA, 2013) yet, frequently report that they feel unprepared to provide services to the rapidly growing population of clients from CLD populations (ASHA, 2015 Healthcare Survey; Kritikos, 2003). Thus, given the fact that speech-language pathologists (SLPs) have an important role in providing services to CLD populations

across the lifespan in both the medical and education systems, the issue of culturally appropriate assessment affects the field as a whole.

### The Changing Demography

Based upon the Census data (2015), the U.S. population is rapidly becoming more diverse than ever before. The changing demographics are due to the immigration of individuals from countries around the world as well as countries whose borders are adjacent to the U.S. (Battle, 2015). Consequently, the term "minority" previously used to describe certain racial groups and the Hispanic ethnic group, is becoming obsolete. The current term for minority is "emerging majority. According to the 2010 U.S. Census, over 20% of Americans speak a language other than English in the home, with Spanish, Chinese, and French being the languages most commonly spoken, aside from English (Dukhovny, E. & Kelly, B. 2015).

According to population projections in the United States (U.S. Census, 2012), African Americans (non-Hispanic), Asian American/Pacific Islanders, Hispanics (all ethnic groups), and American Indian/Alaska Natives will grow in population at a more rapid rate than that of non-Hispanic whites over the next 50 years (J. Payne, 2014). Moreover, the percentage of African Americans and races from countries other than Europe is projected to increase from 10.2% in 1990 to 15.3% in 2020 and to 21.3% by 2050 (Vincent & Velkoff, 2010).

Over the next several decades, the impending demographic changes in the United States, brought about largely by immigration, will change the country's population characteristics in a dramatic way. The non-Hispanic white population is projected to peak in 2024, at 199.6 million, up from 197.8 million in 2012. Unlike other race or ethnic groups; however, the non-Hispanic white population is projected to slowly decrease, falling by nearly 20.6 million from 2024 to 2060 (Colby & Ortman, 2014).

In contrast to the decline in the non-Hispanic white population, projections for Hispanic, African American

and Asian groups are projected to show a dramatic growth. For example, the Hispanic population will more than double, from 53.3 million in 2012 to 128.8 million in 2060. Consequently, by the end of the period, nearly one in three U.S. residents would be Hispanic, an increase from about one in six today. Additionally, the African American (AA) population will also show a steady increase from 41.2 million to 61.8 million over the same period. Thus, African Americans would increase from 13.1 percent of the total U.S. population in 2012 to 14.7 percent in 2060. Demographic projections for the Asian population show that this population/group will more than double, from 15.9 million in 2012 to 34.4 million in 2060, with its share of the nation's total population climbing from 5.1 percent to 8.2 percent in the same period.

Among the remaining race groups, American Indians and Alaska Natives would increase by more than half from now to 2060, from 3.9 million to 6.3 million, with their share of the total population edging up from 1.2 percent to 1.5 percent. During this same period, the Native Hawaiian and Other Pacific Islander population is expected to nearly double, from 706,000 to 1.4 million. Moreover, the number of people who identify themselves as being of two or more races is projected to more than triple, from 7.5 million to 26.7 million over the same period. Consequently, with the continued increase among these minority populations, the U.S. is projected to become a *majority-minority* nation for the first time in 2043. (Colby & Ortman, 2014). These demographic changes are particularly relevant to SLPs making it even more critical that we serve these emerging majority groups in a more culturally competent manner. To accomplish this goal, we must understand how crosscultural differences in communication styles; views toward health, illness and disability; the nature and prevalence of communication disorders and language differences affect the diagnostic evaluation process. This applies to all components of the process which include gathering the case history, test administration, interpretation of test results, differential diagnosis, and report writing. (Wyatt, 1997).

### Demographic Shifts and the Graying of America

By 2060, the U.S. population will be considerably older and more racially and ethnically diverse. Based upon U.S. Census projections a significant increase in the number of older ethnic adults (65 years and older) and the oldest old (85 years and older) will occur largely due to the aging of the baby boomer population (Colby & Ortman, 2014). Also for the first time, the older population is projected to outnumber those who are under 18 years of age. According to projections, the 65 and older population is expected to more than double between 2012 and 2060, from 43.1 million to 92.0 million. As a result, the older population would represent just over one in five U.S. residents by the end of 2060, up from one in seven in 2012. Of those age 65 and older in 2060, 56.0% are expected to be non-Hispanic white, with 21.2% Hispanic and 12.5% non-Hispanic persons of African descent making up the majority of persons of color (U.S. Bureau of the Census, 2014). Census projections also indicate that the increase in the population ages 85 and older would be even more dramatic. This segment of the elderly population is projected to more than triple from 5.9 million to 18.2 million, reaching 4.3 percent of the total population in 2060.

Given these national population projections, it seems reasonable to assume that the number of culturally and ethnically diverse aging adults with language and cognitive disorders secondary to neurological damage will continue to rapidly increase as well. The disparities in health care to elder minorities have been documented such as limited access to services due to lack of transportation, language barriers, low socioeconomic status, and distrust of health care providers (Battle, 2015; CDC, 2015; Payne, 2014, Wallace, 1997). However, with the recent passage of the Affordable Care Act (2013), this previously underserved population will now have more access to speech-language pathology services, making it even more imperative that professionals are both clinically and culturally competent to appropriately evaluate and diagnose individuals from diverse populations (J. Payne, 2014). Over the past decade, the American Speech-Language Hearing Association (2005, 2007, 2011a) has addressed health disparities and cultural competence in position papers that relate to ethical considerations in the assessment of diverse populations. Yet, SLPs still are not equipped to provide evidence based assessment (ASHA SLP Health Care Survey, 2015); therefore, the graving of America and demographic shifts resulting in an increased population of 'minorities' have major implications for the fields of speech-language pathology and audiology.

#### Prevalence of Communication Disorders Among Diverse Populations

"Prevalence" of social communication disorders refers to the number of people who are living with social communication disorders in a given time period. (ASHA, 2011). If prevalence is known for a specific disorder, there

are implications for understanding risk factors as well as training professionals, planning for clinical services, and establishing policy. Current prevalence estimates are based upon data on the general population. Although, the paucity of reliable data on incidence and prevalence of communication disorders among individuals from ethnic, racial and culturally diverse populations in the United States makes this a challenge. If the prevalence of communication disorders is consistent with that of the general population, ASHA estimates that 10 percent or 6.2 million individuals in the U.S. population has a disorder of speech, language or hearing (ASHA, 2011; Battle, 2015).

Likewise, if we examine recent prevalence data on neurological conditions that are the associated causes of communication disorders among adults, we can estimate the prevalence among various diverse populations. Due to the increasing numbers of elderly adults as well as the increase in the diversity of this population, it is likely that there will be a significant increase in disabilities including communication, cognitive and swallowing disorders among CLD populations. It is estimated that 21 in every 1000 African Americans between ages 45 to 65 years have a communication disorder. Due to the high prevalence of chronic conditions such as hypertension, heart disease and diabetes that adversely affect the cardiovascular system, the prevalence of neurologically based communication disorders is higher among African Americans.

According to the Center for Disease Control (CDC, 2015), about 800,000 people in the United States have a stroke each year. (CDC, 2015; Mozzafarian, et al., 2015). However, the rate of stroke death declined by 38.5% between 1999 and 2011, from 61.6 to 37.9 deaths per 100,000 (age adjusted), and varied by race and ethnicity. For example, as shown in Figure 1, in 2010, American Indian or Alaska Native population had the lowest rate of stroke death among all populations with 27.1 deaths per 100,000 (Healthy People 2020). The CDC (2015) reported stroke death mortality rates are as follows:

- 1. American Indian or Alaska Native population = 27.1 deaths per 100,000
- 2. Hispanic or Latino population = 30.7 deaths per 100,000;
- 3. Asian or Pacific Islander population = 31.6 deaths per 100,000;
- 4. Non-Hispanic white population = 36.7 deaths per 100,000;
- 5. Non-Hispanic black population = 52.3 deaths per 100,000.

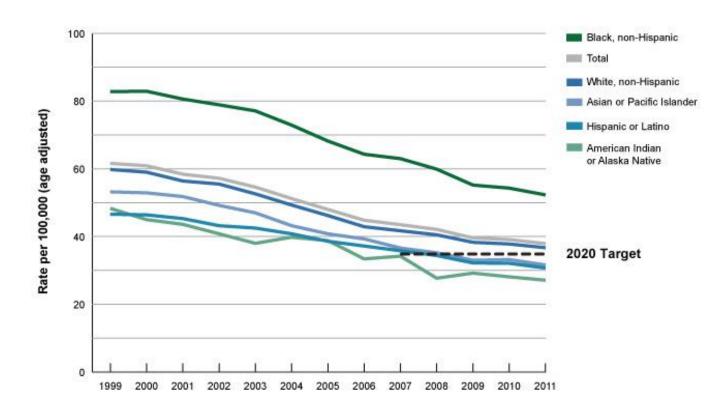


Figure 1. Incidence of Stroke Deaths 1999-2011.

#### Figure 1: Incidence of Stroke Deaths 1999-2011

SOURCE: National Vital Statistics System—Mortality (NVSS-M), CDC/NCHS.

Healthy People 2020. Revised: Monday, August 25, 2014

 $Retrieved \ on \ 6.20/15 \ from: \ http://www.healthypeople.gov/2020/topics-objectives/topic/heart-disease-and-stroke/national-snapshot$ 

Although the mortality rates of African-Americans and other racial/ethnic groups following a CVA decreased, during the period from 1999 to 2011 (See Figure 1), a significant number of these populations survive and live with functional impairments including language, cognitive and swallowing disorders that greatly impact their lives. Moreover, those in the health disparity populations are most likely to experience earlier and more severe CVAs due to the prevalence of chronic diseases, such as heart disease, hypertension, cavernous venous malformations (CVMs) and diabetes. This population also is more likely to have a higher incidence of lifestyle contributors such as alcoholism and obesity that are risk factors which may predispose these individuals to suffer more severe communication disorders.

The incidence for stroke and other chronic illnesses that affect language and cognition is projected to double every decade after age 55 (American Heart Association, 2007). It is also reported that specific chronic and acute disorders, such as stroke, hypertension, and diabetes affect certain nonwhite populations at higher rates. For example, between 2007 and 2012 hypertension was the number one chronic condition in African Americans with an 83% prevalence rate compared to 58% prevalence rate in Whites and a 54% rate in Hispanics. Likewise, AAs had a higher prevalence of diabetes at 28% compared to

24% in Hispanics and 14% in Whites (Mozaffarian, 2015).

### Professional Issues – Clinical and Cultural Competence

Speech, language and communication are an integral part of an individual's culture. According to Keesling (1979), culture can be viewed as a system of competencies shared in broad design and deeper principles and varying among individuals. It consists of what an individual knows, believes and thinks about his/her world. It is more than a collection of symbols fit together by the analyst. It is a system of knowledge sharpened and constrained by the way the human brain acquires, organizes and creates internal models of reality. Culture provides a system of knowledge that allows individuals of a cultural group to know how to communicate with one another. Moreover, the relationship between culture and communication is reciprocal (Keesling, 1979). In other words, culture and communication have mutual components that influence "Therefore, one cannot understand each other. communication by a group of individuals without a thorough understanding of the ethnographic and cultural factors related to communication in that group. These factors are intricately embedded in the historical, geographic, social and political histories, which bind a group, give it a sense of peoplehood, and give it ethnic identity."(Keesling, 1979; Battle, 2015). Finally, Riquelme (2013) states, "Understanding, applying, and believing in concepts of culture and its impact on all we do as persons and as professionals is of great importance if we are to be socially and professionally responsible members of this society and this discipline" (pp. 42).

### **Cultural Competence**

It is imperative that we believe in understand, and apply the concepts of culture and their impact on everything we do as professionals if we are to be responsible members of our society and discipline. Unless we genuinely care for and show interest in people, the assessment process may break down and result in misdiagnosis or negatively influence treatment outcomes (Riguelme, 2013b). According to the Office of Minority Health (2013), cultural competence is "a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. Given the relationship between communication and culture, it is essential that SLP and AUD professionals not only be clinically competent, but also culturally competent. It is the position of the American Speech-Language-Hearing Association (ASHA) that professional competence in providing speech-language-hearing and related services requires cultural competence (ASHA, 2004, 2005, 2013). To do necessitates that professionals develop so, an understanding of the social, cultural, linguistic and differences that exist when evaluating cognitive individua ls from diverse cultural and linguistic backgrounds (J. Payne & Wright-Harp, 2014).

Cultural competence involves understanding and appropriately responding to the unique combination of cultural variables—including ability, age, beliefs, ethnicity, experience, gender, gender identity, linguistic background, national origin, race, religion, sexual orientation and socioeconomic status-that the professional and client/patient/student bring to interactions.

Cross et al., (1989) defined cultural competence "as a set of congruent behaviors, attitudes, and policies that come together in a system agency or amongst professionals and enables those organizations to work more effectively in cross cultural situations" (p.4). In the delivery of services to adults with neurogenic communication disorders, cultural competence entails "understanding the importance of social and cultural influences on the patient's beliefs, health, and behaviors, as well as how these factors interact at multiple levels of the healthcare delivery system with the long-term goal of developing evidence based practice (EBP) interventions that address these issues to insure effective healthcare delivery to diverse patient populations (Betancourt, Carrillo, Fiempong, Park & Green, 2003). Therefore, developing cultural competence is both a complex and dynamic process that entails ongoing self-assessment and continuous expansion of one's cultural knowledge. It has been described by Dixon (2014) as an evolving process, beginning with an understanding of one's own culture, continuing through interactions with people from various cultures, and extending through one's own development of knowledge. See Table 1.

#### Table 1. Components of Cultural Competence.

COMPONENTS	DESCRIPTION
Valuing Diversity	Developing an awareness and acceptance of differences.
Self-Assessment	Conducting a cultural self-assessment
Cultural Dynamics	Being conscious of the dynamics inherent when cultures interact.
Institutional Cultural Knowledge	Integration of cultural knowledge within individuals and systems.
Adapting	Being able to adapt to diversity and the cultural contexts of the communities being served.

Reference: Riquelme, L. (2013). Cultural competence for everyone: A shift in perspectives. *Perspectives on Gerontology*, *18*(2), 42-49.

### Factors to Consider in Assessment of CLD Populations

When evaluating CLD populations, SLPs must take into consideration several factors such as language (content, form an use), voice quality, fluency and prosody that are influenced by the individual's use of a minority dialect or language. For example, the phonemic, allophonic, syntactic, morphological, semantic, lexical, and pragmatic characteristics of a minority language cannot be adequately assessed or treated without a comprehensive knowledge of that language. Furthermore, without the ability to test individuals in the minority language, auditory discrimination and speech reception thresholds may be difficult to assess.

Voice qualities, such as harshness, breathiness, loudness, pitch, and the production of clicks and glottal stops, vary across languages. These factors may make it difficult to rule out vocal pathology when the examiner is unfamiliar with the vocal characteristics common to a given language. For example, Mayo & Grant (1995) report differences in fundamental frequency, perturbation and vocal tract resonance between African Americans and White American males. Thus clinicians should use a family centered ethnographic approach to assessment to gain an understanding of what constitutes normal voice pitch and quality among family members of the same gender (Mayo & Grant; 1995; Mayo, et.al. 1996).

Dysfluencies, false starts, filled and silent pauses, and other behaviors may be exhibited by a bilingual speaker due to lack of familiarity with English. Thus, differential diagnosis of true stuttering from normal dysfluency may be difficult if the examiner is unfamiliar with the client's use of the minority language. Identification of suprasegmental or prosodic problems is extremely difficult if the examiner is not familiar with the prosodic characteristics of the minority language. Even when the examiner is familiar with the given language, dialect differences within that language may be a confounding variable in assessment. As often is the case in assessment of other communication disorders, standardized tests for evaluation of fluency disorders typically do not include culturally relevant items in the clinical protocol (Robinson, 2015)

There are also cultural variables that may influence how speech-language pathology and audiology services are accepted by speakers of a minority language. Differences between the cultures of diverse populations and the general population in traditions, customs, values, beliefs, and practices may affect service delivery. Thus, professionals in the fields of communication sciences and disorders must provide services with consideration of such cultural variables, in addition to consideration of language differences (ASHA, 2004).

### Challenges in Assessment of CLD Populations

Although, there have been numerous discussions as well as an increased focus on research related to best practices in the assessment of children from CLD populations, there are still major challenges in the assessment and

delivery of services to older adults with neurogenic language disorders from diverse racial/ethnic and cultural backgrounds. According to Horton-Ikard, Munoz, Tate, and Keller-Bell (2009), there are too few resources or too little evidence with which to educate current and future practitioners about cultural diversity and cultural competence. This is due in large part to the fact that only a small percentage of academicians in the field of communication sciences and disorders specialize in multicultural research and teaching, and there are a limited number of academicians who have identified multicultural competence as an area of specialty. This lack of information and resources infused in professional training programs affects a significant number of professionals in speech-language pathology. For example, more than one-third of certified speechlanguage pathologists currently work in health care settings, including hospitals, speech and hearing clinics, home health agencies, skilled nursing facilities, and other. similar settings. The largest number, 24,080, practice in hospitals and skilled nursing facilities, where they are most likely to work with older persons with neurogenic language disorders (ASHA, 2011b; 2011c; 2011d).

To further illustrate this point, in a 2015 ASHA SLP Health Care Survey of 1,711 respondents, 6.6% felt that they were "not at all qualified to address cultural and linguistic influences on service delivery and outcomes." Respondents represented six different types of health care settings - 2.8% of 143 respondents worked in rehab hospitals, 2.8% of 71 respondents worked in pediatric hospitals, 5.8% of 478 respondents in outpatient clinics, 7.0% of 378 respondents worked in home health care, 8.6% of 209 respondents worked in Medical/VA/ LTAC Hospitals, and 9.1% of 408 respondents working in Skilled Nursing Facilities. Although no respondents felt that they were not qualified at all, only 11.9% of the total 1,711 respondents rated themselves as "very qualified" to address cultural and linguistic influences on service delivery and outcomes. Although these survey results represent only a small sample of the overall ASHA membership, the respondents' comfort level for working with individuals from CLD populations further illuminates the need for academic institutions and professional organizations to continue educating future professionals to become not only clinically competent, but also culturally competent in their delivery of services to diverse populations (Payne, J & Wright-Harp, 2014).

#### **Evidenced Based Practice**

Professionals in the field of communication sciences and disorders (CSD) are directed to offer "high-quality" services, including referrals when necessary, but according to whose value system? The World Health Organization (WHO) has recognized in its International Classification of Functioning, Disability and Health (ICF, WHO, 2001) that the ability of individuals with impairments in body and structure and function to participate in life activities is influenced by environmental factors that include aspects of culture, language, race, and ethnicity.

Therefore, understanding and appreciating the influence of these factors is critical if we are to provide appropriate evidence-based assessments.

Over the past decade, interest in evidence-based practice (EBP) has steadily increased in the fields of communication sciences and disorders as well as other health fields. At the center of this movement has been the importance of providing empirical evidence to support various assessment and therapeutic approaches (Satake, 2014). Toward this end, Satake (2014) states:

"... in this EBP era, all clinical professionals, not only clinical researchers but also clinical practitioners, are almost required to have the substantial knowledge of (1)how to measure the strength of clinical evidence accurately, and (2) how to interpret and report the findings. These are the essential components of EBP that will lead to improvement of one's scientific literacy. Scientific literacy is fundamental to the understanding of research methodology as well as the statistical assumptions and techniques used for the analysis and interpretation of data. In the absence of such understanding, it will be impossible for professionals to stay abreast of a rapidly flowing and ever-changing stream of information related to the study and treatment of speech, language, and hearing disorders. What is ultimately at stake is the credibility of the field to function as an independent discipline that presumably prides itself on contributing to a fund of knowledge leading to scientific advancements, not only in its own specialty areas but also for its contributions to the arena of the health science specialties at large. In the absence of such credibility, we will practice "unethically" by failing to provide the best possible services for the people we serve."

How can we ensure that our treatment plans are effective? The fundamental basis of providing EBP is culture fair assessment. SLPs must learn how to accurately evaluate the results of a diagnostic test in order to correctly diagnose the presence (or absence) of a specific disorder.

According to ASHA's Executive Board (2004), the goal of EBP is the integration of: (a) clinical expertise/expert

opinion, (b) external scientific evidence, and (c) client/patient/caregiver values to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve. The trilateral principles that form the bases for EBP are illustrated in Figure 2.

### Figure 2. Principles of Evidence-Based Practice.



Source: American Speech-Language-Hearing Association. (2005). Evidence-based practice in communication disorders [Position Statement]. Available from www.asha.org/policy.

Because EBP is client/patient/family centered, a clinician's task is to interpret best current evidence from systematic research in relation to an individual client/patient, including his/her preferences, environment, culture, and values regarding health and well-being. Ultimately, the goal of EBP is providing optimal clinical service to that client/patient on an individual basis. Thus,

EBP is a continuing process, involving a dynamic integration of ever-evolving clinical expertise and external evidence in day-to-day practice (ASHA - EBP, 2004). See Table 2 for suggestions on how audiologists and speech-language pathologists can make clinical practice evidence-based.

 Table 2. EBP in Assessment of CLD Populations.

### Steps to EBP Assessment Procedures

- Recognize the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with best current research evidence and their clinical expertise in making clinical decisions;
- Acquire and maintain the knowledge and skills that are necessary to provide high quality professional services, including knowledge and skills related to evidence-based practice;
- Evaluate prevention, screening, and diagnostic procedures, protocols, and measures to identify maximally informative and cost-effective diagnostic and screening tools, using recognized appraisal criteria described in the evidence-based practice literature;
- Evaluate the quality of evidence appearing in any source or format, including journal articles, textbooks, continuing education offerings, newsletters, advertising, and Web-based products, prior to incorporating such evidence into clinical decision making; and
- Monitor and incorporate new and high quality research evidence having implications for culture fair practice.

Source: Introduction to Evidence-Based Practice: What it is (and what it isn't) retrieved from ASHA at <a href="http://www.asha.org/members/ebp/intro/">http://www.asha.org/members/ebp/intro/</a>

### Issues to Consider with the Use of Standardized Tests

One of the primary methods used to systematically identify adults who exhibit communication disorders and distinguish them from individuals who fall within the norm are standardized or norm-referenced tests. The appeal of such tests is that they are believed to serve as objective and quantitative forms of measurement which may reveal significant distinctions between various groups (Molrine & Pierce, 2002).

Despite the increasing diversity of our clinical SLPs continue to rely on formal, populations, standardized English tests more often than informal (alternative) assessment procedures when evaluating Use of standardized tests has CLD populations. continued despite the fact that: the majority of standardized language tests are normed on nonHispanic whites who are speakers of Standard English making them biased against members of CLD populations (Wyatt, 2002, 2015; Wright-Harp, 2014); the literature is unequivocal in its denunciation of this form of testing for diverse racial/ethnic and language populations (Wallace, 1997; Battle, 2002; Roseberry-McKibbin, 2007, J. Payne, 2013, 2014; Vaughn-Cooke, 1989; Wyatt, 2002, 2015;

and Legislation and legal decisions strongly discourage their exclusive use (Caesar & Kohler, 2007).

Presently, many of the standardized tests utilized to evaluate language and cognitive impairments are limited related to content validity for use with culturally and linguistically diverse (CLD) populations (Turkstra, Coelho, & Ylvisaker, 2005). Moreover, concerns exist regarding the potential bias of current standardized tests in terms of cultural relevance, age of population, and exclusion of diverse racial/ethnic groups in the normative sample (Wright-Harp, Mayo, Martinez, Payne, J., Lemmon (2013, 2012); Brown & Wright-Harp, 2011; Wright-Harp, 2006, 2003a, 2003b; Payne, K., 1997; Taylor & Lee, 1987).

However, factors related to cultural and linguistic diversity may affect the clinician's ability to delineate communication performance profiles for individuals from diverse cultural groups with the same level of accuracy and completeness possible for individuals from the general population (K. T. Payne, 1997; Taylor & Payne, 1983). Thus, when cultural bias exists, the use of formal tests can lead to misdiagnosis, errors in calculation of severity ratings and ultimately over-referrals.

According to Satake (2014), regardless of the numerous applications of diagnostic test findings, the primary objective of any such test is to detect a particular disorder when present. Thus, a good diagnostic test is designed to identify people who have the particular disorder of interest, while excluding those who do not. The challenge faced in assessment of CLD populations is that standardized tests that have served as the "gold standard" are not designed to accurately diagnose the presence of a disorder or difference in individuals from diverse populations.

### Standardized Tests - Reliability, Validity, Sensitivity and Specificity

When selecting tests to use for assessment of diverse populations, four measures must be considered: *reliability, validity, sensitivity* and *specificity*. Reliability, validity, sensitivity, and specificity in the broad sense of obtaining accurate and usable results depends on all the ingredients of the assessment process, including the test itself, the examiner, and the relationship between examiner and the individual being evaluated (Reynolds & Gutkin, 1982). Standardized tests can be useful tools for differential diagnosis of communication disorders; however, when any of these four components is deficient, the results have little or no meaning.

**Reliability** of a test can be defined as the extent to which an instrument yields consistent, stable, and equivalent results over repeated observations or measurements under the same conditions every time (Roseberry-McKibbin & Hedge; 2006). Therefore, a test that has reliability yields the consistent scores over repeated administrations. Reliability is typically assessed using one of the following three methods: test-retest, alternate form and internal consistency.

**Test-retest reliability** refers to the consistency of measures/scores when the a test is administered twice to the same individual (Roseberry-McKibbin & Hedge; 2006). In test-retest reliability studies, the test is administered to the same group at two different times with a reasonable interim of time between test administrations. Correlation coefficients are then computed to determine if the results are stable and whether they correlate. When the coefficient is high, (i.e. close +1.0), it is considered to be reliable. If it is low (i.e., below 0.70), the test-retest reliability is considered too low.

Alternate form reliability refers to the consistency of measures when two versions of the same test are administered to the same person or group (RoseberryMcKibbin & Hedge; 2006). It is typically measured by constructing two versions of the test, then administering it to the same group twice. Scores on the two forms should show a high positive reliability coefficient (correlation). The final type of reliability is *internal consistency* which can be defined as the degree to which every test item measures the same construct. Internal consistency can be measured using a split-half measure which would involve dividing a test into two halves (odd versus the evennumbered items). Then correlating scores on each half. If the test has internal consistency, the scores on the two halves should show a high positive reliability coefficient (correlation).

Validity of a test refers to the consistency of the results of the measure. Two forms of test validity are internal and external validity. Internal validity is the extent to which a test measures what it is supposed to measure. In contrast, the *external validity* of a test refers to how well it is capable of being generalized to other individuals in the population for which it was designed. There are 3 additional standards or types of evidence for test validity: construct, content, and criterion validity. Criterion validity provides quantitative evidence on the accuracy of a test. It is a measure of whether test results match with other known measures of a characteristics (the criterion)? There are two (2) types of criterion validity: concurrent, and predictive. Concurrent validity is the extent to which a new test correlates with an established test known to have validity (Roseberry-McKibbin & Hedge; 2006). Determining concurrent validity would involve comparing the results of a test with another indicator (criterion) at the same time. For example, the Western Aphasia Battery-Revised (WAB-R) Kertesz, 2006), could be compared against the more established Boston Diagnostic Aphasia Exam (BDAE-3) (Goodglass, Kaplan & Barresi, 2000). If the WAB-R correlates with the BDAE-3, then concurrent validity exists. *Predictive validity* refers to the accuracy with which a test predicts future performance in a related area. An example, is the Graduate Record Exam which has been used to predict performance in graduate school. In the fields of communication sciences and disorders, the GRE has served as a criterion for admission to master's degree programs in speech-language pathology. In spite of its widespread use, several studies have shown that the test is not an accurate predictor of academic success and limits access to graduate school for many individuals, particularly women and diverse populations (Hartnett & Payton, 1977; Scott & Shaw, 1985; Onasch, 1994: Jacobson, 1993; and Morrison, T. & Morrison, M.,

1995).). The Pearson correlation coefficient is often used to indicate the strength of the performance in both predictive and concurrent validity.

