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## Improving Access to Communication for Adults with Aphasia using "Aphasia-Friendly" Accommodations

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Improving Access to Communication for Adults with Aphasia using Aphasia-Friendly Tools

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### Improving Access to Communication for Adults with Aphasia Using Aphasia-Friendly Tools

Accessing written health information is vital to any health visit (Blackstone, Beukelman, & Yorkston, 2015). People who have difficulty comprehending written text have difficulty understanding health-related information because it is usually written at a complex levels (Kanj & Mitic, 2009). If health information contains complicated content and is not easily accessible, people may not receive the health care needed (Blackstone et al., 2015). Many populations are considered communication vulnerable relative to health care which means they may not have access to understanding health information documents (Hallowell, 2016). These populations include people who are blind or visually impaired; people who are deaf or hard of hearing; people with a cognitive impairment; people of different cultures; and people with low literacy levels.

Another vulnerable population are people with aphasia, an acquired language disorder that impairs a person's ability to understand spoken and written language (Hallowell, 2016). All of these populations may have difficulty accessing and understanding complex health-related forms and content (Hallowell, 2016). By making health information more accessible to people who are communication vulnerable, patient-provider communication can improve, thus allowing both patients and providers to participate more fully in health care provision and decision making (Blackstone et al., 2015).

### **The Problem of Patient-Provider Communication**

Patient-centered care involves the provider recognizing the needs of the patient and communicating effectively (Burns, Baylor, Morris, McNalley, & Yorkston, 2012). Blackstone et al. (2015) addressed the issues facing patients, especially people with communication challenges, and the complexity of the messages that need to be conveyed to them. These authors explain that

even though communication may be difficult, communication access is mandated by accreditation standards; and health care professionals need to develop a better understanding of how to successfully provide information to their patients (Blackstone et al., 2015).

A current issue surrounding this mandate is whether health care providers know how to communicate with patients who have communication disorders (Burns et al., 2012). Given the diverse populations health care providers treat, it is important for them to have the ability to communicate with people regardless of their background, culture, or ability. Unfortunately, not all medical settings incorporate employee training to a provider to improve communication with patients. “Training to facilitate improved communication with patients with communication disorders has been historically neglected in medical education” (Burns et al., 2012, p. 685). If medical settings incorporated training about communication with all patients, then patient-provider communication could be more effective. Due to time limitations, individual patients are discouraged from bringing communication tools to appointments, hospitals, and other health settings (Blackstone et al., 2015). When patients do not have the tools or strategies to facilitate communication, and when providers do not have the skills to interact with them, effective communication will be placed at risk.

Even though there is a recognized need for effective communication training, “Successful communication is not always easy to achieve in health care settings. The stakes are often very high, the time is very short, and medical content is frequently complicated” (Blackstone et al., 2015, p. 197). These interactions of conditions create stress for both the patient and the provider. Health care providers must have the ability to be flexible when interacting with different patients and caregivers everyday (Blackstone et al., 2015). Without effective communication, the consequences of a communication breakdown could result in patients being put at risk;

breakdowns could affect their satisfaction, safety, healthcare delivery, and outcomes (Blackstone et al., 2015). The result of inadequate communication could also result in increased hospital stays, increased health costs, and increased stress on the patient (Rao, 2011).

### **Communication Vulnerable Adults**

#### **Defining the Population**

A population that is at risk for impaired access to effective communication and language use consists of people described as communication vulnerable adults (Blackstone et al., 2015). The research literature describes adults who are considered communication vulnerable as those with impaired access when required to use standard health-care related forms and documents (Blackstone et al., 2015). Blackstone et al. (2015) describe communication vulnerability as “the diminished capacity of an individual to speak, hear, understand, read, remember or write due to factors that are inherent to the individual or related to the context or situation” (p. 13).

In the text, *Patient-Provider Communication: Roles for Speech-Language Pathologists and Other Health Care Professionals*, Blackstone et al. (2015) define five patient groups as being communication vulnerable.

1. People with disabilities affecting communication (speaking, hearing, seeing, understanding, reading, remembering, and writing)....
2. People who do not speak/understand English....
3. People with personal characteristics, practices, and/or preferences that differ from the dominant culture of the community....
4. People with limited health literacy....
5. People who are unable to communicate because of situational or contextual factors (Blackstone et al., 2015, p. 13-16)

### **Describing the Effects of Communication Vulnerability People with Vision Impairments**

The Center for Disease Control and Prevention (CDC) reports that as many as 21 million Americans have “vision problems” and approximately 80 million Americans have potentially eye blinding diseases (“Why is vision loss a public health problem,” 2015). As the population of older adults increases, so does the number of people with vision loss (Center for Disease Prevention and Control, 2011). There are also 135 million people worldwide with visual loss whose vision cannot be corrected with optical devices or procedures (Chung, 2013).