Sensitivity of a test refers to the probability that the test result is positive when a disorder actually exists (Satake (2014). In other words, the sensitivity of a clinical test refers to the ability of the test to correctly identify those patients with the disease, i.e. a true positive (Lalkhen & McCluskey, 2008). A test is considered to have high sensitivity when the proportion of people previously diagnosed with a disorder according to a gold standard or reference test, score in the positive (or affected) range on a different or index test. A test that has high sensitivity, will have a *low false-negative rate* that is the probability that an individual tests out as negative, but actually should be diagnosed as having a disorder. In such instances, the test result will seldom indicate that the disorder is not present when in fact it exists. For example, an aphasia test that has 100% sensitivity, correctly identifies all patients with the disorder. If the test has 80% sensitivity, it detects 80% of individuals with the disorder (i.e., true positives); however, 20% who have the disorder are undetected (i.e., false negatives). For example, a new test to diagnose apraxia of speech (AOS) is administered to 100 adults who have previously been diagnosed as individuals with the disorder. Of this group, 85 obtain a score on the new test that identifies them as having AOS. In this sample, the sensitivity of the new test is 85/100 =0.85 (or 85%), indicating that the new test only failed to identify15 individuals with AOS.

Specificity of a test may be defined as the probability that the test result is negative when in fact a disorder does not exist, that is a true negative (Lalkhen & McCluskey, 2008). When the proportion of people previously identified as free of a particular disorder score in the negative (normal) range on a new diagnostic test, specificity is rated as high. Thus, a test with 100% specificity correctly identifies all patients without the disorder (i.e., true negative). While a test with 80% specificity correctly identifies 80% of patients without the disease as test negative, but the remaining 20% who are without the disorder are incorrectly identified as test positive (i.e., false positives) (Lalkhen & McCluskey, 2008).

A test that has high specificity has a low false-positive rate; therefore, it will rarely indicate the presence of a disorder when it does not exist. According to Satake (2014), "Although test sensitivity and specificity are important preliminary steps in constructing a diagnostic test, these indices alone have limited application to actual diagnosis and clinical decision making. More specifically, although these values may be used to estimate the accuracy of a particular diagnostic test, it is the predictive values of a test that actually have practical/clinical values in detecting a disorder or disease."

### Types of Test Bias

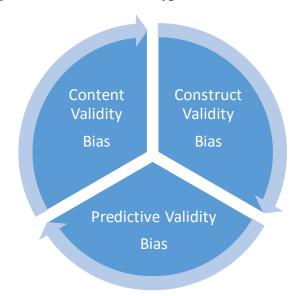
When evaluating individuals from diverse populations, it is critical that the examiner consider all potential types of test bias. Standardized tests are considered to be biased if either the test design (e.g. linguistic bias or format bias), the dynamics of the test situation (e.g., situational bias) or the way in which the results are interpreted (e.g. value bias), systematically identifies a disproportionate number of certain groups as disordered more often than others. Some examples are 1) racial/ethnic background (African Americans, Hispanics, Asians); 2) socioeconomic status (LSES, MSES, USES), 3) language (second language learners and those who are bilingual and multilingual). and 4) acculturation, that is, those less acculturated to the cognitive style or cultural norms of the majority population (Abbott, 2014). Payne & Wright-Harp (2014) state that:

Assessment must be undertaken with consideration for each patient's educational background, culture, language, and experiences. Members of nonwhite ethnic groups may be penalized for use of linguistic features and/or cognitive styles influenced by features of their dialect, language, or cultural background. Although some assessments are in other languages, they may not represent the various dialects of those languages and may not have been translated by speakers who are native to the languages. (p. 45)

Therefore, it is vital that professionals become familiar with the various facets of test bias to prevent increasing the risk of false positives. We must ask whether our diagnosis may be attributed to the particular characteristics of the population being evaluated, the content validity of the test, or the test environment. As the U.S. population becomes more diverse, and tests are increasingly used for differential diagnosis and subsequently treatment design, the question of bias-and how to eradicate it, is an essential focus of our role as SLPs and AUDs. If we are to effectively address the growing health disparities that continue to negatively impact the wellness and the quality of life of individuals from diverse populations, we must critically analyze our assessment tools.

Abbott (2014) states that test bias is closely related to the issue of test fairness. In other words, whether the social applications of test results have consequences that will unfairly advantage or disadvantage certain groups. Standardized tests used to predict an individual's potential success in college (i.e., college admissions exams) often raise concerns about both test bias and test fairness, given their significant role in determining access to institutions of higher education, particularly elite colleges and universities. An example is the difference in performance of males and females on college-admissions exams. The fact that female students tend to score lower than males, even though female students tend to earn higher grades in college on average than males is possibly due to gender bias in test design. This pattern may suggest evidence of predictive-validity bias.

Three general categories of test bias include: constructvalidity bias, content-validity bias and predictive validity bias (see Figure 3).



### Figure 3. Three Common Types of Test Bias.

Each is described below:

**Construct-validity bias** occurs when a test fails to accurately measure the specific concepts for which it is designed to measure. An example, is the Boston Naming Test, which has been shown to penalize African Americans and individuals who speak English, but live in countries other than the U.S. Pedraza, Graff-Radford, and Lucas (2009) investigated performance on the BNT by older African Americans and non-Hispanic whites and found that six items ("dominoes," "escalator," "muzzle,"

"latch," "tripod," and "palette") were identified to represent the strongest evidence for race/ethnicity-based differential item functioning. Similar findings were noted by Kennepohl, Shore, Nabors, and Hanks (2004), who observed that differences in cultural experience may be important factors in the neuropsychological assessment, including the BNT, of African Americans following traumatic brain injury. Other findings strongly suggest that the BNT needs modification to be effective for persons who speak English but live in other countries (Barker-Collo, 2001).

**Content-validity bias** exits when items of a test are comparatively more difficult for one group than for others. It can occur when members of a subgroup, (e.g., African Americans, Asians, Hispanics) have not been given the same opportunity to learn the material being tested, when scoring is unfair to a group (for example, the answers that would make sense in one group's culture are deemed incorrect), or when questions are worded in ways that are unfamiliar to certain students because of linguistic or cultural differences. *Item-selection bias*, a subcategory of content validity bias, occurs when specific test items are included that are more suited to one group's language and cultural experiences than another.

**Predictive-validity bias** (or bias in **criterion-related validity**) refers to a test's accuracy in predicting how well a certain student group will perform in the future. A test would be considered "biased" if it predicted future test performance better for one group than another.

Two examples are the Boston Naming Test (BNT; Kaplan, Goodglass, & Weintraub, 1983; Nicholas, Brookshire, MacLennan, Schumacher, & Porrazzo, 1988) and the Ross Information Processing Assessment-2 (RIPA-2; Ross-Swain, 1996), have reported examples of content validity bias. Pedraza, Graff-Radford, and Lucas (2009) investigated performance on the BNT by older African Americans and non-Hispanic whites and found that six items ("dominoes," "escalator," "muzzle," "latch," "tripod," and "palette") were identified to represent the strongest evidence for race/ethnicity-based differential item functioning. Similar findings were noted by Kennepohl, Shore, Nabors, and Hanks (2004), who observed that differences in cultural experience may be important factors in the neuropsychological assessment, including the BNT, of African Americans following traumatic brain injury. Other findings strongly suggest that the BNT needs modification to be effective for persons who speak English but live in other countries (Barker-Collo, 2001).

Davis and Wright-Harp (2012a, 2012b) and Wright-Harp (2006) also report that the RIPA-2 lacks adequate test sensitivity when used to evaluate African Americans with mild traumatic brain injury (mTBI). In a study of 40 participants (20 normal and 20 mTBI adults), these investigators reported a high rate of false positives among the normal participants as well as content validity bias based upon performance of the mTBI group on interpretation of proverbs used to evaluate figurative language skills. Their findings indicate that the RIPA-2 when used to evaluate cognitive skills of African Americans with mTBI has an increased risk of over rating the test severity of this group.

#### Sociocultural Bias in Assessment

Sociocultural bias is the phenomenon of interpreting and evaluating others by standards inherent to one's own culture. Research has demonstrated that one's culture can influence performance on standardized tests (Stockman & Vaughn-Cooke; 1986; Seymour, et.al, 1998; Wyatt, 1997, 2002, 2015; Wright-Harp, 2012, 2013, 2014; J. Payne & Wright-Harp, 2014). Cultural variables including race, ethnicity, experience, gender, linguistic background, national origin, religion and socioeconomic status, influence one's test performance. Therefore, actual content (face) validity of a test may vary among different cultural groups.

According to Wyatt (2015) there are four sources of bias in normed tests that can result in misdiagnosis. These include: 1) Linguistic bias, that is, assessment probes and desirable answers that either do not exist or operate differently in the respondent's language/dialect; 2) Value bias occurs when test items are scored giving more credit, value or weight to responses that are considered correct or acceptable in certain populations but not in others; 3) Situational bias exists there are social/situational dynamics that affect the client's responsiveness or when there is a mismatch in communication styles and expectations; and 4) Format bias which occurs when testing procedures, vocabulary, items or formats are unfamiliar for the respondent due to differences in experiences, socialization and exposure to information included in the test.

### Normative Sample Bias

Another source of bias when assessing CLD populations occurs with the use of norm-referenced tests (NRT) which are standardized tests designed to compare and rank test takers in relation to one another. Norm-referenced tests indicate whether test takers performed better or worse than a hypothetical average individual, which is determined by comparing the individual's scores against the performance results of a statistically selected group of test takers. typically of the same age or racial/ethnic/cultural group, on which the test was normed. Norm-referenced tests may be biased if the "norming process" either excludes or does not include representative samples of all the tested subgroups. Therefore, if test designers do not include linguistically, culturally, and socioeconomically diverse populations in the initial comparison groups (which are used to determine the norms for the test), the resulting test may potentially penalize excluded groups (Abbott, 2014). The exclusion or underrepresentation of individuals from certain CLD populations in the normative sample of a standardized test impede the clinician's ability to make objective and valid diagnoses of communication disorders. When individuals from diverse racial/ethnic groups are compared to another group or groups, the test can have a high degree of error. Consequently, despite the fact that numerous tests exist for assessment of the adult neurogenic population, very few have been shown to possess reliability and validity for assessment of CLD populations (Pineda , et.al., 2000; Biddle, Watson & Hopper, et.al, 2002; Mosdell, Balchin, & Ameen, 2010; Brown & Wright-Harp, 2011; Qualls, 2015; Wallace, J. Payne. 2011, 2013; Wright-Harp 2006, Barker-Collo, S. 2007; Davis and Wright-Harp; 2012a, 2012b; Davis, et.al, 2014).

Mosdell, Balchin, & Ameen, (2010) describe how much better their patients responded when they modified the "Cookie Theft Picture" in the Boston Diagnostic Aphasia Examination (BDAE) and the Boston Naming Test (BNT) to minimize Western cultural, language, and education bias in neurocognitive screening in South Africa. Pineda et al. (2000), in a study conducted in Colombia, observed the importance of adjusting scores for subgroups of different sociocultural levels. These studies illustrate of the importance utilizing nonstandardized, informal procedures and instruments for the assessment of CLD populations.

Professionals must be aware that the published norms for tests designed for native speakers of English are not valid when administered in a different language. Furthermore, they should not assume that test norms can be applied to distinct populations simply because they share a language. For example, there is evidence that several instruments developed in Spanish speaking countries may not be functionally or linguistically equivalent when used among Spanish speakers in the United States (Manley &

Mayeux, 2004). When test items have not been designed to account for responses that reflect different language, dialect, and/or cognitive styles of a particular racial/ethnic population, misdiagnosis may result. To limit the potential for misdiagnosis, the clinician must be knowledgeable of the rules of the individual's dialect or language (Davis & Wright-Harp, 2012a, 2012b; Wright-Harp, 2005, 2006, 2014).

### Alternatives to Standardized Tests

Because no test can be completely culture-free, speechlanguage pathologists must avoid a "One size fits all" approach to assessment and learn to utilize culturally appropriate and evidence based strategies (Davis & Wright-Harp, 2012; Wright, 2006; Qualls, 2015; Wyatt, 2015; Ulatowska et al., 2001).. Informal assessment procedures have been proposed as a mechanism for evaluation of diverse populations because this approach allows the clinician to tailor the assessment for the specific needs of each client. It is essential that the clinician determine how each client functions in their unique environment and how they function in activities of daily living (ADLs) that are important to both themselves and their family based upon their culture (Qualls, 2015).

The previously described demographic changes are particularly relevant to SLPs making it even more critical that we serve these emerging majority groups in a more culturally competent manner. To accomplish this goal, we must understand how cross-cultural differences in communication styles; views toward health, illness and disability; the nature and prevalence of communication disorders and language differences affect the diagnostic evaluation process. This applies to all components of the process which include gathering the case history, test administration, interpretation of test results, differential diagnosis, and report writing. (Wyatt, 1997). Thus. comprehensive culturally appropriate assessment of communication and cognitive disorders would entail the following five areas: 1) the case history; 2) formal assessment; 3) informal assessment; 4) differential diagnosis and 5) treatment planning.

<u>Case History</u> – The case history is an essential component of the assessment of CLD populations as it provides invaluable information on the individual's background as well as preexisting conditions that may impact performance during the assessment process. Thus, the case history helps the clinician understand the patient/client and his/her communication disorder and any associated variables (Roseberry-McKibben & Hedge, 2006). The case history should include details about the individual's culture, communication style, premorbid cognitive, speech and language functioning and relevant prior medical history (e.g. history of stroke, TBI, drug use, etc...). Information should be obtained regarding the individua l's communication style and linguistic characteristics in comparison to others in the speech community. An ethnographic approach to interviewing is recommended as it allows clinicians to use the case history process to gather specific knowledge on the views of clients and their families. Another advantage is that it allows the respondent to provide information they feel relevant rather than simply respond to the clinician's questions. An ethnographic approach also provides insight into the significant other/caregiver and family's perceptions, desires, expectations and views.

Another consideration when gathering the case history of adults from CLD populations, is to include the individual in the process. This helps avoid patient anxiety and feelings of rejection. Payne (2011) indicates that "generating a culturally sensitive case history takes into consideration the different definitions of who constitutes "family," including fictive kin (persons who are unrelated but who function as family), partners, and church members, as well as other areas of cultural divergence, such as religious customs, primary and secondary languages, preferred approaches to health and wellness, and personal/family perceptions of communicative disability" (Payne, 2011; Payne, 1997). Thus, it is important to observe interactions with multiple communication partners in a variety of communication settings should be observed to gain a true sense of the patient/client's social network. Throughout the case history process, it is recommended that the clinician maintain an attitude of nonjudgmental understanding throughout the case history gathering process (Groher, 1988).

Westby, Burda, & Mehta, (2003) have proposed several strategies for conducting an ethnographic case history interview:

1. Use open-ended questions rather than questions that trigger a "yes" or "no" response,

2. Restate the client's response by repeating the his/her exact words rather than paraphrasing or interpreting,

3. Summarize the client's or spouse/caregiver's statements and provide an opportunity for correction in case of misinterpretation,

4. Avoid multiple questions presented sequentially and/or multipart questions,

5. Avoid leading questions that tend to orient the person to a particular response.

6. Avoid using "why" questions, because this question type tends to sound judgmental and could increase the client's level of defensiveness.

7. Informally evaluate the family members' language features and communication style during the initial interview of the patient.

<u>Formal Assessment</u> – Professionals must carefully examine standardized tests and make appropriate modifications in stimuli to reflect the individual's language/dialect and cognitive style. The following are recommendations for conducting culturally competent and evidence based assessment.

Be knowledgeable about cultural, cognitive and linguistic differences that can influence the individual's test performance; Avoid using tests that have been identified as being culturally or linguistically biased (Hegde (1998); Carefully review the test to determine potential sources of bias (Wyatt & Weddington, 2010); Modify or adjust scoring of items on standardized tests to reflect the language/dialect/ cognitive style of the individual (Brown & Wright-Harp, 2011; Vaughn-Cooke, 1986; Wright-Harp, 2006, 2010); Become familiar with the linguistic, cognitive and cultural aspects of the client to improve the testing accuracy; Consider the influence of cultural/linguistic differences when analyzing test performance of individuals from diverse racial/ethnic groups (Payne, J. 2012, Wright-Harp, 2011); Avoid penalizing the client for the use of linguistic features that are normal for his/her dialect or language; When testing cognitive functioning consider the individuals cognitive style in the interpretation of responses to test items; Use comprehensive assessments including multiple sources of data to determine a diagnosis; Avoid stereotypes. Don't assume that client from a different ethnocultural group will require unique procedures or is unable to code switch to use the standard dialect or language; Consult with a SLP who is a member of the patient's ethnocultural group; Work professionals and with other on the interdisciplinary educate them team to about ethnocultural differences and the need to use functional patient-specific procedures in assessment and treatment. (Hegde, 1998 p. 183).

<u>Informal Assessment</u> - When standardized tests are not appropriate for a given client/patient, the use of informal assessment and dynamic assessment procedures are options that can provide essential information for diagnosis and treatment planning (Davis, Lucker, WrightHarp, & Payne, 2011; Wright-Harp et al., 2012). Informal assessment might entail observations in a variety of naturalistic contexts to evaluate the individual's ability to interact in various situations. Examples include talking with family members, ordering food in a restaurant, taking a message on the phone, scheduling an appointment.

Other measures, including behavioral and pragmatic observations in natural contexts as well as spontaneous and structured language sampling, provide valuable information that standardized tests alone may not. Gathering information from a variety of sources helps minimize the risk of misdiagnosis. Possible sources of information include the family, caregivers, members of the community, other members of the interdisciplinary team, and if possible, the patient. Sampling communication in a variety of contexts gives the clinician a more accurate profile of an individual's functional communication ability and aids in determining the potential effectiveness of intervention and compensatory strategies (Brown & Wright-Harp, 2011; Grice & Wright-Harp 2004a, 2004b; Ulatowska et al., 2001). When evaluating bilingual and monolingual speakers whose dominant language is not English, interpreters, not family members, may be necessary to ensure accurate assessment of the individuals' cognitive and language skills.

<u>Differential Diagnosis</u> – An essential and final component in the assessment of CLD populations is differential diagnosis. Information gathered from the case history, assessment (formal and informal) as well as the examiner's clinical observations are all important to consider in distinguishing features that result from the normal influences of cultural and linguistic differences from those that exist due to a disorder. (Wyatt, 2015).

Treatment Planning - Once assessment is completed, planning intervention should be undertaken with the same degree of sensitivity as the selection of appropriate assessments. Therapy should be client-centered in the context of understanding what the communicative environment of the client demands. This can be accomplished only when the clinician understands and respects the perspective of the patient and the patient's support networks. Ruoff (2002) recommends that the plan of therapy should be culturally sensitive and should include functionally relevant materials and accommodations that are considerate of the patient's worldview (for example, allowing extra time when using a translator). The clinician must also appreciate and

understand linguistic differences and the patient's cultural views on disability and physical/psychological change (Wilson, 2002).

### Table 3. Factors Influencing the Test Environment.

Nonverbal Aspects of the Test Environment	Verbal Aspects of the Test Environment
perception of time	• form of language (i.e. structure)
how one is expected to learn;	functions of language,
how one is expected to respond in a testing context to the examiner, regardless of gender, culture, age, and/or socioeconomic background;	• content of language,
• attitudes toward display of abilities;	organization of the language,
• attitudes towards guessing, using process of elimination, story telling, or conversing with an unfamiliar individual;	and pragmatic rules of social interaction
• test abstraction (e.g., naming protocols that require providing already shared information or situations in which the client is required to assume a "make believe" attitude in order to engage in an expected manner).	

Reference: Abbott, S. (Ed.), The glossary of education reform. Retrieved from http://edglossary.org/hidden-curriculum

Several factors that may contribute to test bias should be taken in consideration when evaluating individuals from diverse populations. (See Table 4).

### Table 4. Factors Contributing to Test Bias

Cultural or Demographic Differences	If the staff developing a test is not demographically or culturally representative of the students who will take the test, test items may reflect inadvertent bias. For example, if test developers are predominantly white, upper-middle-class males, the resulting test could, due to cultural oversights, advantage demographically similar test takers and disadvantage others.
Representativeness of Normative Sample	Norm-referenced tests (or tests designed to compare and rank test takers in relation to one another) may be biased if the "norming process" does not include representative samples of all the tested subgroups. For example, if test developers do not include linguistically, culturally, and socioeconomically diverse populations in the initial comparison groups (which are used to determine the norms used in the test), the resulting test could potentially disadvantage excluded groups.
Cognitive Style	Certain test formats may have an inherent bias toward some groups, at the expense of others. For example, evidence suggests that timed, multiple-choice tests may favor certain styles of thinking more characteristic of males than females, such as a willingness to risk guessing the right answer or questions that reflect black-and-white logic rather than nuanced logic.
Linguistic Differences	The choice of language in test questions can introduce bias, for example, if idiomatic cultural expressions—such as "an old flame" or "an apples-and-oranges comparison"—are used that may be unfamiliar to recently arrived immigrant populations who may not yet be proficient in the English language or in American cultural references.
Cultural Differences	Tests may be considered biased if they include references to cultural details that are not familiar to particular student groups. For example, a student who recently immigrated from the Caribbean may never have experienced winter, snow, or a snow-related school cancellation, and may therefore be thrown off by an essay question asking him or her to describe a snow-day experience.

Reference: Abbott, S. (Ed.), The glossary of education reform. Retrieved from http://edglossary.org/hidden-curriculum

Investigators and practitioners must be aware that the published norms for tests administered in English are not necessarily valid when the tests are administered in another language. Furthermore, they should not assume that test norms can be applied to a different racial/ethnic population simply because they speak the same language.

For example, there is evidence that several instruments developed in Spanish speaking countries may not be functionally or linguistically equivalent when used among Spanish speakers in the United States (Manley & Mayeux, 2004). When test items have not been designed to account for responses that reflect different language, dialect, and/or cognitive styles of a particular racial/ethnic population, misdiagnosis may result.

### Alternatives for Assessment of CLD Populations

The following are recommended strategies for assessment of diverse populations:

Know the Linguistic Features of the Population - To limit the potential for misdiagnosis, the clinician must be knowledgeable of the rules of the individual's dialect or language (Wright-Harp, 2005, 2006; Wyatt, 2002, 2015). Use Tests that are Culturally and Linguistically Appropriate - As a first step, it is necessary to evaluate standardized tests and to either avoid using those identified to have cultural, educational, or linguistic bias (Davis & Wright-Harp, 2012; Wright, 2006) or supplement the results with other measures (Ulatowska et al., 2001). Examples of culturally and linguistically fair tests are the Reliable assessment Inventory of Neuro-Behavioral Organization (RAINBO), a culturally inclusive test consisting of 10 subtests designed to evaluate a variety of skills including linguistic, pragmatic, cognitive, oral-motor and swallowing skills. See Table 5 for a list of tests that can be used with CLD populations and communication disorders of with cognitive neurological etiology.

### Table 5. Tests for Assessment of CLD Populations with Cognitive and Communication Disorders.

TEST	DESCRIPTION
Alzheimer's Quick Test (AQT) Assessment of Temporal/Parietal Function Wiig, et.al. (2002) Ages: Adults	The AQT is a quick and culture-free test that is easy to administer in any language. It is comprised of three subtests (color form naming, color number naming and color letter naming. The AQT measures perceptual (i.e., reaction + response time) and cognitive speed (i.e., perceptual speed + cognitive overhead from demands on attention, working memory and set-shifting). The client/patient is to perform two or ideally three of the naming tasks.
Boston Diagnostic Aphasia Exam	The BDAE 3 <sup>RD</sup> edition is a comprehensive language battery used
Goodglass, Kaplan and Barresi (2000)	to evaluate adults who have suffered a stroke. The test can be used
Ages: 18-89 years	<ul> <li>to evaluate language skills in three perceptual modalities</li> <li>(auditory, visual, and gestural), processing functions</li> <li>(comprehension, analysis, problem-solving), and response</li> <li>modalities (writing, articulation, and manipulation). The test has</li> <li>been translated into 60 different languages. In addition, a</li> <li>computer program has been designed to evaluate responses in</li> <li>more than 100 different languages. The program can also</li> <li>compare performance across languages.</li> </ul>
Cognitive Linguistic Quick Test	The CLQT provides a quick screening of five cognitive domains
Helm-Estabrooks (2001) (CLQT)	(attention, memory, executive functions, language, and

Ages: 18-89 years	visuospatial skills) of adults with neurological impairments
	resulting from strokes, head injury, or dementia. The test is
	available in English and Spanish.
Functional Skills Survey (FSS)	The FSS is a culturally and linguistically fair survey of functional
J. Payne (1994)	language designed to evaluate the importance of everyday
	functional communication skills to elderly clients from diverse
Ages: Adults	educational, cultural and socioeconomic backgrounds. The survey
	is divided into 5 sections. A 5 point scale is used by the client to
	rate communication on the basis of importance rather than
	performance.
NEUROPSI – Attention and Memory	The NEUROPSI – Attention and Memory Test is designed for
(Ostrosky-Solis, et.al. 2005)	assessment of the cognitive abilities in individuals with
	neurological damage resulting from brain lesions (i.e. tumors,
Ages: 6-85 years	traumatic brain injury), developmental disabilities, ADHD,
	dementia, psychiatric disorders, etc. The test is available in
	English and Spanish. The test covers the following domains:
	orientation, attention and concentration, executive functions,
	working memory, immediate verbal memory, delayed verbal
	memory, immediate visual memory and delayed visual memory,
	each having its own subtests. Each area includes assessment of
	different aspects of the particular cognitive domain. Thus,
	assessment of attention includes level of alertness, span or
	efficiency of vigilance-concentration, and selective attention.
	Executive function assessment comprises concept formation,
	flexibility, inhibition and several motor programming tasks.
	Memory assessment includes immediate and delayed recall of
	auditory-verbal and visual-nonverbal functioning. Word list
	learning includes three learning trials of 12 words.
Reliable Assessment Inventory of Neuro-	The RAINBO is a culturally inclusive and comprehensive
Behavioral Organization (RAINBO) G. Wallace	assessment tool comprised of 10 subtests and a functional
(1997)	outcomes measure designed to evaluate a communication and
	swallowing skills (including linguistic, pragmatic, cognitive, oral-
Ages: Adults	motor and swallowing). The test is designed for adults and
	adolescents who have neurologically based communication,

	cognitive and swallowing disorders due to stroke, brain injury and
	cognitive and swanowing aborders due to subke, oran injury and
	other etiologies. The overall score from the FACS is significantly
	correlated with other cognitive tests and the LOCF, but contributes
	unique variance attributable to factors in daily living not captured
	by other standard measures. The RAINBO includes adaptations
	for various nonmainstream English dialects (AAE, Appalachian
	and Hawaiian-pidgin dialect) and language influences from 28
	different languages.
Western Aphasia Battery-Revised (WAB)	The WAB-R full battery consists of 8 subtests (32 short tasks) is
(Kertesz, 1980)	designed to assess adult patients with acquired neurological
	disorders (e.g. stroke, head injury, dementia). It assesses the
Ages: 18-89 years	linguistic skills including content, fluency, auditory
	comprehension, repetition, naming, reading and writing. It
	information useful for provides differential diagnosis information.

When standardized tests are not appropriate for a given patient, the use of informal assessment procedures, that is procedures other than standardized tests, can serve as a successful alternative (Davis, Lucker, Wright-Harp, & Payne, 2011; Wright-Harp et al., 2012). For example, researchers in South Africa, reported that their patients responded better when they modified the "Cookie Theft Picture" of the Boston Diagnostic Assessment Exam (BDAE) and the BNT to minimize Western cultural, language, and education bias in a neurocognitive screening (Mosdell, Balchin, & Ameen, 2010).

<u>Use Multiple Measures</u> – Assessment should include multiple sources of data. The case history often serves as a major source of information for CLD populations, particularly when there are no available tests. Other measures include observations in natural contexts to determine communicative effectiveness. Observations should be gathered in a variety of settings (e.g. home, medical facility, restaurants, church, etc.) to determine the individuals' level of communication functioning in activities of daily living (ADLs).

<u>Ethnographic Data</u> - Gathering information from a variety of sources helps minimize the risk of misdiagnosis. Possible sources of information include the family, caregivers, members of the community, other members of the interdisciplinary team, and if possible, the patient. Sampling communication in a variety of contexts gives the clinician a more accurate profile of an individual's functional communication ability and aids in determining the potential effectiveness of intervention and compensatory strategies (Brown & Wright-Harp, 2011; Grice & Wright-Harp 2004a, 2004b; Ulatowska et al., 2001).

Interpreters - When evaluating bilingual and monolingual speakers whose dominant language is not English, interpreters, not family members, may be necessary to ensure accurate assessment of the individuals' cognitive and language skills. Once assessment is completed, planning intervention should be undertaken with the same degree of sensitivity as the selection of appropriate assessments. Therapy should be client-centered in the context of understanding what the communicative environment of the client demands. This can be accomplished only when the clinician understands and respects the perspective of the patient and the patient's support networks. Ruoff (2002) recommends that the plan of therapy should be culturally sensitive and should include functionally relevant materials and accommodations that are considerate of the patient's worldview (for example, allowing extra time when using a translator). The clinician must also appreciate and understand linguistic differences and the patient's cultural views on disability and physical/psychological change (Wilson, 2002).

See Table 6 for additional recommendations for best practices when assessing CLD populations.

### Table 6. Recommendations for Best Practices in Assessment of CLD Populations.

Reference: Payne, J. & Wright-Harp, W. (2014).

RECOMMENDATION	STRATEGIES
1. Provide health communication that is clear, easy to understand, in the patient's language, and reflective of the communication context of the patient.	<ul> <li>a. Use illustrations that reflect ethnic diversity;</li> <li>b. Prepare text that is easy to read and in the patient's language;</li> <li>c. Provide verbal information through an interpreter.</li> <li>d. Tailor messages to the context of the patient; whether high-context (nonverbal communication and silence are valued) or low-context (spoken and written communication are valued); and</li> <li>e. Avoid cultural faux pas: using the patient's first name, telling jokes, asking for personal information before trust has been established.</li> </ul>
2. Respect divergent views on health and wellness.	<ul> <li>a. Ask the patient to describe his or her views on the illness or disability;</li> <li>b. Become informed about how health care decisions are made in the patient's community; and</li> <li>c. Be aware of how differences in perceptions of disability and coping styles vary within cultures and are often tied to religion among some cultures.</li> </ul>
3. Respect differences in family structures.	<ul> <li>a. Be mindful that there is no model of the perfect family and that cultural norms often govern the hierarchy and membership status within families;</li> <li>b. Understand that in some cultures, families are largely patriarchal; in others, the eldest member speaks for the family; in still others, families are matriarchal or multigenerational; these arrangements work for the families involved; and</li> <li>c. Appreciate that families may be racially mixed or have same gender parents.</li> </ul>
4. Respect diverse views on time and personal space.	<ul> <li>a. Consider that time is relative and meaningful in different ways in different cultures;</li> <li>b. Respect that use of personal space is culture driven and that there are cultural variations in how personal and social spaces are defined; and</li> <li>c. Understand that in some religions, personal space is delineated according to gender and/or marital status.</li> </ul>
5. Respect the important rituals (holidays, religious observances) of other groups.	a. Schedule appointments around important holidays and religious activities for patients. b. Become familiar with important rituals and their significance to patients;

	c. Honor requests for activities within therapy that symbolize
	important rituals to the patient and the patient's family; and
	d. Understand the role of organized religion in the lives of patients
	and their views on the power of prayer in healing.
6. Be flexible about assessment.	a. Use more informal testing, such as proverbs and narratives, to
	tap into verbal and comprehension abilities in culturally diverse
	adults that may not be obvious in standardized testing;
	b. Assess higher cognitive functioning and use of abstract
	language from cartoons and humorous stories from sources in
	other communities or countries and in the patient's preferred
	language;
	c. Use indirect ways to assess, such as observations and family
	interviews; and
	d. Appreciate that culture drives communication styles and that
	differences in communication styles are not disordered.
7 Degraat different viewe on beelth ears	
7. Respect different views on health care.	a. Know that cultures differ in the ways that illness is explained
	and in what is acceptable to hear about illness;
	b. Be sensitive to the fact that technology-driven Western health
	care is not always preferable to alternative health care within a
	cultural community; and
	c. Be aware that distrust of Western health care is rooted in the
	national history of discrimination.
8. Respect language differences.	a. Provide a translator for patients whose primary language is not
	English; and
	b. Appreciate that one's language is a deeply personal aspect of
	culture.
9. Respect other views of work.	a. Be knowledgeable that in some countries, work is defined
	differently than in the United States; and
	b. Understand that status in some communities may be defined by
	parameters other than work or by the type of work done.
10. Respect the family's autonomy in decision	a. With the permission of the patient, include all members of the
making.	extended family in conversations about the patient's progress;
	b. Validate the opinions of the family; and
	c. Do not presume that the family has no knowledge of
	communication disorders; interview the family on this issue and
	build from there.
11. Respect cultural differences in emotional	a. Be aware that a smile does not necessarily mean agreement; it
expression.	sometimes means confusion or respect;
	b. Do not be offended by differences in how a patient can look the
	clinician in the eyes.
12. Become flexible about intervention.	a. Use telehealth with persons who cannot come to therapy;
	b. Select appropriate augmentative and alternative communication
	devices for a multilingual population.
	devices for a multilingual population; c. Use stimuli that are functionally relevant for the patient; and

	d. Tailor therapy for the patient's needs.
13. Involve the family.	a. Involve the patient and the family in decision making for
	therapy goals;
	b. Educate the family about the disorder that caused the
	communication impairment; and
	c. Provide support and information on resources in the family's
	preferred language.

Reference: Payne, J. & Wright-Harp, W. (2014). Delivering culturally competent services to adults with neurogenic cognitive-language disorders, In. J. C. Payne (Ed.), *Adult Neurogenic Language Disorders: Assessment and Treatment: A Comprehensive Ethnobiological Approach to Neurogenic Communication Disorders* (2<sup>nd</sup> ed.). San Diego: Plural Publishing, Inc.

There are several strategies that can reduce the potential for misdiagnosis when evaluating individuals from CLD populations. Abbott (2014) recommends the following:

- 1. Train test developers and scorers to be aware of the potential for cultural, linguistic, and socioeconomic bias.
- 2. Have tests reviewed by experts trained in identifying cultural bias and by representatives of culturally and linguistically diverse subgroups who are targeted to be tested with the instrument.
- 3. Include diverse racial/ethnic groups in the norming processes and normative samples used to develop norm-referenced tests that are large enough to constitute a representative sample.
- 4. Apply the "Golden Rule" by eliminating items that produce the largest racial and cultural performance gaps, and choosing those items that produce the smallest gaps. (Note: However, this strategy may be logistically difficult to achieve, given the number of racial, ethnic, and cultural groups that may be represented in any given testing population).
- 5. Screen the test and eliminate items, references, and terms that are more likely to be offensive to certain CLD groups.
- 6. Translate tests into a testee's native language or use interpreters to translate test items. (Note this is not recommended for certain language groups, ie. Spanish which has over 30 dialectal variations.
- 7. Include more "performance-based" items to limit the role that language and word-choice plays in test performance.
- 8. Use multiple assessment measures to determine academic achievement and progress, and avoid the

use of test scores, in exclusion of other information, to make important decisions about the student.

Roseberry-McKibben (2008) also provides suggestions for modifying standardized assessments to decrease misdiagnosis. Although her guidelines are designed for children from bilingual backgrounds, they are also applicable for use with adolescents and adults from CLD populations. Her strategies include allowing extra time to respond, explaining or rephrasing instructions that may be confusing, providing extra practice items, omitting biased items, testing beyond the ceiling, testing in more than one session, using tokens and/or reinforcers, beginning with tasks that are the easiest or most familiar, and exhibiting warmth and care. Spontaneous language samples are also great ways to determine the language abilities of a client because they can express themselves in a casual way. These suggestions allow the clinician to gather more information about the client's abilities.

Additionally, Payne (2011) makes suggestions for test modifications that include the use of figurative language. First, she suggests that clinicians should become familiar with humor, proverbs, and other figurative language expressions germane to the particular cultural group. Next, clinicians should modify or substitute standard forms of figurative language stimuli with stimuli that are age and culturally appropriate. Finally, Payne (2011) recommends that examiners substitute proverbs and idioms from the local communities when figurative language forms in existing standardized tests are not appropriate. Cultural competence can be accomplished by making allowances in scoring for culturally and linguistically different responses when they are close to the target response. It is essential to acquire an

understanding of the individual's cognitive and communicative style to accurately score responses to figurative language tasks when assessing CLD populations.

Based upon research over the past three decades, it is clear that cultural and linguistic differences should be accounted for in the assessment of CLD populations. Underrepresentation or exclusion of African Americans or other diverse populations in test development prevents the test designer from being able to account for stimulus items, directions, and scoring techniques that are inappropriate for the minority population. The clinician must be objective to avoid a conflict between their values and those of the patient/family (Brown & Ricker, 2003). More specifically, the SLP must make efforts to account for biases that exist when assessing CLD populations.

### Other factors to Consider in Assessment of CLD Populations

### **Health Insurance**

With recent passage of the Affordable Care Act (2013), health care has become more accessible to individual who may not have had such access in the past due to a preexisting condition, financial challenges, or unemployment.

### Time

SLPs should be flexible when scheduling appointments as punctuality may be a factor related to cultural differences in time perception. Some cultures (Hispanic, African American) have been described as having a different concept of time. However, one should avoid stereotypes when providing services to individuals from CLD populations. SLPs must also consider the level of acculturation and assimilation into the main culture. Thus, avoid a "one size fits all" approach to working with CLD populations as many individuals have become more acculturated to the importance of timeliness, particularly related to medical appointments (Kayser, 2015; Wallace, Payne, 2013).

### **Transportation**

Individuals may be impacted in terms of timeliness due to transportation constraints. If public transportation is required, the individual may be either late or very early for an appointment. In addition, availability of public transportation must be considered, particularly in rural areas where an individual may neither have their own transportation nor access to public transportation. In these instances, telehealth may be an option, allowing the clinician to conduct the evaluation via digital means of access to the client (e.g., skype, UVOO, facebook, etc...)

### CONCLUSION

Given the recent demographic changes in the United States, cultural competence in service delivery is increasingly important to eliminate long-standing disparities in the health status of people from diverse racial, ethnic, and cultural backgrounds; meet accreditation, legislative, and regulatory mandates; and improve the quality of service delivery and treatment outcomes (ASHA, 2015).

Change is inevitable. As professionals, we must be aware of two important components of cultural competence which are that cultural differences exist and that no culture is superior to another. Culture is not static, neither for ourselves nor for our clients. Therefore, to remain culturally competent, we must continue to examine ourselves and our clients (Torres, 2015). Moreover, we must be aware of the imminent changes in caseload diversity requiring the need to be culturally competent in the assessment of adults with neurogenic communication disorders (J. Payne & Wright-Harp, 2014).

Professional competence across professions and settings requires that audiologists and speech-language pathologists (SLPs) practice in a manner that considers the impact of cultural variables and language exposure and acquisition on their clients/patients. ASHA-certified practitioners have met rigorous academic and professional standards, including knowledge of cultural variables and how they may influence communication. (ASHA, 2015).

Cultural competence is not a new issue for professionals in the fields of speech-language pathology and audiology. Several recent articles have addressed how clinicians should prepare for a multicultural population of patients in the health care setting (Chin, 2000), for adults with dysphagia (Riquelme, 2004), for adults with neurogenic language disorders (Payne, 2011), for adults with traumatic brain injury (J. Payne, Wright-Harp & Davis, 2014), and for adults with hearing disorders (Scott & Jones, 2003; Wolf, 2004). These articles, taken together with policy statements on cultural competence from the American Speech-Language-Hearing Association (2004, 2005, 2011), are positive indicators that the profession has begun the process of structuring new paradigms for service delivery for an increasingly diverse population (J. Payne, 2014).

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### **ABOUT THE AUTHOR:**

Wilhelmina Wright-Harp, Ph.D., CCC-SLP, is Associate Dean for Research and Academic Affairs in the School of Communication and a Professor in the Department of Communication Sciences and Disorders at Howard University. Her areas of expertise include the design and implementation of mentoring programs as well as the clinical management of individuals with neurogenic disorders, specifically dysphagia, acute traumatic brain injury, and stroke. Dr. Wright-Harp's research seeks to increase the number of African Americans and other racial minority students entering communication sciences, to improve speech and language skills of racial minorities and to assist patients with neurogenic disorders.

### UNDERSTANDING HEALTH LITERACY: A REVIEW OF THE LITERATURE

Shatonda S. Jones Rockhurst University Kansas City, Missouri

#### ABSTRACT

Individuals encounter health information from a variety of sources. In order for this information to be of use to the person, he or she must be able to understand, process, and employ health information in such a way as to promote health. This review of the literature will explore health literacy and its relationship to the management of chronic health conditions. A discussion on the definition of health literacy and how health literacy is assessed will be included in this review. The review will look at the differing means by which people become health literate and examine the strengths and weaknesses of each of these means. Finally, the role of health care professionals with direct contact with patients and caregivers will be noted and discussed.

KEY WORDS: Health literacy

### UNDERSTANDING HEALTH LITERACY: A REVIEW OF THE LITERATURE

Shatonda S. Jones

Rockhurst University Kansas City, Missouri

#### **INTRODUCTION**

In a 1989 interview Aaron Antonovsky stated, "We people are perpetually bombarded by information; we are exposed to stressors that demand a new way of thinking and new conclusions. How we deal with information affects our health, make us move towards either health or sickness." The idea of how people deal with information as a factor in health outcomes recently has become the focus of many health initiatives. The modern health system is a changing field that requires consumers to adapt to those changes in order to maintain and manage their health successfully (Nielsen-Bohlman, Panzer, Hamlin, & Kindig, 2004; Murrow & Oglesby, 1996).

The expectations of people with chronic health conditions have changed over the past half century (Baker, Parker, Williams, & Clark, 1998). Advancements in medicine and technology have led to the survival of people who would have not survived major medical events 50 years ago (Baker, et al., 1998). As these advances continue, the roles and responsibilities of health care consumers also will continue to increase (Nielsen-Bohlman, et al, 2004). These health care consumers, along with their caregivers, will have to find ways to manage their health conditions (Kickbusch, 2001; Bodenheimer, Lorig, Holmann, & Grumbach, 2002; Perrin, 1998). Management of chronic health conditions can require a great amount of skill, knowledge, and advocacy for both survivors and their caregivers (Nielsen-Bohlman, et al., 2004; Murrow & A person must be able to obtain Olgesby, 1996). information about his or her health condition and understand his or her rights and responsibilities in order to successfully manage any health condition (Chang, 2007; Ek, 2004; Nielsen-Bohlman, et al, 2004). People search for, and are provided with, increasing amounts of information (Martensson & Hensing, 2011). Allowing people the independence to learn more about their health may help empower them to be active participants in their own health care and management (Martensson & Hensing, 2011). Simply having information is not always

predictive of positive health outcomes however (Ek & Widen-Wulff, 2008).

The American Academy of Family Physicians (AAFP) defines patient education as the "process of influencing patient behavior and producing changes in knowledge, attitudes, and skills necessary to maintain or improve health" (AAFP, 2008, p. 1). Patient education generally is regarded as a viable means to improve health outcomes (Nutbeam, 2008). Recent research provides evidence that patient education alone is not an effective tool in improving health outcomes (Nutbeam, 2008). Information-rich educational programs have also been found to be ineffective (Ek & Widen-Wulff, 2008). Even the most effective education techniques and best information do not always correlate with desired behavioral changes (Ek & Widen-Wulff, 2008). Many programs lack effectiveness because there is a mismatch between the skills possessed by the person and the content or delivery of the educational program (Ek & Widen-Wulff, 2008; Nutbeam, 2008). Typically, programs have a heavy emphasis on educational attainment and communication skills, which are not always skills possessed by the target audience (Nutbeam, 2008). Schwartzberg VanGeest, and Wang (2003) report findings from studies that looked at the readability of health education materials targeted towards specific chronic health conditions (e.g., cancer, diabetes, asthma, HIV) and found that a majority of the educational materials were written above the reading level of most American adults (assumed to be at the eighth or ninth grade, per Schwartzberg et al (2003)). This again shows that people may have difficulty putting into use any written information they receive because it is inaccessible or incomprehensible to them (Schwartzberg et al, 2003). People may not only have difficulty with comprehension of printed content, but they may also experience poor comprehension when verbal information is presented in an unnecessarily complex manner (e.g., use of medical jargon in patient interactions) (Paasche-Orlow & Wolf, 2007).

Another reason that these programs may not be successful is the way that people receive information (Chang, 2007).

Today there are varieties of sources by which people obtain health information. Some sources are informal, such as education from family, friends, and other survivors, while other sources are formal and can include information gleaned from television programs, magazines, internet news, and other media designed to provide information and ultimately influence a person's health behaviors (Nutbeam, 2006; AAFP, 2008). Health care professionals that have daily contact with people are perhaps one of the most important sources of health information (Chang, 2007). The education given may consist of information designed to inform people about the disease process, how to monitor for changes, and what to do if help is needed (Monsivais & Reynolds, 2003). Health care professionals may provide health education via information as well as technical skills (Monsivais & Reynolds, 2003). There may be no assessment of whether or not a person is able to comprehend, process, and apply health information in order to produce a positive health outcome (Chang, 2007; Paasche-Orlow & Wolf, 2007). Some health care providers cite lack of time during the interaction as a reason for not confirming understanding of health information (Paasche-Orlow & Wolf, 2007). Currently, there is not strong evidence that suggests that health care providers that confirm an individual's understanding of information gained during the encounter led to improved health outcomes, which may also explain health care providers' reluctance to devote interaction time to such a task (Paasche-Orlow & Wolf, 2007).

Socioeconomic status (SES) and educational attainment have a role in how people are able to use health-related information (Williams Davis, Parker, & Weiss, 2002). However, Williams et al (2002) found that literacy in the context of health might be a better predictor of health than either SES or education even when controlling for these two variables. This has implications for the entire health care system. The way that health care professionals provide education, the types and content of the educational material used, and how interactions occur will be key factors in improving individual level and societal level health outcomes (Martensson & Hensing, 2012).

Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, n.p.). Ek and Widen-Wulff (2008) describe health literacy as health information mastery. These researchers cite multiple studies that suggest that health literacy is an essential asset in changing people's health behaviors (Ek & Widen-Wulff, 2008; DeBuono, 2006; Rudd, Kirsch, & Yamamoto, 2004). Basic health information that requires adequate health literacy may include items such as understanding instructions from physicians, consent forms, appointment cards, insurance forms, and following dosing instructions on medication labels (Martensson & Hensing, 2012). Having adequate health literacy means that a person is able to utilize the skills necessary to promote good health (Martensson & Hensing, 2012). The definition of health literacy will be examined further later in this review.

Approximately 38% of Americans are considered to have limited health literacy (White, 2008). Inadequate health literacy may be described as an epidemic that stems from difficulty in understanding health-related material or limited proficiency in English (DeBuono, 2006; White, 2008). Literacy and numeracy skills also influence health literacy (Nutbeam, 2008). The populations thought to be most at risk of having inadequate health literacy are older adults and people living in low socioeconomic conditions (Ek & Widen-Wulff, 2008). Nielsen-Bohlman et al (2004) suggest that even some of the most educated members of society are at risk for low health literacy and may have difficulty with navigating the health system. It is even possible for health care employees to have limited health literacy (Nielsen-Bohlman et al, 2004). Thus, all people, regardless of race, ethnicity, nationality, gender, or socioeconomic status can be at risk for low health literacy (Ek & Widen-Wulff, 2008).

The World Health Organization (WHO) describes health literacy as one of the determinants of health (WHO, 2012). Determinants of health are factors that shape how a person is able to access, understand, and ultimately utilize healthcare services in such a way as to make a difference in their health outcomes (Nutbeam, 2006). Health literacy may be the best predictor of a person's health status (DeBuono, 2006). Therefore, it is important that health care professionals have a clear definition of health literacy as well as a careful plan to continue to increase the health literacy of Americans.

This review of the literature will explore health literacy and its relationship to the management of chronic health conditions. A discussion on the definition of health literacy and how health literacy is assessed will be included in this review. The review will look at the differing means by which people become health literate and examine the strengths and weaknesses of each of these means. Finally, the role of health care professionals with direct contact with patients and caregivers will be noted and discussed.

This review will discuss the relationship between health literacy and management of chronic health conditions. It is noted, however, that more research is needed to establish a direct causal relationship between health literacy and health outcomes (Nielsen-Bohlman et al., 2004). A widely accepted belief exists that sees a causal relationship between health literacy and health outcomes (Nielsen-Bohlman et al, 2004). The literature appears to support a predictive, if not causal relationship (Nielsen-Bohlman et al., 2004). The belief is that people with marginal or adequate literacy will have better health outcomes because they are better able to comprehend, process, and apply the information gained in health education programs (Baker, 1998). However, research has yet to establish definite causality between health literacy and health outcomes (Nielsen-Bohlman, et. al, It is difficult to establish an independent 2004). relationship between limited health literacy and health potentiallv because of the outcomes strong interconnections with other variables (e.g., educational attainment, race and ethnicity, and age) (Paasche-Orlow & Wolf, 2007). Paasche-Orlow and Wolf (2007) suggest that current research limits the ability to establish a causal relationship between health literacy and health outcomes because much of the research is cross-sectional which hinders the ability to establish a strong cause effect Therefore, while a causal relationship relationship. amongst health literacy and health outcomes is likely, it is important to note that there not yet any conclusive evidence that ewxplains the specific nature of this relationship (Nielsen-Bohlman et Al., 2004).

### **Defining Chronic Health Conditions**

The review will focus on persons with chronic health conditions and their caregivers. Chronic health conditions may appear slowly, progress over the course of one or more years, and are not usually curable by surgery or medicine (e.g., glaucoma, Parkinson's disease, and diabetes) (Dugdale, 2011; AARP, 2009; Murrow & Oglesby, 1996). Other conditions may begin acutely and become chronic (e.g., heart attack) or have lasting effects that are chronic in nature (e.g., hemiparesis after stroke) (Centers for Disease Control, 2009; AARP, 2009). Chronic health conditions are differentiated from acute health conditions in that acute conditions appear suddenly and typically involve a rapid decline or bettering of symptoms (Dugdale, 2011). In 2005, the Centers for Disease Control (CDC) estimated that there were 133 million Americans (i.e., one in two adults) with at least one chronic health condition. Twenty-five percent of people with chronic health conditions were estimated to

have difficulty with at least one activity of daily living (CDC, 2010).

This review is limited to chronic health conditions because of the implications that chronic health conditions have on the individual and caregivers, society as a whole, and the health care system. Chronic health conditions are persistent in nature and require that the person and his or her caregivers provide a fair amount of time, energy, and often funding to the management of the disease (Murrow & Oglesby, 1996). People with chronic health conditions and their caregivers may require extensive training and education to manage the disease, which indicates that health literacy is of the utmost importance in the management of chronic health conditions (Murrow & Olgesby, 1996).

### **Defining Literacy**

In 1993, the National Adult Literacy Survey found that approximately 20% of adult Americans were not considered functionally literate (Kirsch, Jungeblut, & Kolstad, 1993). The survey found that people who were not functionally literate had difficulty with reading tasks required in everyday life (Kirsch et al., 1993). Research on understanding literacy is not new. However, recently there has been more attention paid to how to define and assess literacy.

Argument exists among educators, policy makers, and researchers as to how to define literacy and determine when a person has met this definition (Richmond, Robinson, & Sachs-Isreal, 2005). The definition of literacy has changed since the beginning of formal education in the United States (Richmond, et al. 2005). Historically, if a person could read and write, he or she would be considered literate (Shomos, 2010). Early United Nations Educational, Scientific, and Cultural Organization's (UNESCO) definitions of literacy considered a person literate if he or she had completed five years of schooling (Shomos, 2010). UNESCO's (2005) definition of literacy changed to be more reflective of the fact that literacy exists on a continuum and is not iust reflective of a person's skills in reading and writing but includes skills in many different areas (Richmond, et al, 2005). UNESCO offers a definition of literacy that states the following:

Literacy is the ability to identify, understand, interpret, create, communicate, and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve his or her goals, develop his or her

knowledge and potential, and participate fully in community and wider society. (Richmond, et al, 2005)

UNESCO cautions that no one definition of literacy encompasses its many facets (Richmond, et al, 2005). The definition proposed by UNESCO is intended to be a working definition of literacy that reflects a person's concept and use of their literacy skills (Richmond, et al, 2005).

The definition of literacy continues to evolve because of the changing nature of the workplace and communication responsibilities of people (Richmond, et al, 2005). Today people are required to do more than just read and write in all aspects of their lives, which gives rise to the concept of "situational literacies." These are a person's literacy skills in various areas (e.g., technology, health, etc.) (Richmond, et al, 2005). Thinking of literacy as situationally mediated allows for a more diverse definition of literacy that encompasses the social, cultural, and political aspects of how people gain and use their literacy skills (Richmond, et al, 2005). Situationa1 literacy also allows for further exploration of the idea of "functional literacy" (Richmond, et al, 2005). A person is considered functionally literate if he or she can obtain and use information in differing environments, including work, home, and community (Shomos, 2010; OECD, 1997). Functional literacy also includes being able to use one's literacy skills in the achievement of goals and in the development of knowledge (Shomos, 2010; OECD, 2000). Functional literacy would suggest that a person would be able to use their literacy skills to achieve their maximum potential in all areas (Shomos, 2010; OECD, 2000).

Literacy in the context of health is not also easily defined. Health is a concept that has social, cultural, and political implications (Nielsen-Bohlman, et 2004). al. Historically, health was regarded as the absence of physical illness (World Health Organization, 1948); however, as society and health care continues to change there has been more recognition that multiple factors go into producing a healthy society (Brundtland, 2002; World Health Organization, 1948). In 1948, the World Health Organization stated that to be healthy was more than just not having a disease or sickness; in order to be defined as healthy, a person would also have physical, social, and mental well-being. In 2002, the National Committee of Vital Statistics (NCVS) further defined health in functional terms. The committee proposed a broad view of functional health that included an individual's ability to carry out activities of daily living as well as engage in age appropriate life situations and society as a whole (NCVS, 2002). This definition of health, along with the 1948 WHO definition, shows that many factors must be considered when defining health (NCVS, 2002; WHO, 1948). Considering the definition of health as defined by the WHO (1948) and further defined by NCVS (2002) along with the UNESCO definition of literacy helps to conceptualize what a definition of health literacy must include.

### **Defining Health Literacy**

Prior to the 1990s, health literacy was only considered in terms of how well a person could understand information passed on to them from health care professionals (White, 2008). Researchers began looking at health literacy and its relation to health outcomes in the 1990s (White, 2008). There now are two widely accepted definitions of health literacy. The U.S. Institute of Medicine (IOM) and Healthy People 2010 define health literacy as the following:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions regarding their health...based on the interaction of the individual's skills with health contexts...and broad social and cultural factors at home, at work, and in the community. (Ratzan & Parker, 2000, n.p.).

The World Health Organization proposes a slightly different definition of health literacy that suggests it should be thought of more broadly; the definition includes reference to a person's ability to participate in society and have some control over everyday events (Nutbeam, 2008; Nutbeam, 2000). This definition is also reflective of the WHO (1945) definition of healthy. The WHO definition of health literacy is as follows:

The cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand and use information in ways, which promote and maintain good health... [it is] more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (WHO, 2007, n.p.).

Nielsen-Bohlman, et al, (2004) also include health services, education, culture, and language as important factors through which health literacy skills and capacities are mediated. These researchers suggest that health literacy has both social and individual factors that must be considered and that a person becomes health literate when

the expectations, preferences, and skills of both the consumer and the provider are in harmony (Nielsen-Bohlman, et al., 2004).

The definitions of health literacy provided by the IOM and by the World Health Organization are similar in some regards but distinctly different in others (Nutbeam, 2008). Baker (2006) suggests that the IOM definition of health look at health literacy as a defined set of individual capacities. The capacities are thought to remain stable throughout a person's life unless improved by educational attainment or education programs or declined by aging or disease or infirmity (Baker et al., 2000). If the IOM definition of health literacy is used, one could assume that health literacy may be developed by providing people educational intervention with (Nutbeam, 2008). However, it has been proven that educational intervention alone is not very effective (Nutbeam, 2008). Additionally, the IOM definition would suggest that a person is capable of achieving a certain level of health literacy if the person has the capacity and motivation to learn (Baker, 2006). Baker (2006) suggests that the idea of knowledge attainment is reflective of health knowledge as a component of health literacy.

The World Health Organization definition looks at health literacy in terms of a person's skills rather than a person's capabilities and further suggests that individuals may gain skills needed to make them active participants in society (Nutbeam, 2008). These skills allow people to engage in their world and affect changes needed to be successful, which would include navigating the health system (Nutbeam, 2008). Nutbeam (2008) suggests that these individual skills are the building blocks for which additional complementary skills are built. Thus, the difference between the IOM and WHO definitions of health literacy is in how the person is thought to acquire health literacy, either by building upon capacities through educational intervention or by using existing skills to grow new skills (Nutbeam, 2008). The World Health Organization essentially views health literacy as an asset, a concept distinct from general literacy, and a product of health education (Nutbeam, 2008). The Institute of Medicine definition views health literacy as goal directed and useful in increasing compliance to medical recommendations (Nutbeam, 2008). Health literacy as an asset will be explored later in this review.

The IOM and WHO definitions of health literacy provide broad means to shape the idea of health literacy (Nutbeam, 2006). However, Nutbeam (2006) argues that there are three different types of health literacy. Each of the three types will enable a person to perform a specific skill (or set of skills) (Nutbeam, 2006; Freebody & Luke, 1990). Nutbeam (2006) defines the three types of health literacy are basic/functional literacy, communicative/interactive literacy, and critical literacy. Basic/functional literacy skills enable to a person to participate in everyday situations by having sufficient reading and writing skills (Nutbeam. 2006). Communicative/interactive literacy is combined with social skills to enable a person to obtain information, get meaning, and apply information to new situations (Nutbeam, 2006). Critical literacy enables the person to analyze information and gain control over situations (Nutbeam, 2006). These three types of literacy exist on a continuum, and at each level, the person gains more skill, independence, and empowerment to make health decisions (Nutbeam, 2006). The WHO definition of essentially literacy combines elements of both communicative/interactive literacy with critical literacy and provides for the social and personal benefits of being health literate (Nutbeam, 2006).

### Health Literacy and Sense of Coherence

In considering the WHO definition of health literacy, it is important to discuss Sense of Coherence (SOC). This is the idea that if a person finds a situation to be comprehensible, manageable, and meaningful, he or she is more likely to find solutions to problems, increase effective coping skills, and reduce tension (Eriksson & Lindstrom, 2008; Antonvosky, 1987). Critical literacy, which is part of the WHO's definition of health literacy, suggests that when a person achieves critical literacy skills he begins to use this skill to gain control over circumstances (Nutbeam, 2006). Sense of Coherence and the WHO's definition of health literacy appear to complement each other. Both definitions suggest that given the right information, including the ability to use that information, people will be more likely to manage, control, and determine the outcomes of their own health (Antonvosky, 1987; WHO, 2007). Given this idea, health literacy becomes an important determinant of health.

The World Health Organization's Commission on Social Determinants of Health and Healthy People 2020 defines determinants of health as those things that when gathered together influence a person's health and wellbeing (CSDH, 2008). There are several categories of items that are thought to be determinants of health (CSDH, 2008; Healthy People 2020, 2012) including policymaking, social factors, health services, individual behaviors, and biology and genetics (Healthy People 2020, 2012).

General literacy is considered an important determinant of health (Kickbusch, 2001). While health literacy may not fit neatly into one of the broad categories, it may underscore many of the other determinants of health, thus itself becoming a determinant of health (Perrin, 2008; Kickbusch, 2001).

Health literacy is an important aspect of health promotion. This is defined as strategies designed to make improvements to people's health knowledge, attitude, skills, on individual, and behaviors societal, organizational, and political levels (WHO, 1986). Health promotion helps to strengthen a person's control over the modifiable determinants of health (Nutbeam, 2006). Organizations that engage in health promotion may look to health literacy as an outcome to measure the success of the program (Kickbusch, 2001). Health literacy also may be used as a tool in health promotion (Nutbeam, 2006). Outcomes of health promotion are hierarchical in nature and explain how health promotion activities, determinants of health, and health outcomes are related (Nutbeam, 2006; Nutbeam, 1998). Nutbeam (1998) provides a model that summarizes health promotion outcomes. In this model, health literacy falls under the category of health promotion outcomes (Nutbeam, 1998). In this model, health promotion outcomes are personal, social, and structural factors that may be changed to influence the determinants of health (Nutbeam, 2008). Health promotion activities are generally aimed at these targets (Nutbeam, 2008). Health literacy in this model is representative of a person's ability to access, understand, and use health information in such a way as to have a positive effect on his or her health outcome (Nutbeam, 2008).

### Framing Health Literacy: Asset or Liability

Health literacy continues to emerge as an important aspect of health, yet it is typically discussed in a negative context (Nutbeam, 2008). Many health care professionals and researchers frame a person's decreased health literacy skills as a liability, with health literacy being described in terms of cost, burden, and disparity (Nutbeam, 2008). McLaughlin (2009) states that poor health literacy may lead to health disparities, poor health outcomes, decreased patient safety, and higher costs (\$73 billion dollars annually). While the idea that poor health literacy can lead to poor outcomes is known, viewing health literacy as a problem may have some negative consequences as well. For example, if viewed as a liability, health literacy may be restricted to only clinical interactions, thereby limiting the scope in which health literacy may be used (Nutbeam, 2008).

Nutbeam (2008) suggests that health literacy should be framed as an asset, because as an asset, the interpretation, evaluation, and use of health literacy are strengthened (Nutbeam, 2008). Health literacy as an asset means that it is no longer viewed as a problem that needs to be fixed but rather is viewed as a resource that can be used to improve the management of chronic health conditions and ultimately as a health promotion tool (Nutbeam, 2008). Health education and communication can be used in various settings and for much more than just individual health outcomes, if the product of health literacy is empowerment (Nutbeam, 2008). Nutbeam (2008) suggests that there could be increased awareness of the social determinates of health. These determinants of health may become modifiable because of the actions of the community (Nutbeam, 2008). People would be empowered to make change at the community and individual levels. They would gain skills that increase their confidence in navigating the health care system and communicating with health care providers (Nutbeam, 2008). Sorensen and Brand (2011) suggest that health literacy would be a strategic asset that would help to increase the overall health of the population and workforce. This would separate health literacy as its own concept, distinct from general literacy skills, that in effect becomes the outcome of health education and patient provider communications rather than just an influential factor in the outcome (Nutbeam, 2008).

Health literacy as an asset would task health care professionals with building upon the skills people have instead of focusing on remediation of deficits (Nutbeam, 2008). This shift in view may influence how assessments of health literacy are designed and ultimately how people are evaluated by these assessments (Nutbeam, 2008). Industries other than health care may also desire a role in health literacy if it is framed as an asset (Berkman, DeWalt, Pignone, Sheridan, Lohr, & Lux, 2010). Sorensen and Brand (2011) argue that corporations could contribute to the health literacy of people in such a way that is mutually beneficial for the employee, population at large, and the corporation. The authors suggest that businesses could engage in health literacy promotion in a number of ways. First, the authors suggest that existing programs in the corporation be integrated with health literacy activities (Sorensen & Brand, 2011). Second, corporations could engage in conversations with stakeholders about how best to approach health literacy (Sorensen & Brand, 2011). Finally, corporations could

begin to develop an action plan to improve health literacy, thereby designing a framework from which the corporations or society could work (Sorensen & Brand, 2011). Corporations taking these actions not only position themselves as socially responsible but also arm their employees with the skill of health literacy (Sorensen & Brand, 2011)

### Assessing Health Literacy

Defining health literacy has its challenges, as does assessing health literacy. There are several commercially available health literacy assessment tools. Currently, the most commonly used assessments are test reading ability and vocabulary skill in the context of health-related information (Nutbeam, 2008; Nielsen-Bohlman, et. al, 2004). When the health literacy assessments are considered along with the definitions of health literacy, a few limitations begin to emerge. Baker (2008) suggests that health literacy assessments must take into account the definition of health literacy when determining what items to assess. For example, Baker (2006) and Nutbeam (2008) argue that if the definition of health literacy encompasses the idea that a person must have knowledge. then the most commonly used assessments of health literacy do not provide an adequate assessment. None of the more commonly used health literacy assessments address the idea of knowledge, yet the definition provided by the Institute of Medicine and the WHO would suggest knowledge as a critical piece in a person's health literacy (Nutbeam, 2008). Additionally, if health literacy truly involves an interaction between the system and the person in which the system serves, then limiting health literacy assessments to the individual only would not be appropriate (Nutbeam, 2008; Baker, 2006). Assessing only the individual does not account for the individual's relationship and interaction with the healthcare system (Nutbeam, 2008).

The Committee on Health Literacy of the Institute of Medicine found that assessment tools do not offer ways to differentiate between the types of abilities the person has (Nielsen-Bohlman, et. al, 2004). For example, the current tools cannot differentiate whether a person has difficulty with reading or simply difficulty with content knowledge (Nielsen-Bohlman, et. al. 2004). Furthermore, the tools do not account for differences in a person's cultural beliefs about health (Nielsen-Bohlman, et al. 2004). Current assessments do not account for the different ages and stages of life, which if they did would help keep health literacy in an appropriate context for the person (Nutbeam, 2008).

The IOM's Committee on Health Literacy suggests that having written and oral communication evaluation would be of benefit in a health literacy assessment to evaluate the range of communication abilities of the person (Nielsen-Bohlman, et al, 2004). An assessment of oral and written language along with social skills may be helpful in assessing the person's ability to navigate the health care system and advocate for his or her needs (Nutbeam, 2008). Health literacy is best assessed when cultural factors, conceptual knowledge, listening. speaking, numeracy, writing, and reading skills are all included in the assessment (Nielsen-Bohlman, et. al, 2004). Nutbeam (2008) adds that health literacy assessments should be able to measure how a person is able to gain access to information, discriminate information, personalize information to his or her own needs, and apply information once it is obtained.

### Health Literacy and Health Outcomes

### Products of Adequate Health Literacy

People with adequate health literacy typically engage in health promoting behaviors and have better health outcomes (Nielsen-Bohlman, et al., 2004; Baker, 1998). People with adequate health literacy may unite as communities and work together for health causes at the community level (Nutbeam, 2006). Individuals with adequate health literacy are more likely to engage in activities, such as exercise, regular checkups, and healthy eating, that are all thought to reduce a person's risk of illness, disease, and complications for illness and disease (Nielsen-Bohlman, et al., 2004). A person with adequate health literacy may also find it easier to navigate the health care system and may be more likely to seek treatment sooner and feel more confident in their ability to communicate their questions and needs to health care providers (Paasche-Orlow & Wolf, 2007). Adequate health literacy may useful in patient provider communications in that people with adequate health literacy are better able to adhere to medication and other health recommendations, provide better medical histories, and give accurate and relevant information to help guide diagnosis and treatment because they are able to understand what is being required of them (Williams, et People have a decreased likelihood of al. 2002). hospitalization when they have adequate health literacy (Baker, 1998). They also tend to report a higher sense of good health than do their peers with inadequate health literacy (Win & Schillinger, 2003).

People with adequate health literacy tend to have more disease-specific, practical, and instrumental knowledge

needed to manage successfully their chronic health conditions (Paasche-Orlow & Wolf, 2007; Kalichaman, Benotsch, Suarez, Catz, Miller, & Rompa, 2000; Williams et al., 1998). Schillinger, et al (2002) found that people with type 2 diabetes and adequate health literacy demonstrated better glycemic control and lower rates of retinopathy than did their peers with poorer health literacy. In another study, people diagnosed with HIV who presented with adequate health literacy were more likely to have undetectable viral loads, know their CD4 (an important immune cell) count, and understand the importance of a CD4 count (Kalichman, et al., 2000). Men with prostate cancer who exhibited adequate health literacy were found to participate in decision making about their disease management (Kim, Knight, Tomori, Colella, Schoor, et al., 2001).

People with adequate health literacy are thought to be better health advocates than their peers with insufficient health literacy (Tappe & Galer-Unti, 2001). Health advocacy is done at the level of both cases and causes (Carlisle, 2000). Advocacy on the case level is reflective of attempts advocate for vulnerable populations while advocacy on the cause level is reflective of attempts to change structural and political barriers to equal access to health (Carlisle, 2000). There is a continued need for those in public health to be advocates for those that they serve (Carlisle, 2000). However, in health promotion the goal is to empower people to advocate for themselves (Carlisle, 2000). Health advocacy takes on two forms, representational and facilitational (Carlisle, 2000). Representational advocacy is reflective of public health initiatives designed to protect vulnerable populations (Carlisle, 2000). Facilitational advocacy is reflective of initiatives designed to empower people with the skills needed to take control and lobby for their own health (Carlisle, 2000). Critical health literacy is one step to empowerment that enables people to advocate for their health on both the case and cause levels (Nutbeam, 2006).

The health literacy skills of individuals may also influence the health care system as a whole (AARP, 2004). Nielsen-Bohlman, et al, (2004) reports that there are financial advantages to improving the health literacy of health care consumers. It is noted that "health care consumer" is a term used to describe people who use health care services; however, Stavri (2001) suggests that consumer may not be an appropriate term as health care is not a consumable. For purposes of this review, the term health care consumer will be used, because while not a consumable, there are economic and political implications surrounding health care (Stavri, 2001). Nielsen-Bohlman, et al, (2004) cites a report by Baker, et al, (2002) that states that health expenditures for people with inadequate health literacy was much higher than for people with adequate health literacy (Nielsen-Bohlman. et al., 2004). The study found that people with inadequate health literacy had more emergency room care and less outpatient care (Nielsen-Bohlman, et al., 2004). People exhibiting inadequate health literacy may not fully understand health-related information and in turn have to seek more services or more expensive care (e.g., Emergency Room services) (Murphy, Davis, Jackson, Decker, & Long, 1993). It is estimated that health care costs that stem from low or inadequate health literacy are as high as \$73 billion annually (Friedland, 1998). Nielsen-Bohlman, et al, (2004) suggests that while there are few studies that specifically look at the relationship between health literacy and health care expenditures, the evidence that is available suggests that there is a relationship worth further investigation.

### **Becoming Health Literate**

### How Do People Become Health Literate?

Improving the health literacy of health care consumers is a responsibility mostly shouldered by health care professionals; however, other disciplines are also implicated in improving health literacy (Nielsen-Bohlman, et al, 2004). There is an interaction between the health care and educational systems, culture, and society that helps to improve an individual's health literacy (Nielsen-Bohlman, et al. 2004). People with inadequate general literacy skills, including verbal communication and numeracy, are at a greater risk of not having an opportunity to receive health education and are also at risk of not being able to use the health information that they do receive (Nutbeam, 2008). Children are provided with health information beginning in the kindergarten and throughout high school (Nielsen-Bohlman, et al, 2004; Tappe & Galer-Unti, 2001). There are certain health-related skills that children are expected to possess as they continue through primary and secondary education (Tappe & Galer-Unti, 2001). For example, the Joint Committee on National Health Education Standards (1995) suggests that children in the eighth grade should have the skills necessary to work cooperatively when advocating for health, express health information and ideas, and identify barriers to communication (Tappe & Galer-Unti, 2001). Other programs may serve adults who do not acquire health literacy skills in school. The Adult Basic Education and Literacy program (ABEL) provides some basic skills in

reading and math necessary to develop literacy skills (Nielsen-Bohlman, et al, 2004).

Health care professionals are responsible for promoting health literacy; however, many health care professionals are uncertain as to how to accomplish this task (Tappe & Galer-Unti, 2001). They do not recognize that the people to whom they provide care have inadequate health literacy (Paasche-Orlow & Wolf, 2007; AARP, 2004; Murphy, et al, 1993). AARP (2004) reported that in an AMA survey, only 33% of physicians reported knowing about health literacy. Tappe and Galer-Unti (2001) suggest that health professionals should be trained in undergraduate and graduate level work in the understanding and promotion of health literacy and advocacy. The authors encourage universities and colleges to provide course work in health advocacy and education and to encourage student involvement in health advocacy and education (Tappe & Galer-Unti, 2001). Additionally, health professionals should engage in evaluation of health-related material in an effort to help the health care consumer find the information he or she needs and use it appropriately (O'Sullivan, 2011). Providing information in easy to understand language supplemented by pictures, multimedia, and decision aids may increase the likelihood that a person will understand what the provider is trying to communicate (Paasche-Orlow & Wolf, 2007). Monsivais (2003)recommends that health care professionals provide health consumers with three items: information that is clear, time to work on skills gained from interactions with providers, and resources to help with management of care.

### Where Do People Get Health Information?

People are inundated with a variety of information regarding health (Antonovsky, 1989 as cited in Ek, 2004). Yet, the type and quality of this information may be of concern. It is not common for individuals to have access to information in medical journals, which is not easily available to the public in terms of both ability to access and ability to comprehend the information (Monsivais, 2003). This leaves many people with the option of relying on less formal sources of information. Health information is available from print media, television, and internet sources (Cutilli, 2010; Nielsen-Bohlman, et al, 2004). Health-seeking behavior, or consumer health information seeking behavior, is the terms used to describe how people get information about health, illness, and health promotion (Cutilli, 2010). The information people receive regarding health may be contradictory at times (Nielsen-Bohlman, et al, 2004). People with inadequate

health literacy may have difficulty sorting out all the information and in turn may not always use the information at their disposal (Nielsen-Bohlman, et al, 2004).

Diaz, Griffith, Ng, Reinert, Friedmann, and Moulton (2002) conducted a survey to look at internet usage for health information amongst patients. The study found that 53.5% of patients admitted using the internet for medical information. Of those that use the internet for health information, 60%, thought that the information gained from the internet was the "same as" or "better than" information they had received from their physicians (Diaz, et al, 2002). Most patients in the survey did not inform their physicians of their usage of the internet for health information nor did the patients engage in any evaluation of the accuracy and trustworthiness of the material reviewed (Diaz, et al, 2002). This study suggests that many people are turning to the internet in an effort to gain more information about their health (Diaz, et al, 2002).

Younger adults tend to seek more information from the internet than do older adults: however, older adults who use the internet tend to use it more for health information than do younger adults (Cutilli, 2010). Hispanics and African Americans tend to use the internet less than European Americans (Cutilli, 2010). Even though minorities are less likely to use the internet for health information, this material is available to anyone who can access it. What is of concern is the type and quality of information that can be obtained from these sources, especially in the face of limited health literacy (Diaz, et al, 2002). Williams, et al (2000) state that health information written on 100% of the websites reviewed were written at or above a ninth grade level. This would present a challenge to those with limited health literacy, as they may not be able to understand and subsequently use the information (Williams, et al, 2000).

It is important that health care professionals know where individuals get their health care information (Cutilli, 2010). Kutner, Greenberg, Jin, &Paulsen (2006) found that people with limited health literacy tended to use fewer sources for health information and relied more on television and radio as sources of information. Those with higher levels of health literacy used a more diverse mix of sources including internet, print media, television, family, friends, and health care professionals (Kutner, et al, 2006). Guiding an individual's use of the internet for health purposes poses a difficult challenge to health care professionals (O'Sullivan, 2011). Some health agencies

may design specific health portals that limit the complexity of information to help individuals be successful with both navigation and usage of the information (Sarkar, Karter, Lin, Adler, Ngyuen et al., 2010). However, many people do not have access to health portals and rely on general internet searchers for health information.

O'Sullivan (2011) suggests that health care providers be willing to evaluate information available on the internet and make suggestions to their health care consumers. Fox (2009), as cited in O'Sullivan (2011), gives the acronym TRUTHFUL as a way for health care providers to help individuals evaluate the internet sources of health information. Fox (2009) suggests that nurses and their health consumers look for the technical aspects, reviewers, purpose, funding, and legitimacy when considering using information from an internet source (O'Sullivan, 2011). Health care providers who assist people with evaluating information are helping them to become more health literate (O'Sullivan, 2011). People with adequate health literacy experience better success using the health information that they obtain from the internet in such a way as to influence their health outcomes than do their peers with limited health literacy (O'Sullivan, 2011; Sarkar, et al, 2010; Diaz, et al, 2002).

### What Kind of Health Information Do People Seek?

Health information is a generic term used to describe information that can be used to improve one's health. People with chronic health conditions and their caregivers may seek information for a variety of reasons. Some seek information about their specific disease, while others look more into new treatments and technologies. People may also seek information to educate themselves on health care costs and funding. Vermaas and Winjgaert (2005) found that men and women seek different information online regarding health. The study suggests that men tend to seek information on more topics including mental health, sensitive topics, new diseases, and new medications (Vermaas & Winjgaert, 2005). Women in the study were found to seek information on chronic health conditions and health insurance (Vermaas & Winigaert, 2005). Women were also found to seek information for family and friends (Vermaas & Winjgaert, 2005). Vermaas and Winjgaert (2005) believe the difference in information seeking behaviors between men and women may be a reflection of women's roles as caregivers.

Cultural differences also exist in the sources and types of information sought. Cutilli (2010) cites a study by

Thompson, et al. (2008) that found African Americans searching for information about cancer were more likely to seek information regarding support services and medical referrals. Additionally, Cutilli (2010) cites studies that found that African Americans were more likely to seek their information from health professionals, whereas people of Hispanic descent were more likely to seek information from friends and relatives. Older adults also valued the information gathered from a physician over that of other sources (Cutilli, 2010). While this indicates that people are seeking health information, there does appear to be a disparity between an individual's willingness to seek information and the low rates of health literacy (Cutilli, 2010). This suggests that although people have information, they may not know what to do with this information (Nutbeam, 2006).

### How Does a Health Literate Society Function?

Nielsen-Bohlman, et al (2004) describe how their committee believes a health literate American society functions. The authors state that in a health literate society, opportunities are available to all persons to improve health literacy. Moreover, they note that people have the ability to use and evaluate health information available to them in promoting good health. Health literacy is taught from kindergarten until twelfth grade, not just when the person becomes. Policies regarding health are monitored and policy makers are held accountable for these policies (Nielsen-Bohlman, et al, 2004). Public health alerts are presented in such a way as to inform and allow people to take action (Nielsen-Bohlman, et al, 2004). All health communications are presented in such a way that everyone can understand, including people who do not speak English (Nielsen-Bohlman, et al. 2004). Patients are afforded time and made to feel comfortable in discussions with their health care providers (Nielsen-Bohlman, et al, 2004). People are able to understand informed consent documents and make choices based on those documents (Nielsen-Bohlman, et al, 2004). Lastly, Nielsen-Bohlman, et al, 2004 state that while this vision of a health literate society will be difficult to achieve, it is important that work continue in order to give everyone a chance to benefit from optimal health.

Nielsen-Bohlman, et al (2004) makes several recommendations regarding how the United States might achieve this vision of a health literate society. The authors describe in detail each of the recommendations and give specific ways by which each of the recommendations should be implemented. The themes that emerge in the

recommendations include: providing adequate funding for promoting health literacy and developing tools, examining policy changes that promote health literacy, providing education to consumers and health care professionals on health literacy, and supporting research in the field of health literacy.

### CONCLUSIONS

A health literate society is recognized as a goal of many health agencies. Health literacy is important in improving the health of individuals and society as a whole. Increasing health literacy empowers people to take control of their individual health as well as advocate for changes in policies that may affect their access to positive health outcomes. Providing people the means by which to improve their health literacy is of the utmost importance. As reflected in this review, improving health literacy in the population will involve changes at the individual, societal, and health care agency levels. How health literacy is assessed will also be an important factor in producing health literate individuals. Looking at it will require that health literacy be examined at the individual, social, and agency levels. There must also be a discussion of cultural factors in defining and assessing health literacy.

Several pieces of research look at information-seeking and usage with regard to health literacy. Research suggests that people use the internet to gain information about their conditions as well as other health related topics. It may be of interest to look at how specific cultures access health information and what types of health information are targeted towards these cultures. This information could help guide researchers and health educators to understanding what specific cultures needs and values are regarding health information. This information may also lead to improving the type and quality of health information targeted towards specific cultures. Understanding the needs of a culture and meeting those needs may empower the people in that culture to manage their health conditions, increase their health literacy, and ultimately improve their overall health outcomes.

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### **ABOUT THE AUTHOR:**

Shatonda S. Jones, Ph.D., CCC-SLP, is an Assistant Professor in the Department of Communication Sciences and Disorders at Rockhurst University. Her research focuses on how knowledge of stroke shapes response to stroke symptoms, stroke survivor perceptions of treatment post-stroke, health awareness and health behavior in communities of color, diffusion and dissemination of health information, and health literacy among populations at increased risk of neurological impairments.

### HEALTH LITERACY AND LITERACY AS DETERMINANTS TO HEALTH STATUS: ISSUES AND STRATEGIES FOR CLINICIANS

Silvia Martinez, Ed.D. Howard University Washington, D.C.

#### ABSTRACT

There is considerable amount of attention being placed on health literacy. Following recommendations by the World Health Organization and Healthy People 2010, many organizations have prioritized health literacy when developing missions, goals, activities, and materials. The present article presents the issues surrounding health literacy as they relate to the health status of individuals and communities. The principle point made is that increasing health literacy in individuals and communities leads to empowering them to take action at different levels and become self-sufficient in creating policy changes as well as tending to their own health and that of their family members. While health literacy is dependent upon a variety of individual and societal factors, the present article will address the issues of literacy. Therefore, a summary of issues is presented accompanied by strategies that can be used by clinicians during personal exchanges with clients, and when developing hard copy and technology-based reading materials.

KEY WORDS: Health literacy, health disparities, patient/client education

### HEALTH LITERACY AND LITERACY AS DETERMINANTS TO HEALTH STATUS: ISSUES AND STRATEGIES FOR CLINICIANS

Silvia Martinez, Ed.D.

Howard University Washington, D.C.

### **INTRODUCTION**

uring the last decade attention has been placed on a diversity of factors affecting the health of individuals and communities, beyond the condition itself. The focus, therefore, has shifted from a solely medical model to a more social model that gauges how individual traits and lifestyles impact the health status of our clients and their environments. Thus, as we carry out activities related to prevention, assessment, treatment, and counseling we must address social, economic and environmental determinants which have been identified as impacting health standards as well as disability prevalence and severity. This paper presents and overview and recommendations addressing health literacy as a determinant to health status. It also offers recommendations for clinicians to increase their with low literate effectiveness when engaging populations.

### Health Literacy

The demands placed on clients to understand scientific based knowledge and carry out complex suggestions may be challenging to close to one third of the population in the US. Clients are expected to understand both oral and written information that is highly sophisticated. Not offering them satisfactory communication modes when, for example, filling out forms, sharing health history, treating conditions, and offering them prevention information such as statistics, may lead to inappropriate care, increased health problems, health complications, as well as dissatisfaction, frustration, distrust and disempowerment. Health literacy responds to these issues.

Health literacy is basic for effectively navigating through healthcare systems. It is the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (US Department of Health and Human Services, 2000). Health literacy comprises a set of higher level skills to facilitate evaluating information, analyzing risks and benefits, making calculations of medicines, and interpreting test results among others. They also include skills such as reading abilities, and oral and visual abilities used to clarify and understand pictures and graphs (Doak, Doak, & Root, 1996). They also depend on the following (US Department of Health and Human Services, 2015):

- The communication skills of lay persons and professionals,
- The lay and professional knowledge of health topics,
- Cultural understanding,
- Demands of the healthcare and public health systems, and
- The demands of the situation/context.

The World Health Organization (2015) defines Health Literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health Literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment." Thus, there is a focus on social and political issues that affect and are beyond the client's health status. This definition, as recognized by Nutbeam (2000), Matthews (2014), and Wallerstein and Bernstein (2988) aligns very much to Paulo Freire's (1970) education for empowerment philosophies with outcomes such as "client resiliency against social and economic adversity,..... improved community empowerment [and]..... obtaining policy and organization change to increase health (Nutbeam, 2000, p266)".

As clinicians, we recognize that some of our clients lack these skills. Similarly, studies such as the 2003 National Assessment of Adult Literacy (NAAL) (Baer, Kutner & Sabatini, 2009) have found that a large proportion of our

population is in need of furthering their skills. When assessing health literacy skills it was found that 14% of those gauged had below basic health literacy skills. They can, for example read a set of short instructions, and identify what is permissible to drink before a medical test. Another 22% of the population had basic health literacy skills, enabling them to read a pamphlet, and give two reasons a person with no symptoms should be tested for a disease. In total they identified a population of 77 million belonging to these two categories. They also found that only 12% of the population had proficient health literacy skills (US Department of Health and Human Services, 2008).

Other studies about the skills of patients also point to gaps. Williams, et al. (1995) demonstrated that 35% of English speaking and over 61% of Spanish speaking acute care patients had inadequate or marginal levels of functional health literacy. The Council of Scientific Affairs of the American Medical Association's report on functional literacy (1999) described that at two public hospitals, only one-third of English-speaking patients were unable to read basic health materials. Further, among Medicare recipients, 34% of the English speaking and 54% of the Spanish speaking patients exhibited inadequate or marginal health literacy (Gazmararian, et al., 1999). Wallace and Lennon (2004) also estimated that 25% of patients may have reading skills equivalent to the fifth grade or lower. Martinez, Calderon and Vora (2013) assessed Spanish dominant elderly Hispanics using a literacy screener Spanish Test of Functional Health Literacy in Adults-S-TOFHLA – Short Version (Parker, Baker, Williams & Nurss, 1995). The resulting scores were equal to "inadequate functional health literacy and found the average literacy level to be inadequate functional."

### Literacy Issues

Health literacy, as described above, is affected by a number of determinants, including individual literacy skills. It is unsurprising, therefore, that the report *Healthy People 2010* (U. S. Department of Health and Human Services, 2000) recommended the aim of "*improved consumer health literacy* (Objective 11-2)" and identified health literacy as an important component of health communication. Thus, to address Healthy People 2010 overarching goal of eliminating health disparities, it is recommended that literacy skills of communities be considered when health education materials and activities are developed and carried out.

There are different literacy skills that can be used when gauging what our clients can do with the information offered them. In keeping with the concept of selfsufficiency and empowerment, Freebody and Luke (1990) have offered these definitions:

- Basic/functional literacy sufficient basic skills in reading and writing to be able to function effectively in everyday situations, broadly compatible with the narrow definition of "health literacy".
- Communicative/interactive literacy more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and drive meaning from different forms of communication, and to apply new information to changing circumstances.
- Critical literacy more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life and events and situations.

One way of gauging some of these skills is by looking at a particular set of sub-skills used by the 2003 National

Assessment of Adult Literacy (NAAL): prose skills, document skills, and quantitative skills (Baer, Kutner & Sabatini, 2009). The Educational Testing Service offers the following definitions of these three (2015). First. prose skills measure how well you understand and use information found in newspapers, magazines, novels, brochures, manuals or flyers. Most adults use prose literacy to answer questions, to learn how to do something or for entertainment. Second, ddocument skills measure how well you find and use information in forms, schedules, charts, graphs and other tables of information. Most adults use document literacy to find information they need or want or to give information to someone else. Third quantitative skills measures how well you can use numbers found in ads, forms, flyers, articles or other printed materials. Quantitative literacy is a little different from prose and document literacy because in addition to using a text to identify needed information, you also have to add, subtract, multiply, divide or do other math to get the information you need.

When assessing prose, NAAL found that a population of thirty million (14%) presented with "below basic skills", described as having no more than the most simple and concrete skills. Sixty three million (29%) individuals presented with "basic skills" which enabled them to only

perform simple and everyday literacy activities. These two groups –below basic and basic – comprised 43% of the population surveyed. Those individuals most at risk had the following demographic characteristics: Race (Blacks and Hispanics represented 68%; Age (individuals over 65 represented 26%); Language Background (individuals speaking Spanish or used Spanish/another non-English language before school represented 35%); Education (individuals without a high school degree or GED represented 55%); persons with one or more disabilities represented 46%; and Health Insurance (individuals without health insurance comprised 53%) (National Center for Education Statistics, 2006).

### Health Information Issues

The community gathers information about health issues through printed and oral formats in hospitals, clinics, health fairs and other settings. They also obtain information via television and technology devices such as computers and cell phones. Specifically, as it pertains to the written form, brochures and handouts are usually printed at above reading levels of their intended audiences' literacy skills. In this regard, The Institute for Healthcare Advancement (2011) described that many written health materials appear at the 10<sup>th</sup> grade level or higher (above average abilities), that they include too much information and no explanation of uncommon words, and that treatments are explained using complex instructions.

In the field of communication sciences and disorders the picture is quite similar. For example, Martinez (2010) gauged the readability levels of handouts and brochures disseminated by the American Speech, Language, Hearing Association (ASHA), National Institutes of Health (NIH), and the American Academy of Audiology (AAA). These are the agencies that are charged with educating the population about communication disorders, including the impact of stroke on communication skills. The assessment of readability levels using the FOG, SMOG, Flesch Grade level and Flesch Reading Ease Readability Measures, determined that the average readability level of the brochures with a diversity of health topics was gauged (N=51) at a grade level of 8.8. The reading levels ranged from grades 5.0 to 12.8. Only one fourth of the brochures contained information at the sixth grade level or lower. In addition, the readability level of brochures related to stroke (n=5) averaged at a  $12^{th}$  grade. Martinez's results run in concert with other studies about stroke related materials, that were also found to be written at high readability levels (Eames, McKenna, Worall &

Read, 2003; Estrada, Hryniewics, Higgs, Collins & Byrd, 2000; Hoffman & McKenna, 2006; Hoffman, McKenna, Worrall & Read, 2004; Sullivan & O'Connor, 2001; Vallance, Taylor & Lavallee, 2008).

It is common knowledge that people are relying more on the internet to obtain information about their health Health information delivered through interests. computers do not fair better than written materials, because the readability levels of sites continue to be high. Such is the case as reported by Walsh and Volsko (2008). They used similar readability tools as used by Martinez (2010) to assess the websites of the American Heart Association, American Cancer Society, American Lung Association, American Diabetes Association, and American Stroke Association. Most of the randomly selected consumer information were assessed at the 7th grade or higher. Similarly, Risoldi, Cochrane, Gregory, and Wilson (2012) found that website materials' readability levels were poor when assessing government and private funded health websites. They also found privately funded website information to be more difficult. Some studies have also looked at Spanish information. Berland, et al (2001) reviewed the quality and content of 24 health websites. They observed that the mean average reading level in English was at the collegiate level and for Spanish the mean average was a 9.9 grade level. This situation is not unique to the United States since Cheng and Dunn's (2015) investigation of Australian health internet sites obtained similar results.

### Strategies to Enhance Health Literacy Policy

To address the discrepancies between readability levels of health materials and literacy levels of the intended populations, and following through with the Healthy People 2010 agenda, the US Department of Health and Human Services (2015)offered policy-based recommendations. First, they suggest promoting universal access to health information by setting guidelines for developing materials, similar as guidelines have been developed for universal access to buildings. Further, testing for readability is encouraged so that information distributed is understood. Second, they recommend that health literacy, together with cultural and linguistic competencies, be prioritized when developing disparity initiatives. Third, public and private insurers are urged to develop accessible communication materials and processes. Finally, they also support the strengthening of health education for elementary and high school students.

### Clients

Assessment. At the user-level, figuring out the literacy levels of clients may be a daunting task. Relying solely on interactions with clients to gauge literacy levels is ineffective. This point was demonstrated when Bass, Wilson, Griffith and Barnet (2002) looked at residents' abilities to identify patients with poor literacy skills when compared to literacy testing results. Residents tended to overestimate patient skills. Similar results were obtained by Kelly and Haider (2007) when they investigated physicians' estimation of patient skills. This is because neither conversing nor gathering data about level of education may necessarily accurately identify reading skills (Kirsch, Jungeblut, Jenkins, and Kolstat (1993). Furthermore, clinicians may not be able to rely on patient self-assessment since they also will overestimate their skills (American Medical Association, 1999). Finally, depending on reported educational achievement may be misleading. Many persons graduate without comparable reading abilities, some individuals may have reading disabilities, reading efficiency may be affected by declining cognitive/sensory functions, they may be learning English as a second language, and time lapse from formal schooling may be determinants of reading proficiencies.

There are, nevertheless, some behaviors to hone which may indicate inadequate reading abilities in our clients. Safeer and Keenan (2005) emphasize noting when clients ask staff for help, bring someone to help them read, are unable to make appointments, make excuses (forgetting glasses), are in non-compliance with their medication, do not adhere to recommendations, postpone decisionmaking by taking instructions home to read, and watch and mimic others. Interesting are the results of Chew, Bradley and Boyko (2004) who aimed at identifying specific questions that would help to identify patients with inadequate health literacy. They concluded that three questions were effective: "How often do you have someone help you read hospital materials?" "How confident are you filling out medical forms by yourself?" and "How often do you have problems learning about medical condition because vour of difficulty understanding written information?"

Apart from this sort of informal observations, there are tools designed to address literacy in clients. The two most common are The Rapid Estimate of Adult Literacy in Medicine (REALM) (Institute of Medicine, 2004) and the Test of Functional Health Literacy in Adults TOFHLA (screener and test) (Parker, Baker, Williams & Nurss (1995). These ask patients to read medical terminology aloud, and/or to complete medically related sentences. The TOFHLA is also available in Spanish. The REALM and the TOFHLA contain generic medical terminology and content, but other tools have been developed for specific medical fields, such as diabetes. To date, there are no tools in the field of communication sciences and disorders.

Strategies. To increase understandability during oral exchanges Williams, Davis, Parker and Weiss (2002) list some ideas. Clinicians should slow down their exchange to be able to deliberate on health literacy skills of their clients. This gives clinicians time to make observations as described above and ask questions in unthreatening manners to foster trust. Another strategy addresses the language used. They suggest that the amount of medical terminology used should be reduced, and in place, "living room" language should be used. Clinicians need to engage in ways that family members would converse about ailments in their homes and communities. Nevertheless, teaching moments do occur when vocabulary can be explained. Another suggestion is to enhance clinician-client interactions with pictures. Pictures may be used as well as drawings prepared during explanations. These can be taken home and used for later During exchanges it is important to exchange recall. information that is only necessary for the purpose of the meeting which offers the client time to appreciate and integrate the information to their present needs. Use repetition and rephrasing as necessary. As previously mentioned visits with clients will be educational opportunities. Therefore, use "teach back" or "show me" techniques for confirming if they have understood. Finally, they urge to "Be respectful, caring, and sensitive, thereby empowering patients to participate in their own health care (p.385)".

### **Materials**

<u>Assessment</u>. When selecting and developing written materials (hard-copy and technology-based), their suitability should be prioritized. "Suitability" may be described as "the material's ability to enhance patient understandability, usability, relevance and motivation" (Doak, Doak, Friedel & Meade, 1998, p1305). A global way of judging for suitability can be achieved by asking the following questions proposed by Mayer and Villaire (2009):

• What role will the printed piece play in the overall communication plan? Written material is not

enough to educate patients and families about their health and plan of care.

- How will the information be utilized?
- Will there be follow up on the initial education?
- Who is the target audience?
- Who will review the information and how will it be distributed?
- Is there a budget for the materials and educational process?
- How much time is available to get the materials ready and tested?
- Once the material is distributed, how will it be tested and evaluated?
- Who will do the evaluation and who will review and update the materials if needed?

A more formalized procedure to assess written materials is by using the Suitability Assessment of Materials (SAM) (Doak, Doak, & Root, 1996). This instrument is more global when gauging the appropriateness by looking at a variety of areas. It taps on the readability (relative difficulty of decoding words) and the comprehension (the relative difficulty of understanding the meaning) in six areas: content, literacy demand, graphics, layout and type, learning stimulation and motivation, and cultural appropriateness. SAM helps to rate the adequacy of materials for the particular audience by asking questions such as if the purpose is understandable, does it help to solve the problem, are summaries given, what are the literacy demands and writing styles, are graphics relevant to content and understood, are fonts appropriate, do subheadings help, is interaction between reader and information present, is there cultural matching, among others.

Other tools are more discrete in what they measure, particularly those that measure readability. Readability is a measure of how easily a text can be read. For the most part, readability results offer school grades equivalents. These tools can be used for testing of printed and/or webbased materials. The most popular ones are available free on-line, are contained in word processing packages such as Microsoft Word (Microsoft, 2013), or can be purchased as separate software programs. There are also free internet assessment programs to gauge web-site pages and Readability formulas such as the ones materials. described below, measure surface structures since they rely on, for example, word and sentence counts and/or complexities, and use mathematical regression formulas to reach their conclusions. These formulas do not offer the opportunity to assess deep structures of the written form such as coherence, nor other important aspects such as layout or culturally appropriate content.

The Flesch Kincaid Reading Ease (Flesch, 1948) and the Fry Readability Graph (Fry, 1968) use random 100 word passages and average the number of syllables and sentences, and the Flesch-Kincaid Grade Level (Kincaid, Fishburne, Rogers & Chissom, 1975) measures syllables and sentence length. The Gunning Fog Index (Gunning, 1952) uses words with three or more syllables and omits proper nouns, jargon and compound words, while the SMOG Index (McLaughlin, 1969) uses 30 sentences to count words with three or more syllables. The Coleman Liau Index (Coleman & Liau, 1975) only uses the number of characters similar to the Automated Readability Index (Smith & Senter, 1967) which makes use of characters per word and words in sentences. Further descriptions of the procedures and formulas used are readily available in different internet sites. While beyond the scope of this article, it must be noted that these formulas are not free of criticism; therefore, professionals should select which formula to use depending on their audience and the materials. Reviewing the instructions for each will offer information as to criteria and constraints of the programs. For those interested in obtaining a list of free web-site assessment tools that also make use of these formulas, Holland (2012) has listed ones that are easy to use.

Strategies. A number of government agencies have published documents that explain strategies to enhance the effectiveness of communication. Three such on-line resources are *Health literacy on-line*: A guide to writing and designing ease-to use health Web sites (US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010), Ouick Guide to Health Literacy (US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2007), and the TOOLKIT for Making Written Material Clear and Effective (US Department of Health and Human Services, Centers for Medicare & Medicaid Services, 2010). The TOOLKIT, in particular, is quite comprehensive by offering eleven sections of guidelines. From this information a checklist has been adapted (see Table 1 Appendix A) which will facilitate clinicians as they review and develop materials for print and for technology-based formats. Some of these strategies are summarized below.

A. Writing

The guidelines for writing include the following four parameters: content, organization, writing style, and engaging, supporting and motivating readers. As may be

evident, the "Toolkit" guidelines for writing include recommendations that may also be useful during oral exchanges with clients.

For content, the material's topic must be made 1. evident by making titles specific, using words and phrasing that draw attention, and limiting the number of words to only the necessary for meaning. The information should be client-centered so that it addresses their interests, knowledge and needs. The clinicians need to be aware of the gaps between them and their clients such as understanding of the subject matter, literacy skills, amount spent by the reader to understand the material's content, how positive are they about the benefits of the knowledge they will gain, and the expectations placed by clinicians on the material distributed. Content should be culturally appropriate, therefore clinicians should perform research activities on the materials, such by obtain feedback from intended audiences. Preferably, the materials should be culturally sensitive to the cultures' experiences, languages, and differences in dealing with conditions. With regard to language, one must use their dominant language, phrasing and words that belong to the culture, as well as examples. To help readers internalize the material, strategies like repetition, summarizing, explaining new terminology and concepts using different words, and making use of formatting designs to highlight points can be used. One must also consider the amount of information offered - limiting it to what is necessary to address the condition.

2. The guidelines for organization suggest that no more than five points be covered, and that the material should be presented in short segments or chunks. Instead of long lists of bullets, grouping by chunks is preferable. Do not go beyond one page or panel per topic. By presenting the information in an orderly fashion the readers are better able to make sense. Therefore, main messages should be presented at the beginning, and new information scaffolded by giving backgrounds and definitions. Using headings and subheadings also helps with organization, so that the content is more manageable to the working memory and visual demands. Headings, subheadings and captions should be short, but not ambiguous. Finally, navigational tools such as page numbers, and table of contents may also be used.

3. Writing style guidelines recommend using conversational and active styles. Sentences should be simple by considering what the reader really needs to know, separating main and secondary messages, and identifying which concepts need to be explained in advance for scaffolding purposes. Specifically, sentences should be short, contain simple conjunctions (or, but, and), and use a limited number of clauses. One might consider using lists instead of sentences, and also offering illustrations or examples. These constraints obligate writers to be direct, specific, concrete, and actionoriented, therefore increasing the readers' interest. Another writing style suggestion is to offer the context first and follow with definitions and explanations. The definitions should be incorporated into the text and not offered "dictionary style." Definitions should be repeated and paraphrased throughout the readings. Symbols should be reduced to a minimum. Cohesion is an important factor for understandability. Logical progression between ideas, repeating key words and phrases help the reader learn. As previously alluded to, the readers' cultures must be considered. Therefore, choosing familiar and culturally appropriate words (and avoiding slang) over technical jargon and figures of speech is preferable. As well, legal language should be The use of technical terminology and simplified. acronyms is very hard to manage because of the customary use in the workforce. However, efforts should be made to simplify expressions. Only if readers need to use them should they be taught by explaining them with familiar words, drawing comparisons to familiar experiences, and using easy-to-read resources. Finally, as explained in previous sections, clients' literacy levels are varied. Therefore, by writing simple the audience is wider, since a variety of populations with different reading levels are reached. Maintaining appropriate readability levels by using readability formulas can be used keeping in mind that they are surface level assessment tools.

4. For engaging clients, materials should be positive, polite and should invite the reader to be an active participant in the reading process. A conversational style that shows respect, support, acceptance of differences, and is personalized will positively tap into the readers' emotions. Hence, a client will be motivated and will want to learn more and consider the recommendations with regard to their condition. Some suggestions for being effective in this area include using devices such as questions and answers, True/False quizzes, stories and vignettes, dialogues and brief quotations, and fill in the blanks. To assure that the instructions given are culturally appropriate, the TOOLKIT guidelines recommend that materials should be very specific, be realistic, avoid suggestions based on fear, and consider specific cultural and linguistic practices of the intended population. When

using statistics, offer examples to populations your reader can relate to. As a final point, offer information about other resources for clients' to obtain further knowledge and support.

### Design

When addressing design there are several topics that have been described in these guidelines. They include: overall design and page layout; fonts, size of print, and contrast; headings, bulleted lists, and text emphasis; use of color; use of photographs, illustrations, and clip art; tables, charts, and diagrams; and forms and questionnaires.

5. The overall design of materials should consider For example, small materials the user-friendliness. facilitate transporting and reduce mailing costs, magnets help with usefulness, and websites (providing color, and black and white PDFs) tap on a wider audience. Clinicians should consider using wide panels and/or portrait orientation when designing brochures (tri-folds should be avoided). The appearance should create favorable first impressions. Avoiding crowding information by using white space that is consistent and generous margins, together with consistent alignments is best for populations with low literacy. As mentioned before, boxing information is a good example of using space appropriate. However putting lines around boxes may not be advisable. Consider the linguistic system your client is used to, since the reading habits may be different. Some cultures read from right to left, and others from top to bottom. The layout of information should take into account the different reading behaviors of their readers. Therefore, materials should avoid having the reader jump around the page unsystematically, so that photographs, graphics, headings and subheadings should be carefully placed. Text off the side is difficult for lessskills readers. The guidelines offer further tips: establish a clear hierarchy of importance for each page; use prominent headings, bullet points, and text emphasis, to help readers skim and find information; maintain general consistency of layout and design elements; avoid crossreferencing; and be alert to navigation formats that are difficult. In conclusion, the layout should have a consistent and clear structure that is organized and predictable, containing consistent styles.

6. Font recommendations are of upmost importance for readers who need help. Generally, no more than two or three highly readable fonts are preferred. The third font can be used for a special purpose. Recommendations are for using "sans serif" styles in headings and "serif" styles in the body, avoiding "all caps." For headings, capitalizing the first word may suffice. A size 12 font or higher is preferable for the body of the material (keeping in mind that not all size 12 fonts are the same). If an older audience is the target, the size may need to be larger. Bold and italics should be used sparingly but are helpful for highlighting key words and short phrases, and can substitute for quotations marks. They should not be used in combination. The materials should not contain any underlying. It is preferable to use dark (best is black) text over non-glossy backgrounds (preferably white) without patterns, or on top of graphics. Select extra spacing between lines in the content but not necessarily between titles and their corresponding segments. Spacing should also be enough between a bullet and information following it. To help with reading, left justification in preferred, including headings. Blocks should be avoided. Lines should not be longer than five inches (very short lines should also be avoided), and care must be taken to avoid hyphenations, and splitting headlines. When splitting headlines is unavoidable, it is best to split to reflect natural phrasing.

Headings are an important part of helping the 7. reader place importance on sections and navigate the material. They should be informative and written in easyto-read font, always using left-justification. By using different size fonts, hierarchies are made, again, facilitating navigation. As explained before, by leaving less line spacing between the heading and the text it introduces, both are linked visually. Concerning bullets, these should be placed leaving enough space between them, and indent the entire block slightly. The same solid bullets, proportional to the material, should be used throughout. As a final parameter, when blocking text avoid using background shading and outlining. Emphasis can be accomplished by using simple graphics (such as an arrow) close to the block to draw attention to it.

8. The guidelines also include recommendations for using color. They emphasize that color is not essential and that black and white may be sufficient for some materials. Most importantly, if the materials will be photocopied, clinicians must consider how color will look like in the end result. Colors appealing to readers should be used keeping in mind cross-cultural differences. Some colors may be associated with sicknesses or even death. By using color sparingly and in concentrated sections, it will then serve to effectively highlight words or phrases. One must avoid using colored paper, color on color, and font colors that are less readable such as oranges and yellows. Clinicians must keep in mind that color coding for low literate populations is not useful. Further, some

clients may be color blind or loose color perception because of aging.

9. Images used in materials should not be used for decorative purposes, but rather, should serve a direct purpose related to the material. Rather they should illustrate content and behaviors discussed. They should not stand alone, and should be accompanied by captions to create a learning opportunity. For populations with low literacy, images can be very powerful in that they may not read the text, but will focus on the photographs and drawings instead. Therefore, these cannot be confusing to the reader. It is better to illustrate the right way of doing things instead of the wrong way. Abstract and stylized images are to be avoided, and instead images should be real, even if line-drawn. By keeping the images concrete, clinicians need to consider if proportions of items illustrated are correct. Furthermore, they must be uncluttered, and a consistent style should be maintained. Images may contain culturally appropriate elements to attract attention and should remove cultural barriers. Thus, a clinician may consider choosing elements for broader audiences. To be culturally responsive, the following tips are included in the guidelines: illustrate with familiar foods and settings, use story telling devices, use specific cultural symbols and patterns, include persons with comparable age to audience, choose a broad range of ethnic images (unless the intended audience is specific), or images that are hard to classify (neutral), portray "ordinary" people, and avoid dated materials or stereotyping. People in illustrations should reinforce the behaviors highlighted, and should depict drama and relationships that are realistic and natural. When choosing symbols, caution must be taken because they may not be self-explanatory, their meaning may not be understood by all cultures, and can lead to misinterpretation. Humor and irony are other aspects to be considered with caution since cultural differences may also lead to misinterpretation or confusion. As well, they may also be offensive to some sectors of the population. Just the same, cartoons may lack clarity and are unappealing. Additional rules for images include using fewer larger pictures instead of many small ones, reducing the backgrounds in photos, and choosing images that belong together. Placing images at the beginning of the material sets a friendly tone. They should be close to text to serve as reinforcements, and can help to signal the start of new sections in long documents.

10. While using tables, charts and graphs may not be the best way to educate, there are some tips that can be considered if these must be used. When used appropriately they can help to better explain the content and to remember explanations. For that reason, it is important to consider the clients' skills with the goal of formatting to create ease in understanding. Thus, tables, diagrams and other similar tools should be accompanied by simple titles that are specific and easy so that text and numbers are readable and understandable at a glance. Abbreviations and acronyms should be avoided. Examples can help to illustrate their content, but crossreferencing (coding, asterisks, column heads) should be avoided. Clinicians can help by offering strong visual and written cues like formatting elements. For example, in a chart categorizing importance of prevention behaviors, "importance" may be illustrated by making fonts bolder, wider, or by adding more "stars." Numbers and calculation need to be explained carefully by giving examples, rounding numbers, breaking them down into steps, making comparisons to familiar objects, converting numbers into different and easier formats.

The last set of TOOLKIT guidelines related to 11. design address forms and questionnaires. Needless to say, these tools are important for clinical practice. These should be introduced by being informative as to their purpose, starting from their titles. Therefore, one should avoid using generic titles, bureaucratic terminology, and instead familiar words and simple syntax should be used. It is the responsibility of clinicians to ask for only the information needed and avoid asking for information that may be readily available elsewhere, or that is redundant. As alluded to previously, the layout should be uncluttered and appealing allowing generous space to fill out answers. Ouestionnaire length is a consideration again limiting the questions to those of most relevancy. Instructions should be brief and appropriately placed so that they are not overlooked or skipped. Instructions should not contain footnotes or asterisks. These tools should be formatted so that the shortest and simplest answer is provided. Formats, wordings, and number schemes should be consistent in all sections. If needed, the questionnaire may include some brief definitions, using familiar terminology. If a person does not have an answer, they should be able to easily say so. Grid and matrix formats are more difficult for persons with limited reading abilities. Instead, convert them into separate questions. Create a logical path to help the respondent navigate through the document by minimizing cross-referencing, reducing "skip over" instructions, and attaching followup questions to the main question.

### CONCLUSION

This article presented the issues related to health literacy. The job of clinicians comprises continually educating caregivers and the clients. community about communication sciences and disorders. The aim is to help them manipulate the health care system so that they can be effective in change, at the policy level, as well as individua llv as they strive to address specific communication disorders. Health literacy, in many instances, is very much related to individual communication skills, both oral and written. Clinicians must be cognizant of their own styles and become more aware of the styles their clients bring to the clinic. In particular, populations with low literacy skills are those most at risk for reduced health literacy skills and, consequently, reduced health status. Demographics point to populations who tend to be minorities, are elderly, speak languages other than English, have low education, are have disabilities, and lack insurance. They also present with low literacy skills.

When communicating with individuals whose literacy skills are reduced, steps have to be taken to assure that knowledge sharing is effective. To that effect, the clinical field has been elaborating guidelines to address the gaps that usually occur between service providers, education materials, and their clients. For the purposes of this article, guidelines published by the Department of Health and Human Services (20109) in their TOOLKIT for Making Written Material Clear and Effective were highlighted and used to offer advice about communication. The TOOLKIT is quite comprehensive, therefore, for practical purposes a chart was adapted to summarize guidelines for professionals to use when evaluating and developing materials.

Finally, with the number of parameters to address as we conduct health literacy endeavors, it is evident that improving communication is not an effort that should be tackled alone. It requires the commitment of agencies and the work of collaborative teams. Those charged with these tasks can work together with literacy agencies, webdesigners, graphic designers, culturally diverse colleagues, translators, and clients in order to produce the best outcomes possible. As professionals in disorders, the American Speechcommunications Language-Hearing Association (ASHA) offers a number of resources. There are also a number of health organizations that aim at educating the public, such as the American Public Health Association (APHA), the Society for Public Health Education (SOPHE), the American School Health Association (ASHA), the American Association of Health Education/American Alliance for Health, Physical Education, Recreation, and Dance (AAHE/AAHPERD), the Eta Sigma Gamma (ESG), American College Health Association (ACHA), and the Directors of Health Promotion and Education (DHPE), National Commission for Health Education Credentialing (NCHEC).

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### **ABOUT THE AUTHOR:**

Silvia Martinez, Ed.D., CCC-SLP, is an Associate Professor in the Department of Communication Sciences and Disorders at Howard University. Dr. Martinez's research interests are in the areas of phonology, Spanish dialectology, bilingualism/second language development, speech and language development, health literacy, health disparities/e-health and international development.

### Appendix A

### Table 1. Guidelines for Writing Health Information for Print and Technology-Based Formats.

Adapted from "Toolkit for Making Written Material Clear and Effective" (US Department of Health and Human Services, 2010)

	Guidelines for Writing	$\checkmark$
1	Content	
1.1	Make the purpose and usefulness of the material immediately obvious.	
1.2	I choosing which content to include, be guided by the readers' interests, knowledge, and needs	
	(which may be quite different from your own.	
1.3	Show awareness of and respect for diversity among intended readers.	
1.4	Repeat new concepts and summarize the most important points.	
1.5	Make sure that the information is accurate and up to date.	
1.6	Limit the information to an amount that is reasonable for the intended readers.	
1.7	Identify the organization that produced the material, and include a publication date and contact	
	information.	
2	Organization (sequencing, grouping, and labeling)	
2.1	Group the information into meaningful "chunks" of reasonable size.	
2.2	Organize the information in an order that will make sense to the intended readers.	
2.3	Use headings, subheadings, and other devices to signal what is coming next.	
2.4	Use specific and informative working for sections, headings, and subheadings.	
2.5	Use the navigational tools to help orient readers and make important information easy to read.	
3	Writing Style	
3.1	Write in a conversational style, using the active voice.	
3.2	Keep your sentences simple and relatively short.	
3.3	Be direct, specific, and concrete.	
3.4	Give the context first, and incorporate definitions and explanations.	
3.5	Create cohesion by making strong, logical connections among your sentences and paragraphs.	
3.6	Choose words that are familiar and culturally appropriate for the intender readers.	
3.7	Use technical terms and acronyms only when readers need to know them.	
3.8	Write as simply you can, taking into account the reading skills of your intended audience.	
4	Engaging, Supporting, and Motivating your Readers	
4.1	Be friendly and positive.	
4.2	Use devices that engage and involve your readers, such as stories and quotations, questions and	
	answers, quiz formats, and blank spaces for them to fill in.	

	Guidelines for Design		
5	Overall Design and Page Layout		
5.1	Design the size, shape, and general look of the material with its purpose and users in mind.		
5.2	Make the material appealing at first glance.		
5.3	Create a clear and obvious path for the eye to follow through each page.		
5.4	Create an overall design for the material that has a clear and consistent style and structure.		
6	Fonts (Typefaces), Size of Print, and Contrast.		
6.1	For the regular text in printed materials, use a "serif" font that is designed for ease of reading.		
6.2	For the headings in your printed materials, use an easy-to-read "sans serif" font, preferably one that is a "font family" with different weights (some bolder than others).		
6.3	In general, use no more than two or three different typefaces in a single piece of material.		
6.4	Make the type size large enough for easy reading for your intended audience.		
6.5	For all of your text, including titles and headings, use upper and lower case letters in combination – nothing written in "all caps."		
6.6	To emphasize words and short phrases that are part of your regular text, use italics or boldface type.		
6.7	For ease of reading, use dark colored text on a very light non-glossy background.		
6.8	For ease of reading, do not print text sideways, on patterned or shaded backgrounds, or on top of photos or other images.		
6.9	For ease of reading and a cleaner look, adjust the line spacing in your material.		
6.10	For ease of reading use left justification throughout the material for both text and headings.		
6.11	Keep your lines of text to an appropriate length for easy reading – neither too short nor too long.		
6.12	For ease of reading, watch where the lines bread (avoid hyphenation; split long headings carefully to		
	reflect natural phrasing.		
7	Headings, Bulleted Lists, and Emphasizing Blocks of Text		
7.1	To make the material easy to skim and show how it is organized, create a clear hierarchy of		
	prominent headings and subheadings.		
7.2	Use contrast and other devices to make the main points stand out on each page.		
7.3	For ease of reading, use care in formatting bulleted lists.		
7.4	Choose effective ways to emphasize important blocks of text.		
8	Use of Color		
8.1	Choose colors that are appealing to the intended readers and free from unwanted connotations or		
	problematic cultural significance.		
8.2	Use color sparingly, in a consistent and deliberate way that reinforces the meaning of your messages and enhances their impact.		
8.3	Verify that the color scheme and shades of color work well from a design standpoint (including when		
	the material is photocopied and printed in black and white.)		
8.4	Take into account that some readers are likely to have diminished or limited color perception.		
9	Photographs, illustrations, clip art, and symbols		
9.1	Use photos, illustrations, symbols, and other visuals that relate directly to the information in the material and reinforce our key messages.		
9.2	Use images that are clear, uncluttered, and consistent in style.		
9.3	Use photos, illustrations, symbols, and other visuals that are culturally appropriate for your intended		
7.5	readers.		
9.4	When images include people, make sure that their poses, facial expressions, and body language are		
	appropriate to the situation and appealing to the intended audience.		
9.5	Be very cautious about using symbols or icons to represent concepts or to serve as markers to guide		
	readers through the material.		
9.6	Avoid using cartoons, "cute" or humorous images, and caricature, because these kinds of images may		
	bewilder, confuse or offend some of your readers.		
	bewilder, confuse of offend some of your readers.		

9.7	Pay careful attention to the total number, quality, size, placement, and labeling of the images you use.
9.8	Check for accuracy, if applicable, and pretest the images with your intended readers.
10	Tables, Charts, and Diagrams
10.1	Take a reader-centered approach to the use of tables, charts and diagrams.
10.2	Make titles, headings, and other labeling specific and complete enough for easy understanding.
10.3	Create a clean, uncluttered layout with strong visual and written cues to guide readers and help them
	interpret the information correctly.
10.4	If there are any numbers or calculations, explain them carefully and give examples.
10.5	Test you tables, charts, and diagrams to be sure that your intended readers can understand and use
	them.
11	Forms and Questionnaires
11.1	Begin and form or questionnaire with an informative title and brief explanation.
11.2	Ask only for information you really need and will definitely use.
11.3	Make the layout clear, uncrowded, and appealing.
11.4	Integrate instructions and explanations into the form or questionnaire, placing them right where they
	are needed by the reader.
11.5	Limit the number of formats for collecting answers and use them in a consistent way.
11.6	In a form for people with low literacy skills, avoid using a grid or matrix format to collect
	information.
11.7	Create a clear and obvious path through the form that minimizes cross-references and skip patterns.
11.8	Conduct usability testing.
11.9	Take into account how the form or questionnaire will be produced, distributed, and processed.

#### ETHNOCULTURAL CONSIDERATIONS IN TREATMENT OF DIVERSE POPULATIONS

Wilhelmina Wright-Harp, Ph.D.

Howard University Washington, D.C.

Joan C. Payne, Ph.D. Howard University Washington, D.C.

#### ABSTRACT

The rapidly changing demography of the U.S. population signals an increasing need to develop treatment approaches that take into account the cultural and linguistic differences of the population we serve as well as their values and needs (Qualls, 2012). Failure to do so will further exacerbate the disparity of service delivery to diverse populations in the coming decades. Additionally, with the continual graying of the U.S. population, there will be a significant increase in the elderly population who will be living longer with disabilities. Consequently, all health professionals, including speech-language pathologists (SLPs) will be called upon to provide services to a growing elderly and culturally diverse adult patient population. The purpose of this article is to provide strategies that SLPs can use to design and implement treatment protocols that not only reflect evidence-based practice, but also can provide services that are culturally relevant to individuals from diverse backgrounds. Toward this end three areas will be addressed: 1) clinical and cultural competence; 2) Evidence-based therapy approaches for rehabilitation of culturally and linguistically diverse (CLD) populations; and 3) Recommendations for community based care and working with organizations to reduce the longstanding disparities in health care to individuals from diverse populations.

KEY WORDS: Ethnocultural, health demographics, disparities in health care

### ETHNOCULTURAL CONSIDERATIONS IN TREATMENT OF DIVERSE POPULATIONS

Wilhelmina Wright-Harp, Ph.D. Howard University

Washington, D.C.

### Joan C. Payne, Ph.D.

Howard University Washington, D.C.

#### **INTRODUCTION**

A primary purpose for treating communication and cognitive disorders is to effect positive measurable and functional change in an individual's communication status in order that he or she may fully participate as much as possible in all aspects of life whether social, educational and/or vocational (ASHA, 2003). The rapidly changing demography in the U.S. signals an increasing need to address the disparity of efficacious treatment delivery to diverse populations in the coming decades. Consequently, all health professionals, including speech-language pathologists, will be called upon to provide services to an expanding and aging diverse adult patient population.

The passage of the Affordable Care Act (ACA), often referred to as *federal health care reform* (2015) has increased access to quality and affordable health care for a large segment of the population. Many of these individuals who are poor, from diverse populations and have experienced a history of limited access to preventive health care, will present with cognitive and language disorders. As J. Payne (2014) states, "It is therefore incumbent upon professionals in speech-language pathology to be aware of the coming changes in caseload diversity and to be well prepared to deliver culturally competent assessment and treatment to diverse adults with neurogenic communication disorders." (p.41).

### **Clinical and Cultural Competence**

Not only must speech-language pathologists be clinically competent in their service delivery to individuals with communication disorders, but it is imperative that they also be culturally competent to effectively address the needs of the rapidly growing population of individuals from diverse ethnic/cultural backgrounds on their caseloads. Professionals who are engaged in service delivery and research on adults with neurologically based disorders of cognition and language have already initiated discussions about the issues of cultural and clinical competency (Huer & Wyatt, 1999; Ulatowska, Wertz, Chapman, Hill et al., 2001; Tomoeda & Bayles, 2002; Moxley, Mahendra, & Vega-Barachowitz, 2004;Wolf; 2004; Cheng, 2005; Mahendra, et al., 2005; Centeno, 2005; Threats, 2005; Goldberg, 2007; Torres, Rodriquez & K. Payne, 2011; Blackstone, Ruschke, & Stronks, 2012; Harris, Fleming, & Harris, 2012; Mashima, 2012; Riquelme, 2006; 2013; Salas-Provance, 2012; Ellis, Payne, Harris, & Fleming, 2013; Williams & Harvey, 2013; Wright-Harp, Mayo, Martinez, Payne, & Lemmon, 2013; Payne and Wright-Harp, 2014; Torres, 2015).

Speech-language pathologists are fortunate to have a national association that has formulated a policy statement regarding cultural competency and one that has tied professional ethics to cultural awareness and sensitivity. According to the ASHA (2013) policy on cultural competency:

The professional must recognize that differences do not imply deficiencies or disorders. Culture and language may influence the behaviors of individuals who are seeking health, habilitative, or rehabilitative care and their attitudes toward speech, language, and hearing services and providers. Similarly, the delivery of services is impacted by the values and experiences of the provider. Competent care is providing service that is respectful of, and responsive to, an individual's values, preferences, and language. Care should not vary in quality based on ethnicity, age, socioeconomic status, or other factors.

With regard to the Code of Ethics, ASHA (2005) established a policy statement for certified professionals which states:

The Code of Ethics requires the provision of competent services to all populations and recognition of the cultural/linguistic or life experiences of both professionals and those they serve. Everyone has a culture. Therefore, cultural competence is as important to successful provision of services as are scientific, technical, and clinical knowledge and skills. Caution must be taken not to attribute stereotypical characteristics to individuals. Rather, an attempt should be made to gain a better understanding of one's own culture, as well as the culture of those one serves. All professionals must continually improve their level of competence for providing services to all populations. Members and certificate holders should explore resources available from ASHA and other sources.

### **Definition of Cultural Competence**

According to the Office of Minority Health at the National Institutes of Health (2013), cultural and linguistic competence for health professionals, such as speechlanguage pathologists and audiologists, may be defined as:

... a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. 'Culture' refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.

The concept of cultural competency has a positive effect on the health care, because it enables providers to deliver services that are both respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients (NIH 2015). Recently, the American Speech-Language-Hearing Association (2011) issued a policy statement that defines professional competence as inclusive of cultural competence:

It is the position of the American Speech-Language-Hearing Association (ASHA) that professional competence in providing speech-language-hearing and related services requires cultural competence. Cultural competence is a dynamic and complex process requiring ongoing self-assessment and continuous expansion of cultural knowledge. Cultural competence involves understanding the unique combination of cultural variables that the professional and patient/client bring to interactions. These variables include, for example, age, ability, ethnicity, experience, gender, gender identity, linguistic background, national origin, race, religion, sexual orientation, and socioeconomic status.

In addition, cultural competence includes the following:

- valuing diversity: awareness and acceptance of differences
- conducting cultural self-assessment
- being conscious of the dynamics inherent when cultures interact
- having institutional cultural knowledge: integration of cultural knowledge within individuals and systems
- adapting to diversity and the cultural contexts of the communities served (J. Payne & Wright-Harp, 2014).
- recognizing that differences do not imply deficiencies or disorders.

### ASHA (2013) further states that...

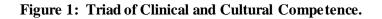
Culture and language may influence the behaviors of individuals who are seeking health, habilitative, or rehabilitative care and their attitudes toward speech, language, and hearing services and providers. Similarly, the delivery of services is impacted by the values and experiences of the provider. Competent care is providing service that is respectful of, and responsive to, an individual's values, preferences, and language. Care should not vary in quality based on ethnicity, age, socioeconomic status, or other factors." (ASHA, 2013).

This means that not only individual professionals must become culturally competent service providers, but the organizations in which they work must make every effort to eliminate institutional barriers and provide an environment for services that is sensitive and respectful. The importance of culturally competent health services in eliminating health disparities and fostering health and wellness is described by the NIH U.S. Department of Health and Human Services (2015) as follows:

Cultural competency is critical to reducing health disparities and improving access to high-quality health care, health care that is respectful of and responsive to the needs of diverse patients. When developed and implemented as a framework, cultural competence enables systems, agencies, and groups of professionals to function effectively to understand the needs of groups accessing health information and health care—or participating in research-in an inclusive partnership where the provider and the user of the information meet on common ground.

Cultural competence in the treatment of individuals with a communication disorder can be viewed as a triad (See Figure 1). One component is the clinical expertise of the speech-language pathologist or audiologist as well as an understanding of his/her own values and culture. A second part of the triad is the patient who also brings his/her values to the therapy session. The third component is cultural

competence which involves the speech-language pathologist's ability to interface their knowledge, skills and understanding of the patient's language, cultural background and values in the design and implementation of an effective therapy program for the patient/client (Lemmon, 2012).



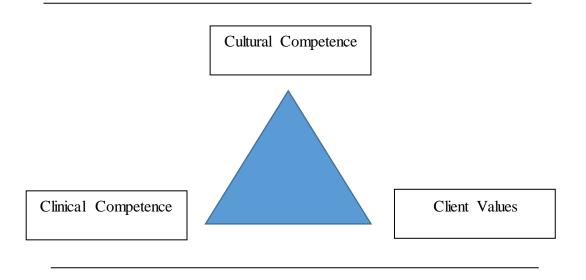


Figure Adapted from Lemmon, R. (2012). Confronting Health Disparities in Minority Populations with Communication Disorders, Miniseminar, NBASLH Annual Convention.

#### Maintaining Cultural Competence In An Ever-Changing Dynamic World

The increasing racial, ethnic and cultural (ERC) diversity of the U.S. obligates professionals in the field of communication sciences and disorders to maintain cultural competence as a mechanism to not only improve the outcomes of our service delivery, but ultimately enhance the quality of life of those we serve. In the quest to become culturally competent, it is inevitable that one will encounter challenges which can hinder the providerpatient relationship. Riquelme (2013) refers to these challenges as "sociocultural mismatches" and identifies three types which can compromise the dynamics of the relationship. First, the provider may lack knowledge about the patient's health beliefs and life experiences. Second, the provider may bring unintentional or intentional processes of classism, racism, homophobia or sexism to the clinical interaction. Consequently, clinicians can never expect to fully achieve cultural competence. Rather it is a continuous process that involves а lifelong commitment to learning. Professionals must constantly strive to bridge cultural gaps and question cultural assumptions (Riquelme 2013). Riquelme proposes three paradigm shifts (ethnocentrism, essentialism and power differences) that must be considered in the quest to achieve cultural competence (See Table 1).

### Table 1. How to Achieve Cultural Competence (Source: Riquelme, (2013).

Culturally competent care requires several paradigm shifts for both the practitioner and client.

Paradigm Shift Types	Description
Ethnocentrism	• The belief that one's way of life and view of the world are inherently superior to others and more desirable. Ethnocentrism in health care may prevent professionals from working effectively with a patient whose beliefs or culture does not match their own worldview. An ethnocentric care provider or client may hinder the processes of assessment, treatment or management of a communication or swallowing disorder. An example of ethnocentrism is the clinician who can see only his or her recommended treatment plan and does not entertain other options presented —if allowed—by the patient/client.
Essentialism	<ul> <li>Defines groups as "essentially" different, with characteristics "natural" to a group. Essentialism does not take into account variation within a culture, and can lead health care professionals to stereotype their patients. The clinical practice of an essentialist focuses on beliefs about groups instead of observations of individuals. This situation is disadvantageous to the practitioner and the client. The essentialist viewpoint needs to be replaced with an ethnogenetic one, which recognizes that groups, cultures and the individuals within them are fluid and complex in their identities and relationships. An example would be any situation in which the practitioner automatically identifies a person as being a part of a group without obtaining confirmation.</li> </ul>
Power differences	<ul> <li>Power differences reflect an imbalance in client-provider relationships. Interestingly, those with power often are not aware of its daily effects. Some ethnic groups may feel powerless when faced with institutionalized racism and other forms of privilege enjoyed by the dominant group. Examples of this imbalance may include the patient's perception that the clinician has all the answers, or a sense of the clinician's superiority due to his or her advanced education. Tervalon and Murray-Garcia refer to power differences in their discussion of cultural humility: Without knowing about power differences and their effects, health care professionals can perpetuate health disparities.</li> </ul>

### The rapy Strategies for Use with CLD Populations

Several recommendations are available to enhance cultural competency in therapy.

The following strategies have been proposed to provide an environment that will enhance therapy outcomes when treating individuals from ERC diverse populations.

<u>Establish the Client's Trust</u> - The SLP must establish the client's trust, engage in active listening to learn, and research not only information related to best practices of the etiology of the cognitive or communication disorder, but gain an understanding about the client's culture. The SLP must be able to have an open dialog with the client.

Payne (2011) referred to this aspect of therapy as cultural influences on communication: How to open or close a conversation, turn taking during conversations, interruptions, silence as a communicative device, appropriate topics of conversations, humor and when to use it, non-verbal modes to accompany conversations, laughter as a communicative device, appropriate amount of speech to be used by participants, logical ordering of events during discourse. If the patient/client in not speak English, the SLP may utilize an interpreter.

Maintain effective communication - Effective communication between the provider and patient is fundamental to patient-centered care. Moreover,

effective communication strongly correlates with better patient outcomes, increased patient safety and improved patient satisfaction. Thus, "it is not only good practice, but good economics." Wilson-Stronks, & Blackstone, 2013).

<u>Cultural norms regarding physical space/eye contact</u> – Physical space and eye contact between people is considered differently among cultures. Discussion should occur prior to touching a patient, invading their space or looking him/ her directly in the eye to avoid offending them. For example, many areas of East India are overcrowded resulting in an acceptance to be in close proximity or in another person's "personal space."

<u>Time</u> –Although all cultures value time, the concept of time varies among ERC populations (Payne, 2011). For example, African, Caribbean, Latin and Native American cultures may value time but have a more relaxed view of time in comparison to western society. Open conversations may need to occur about reasons or the necessity for timeliness to appointments.

<u>Family dynamics</u> - requires that the SLP know the patient, his or her familiy, living situation and the community over time to allow yourself to be known. (Masson, 2005, p. 94-98).

<u>Locus of Control</u> – In some cultures, decisions may be made by the male head of the household or a senior male member of the family. In this case, provide the patient with the time to discuss treatment options with family members and return for discussions on how to proceed with therapy.

Use Appropriate Terminology – When communicating with the patient and family it is imperative that the practitioner know and use the appropriate terminology for the specific cultural group. For example, referring to an Asian person as an "Oriental" is not appropriate because the Orient is a region to the east of Asia and geographically located in a different region. Latin Americans have been referred to as "Latino" or "Hispanic" The term Hispanic alludes to a person's place of origin, referring to persons from Mexico, Puerto Rico, Cuba, Central and South (Retta & Brink, 2007). "Hispanic" thus includes persons from Spain and Spanishspeaking Latin Americans but excludes Brazilians, while "Latino" excludes persons from Spain but includes Spanish-speaking Latin Americans and Brazilians. The term Hispanic as used in the USA, was coined by the U.S. Census Bureau in the 1970s to describe people of Spanish-speaking origin. It is not a term that originated from within the culture. Primarily people who have been formed and educated in the USA use Hispanic. They are accustomed to the term by education or by family custom. Latin American nationals, recent immigrants to this country, will not self-identify as Hispanic. Also, there has been a controversy over the name "Native American" used to refer to the indigenous pre-Columbian people of the Americas. Objections to the terms "Indian" and "American Indian" arose from the fact that the term "Indian" originated from an historical error, and therefore, does not accurately reflect the derivation of the people to whom the term refers (Wolf, 1996). Preferred terms vary primarily by age and region of origin. Because these populations of indigenous people are diverse, there is no one consensus on the name. Most individuals prefer to be referred to by their specific tribe or Nation.

Historically, speech-language pathologists are trained to treat adult patients from the perspective of a Western specialist culture. The specialist is acculturated to be individua listic, secular. egalitarian, independent, innovative, time conscious, and future oriented. Many cultures outside of the Western specialist culture are best described as generalist cultures in which emphasis is placed on holism, spirituality, interdependence, acceptance of authority and tradition, orientation to the present, fluidity of time and orientation to the community. Generalists want to find someone with whom they can establish and maintain a trusting. personalize d relationship. They are far more likely to be concerned about immediate health needs, are far less time conscious, and are more likely to seek health care when it is needed. The frustrations and lack of acceptance between the specialist health care provider and the culturally and ethnically diverse generalist patient occur when the provider does not understand the patient's system of values, norms, and beliefs (Damon-Rodriguez, Wallace, & Kingston, 1994).

This incongruence is at the heart of the dilemma facing the profession. Mahendra and her colleagues on the ASHA Multicultural Issues Board (2004) identified eight key parameters of culture which included: (1) the extent to which an individual or group is considered to be the key unit of society; (2) views of time and space; (3) language and communication styles; (4) roles; (5) importance of work; (6) class and status; (7) rituals and superstitions; and (8) beliefs and values. In the view of the authors, cultural competence, "requires a commitment to life-long learning and enhancement of our knowledge, skills, and attitudes" (Mahendra et al., 2004, p. 4).

At the heart of the discussion about eliminating bias is how professionals can render fair and objective assessment and from that assessment, appropriate and meaningful intervention. Effective and evidence-based practice in the assessment and treatment of culturally and linguistically diverse populations requires that the speechlanguage pathologist know about the pathophysiology of language and cognitive impairments as well as cultural and linguistic differences that affect communication. It is also essential to understand the culture and environment(s) in which the individual functions daily. The speech-language pathologist and the client/patient each bring their own backgrounds that will influence the therapy process (Ruoff, 2002). The success or failure of the process is dependent largely upon the clinician's ability to approach each client as being unique rather than using a "one size fits all" approach in service delivery, particularly in assessment of ethnically and culturally diverse individuals (Wright-Harp et al., 2012).

### Treatment Strategies for Ethnically, Racially and Culturally Diverse Populations

Once assessment is completed, planning intervention should be undertaken with the same degree of sensitivity as the selection of appropriate assessments. Therapy should be client-centered in the context of understanding what the communicative environment of the client demands. This can be accomplished only when the clinician understands and respects the perspective of the patient and the patient's support networks. Ruoff (2002) recommends that the plan of therapy should be culturally sensitive and should include functionally relevant materials and accommodations that are considerate of the patient's worldview (for example, allowing extra time when using a translator and providing instructions in the patient's preferred language). The clinician must also appreciate and understand differences in acceptance of the Western health care model and preferences for alternative treatments and healers as well as the patient's cultural views on disability and physical/psychological change (Wilson, 2002; Payne, 1997). Table 2 provides information on these strategies, rationale and possible solutions for clinicians.

It is critical that clinicians understand how family perceptions about assessment and treatment influence the clinical process and their expectations for recovery (Wright-Harp et al., 2012). Perceptions and viewpoints regarding disability vary among racial/ethnic groups (O'Neil-Pirozzi et al., 2008). Views of disability appear to be influenced more by geographic, ethnic and/or cultural factors than by race, and that these factors are associated with particular beliefs, attitudes, and behaviors around a particular disability that may affect the likelihood of seeking services and participating in treatment. Disability is variously viewed as a tragedy, a disgrace, shameful, the result of sin, and a punishment from God. People with disabilities are repeatedly seen as objects of pity which produce guilt feelings in their family members and associates. They are frequently viewed as a burden to others, to their family, to themselves, and to society, and are continually perceived to be useless and to behave in inappropriate ways. (Pfeiffer et al. 2003).

#### Table 2. Recommendations for Culturally Competent Intervention for Adults with Communication Disorder.

Appropriate Approach	Rationale	Solution
Respect divergent views on disability.	Many cultures do not view disabilities in the same ways(s) as clinicians may expect based on a Western health care model.	Ask the family and the patient how they view the communication disorder.
Respect divergent views on formal intervention.	Some cultures attach more importance To folk remedies for wellness or to community healers than to health professionals.	Ask whether alternative methods are used. If needed, include the respected community healer as a member of the patient's support network.
Respect divergence views based on religion.	There are religions (Muslim, for example) that have strict views on gender roles.	In this case, women patients should have a female clinician.
Respect patient preferences for their salutation.	A history of discrimination has made some patients particularly sensitive about respect, particularly from a person outside of their community.	Always refer to patients as "Mr." or "Ms." in therapy.
Provide information about therapy goals and activities in clear, easy-to- understand language, in the patient's preferred language.	Language and literacy differences pose barriers to understanding therapy.	Provide translators During therapy. Use photonovelas and other user friendly methods materials to explain therapeutic process.
Use stimuli that is relevant to the patient.	Patients progress when the stimuli are relevant to their environments.	Use pictures and other Stimuli from the patient's community.

Sources: Payne & Wright-Harp (2014), Payne (2009), Payne (1997); Shamat (1987).

In light of these perceptual and cultural differences, Asian, African American, Native American and Hispanic populations each have distinct and varied views on disability (Payne, 1997; National Council on Disability, 1999; Parette & Huer, 2002).

These are approaches to interventions that enhance knowledge about the relationship between sociocultural factors, health beliefs. These approaches are also recommended to equip providers with the tools and skills to manage these factors appropriately with quality health care delivery as the gold standard (Betancourt et. al, 2003). Practitioner must be willing to engage in crosscultural training to be successful, and in so doing, develop goals that are individual-centered, functional, attainable, and that are "consistent with the family's cultural values and beliefs and capable of being utilized within the context of the family and the community" (California Speech-Language and Hearing Association, 2016, p. 3).

### **Bilingual and Multilingual Populations**

When the adult with a communication disorder is bilingual or multilingual, the following recommendations are given to make the client/patient comfortable in therapy and to be assured that all information and instructions are understood:

- 1) Initially provide therapy in the dominant language.
- 2) Encourage clients/patients and their families to express themselves in the language of their choice.
- 3) The amount of time L1 (native language) is spoken may be dependent upon the clients'/patients' and their families' proficiency in L2 (second language).
- 4) To maximize the use of each language, it may benefit the clients/patients and their families to speak in L2 when discussing home or job related events; then, speak in L1 at other times (Langdon, 2008)
- 5) Relate therapy to cultural experiences in the preferred language(s).
- 6) Use words and pictures in the preferred language(s) in therapy.
- 7) Use books, magazines and newspapers and other forms of information that use the individual's preferred language.
- 8) Include caregivers and extended family members in therapy to carryover skills to the home environment.

### **Community-Based Care**

The Affordable Care Act includes a provision for longterm care services to help guarantee that individuals who require such care receive it and to find ways to help ensure that such care is not only available in institutions, but also in the community (ACA, 2010, §2406(b)1-2). One such example is the Community First Choice Option which offers incentives through Medicaid to encourage states to provide programs that will help seniors stay in their homes instead of being placed in a long-term care or other facility.

Through the ACA, provisions for community-based care states will determine models for care coordination. As interdisciplinary teams are established, speech-language pathologists (SLPs) and audiologists will have additional opportunities to provide services in the home, increasing access for care to individuals from diverse populations who have limited access to transportation to seek services in an outpatient rehabilitation facility.

### **Eliminating Bias in Counseling**

Effective and compassionate counseling for patients and their families from culturally and ethnically diverse backgrounds requires that the clinician should appreciate how difficult it may be for some persons to share their innermost feelings with others outside of their sphere of comfort, and then take steps to minimize this difficulty. Salas-Provance (2013) recommends that counselors greet their patients and families in their own language and bring special skills to the counseling session. These are: (1) being comfortable with issues of race, culture and class; (2) creating an environment where the client is comfortable and can talk freely; and (3) building a trusting relationship. Both Salas-Provance (2013) and Payne (1997) advise that a warm but formal approach is preferred. There are demonstrated cultural and ethnic differences in how families function when the patient has sustained a major neurologic episode. Harris and her colleagues (2012) noted that, among African American families, feelings of embarrassment or stigma, distrust of mainstream institutions and agents, religiosity, lack of knowledge, and denial become barriers to acceptance of speech-language pathology services. Li (2005) observed that Asian immigrants do not encourage members to express problems to those outside their in-group. This is particularly true of mental and/or physical problems that could carry a stigma. Emphasis on shame and guilt are sometimes used to enforce norms in the family and prevent Asians from reporting their problem in public.

Counseling patients and their families from Native American communities may be unsuccessful unless the clinician appreciates the differences in communicative style and acceptance of a natural order of things as fate. If the clinician uses a more direct communication style, the Native American listener may perceive the communication style as intrusive or rude (Westby & Begay Vining (2004). Hispanic and Arab Americans view counseling as a collective rather than a traditional individualist society view with an emphasis on accepting the disability rather than curing it (Salas-Provance, 2012). Given how important appropriate counseling is to assisting the entire family to cope and accept a patient's disability, it may be necessary for the clinician to seek advice from others in the patient's community, including respected persons from religious and health care arenas who understand the culture.

### **Recommendations for Clinician Cultural Competence**

Because a substantial number of professionals work in health care settings where persons with neurogenic

disorders are seen, many of the professional conversations about cultural competence cite the Joint Commission's report on Advancing Effective Communication, Cultural Competence, and Patient-and Family-Centered Care: A Roadmap for Hospitals (2010). This is particularly important because most adults with neurogenic disorders are seen in hospital or other health settings where over one-third of speech-language pathologists are delivering services. The American Speech-Language-Hearing Association (ASHA) reports that 38% of speech-language pathologists work in health care settings; 13% of these work in hospitals and 9% work in skilled nursing facilities.

There remains a need to bridge the divide between speech-language pathologists who are specialists and culturally diverse persons with neurogenic disorders who are more likely to be generalists. Researchers agree that speech-language pathologists and audiologists are highly qualified and in the unique position to assume leadership in providing the highest quality of health-related services to patients regardless of their ethnic background, age, socioeconomic status, education, language, gender, sexual orientation, or country of birth. It is in this spirit that there are common threads in the recommendations offered in the conversations within and to the professions. Adherence to respect for cultural and ethnic identity and different religions signal welcoming to patients and their families, encourage continuation of therapy and reinforce compliance with the therapy plan. Other considerations are that clinicians should:

- 1. Use illustrations that reflect ethnic diversity.
- 2. Avoid cultural faux-pas: telling jokes, asking for personal information before trust has been established.
- 3. Be mindful that there is no model of the perfect family and that cultural norms often govern the hierarchy and membership status within families.
- 4. Understand that, in some cultures, families are largely patriarchal; in others, the eldest member speaks for the family; in still others, families are matriarchal or multigenerational; these arrangements work for the families involved.
- 5. Appreciate that families may be racially mixed or have same gender parents.
- 6. Consider that time is relative and meaningful in different ways in different cultures.
- 7. Respect that use of personal space is culturedriven and that there are cultural variations in how personal and social space are defined.

- 8. Understand that in some religions, personal space is delineated according to gender and/or marital status.
- 9. Respect important holidays and religious activities for patients.
- 10. Understand the role of organized religion in the lives of patients and their views on the power of prayer in healing.
- 11. Know that cultures differ in the ways that illness is explained and in what is acceptable to hear about illness.
- 12. Understand that status in some communities may be defined by parameters other than work or by the type of work done.
- 13. With the permission of the patient, include all members of the extended family in conversations about the patient's progress.
- 14. Respect differences in emotional expression: a smile does not necessarily mean agreement; it sometimes means confusion or respect.
- 15. Become flexible about intervention and rely on telehealth and AAC when needed
- 16. Provide support and information on resources for the family in the family's preferred language.

### **Recommendations for Cultural Competence within Organizations**

Cultural competence for the professional means that the clinician endeavors to be culturally intelligent about patients who are culturally and ethnically diverse. The clinician, however, works within an employment setting, whether a hospital, clinic, or private practice. This setting establishes the tone and the agenda for cultural inclusion and sensitivity within the organization. Institutional policies determine whether the culture of the organization will be inclusive or exclusive. In 2000, the Office of Minority Health, in the Department of Health and Human Services (DHHS), published the first National Standards for Culturally and Linguistically Appropriate Services in Health Care (National CLAS Standards), which provided a framework for all health care organizations to best serve the nation's increasingly diverse communities. In fall of 2010, the Office of Minority Health in DHHS launched the National CLAS Standards Enhancement Initiative in order to revise the Standards to reflect the past decade's advancements, expand their scope, and improve their clarity to ensure understanding and implementation. With the enhancement initiative, the National CLAS Standards will continue into the next decade as the cornerstone for advancing health equity through culturally and linguistically appropriate services (Office of Minority

Health, DHHS). The fifteen (15) enhanced CLAS Standards are shown in Table 3.

The CLAS standards mandate that the organization work in partnership with the communities of the persons they serve and engage in continuous dialogues. These dialogues are to ensure that persons with communication disorders from diverse populations are well served by the organization. For example, the Blueprints (Office of Minority Health, DHHS) for the CLAS standards for health communication materials recommend that the organization consult local librarians to build an appropriate collection of health materials and that the organization to assess the diversity shown in graphics and to point out culturally offensive or embarrassing content.

Another recommendation from the Blueprint, to provide responsive and appropriate service delivery to a community, leads to the creation of an organizational culture that insures accountability to the community. Members of the community become active participants in the health and health care process as well as in the design and improvement of services to meet their needs and desires. Other recommendations from the Blueprint encourage organization to recruit and hire persons representative of and sensitive to the community who will be trained in culturally competent service delivery by the organization. The purpose of these recommendations is to create an environment in which culturally diverse individuals feel welcomed and valued. This purpose applies to the staff and leadership of the organization and to the governance of the organization. It is necessary to ensure that diverse viewpoints and multicultural perspectives are well represented in the major decisions of the organization. This does not mean that the entire workforce has to look like the persons from the community, but it does mean that there should be some representation in the workforce from the cultural and ethnic groups represented in the patient population. It also means that persons hired by the organization must be open to and educated about diversity in order to engage in culturally appropriate assessment and treatment.

Finally, the organization has a responsibility to provide translators for patients who have difficulty with English. It also has an obligation to engage in ongoing collection and monitoring of demographic data about the service communities. In the first instance, patients who speak a language other than English are entitled to competent translators who can provide them with the means to achieve their goals in therapy. The organization, likewise, has a responsibility to identify population groups within the service area and to allocate organizational resources to patient needs, service planning and quality of care.

### **Resources for Culturally Competent Service Delivery**

The Office of Multicultural Affairs in the American Speech-Language-Hearing Association has developed a series of tools that are helpful to clinicians who wish to self-appraise their cultural knowledge and become more culturally intelligent about a variety of topics related to cultural competence. These resources include the Cultural Competence Checklists (Personal Reflection, Policies and Procedures, Service Delivery), the Self-Assessment for Cultural Competence, and the Cultural Competence Awareness Tool, which is an interactive web-based tool that allows the user to assess areas that need strengthening in cultural competence. These tools be accessed can at http://www.asha.org/practice/multicultural/self.htm. The National Black Association for Speech-Language and Hearing (NBASLH) is accessible at www.nbaslh.org. NBASLH publishes the e-journal, Echo: Journal of the National Black Association for Speech-Language and Hearing, which has articles on issues affecting African Americans and other culturally and linguistically diverse groups. Readers can also access the Asian-Indian Caucus at http://www.asianindiancaucus.org; the Asian Pacific Islander Caucus at http://www.ashaapicaucus.org/; the Caucus Hispanic at http://www.ashahispaniccaucus.com/; and the Native American Caucus at http://libarts.wsu.edu/speechhearing/overview/napcaucus.asp.

ASHA has published policy statements regarding services to culturally and ethnically adverse populations. The reader is referred to the following sites for ASHA position papers on best practices in service delivery to diverse persons:

- Clinical Management of Communicatively Handicapped Minority Language Populations available at <u>http://www.asha.org/docs/html/PS1985-00219.html</u>
- Knowledge and Skills Needed to Provide Culturally and Linguistically Appropriate Services available at <u>http://www.asha.org/docs/html/KS2004-00215.html</u>
- ASHA's Policies and Procedures Related to Working with Multicultural Populations

available a http://www.asha.org/practice/multicultural/issue s/pp.htm

Policy statements on ethics and best practices from the American Speech-Hearing-Association mandate that certified professionals in speech-language pathology and audiology engage in culturally competent service delivery. The parameters of this service delivery have been identified in the professional literature, in the report of the Joint Commission for hospitals, and by the Office of Minority Health of the Department of Health and Human Services. Using current research and the national enhanced CLAS standards, recommendations are given for individual practitioners and for organizations. The enhanced CLAS standards are designed to help organizations to develop culturally competent health services to diverse adults. There are resources available through the Office of Multicultural Affairs of the American Speech-Language-Hearing Association to assist clinicians in strengthening their cultural knowledge through a variety of online tools. Additional resources and their websites can be accessed to further develop an information base for cultural competence. The Enhanced CLAS Standards may be found in Table 3.

#### Table 3. Enhanced CLAS Standards

#### **Principal Standard**

• 1 Provide Effective, Equitable, Understandable, and Respectful Quality Care and Services (Principal Standard)

#### Governance, Leadership, and Workforce

- 2 Advance and Sustain Governance and Leadership that Promotes CLAS
- 3 Recruit, Promote, and Support a Diverse Governance, Leadership, and Workforce
- 4 Educate and Train Governance, Leadership, and Workforce in CLAS

### Communication and Language Assistance

- 5 Offer Communication and Language Assistance
- 6 Inform Individuals of the Availability of Language Assistance
- 7 Ensure the Competence of Individuals Providing Language Assistance
- 8 Provide Easy-to-Understand Materials and Signage

#### Engagement, Continuous Improvement, and Accountability

- 9 Infuse CLAS Goals, Policies, and Management Accountability
- 10 Conduct Organizational Assessments
- 11 Collect and Maintain Demographic Data
- 12 Conduct Assessments of Community Health Assets and Needs
- 13 Partner with the Community
- 14 Create Conflict and Grievance Resolution Processes
- 15 Communicate the Organization's Progress in Implementing and Sustaining CLAS

The enhanced National CLAS Standards and *The Blueprint* are the culmination of the HHS Office of Minority Health's 2010-2012 Enhancement Initiative.

### SUMMARY

Throughout this discussion, the emphasis has been on cultivating an environment in which patients or clients and their families from diverse communities can participate freely in speech-language intervention without personal or institutional barriers. It is hoped that as more adults with communication disorders are referred to speech-language pathologists, that clinicians will endeavor to make all patients feel respected, valued, and appreciated for the richness that diversity brings to the profession.

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#### **ABOUT THE AUTHORS:**

Wilhelmina Wright-Harp, Ph.D., CCC-SLP, is Associate Dean for Research and Academic Affairs in the School of Communication and a Professor in the Department of Communication Sciences and Disorders at Howard University. Her areas of expertise include the design and implementation of mentoring programs as well as the clinical management of individuals with neurogenic disorders, specifically dysphagia, acute traumatic brain injury, and stroke. Dr. Wright-Harp's research seeks to increase the number of African Americans and other racial minority students entering communication sciences, to improve speech and language skills of racial minorities and to assist patients with neurogenic disorders.

Joan Payne, Ph.D., CCC-SLP, is Interim Department Chair and a Professor in the Department of Communication Sciences and Disorders at Howard University. Her research interests are in the areas of stroke, closed head injury, aphasia, dementia, neurogenic language disorders, cultural differences, health communication, caregiving for adults with brain based communication disorders, and health disparities. She is internationally recognized for her work in neurogenic language disorders from an ethnobiological perspective, and is a recent recipient of ASHA Honors.

### RACIAL DISPARITIES: AN OLD PROBLEM THAT NEEDS A NEW APPROACH IN SPEECH-LANGUAGE PATHOLOGY--ISSUES IN PEDIATRIC POPULATIONS

Yolanda F. Holt, Ph.D.

Charles Ellis, Ph.D.

Department of Communication Sciences and Disorders, East Carolina University, Greenville, NC

#### ABSTRACT

A substantial percentage of the literature on racial disparities in health care in the United States focuses on health outcomes in adults. Evidence suggests that similar disparities exist in the pediatric population. The underlying factors associated with racial disparities in the pediatric population do not necessarily parallel those of adults. In the adult population access to care is cited as a primary cause of racial disparity and ultimately health outcomes. In the pediatric population multiple government programs are in place to reduce the impact of limited access to care for this group. In the field of Speech-Language Pathology (SLP) evidence suggests that racial disparities in clinical outcomes may be the result of limited access to services and uneven quality of services. The purpose of this paper is to explore the issue of racial disparities in the field of SLP among pediatric populations and factors that may contribute to limited access to services, uneven quality of service and clinical outcomes.

**KEY WORDS:** Health disparities, African Americans, pediatrics, child, healthcare, speech-language pathology, access, outcomes, therapy

### RACIAL DISPARITIES: AN OLD PROBLEM THAT NEEDS A NEW APPROACH IN SPEECH-

### LANGUAGE PATHOLOGY -- ISSUES IN PEDIATRIC POPULATIONS

#### Yolanda F. Holt, Ph.D.

#### Charles Ellis, Ph.D.

Department of Communication Sciences and Disorders, East Carolina University, Greenville, NC

### **INTRODUCTION**

Indicators used to quantify racial disparities in health care fall under three categories patient, provider and system factors. These factors have been used to explain potential contributors to racial disparities in healthcare access and outcomes in adult populations; yet studies by Weitzman, Byrd and Auinger (1999) and Ashiabi (2013) collectively show that children have far less control over healthcare access and service utilization. While this fact may seem obvious it complicates the study of racialdisparities in healthcare access and outcomes in the pediatric population. In this paper we will explore the unique issues and contributing factors to racial disparities in healthcare access and outcomes in pediatric populations receiving Speech Language Pathology services.

#### Access to Pediatric Services

Access to care is one member of a complex set of factors that contribute to racial disparities in receiving care for communication disorders. However, because less attention has been given to access to care issues in the field of Speech-Language Pathology and among pediatric populations, it is unclear how access to care relates to observed racial disparities in clinical outcomes. There is evidence in the general pediatric literature that suggests the presence of insurance and usual source of care are likely contributors to access to care issues among children.

According to the 2011-12 National Survey of Children's Health (NSCH) 9.7% of Hispanic children and 4.9% of Non-Hispanic Black children did not have any kind of insurance coverage compared to 3.9% of Non-Hispanic White children. At the same time, 56.9% of Hispanic children and 56.7% of Non-Hispanic Black children have public insurance. In contrast, only 23.5% of Non-Hispanic White children reported having public insurance. Collectively, minority children are more likely to have insurance through publically funded programs or no insurance. A lack of insurance and an increased reliance on publically funded insurance programs strongly parallel reports of limited likelihood of a usual source of care. According to the 2011-12 NSCH, 16.2% of Hispanic children and 12.2% of Non-Hispanic Black children have no usual source of care when they are sick compared to only 4.2% of Non-Hispanic White children. The pervasive lack of a usual source of care is an area of concern for minority children. By definition, children without a usual source of care lack an established relationship with health care providers knowledgeable, via regular interaction, of the child's growth and development including speech, language and hearing development. The primary care relationship is important for all children. Regular pediatric examinations are an integral part of child healthcare and provide ongoing opportunities for checks on the child's communication skills. Because pediatric communication disabilities can be complex, idiopathic and unexpected, ongoing parent to provider discussions of the broad and dynamic range of typical pediatric development are likely to enhance the opportunities for early intervention. Pediatric communication disorders are generally described as the failure to develop speech and language skills in the time and sequence expected for the child's age (Anderson and Shames, 2006). Therefore, in the absence of a usual source of care, children with communication disorders requiring SLP services may lack access to the primary care professional able to recognize the need for and provide a recommendation to the necessary services. Lack of a usual source of care can reduce the likelihood of a timely referral to appropriate SLP services. Regardless of

the population served, adult or pediatric, the evidence consistently shows that access to care remains a fundamental contributor to the racial disparities observed in clinical and health-related fields. It is critical to understand that access to care issues do not operate in isolation

### Assessment Issues: Disorders vs Differences

In contrast to access to care issues, a substantial literature exists related to potential disparities in clinical outcomes. For African American children the issue that has received the most substantial clinical research attention is the use of African American English (AAE). AAE is a rule governed dialect of American English spoken by some African Americans of historical African descent (Green, 2002). AAE is not spoken by all African Americans and its use is not restricted by socio-economic status (Horton-Ikard & Miller, 2004) or geographic region (Oetting & McDonald, 2002). AAE can be the primary mode of communication for African American children (Connor & Craig, 2006). AAE and General American English (GAE) are, with a few exceptions, mutually understandable. However, some AAE and GAE rules are discordant. For example the sound /th/ follows a different set of rules for use in AAE and in GAE. In AAE the substitution of /d/ for /th/ as in *den* for *then* is acceptable, but not obligatory. In GAE the production of *den* for *then* would be considered an error, and perhaps indicative of an underlying articulation disorder.

Understanding the rule systems of AAE and GAE are critical to accurate assessment of children who speak When African American child speakers, AAE. particularly those who speak AAE, are referred for speech and language assessment, SLPs are required to differentiate the use of dialect variation such as AAE from an articulation disorder. Traditionally the assessment tools used by SLPs are based on GAE norms (Wilson, 2012). The indiscriminate use of GAE norms by SLP practitioners unfamiliar with the rules of AAE have the capacity to yield inaccurate diagnostic results than can translate into inappropriate or inadequate service recommendations for African American children. This issue has two separate but overlapping components, SLP tools and SLP training.

Currently there is a single, two-part, tool, the Diagnostic Evaluation of Language Variation Screening Test (DELV-S) and Norm Referenced Test (DELV-NR) (Seymour et al., 2005). The DELV (Seymour et al., 2005) was developed with the express purpose of differentiating a language difference, such as the rule governed use of African American English, from a language disorder. A psychometric evaluation of the DELV-S Part II (Seymour et al., 2005) was completed by Petscher, Connor & Otaiba (2012). The DELV-S Part II was administered to 1,764 White and minority children in kindergarten through second grade. The DELV-S was found to be a reliable measure of language skills for children with low language ability. However even though the test was designed to remove cultural bias, Petscher et al., (2012) found that several questions were more difficult, based on obtained correct/error scores, for the African American children than for the White children. The DELV-S Part II was found to accurately differentiate language difference from language disorder in children with low language skills. The findings of Petscher et al., (2012) reveal the difficulty in developing a totally bias free testing instrument as even the DELV-S Part II contains questions that are more different for African American than White children. Other standardized assessment tools that are part of the SLPs test battery are likely to include African American children as part of the standardization pool but may have inherent test bias. In order for the SLP to accurately differentiate dialect variation from communication disorder the practitioner must be aware of the possibility of inherent test bias. This knowledge alone however is not enough to guarantee that the test can be administered and interpreted in such a way as to be psychometrically valid and culturally unbiased.

In the absence of psychometrically valid and culturally unbiased assessments, the SLP who relies on a standardized score obtained from any of the traditional mass market testing instruments, has the potential to obtain a test result that either over or under diagnoses communication disorder for African American children. Under referrals may occur as the SLP incorrectly identifies a true communication deficit as dialectal variation. Conversely the SLP who strictly adheres to the test administration protocol may over refer children who are acquiring a dialect other than General American English as the SLP conservatively, but inaccurately diagnoses AAE as a communication disorder. The issue of identifying disorder or differences is not a simple dichotomous identification of African American children acquiring the rules of and using AAE or GAE. Instead the issue is multidimensional and encompasses an understanding of language rule use in AAE and GAE, the appropriate choice and use of assessment/measurement tools and approaches, referral patterns and ultimately clinical outcomes. Two approaches have been proposed to assist the SLP in identifying true communication

disorders in children who use a dialect or language other than GAE. Both approaches require the SLP to analyze the testing instrument, the individual being tested, and the testing outcomes beyond the dichotomous correct/error response identification of a standardized test instrument. Taylor and Payne (1983) describe the multiple types of biases (e.g. test, situational/pragmatic, cultural, linguistic, value) and provide a twelve point outline for the SLP to use when using a standardized assessment with minority children. The protocol described by Taylor and Payne (1983) may be both helpful and informative for the SLP however without a standardized method of assessing the use of that protocol it is not possible to determine its effectiveness in discriminating difference from disorder. A second method of eliminating test bias is Dynamic Assessment (DA) typically involves a test, teach, retest model. This model is believed to remove some aspects of bias (e.g. test, situational/pragmatic, cultural, linguistic) as the child is taught absent skills and allowed to demonstrate the ability to learn new material and apply what was learned, or alternatively to learn what is expected in a formal testing situation and demonstrate the skill in the expected manner. Several researchers have employed this method such as Gutierrez-Clellen & Pena (2001), Laing & Kamhi, (2003) and Peña et al., (2006). Again, multiple methods of intervention have been employed during the teach method and a definitive explanation of which method is best with which nonmainstream group, AAE users, Bilingual children, etc., has not been determined. Although DA may be a helpful and effective method of differentiating communication difference from disorder there is currently no validated or standardized protocol available for its implementation. The overlapping issues of SLP training and SLP tools for use with non-mainstream American English users remains an area in need of research.

### **Populations and Competent Assessments**

At a minimum, the competent SLP must be able to: (a) identify the presence or likely development of a disorder, (b) analyze the contributing factors in the development of a communication disorder including cultural variation, (c) understand the typical course of communication development including cultural and linguistic variation, and (d) develop a course of habilitation treatment that includes culturally competent intervention to assist the child's acquisition of functional communication skills.. As a critical first step, SLPs who serve minority children must understand models of language acquisition including the acquisition among typically developing

African American children. These reports include data on the acquisition and use of: (a) phonology (e.g. Bland-Stewart, (2003), Pearson, Velleman, Bryant, Charko, (2009); Stockman, (2006, 2008) (b) morphology (e.g. Stockman & Vaugh-Cooke, 1992; Steffensen, 1974; Stockman, 1996; Washington, Craig & Kushmaul, 1998; Wyatt, 1995) and (c) semantics and syntax (e.g., Craig & Washington, 2004; Stockman, 1998). To date, it is unclear whether these data are consistently considered during the assessment of children who are AAE speakers.

A review of language research using African American children completed by Stockman (2010) notes that the accumulated data "reflect palpable gains in professional sensitivity to linguistic and cultural diversity" (p.23); yet a survey of accredited SLP programs suggests the majority of professional preparation programs do not provide specific instruction on linguistic diversity issues as part of their education and training program (Stockman, Boult, & Robinson, 2008). Consequently, it is unclear whether this lack of specific training related to linguistic diversity offers the clinical service provider the ability to accurately distinguish communication disorder from communication difference, particularly among speakers of AAE. A 2012 review designed to explore reasons SLPs misdiagnose articulation and phonological disorders in children who speak AAE suggests the lack of professional SLP training may be a potential contributing factor in the disparity in clinical outcomes (Wilson, The review reported that when SLPs use 2012). standardized assessments normed with GAE speakers, some AAE dialect variations were characterized as errors. The review also reported that SLPs inexperienced in the evaluation of contrasting features in the context of AAE were unable to accurately determine disorder from difference in that population. Finally, the use of standardized assessment tools with binary pass/fail responses appear to penalize AAE speakers due to the observed dialectical differences associated with AAE and a limited understanding of typical AAE language acquisition by SLPs. In summary, SLP limitations in understanding AAE development and consequently their inability to distinguish differences from disorders are potential contributors to racial disparities in receipt of quality service provision.

### Strategies to Address Pediatric Disparities

A critical first step in operationalizing a plan to address racial disparities in pediatric SLP outcomes includes the identification of a research framework that allows for careful analysis of the multiple factors that contribute to

racial disparities. Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine (2006) proposed a three phase approach that begins by determining if health disparity exists between population groups followed by understanding the factors that contribute to the disparity and concluding with the development of interventions to eliminate the disparity.

Applying the three phase approach to study health disparity (Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006) requires an understanding that additional research is required to accurately answer primary questions related to the true presence of racial disparities in SLP clinical outcomes. Answering these questions will require systematic and programmatic research that considers access to care issues, the impact of disparate usual sources of care, the contribution of assessment issues associated with communication difference versus disorder in pediatric populations and clinician training and experience with people who use non-mainstream dialects of American English, such as AAE.

### CONCLUSIONS

This paper has attempted a brief introduction to potential contributors to racial disparities in pediatric populations. While evidence suggests that racial disparity exists among minority children receiving SLP services, the mechanisms of that disparity remain unclear and are likely far more extensive and complicated than those introduced in this paper. Future research must be designed to focus on the key measurable factors that translate into identifiable racial disparity. The next level of research must be completed in the context of national healthcare reform. This next level must be systematic and programmatic research designed to address these issues while developing a common goal of identification of true disorder and the appropriate and quality provision of services for all children including African American children, children who use non-mainstream dialects of American English and children from minority backgrounds.

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### **ABOUT THE AUTHORS:**

**Yolanda F. Holt, Ph.D., CCC-SLP**, is an Assistant Professor in the Department of Communication Sciences and Disorders at East Carolina University. Her research interests focus on dialect variation in African American English and Southern American English, sociophonetics, speech production and speech perception.

**Charles Ellis, Ph.D., CCC-SLP**, is an Associate Professor in the Department of Communication Sciences and Disorders and Director of the Communication Equity and Outcomes Laboratory at East Carolina University. His research focuses on utilization patterns of speechlanguage pathology services for neurologically-based disorders of communication, cost analysis of speech pathology utilization for neurologically-based disorders of communication, and examining potential disparities in utilization patterns for patients receiving services for neurologically-based disorders of communication.

### COMMUNICATION WELLNESS: A PATHWAY TO REDUCING HEALTH DISPARITIES IN POPULATIONS OF COLOR

#### Carolyn M. Mayo, Ph.D.

Communication Research, Evaluation and Wellness Specialists, LLC Burlington, NC

> **Robert Mayo, Ph.D.** University of North Carolina at Greensboro Greensboro, NC

#### ABSTRACT

In this article, the authors provide an operational definition of communication wellness for use by communication sciences and disorders professionals. The rationale for developing and promoting communication wellness activities in individuals and communities of color is that these activities can become a contributing factor to eliminate or at least minimize health disparities. Because SLPs and AUDs routinely incorporate screening and intervention or treatment strategies into their service delivery protocols, known as secondary and tertiary prevention, respectively (Marge, 1988 and ASHA 1988; 1991), special emphasis is placed on *primary* prevention strategies or those lifestyle behaviors that minimize the occurrence of a communication disorder.

**KEY WORDS:** Health disparities, communication wellness, prevention of communication and eating/swallowing disorders

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#### Carolyn M. Mayo, Ph.D.

Communication Research, Evaluation and Wellness Specialists, LLC Burlington, NC

#### Robert Mayo, Ph.D.

University of North Carolina at Greensboro Greensboro, NC

#### **INTRODUCTION**

In 2016, the American Speech-Language-Hearing (ASHA) published an updated model that summarized the Scopes of Practice for service delivery by audiologists and speech-language pathologists. Shown in Figure 1, the model incorporates the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO). Briefly, ICF is a framework for measuring health and disability at both

individual and population levels. It was endorsed by all 191 WHO Member States at the 54th World Health Assembly in 2001 (i.e., Resolution WHA 54.21) and is considered to be the international standard to describe and measure health and disability (WHO, 2016). The ICF framework is surrounded by five service domains that have traditionally been considered those practice duties and responsibilities for communication disorders specialists. These domains include diagnosis, habilitation, rehabilitation, enhancement and prevention.

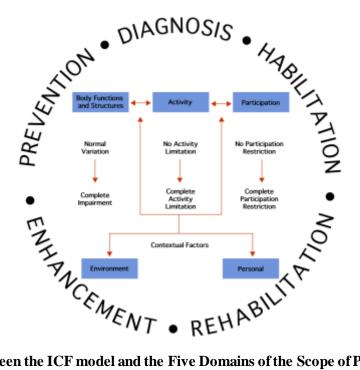


Figure 1. Interaction between the ICF model and the Five Domains of the Scope of Practice for Audiologists and Speech-Language Pathologists as depicted by the American Speech-Language-Hearing Association (ASHA). This model applies to individuals, groups and communities (Source: ASHA, 2016).

The professional scope of practice model was adopted as part of the evolving role of speech-language pathology assistants working under the supervision of ASHAcertified and/or licensed speech-language pathology practitioners (ASHA, 2013). As presented, this model becomes a useful, comprehensive and visual tool to educate members of our profession and various public constituents about what we do when providing healthcare services to patients, clients and family members. Emphasis is not only placed on care of the individual but also care of the broader community.

In this article, we focus on a single domain of the ASHA Practice model—the Scope of prevention of communication disorders and its implications for reducing health disparities. The goal of prevention activities is to reduce the risk or mitigate the effects of risk factors on a child's development or an adult's wellbeing so as to prevent future problems and promote the necessary conditions for healthy development or function. SLPs have the opportunity to play an important role in the prevention of communication disorders, especially in the field of early intervention (ASHA, 2008). Prevention encompasses (a) health promotion activities that encourage healthy living and limit the initial onset of chronic diseases, (b) early detection efforts, such as screening at-risk populations, and (c) strategies for appropriate management of existing diseases and related complications. Prior to discussing strategies to prevent communication disorders, we define wellness in general, and then operationally define communication wellness.

### Wellness and Communication Wellness Defined

The National Wellness Institute (2016), defines wellness as an active process through which people become aware of, and make choices toward, a more successful existence. Wellness is a conscious, self-directed and evolving process of achieving one's full potential; it is multidimensional and holistic, encompassing lifestyle, mental and spiritual well-being and care for the environment in a positive and affirming manner. Having presented this broad definition of wellness, we narrow our focus to operationally define *communication wellness* as an individual or group being fully aware of, and educated about those bodily systems that are responsible for human communication (cognitive/mental, auditory, respiratory, phonatory, articulatory and resonatory) and eating/swallowing pharyngeal-laryngeal, (oral. esophageal), and then consciously engaging in health

related practices-both intrinsic (personal) and extrinsic (environmental)—that promote and achieve the highest level of functional and/or effective communication, eating and swallowing across his/her lifespan. Emphasis is placed on communication wellness—the prevention of communication and eating/swallowing disorders—for four reasons:

- 1. Prevention is often overlooked or minimized as part of the communication disorders specialists' scope of practice because traditionally, it has been non-billable service for insurance я reimbursements paid by public and private insurers. Creating health care environments that promote healthy behaviors and reduce risk factors requires renewed commitment to prevention irrespective of traditional reimbursement practices on the part of insurance companies. Gradual changes are happening in the health care industry with increased emphasis on preventive practice. For example, although politically controversial since its enactment into law in 2010, the Patient Protection and Affordable Care Act (aka ACA or Obamacare) instituted a new national focus on prevention and wellness through the Prevention and Wellness Public Fund (Schearer, 2010, Shaw, et. al., 2014). Among the prevention initiatives established by ACA was the National Prevention Strategy (National Prevention Council, 2011) which aims to guide the U.S. in the most effective and achievable means for improving the health and well-being of all its citizens. The Strategy prioritizes prevention by integrating recommendations and actions across multiple settings to improve health and save lives.
- 2. Racial/ethnic minority populations tend to be overrepresented in acquiring acute and chronic diseases and disorders that negatively impact their body systems and functions responsible for human communication (e.g., cerebral vascular accidents resulting in aphasia and motor speech disorders, traumatic brain injury leading to mild-severe cognitive deficits, progressive degenerative neurogenic disorders like Parkinsonism or myasthenia gravis resulting in motor speech disorders, etc.). The prevalence of these diseases, combined with issues of access, utilization and negative attitudes toward and/or adverse experiences with health care systems (Smedley et al. 2003), makes it imperative that an increase in education, awareness

and self-promotion of wellness and good personal health practices be introduced to promote the health and well-being of racial/ethnic minority individuals, their families and their communities at large.

3. A focus on prevention within racial/ethnic minority individuals and communities via clinical intervention and community education and training, especially if done well, can reduce the economic burden of communication disorders on our society and improve the quality of people's lives. For example, in a study which looked at the economic burden of health inequalities in the United States, LaVeist, Gaskin and Richard (2010), concluded that "the combined costs of health inequalities and premature death in the United States was \$1.24 trillion" between 2003 and 2006. Studies related to the economic burden of communication disorders on society have also been published. In reporting on behalf of the 2010 Royal College of Speech and Language Therapists in the United Kingdom (UK), Cummings (2013) found that speech and language therapy provided to UK clients with aphasia, specific language impairment and autism delivered an estimated net benefit of £765 million to the British economy each year. This UK figure translates to a savings of \$1,127,066,850 or 1.13 billion U.S. dollars based on the current (2016) economic market (where the ratio is 1 pound being equivalent to 1.47 dollars). By contrast, (Ruben 2000) purported that the economic cost of communication disorders in the U.S. was estimated to be between \$154 billion and \$186 billion per yearequal to 2.5% to 3% of the Gross National Product. Ruben labeled this economic deficit resulting from communication disorders as a burden to our economy and to society as a whole. He stated that this segment of the U.S. citizenry is perceived as being nonproductive, functionally disabled and are, thus, disavowed by our society as fully participating and contributing members secondary to their communication disorders. Cummings (2013)society concluded that а which neglects communication disorders among its citizens can expect to sustain significant economic harm and further is abdicating its social responsibility to the welfare of its people. Given today's information age, the *inability* to communicate effectively and rapidly can have detrimental and often devastating effects on a person's capacity to successfully participate and function in our society. In fact, we speculate that there is a positive correlation between individuals who have adapted to the computerized, information age and their position of power and well-being in both the U.S. and global economy.

4. The lack of underrepresented groups in the health allied health professions significantly and contributes to the negative health care statistics being experienced within communities of color. With growing national population diversity and a continuous influx of internationals residing and working in the U.S., the gap between the racial and ethnic composition of the healthcare workforce and that of the U.S. population widens as well. Ideally, in terms of a beginning point with respect to equity, there should be a one to one (1:1) ratio between the presence of a minority group in the general population and its representation in the health care industry across the myriad health professions, including speech-language pathology and audiology. We examine the demographic composition of communication sciences and disorders (CSD) professionals to further emphasize this point. As of 2015, the report on ASHA membership demographics noted that only 7.8% of ASHA members, nonmember certificate holders, international affiliates, and associates were members of a racial minority group including members who self-identified as multiracial (ASHA, 2015). Given that the combined racial minority population for the U.S. is approximately 27.6% (based on 2010 U.S. Census population statistics), there is about a two-thirds disparity gap in terms of minority presence within communication sciences and disorders. The ethnic disparity gap is even wider with only 4.7% of the aforementioned 2015 ASHA constituents identifying their ethnicity as Hispanic or Latino, compared with 16.3% ethnic representation in the U.S. population (ASHA, 2015). Although the statistics vary across health care professions, the disparity gap is a common issue for all of the health and allied health fields. Sample strategies to improve the disparity gap include such activities as 1) expanding the use of lay health interpreters to overcome language barriers; 2) cultural competence education and improving training for all health care professionals; and 3) heightening efforts to increase racial and ethnic diversity in the healthcare workforce by recruitment and retention of minority students and mature career changers of color in the health professions (Institute

of Medicine, 2004; U.S. Department of Health and Human Services, 2006; 2016).

### The Marge Model of Primary, Secondary and Tertiary Prevention and Its Relationship to Communication Wellness

The seminal work of Michael Marge (1988) purported that the goal of health promotion was twofold, 1) to educate the public about the risks related to health abuses; and 2) to increase commitment to healthy lifestyles which can prevent premature death and disability. Although Marge did not use the term *communication wellness* in his article, he challenged our profession nearly three decades ago to fully embrace one of our roles as being to prevent communication disorders by educating and promoting wellness practices among communication sciences and disorders professionals and the patients and family members we serve, and doing so through three prevention modalities: primary, secondary and tertiary prevention. Table 1 provides the reader with Marge's 1988 definitions of these three prevention modalities and compares them with the definitions of the modalities set forth by ASHA (1988, 1991).

### Table 1. Definitions of Primary, Secondary and Tertiary Prevention According to Marge (1988) and ASHA (1988, 1991).

	Marge (1988)	ASHA (1988, 1991)
Primary Prevention	The reduction of risk for disease or disability in susceptible or asymptomatic individuals. Approaches include interventions or behaviors that eliminate the cause or causes of disabilities before individual exposure.	The elimination or inhibition of the onset and development of a communication disorder by altering susceptibility or reducing exposure for susceptible persons.
Secondary Prevention	The early identification and treatment of disease and disability in individuals who are displaying problems in the beginning phases of a condition. The major strategy used is screening of asymptomatic or susceptible populations,	The early detection and treatment of communication disorders. Early detection and treatment may lead to the elimination of the disorder or the retardation of the disorder's progress, thereby preventing further complications.
Tertiary Prevention	Reducing the debilitating effects of a disability by intervention as soon as possible after the acquisition of the disability. The strategy used is the provision of a comprehensive intervention program to restore as much function as possible.	The reduction of a disability by attempting to restore effective functioning. The major approach is <i>rehabilitation</i> of the disabled individual who has realized some residual problem as a result of the disorder.

All three forms of prevention are useful and defensible (Albee, 1987). Of particular interest to the authors are both Marge's and ASHA's definition of primary prevention. Both of these definitions advocate for the inhibition, elimination, or reduction of risk factors that may lead to communication and eating/swallowing disorders by members of our society by engaging in wellness practices that minimize self-induced or environmental causal factors. To be clear, taking action before a problem arises in order to avoid it entirely, rather than treating or alleviating its consequences, is called primary prevention (Cohen & Chehimi, 2007). Sample important health practices that are controllable by individuals to improve healthy lifestyles include physical fitness, weight management, well-balanced nutrition, smoking cessation, significantly reducing alcohol beverage intake, minimizing use of over-the-counter and prescription drugs, avoiding illegal substance abuse, stress control, getting adequate rest and accident and injury prevention. Traditionally and even now, the major foci of service provisions by CSD practitioners have been secondary (screening) and tertiary (diagnosis, intervention) prevention. As stated previously, the U.S. health care system reinforces this focused attention on secondary and tertiary prevention practices due to existing insurance reimbursement policies. Additionally limited emphasis is placed on educating CSD students about primary prevention measures and how they can get involved in implementing these measures. Still, it is important and even ethically appropriate for members of the CSD profession to support and participate in primary prevention activities with clients, their families and the communities in which they reside, especially those residents from more vulnerable populations in the U.S. society who are typically low-income, unemployed or underemployed persons residing in communities with limited health care personnel and services, and who are at greater risk for diseases and disorders that can lead to the communication disorders.

In summarizing selected highlights of the ASHA Scope of Practice (2016) mentioned in the introductory portion of this article, primary prevention education and services should:

- 1. Be conducted by credentialed/licensed speechlanguage pathologists, speech-language pathology assistants and/or audiologists;
- 2. Identify and educate clients, families and communities about risk behaviors that can lead to communication and swallowing disorders, and how to minimize or avoid those risk behaviors;

- 3. Inhibit or delay the onset of communication and swallowing disorders by maintaining and or strengthening bodily structures and functions associated with normal communication and swallowing activity through health enhancing exercises, activities and levels of participation;
- 4. Be developed and implemented as an interprofessional service delivery protocol in concert with prevention experts from other health- and social science disciplines (e.g., public health, social work, psychology, sociology, urban planning, political science, environmental health sciences, etc.).
- 5. Be implemented with strong consideration given to the culture (values and beliefs), language preferences, health literacy issues, social marketing strategies, and the historical benchmarks that address how the individual, family and community have interfaced with the health care industry during previous encounters.
- 6. Adhere to research processes that identify best practices. Best practices research refers to a systematic process used to identify, describe, combine, and disseminate effective and efficient clinical and/or educational strategies developed and refined by practicing clinicians (Mold & Gregory, 2003). Synonymous with Evidence Based Practice within the CSD profession, the ASHA's Coordinating Committee on Evidence Based Practice (ASHA, 2005) triangulates Best Practices Research or EBP into three components: Current Best Evidence, Clinical Expertise and Client/Patient Values.

Below we present slight modifications within the fivestep process that leads toward EBP:

- 1. Recognize the needs, abilities, values, preferences, and interests of individuals and families to clinical services are provided, and integrate those factors along with best current research evidence and their clinical expertise in making clinical decisions.
- 2. Evaluate *primary prevention*... using recognized appraisal criteria described in the evidence-based practice literature.
- 3. Evaluate the efficacy, effectiveness, and efficiency of clinical protocols for *primary prevention*... using recognized appraisal criteria described in the evidence-based practice literature.
- 4. Evaluate quality of evidence on *primary prevention* appearing in any source or format, including journal articles, textbooks, continuing education offerings, newsletters, advertising, and Web-based products,

prior to incorporating such evidence into clinical decision making;

5. Monitor and incorporate new and high-quality research evidence having implications for *primary prevention* practice.

### Suggestions to Implement a Primary Prevention Program for CSD Professionals

Communication disorders specialists who want to include primary prevention activities in the education, counseling and service delivery to clients and their families should think outside the box of literature associated directly with the CSD profession. In fact, numerous resources on primary prevention are found in government health documents and research and general literature in the area of public health. A major government document published by the Office of the U.S. Surgeon General titled 'The National Prevention Strategy' (National Prevention Council, 2011) identifies four "Strategic Directions" that are the foundation for all prevention efforts and form the basis for a prevention-oriented society. These Strategic Directions include, 'Elimination of Health Disparities', 'Clinical and Community Preventive Services', 'Healthy and Safe Community Environments', and 'Empowered People'. The document also offers a list of evidencedbased recommendations under seven priority categories designed to improve health and wellness for the entire U.S. population, including those groups

disproportionately affected by disease and injury. If implemented fully and appropriately, the priorities most likely will reduce the burden of the leading causes of preventable death and major illness in the U.S. and conceivably reduce or eliminate health disparities thereby improving the quality of life for all Americans. Included among the seven priorities are healthy eating, active living, injury and violence free living, mental and emotional well-being, tobacco free living, preventing drug abuse and excessive alcohol use and reproductive and sexual health.

As noted in the National Prevention Strategy, while the four Strategic Directions together create the web needed to fully support Americans in leading longer and healthier lives, each Strategic Direction can stand alone and can guide actions that will demonstrably improve health Strategy' (National Prevention Council, 2011). In Table 2 we focus on three of the Strategic Directions, elimination of health disparities, clinical and community preventive services and empowered people as we present the purpose and descriptions of each strategy and outline the roles of CSD professionals and their partners (i.e., health care systems, early learning schools centers. and colleges/universities) efforts in to promote communication wellness as a primary prevention approach and reduce health disparities in populations of color.

Strategic Directions	Purpose and Description	Primary Prevention Roles of CSD
		<b>Professionals and Partners</b>
	Purpose:	CSD Professionals & Health Care
	Eliminate disparities, improving the	Systems:
Elimination of Health Disparities	quality of life for all Americans.	Educate patients, families and communities about
	Description:	ways to prevent communication and eating/swallowing disorders.
	In the United States, health disparities are often closely linked with social, economic, or environmental	Increase the cultural and communication competence of health care providers.
	disadvantage. Clear evidence exists that with appropriate focus and investment, health disparities can be eliminated	Train and hire more qualified staff from underrepresented racial and ethnic minorities and people with disabilities.
	while simultaneously improving the health of all Americans.	Help ensure that prevention strategies are culturally, linguistically and age appropriate to match people's health literacy skills.

Table 2. Prevention Strategic Directions and Roles of CSD Professionals and Partners. Adapted from the NationalPrevention Council (2011) and Mayo & Mayo (1996).

		Educate patients, families and communities about ways to prevent communication and eating/swallowing disorders.
		Offer prevention services (e.g., speech-language- hearing screenings, pre-literacy and literacy screenings, oral care, vision screenings) for all children especially those at risk.
		Move adults toward optimal health by helping them discover health-enhancing behaviors; modify sources of environmental stress and internal and external barriers to good health; and developing social networks (or strengthening existing ones) that will support their continuous movement toward optimal health.
		Develop prevention lectures and educational seminars and social media offerings on topics such as communication wellness or stroke prevention and present them to community groups.
		Offer risk appraisals as part of screening activities during community-based or work site health fairs.
		Develop other prevention and communication wellness projects with professional colleagues at the local, state and national levels.
		Conduct evidence based research focusing on communication wellness strategies and their effectiveness in eliminating communication health disparities.
		Early Learning Centers, Schools & Colleges/Universities
		Train early intervention specialists how to educate patients, families and communities about ways to prevent communication and eating/swallowing disorders.
		Conduct outreach to increase diversity (e.g., racial/ethnic, income, disability) in health care and public health careers
		Offer prevention services (e.g., speech-language- hearing screenings, pre-literacy and literacy screenings, oral care, vision screenings) for all children especially those at risk.
		Develop and implement local strategies to reduce health, psychosocial and environmental conditions that affect school attendance and performance.
	Purpose:	CSD Professionals & Health Care
Clinical & Community	Ensure that prevention-focused health	Systems:
Prevention Services	care and community prevention efforts are available, integrated, and mutually reinforcing. Description:	Inform persons and families about the benefits of preventive services and offer recommended clinical prevention services (including communication wellness) as a routine part of care.
	1	

	The provision of evidence-based clinical and community preventive services and the integration of these activities are central to improving and enhancing physical and mental health. Certain clinical preventive services have proven to be both effective and cost-saving through decades of practice and research; The Affordable Care Act reduces barriers to people receiving many clinical preventive services. Clinical preventive services can be supported and reinforced by community prevention efforts that have the potential to reach large numbers of people.	<ul> <li>Encourage individuals and families to visit health care providers to receive prevention services.</li> <li>Assist families with use of various tools to access and learn about health prevention, communication wellness and ways to better manage health (e.g., personal health records, text reminder services, smart phone applications).</li> <li>Help reduce or eliminate client out-of-pocket costs for certain preventive services, as required for most health plans by the Affordable Care Act, and educate and encourage enrollees to access these services.</li> <li>Promote the use of evidence based prevention services such as communication wellness within existing health services (e.g., school health programs).</li> <li>Early Learning Centers, Schools &amp; Colleges/Universities</li> <li>Help train other providers (e.g., doctors, nurses, dentists, allied health professionals) to use health information technology and offer persons recommended clinical prevention services as a routine part of their health care.</li> </ul>
Empowered People	Purpose: Support people in making healthier choices. Description: Although policies and programs can make healthy options available, people still need to make healthy choices. When people have access to actionable and easy-to-understand information and resources, they are empowered to make healthier choices. Efforts to educate and motivate people to make healthy choices should occur across the lifespan, with a particular emphasis on ensuring that young people are provided with the knowledge, skills, and opportunities they need to allow them to become healthy adults. In addition, we should provide knowledge and opportunities that support the unique needs of our growing older adult population.	<ul> <li>CSD Professionals &amp; Health Care Systems:</li> <li>Use proven methods of checking and confirming of client and family understanding of health promotion and disease prevention (e.g., teach-back method).</li> <li>Use alternative communication methods and tools (e.g., mobile phone applications, personal health records, credible health websites) to support more traditional written and oral communications.</li> <li>Refer clients and families to adult education and English-language instruction programs to help enhance understanding of health promotion and disease prevention messages.</li> <li>Aid clients and families in providing clinicians with relevant information (e.g., health history, symptoms, medications), ask questions and take notes during appointments, learn more about diagnoses or conditions and follow up with recommended appointments.</li> <li>Early Learning Centers, Schools &amp; Colleges/Universities</li> <li>Incorporate health education into coursework (e.g., by embedding health-related tasks, skills, and examples into lesson plans).</li> </ul>

### CONCLUSIONS

We have provided a definition of communication wellness and a rationale for developing and promoting communication wellness activities with populations of color as one mechanism for reducing health disparities in these groups. Specific attention has been given to primary prevention as defined by Marge (1988) and ASHA (1991). An examination of how communication wellness ties in with the current focus and incorporation of wellness and prevention strategies through the Affordable Care Act and other national agencies and programs has also been presented. Examples of primary prevention roles CSD professionals can lead solely or with partners were discussed. Emphasis was also placed on the need to examine programs being used for prevention purposes through the rigorous lens of evidence based research.

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#### **ABOUT THE AUTHORS:**

**Carolyn M. Mayo, Ph.D., CCC-SLP**, is Chief Executive Officer of Communication Research Evaluation and Wellness Specialists, LLC. Her areas of interest and research include evaluation of higher education health systems and organizations, personnel preparation, communication wellness and adult neurogenic communication disorders.

**Robert Mayo, Ph.D, CCC-SLP**, is a Professor in the Department of Communication Sciences and Disorders at The University of North Carolina at Greensboro. His areas of interest and research include fluency disorders, craniofacial anomalies, public perceptions of communication disorders and differences, and exploring disparities in access to communication healthcare services.