People who are blind and have low vision do not have the same access to information as those who are seeing which puts them at a greater risk of having a communication breakdown with a health care provider. Measuring literacy in adults who are blind or have low vision is difficult. Professionals need to be aware of the definition of literacy so they are able to evaluate it efficiently (Reid, 1998). Providers must also be aware of the medium used in literacy testing so that individuals are not disadvantaged because of the context (Reid, 1998). For example, studies show that blind children who use braille tend to read slower than those that do not (Kamei-Hannan & Ricci, 2015). In other words, speed of reading is not a measure of comprehension of reading. Even though it may take a person longer to read braille, it has no indication of a readers' comprehension of literacy.

Providing people who have visual impairments with health related documents that are suitable is not simple because of the wide variability and range of different types of visual impairments (Harrison, Guy, Mackert, Walker, & Pound, 2012). One health literacy adaptation or accommodation may not be suitable for every person with a visual impairment because of individual differences (Harrison & Lazard, 2015). The medium that is used to convey health

information is very important and affects how a person with a visual impairment understands information (Harrison, Mackert, & Watkins, 2010).

Experts recommend several alternative solutions to increasing access to health information for people who are blind or who have low vision. One important strategy to improve access is to use braille and large print. Using teaching materials that are in braille and large print would allow for information to be more accessible for people who are blind or who have low vision and who use braille (Dreger, Vicki, & Tremeck, 2002). Another strategy could be using magnifying devices. Providers could supply optical magnifiers for the patient to wear, or a hand held magnifier to use as needed (Crossland, 2011).

Warren (2013) also expressed the need for health care providers to understand the effects vision impairment can have on people who are not blind. The loss of vision detracts from understanding printed health information accurately and interferes with healthcare provider interaction (Warren, 2013). Warren (2013) concluded that there are general strategies that could be used when developing written materials for people with vision impairments. The first strategy recommends using an appropriate size font such as 18-point font or larger when producing materials for distribution (Warren, 2013). Using upper and lowercase letters and non-italicized words are usually easier to perceive for a person with a vision impairment (Warren, 2013). Using all capitalized words and/or italicized words makes it harder to distinguish the letters from one another (Warren, 2013). Another enabling strategy suggests using larger amounts of white space in the document (Warren, 2013). This formatting can be implemented by widening margins, double spacing between lines, and inserting larger spaces between paragraphs (Warren, 2013). Warren (2013) emphasized that health care providers need to understand the impact that low vision has on understanding health documents and that use of these simple

strategies can make documents more readable. Revising health documents to promote access for individuals with visual impairments can lead to creating more accessible health communication (Harrison et al., 2012).

### **People who are Deaf and Hard of Hearing**

In 2006, the CDC reported that there are approximately 37 million adults in the United States who have trouble hearing, ranging from people with little trouble hearing to deafness (Schoenborn & Heyman, 2010). There is a difference in connotation between the word Deaf when capitalized and deaf uncapitalized. The word Deaf when capitalized describes a sociocultural identity and cultural perspective for people who are non-hearing. Alternately, the word deaf when uncapitalized is associated with a description only of the auditory abilities or sensory loss among the general population (Berke, 2016).

Both deaf and hard of hearing (HOH) individuals live with a wide range of communication and language difficulties that may reduce their opportunity to benefit from health care communication (Mckee et al., 2015). Individuals who are deaf and HOH have lower literacy compared to hearing individuals which puts them at risk for patient-provider communication breakdown (Smith & Samar, 2016). The health care provider may not associate deaf individuals with low literacy levels, and as a result, their communication needs may be overlooked (Pollard, Dean, O'Hearn, & Haynes, 2009). The use of accessible health information and documentation could help individuals who are deaf and HOH and improve their communication with health care providers. "The reduction and prevention of health disparities in the deaf population may depend heavily on the creation and distribution of such adapted health education materials" (Pollard et al., 2009, p. 237). There is a need for people who are deaf and HOH to receive materials that are accessible to them.



Another misconception hearing individuals and medical professionals may have is that all deaf and HOH individuals are able to generate written language effectively and efficiently (Mckee et al., 2015). As a result, because some deaf and HOH individuals may have low literacy levels, they may be impaired in understanding written communication (Mckee et al., 2015). This impairment can limit a deaf or HOH individual's ability to accurately understand written health information.

Neuhauser et al. (2013) studied people who are Deaf and HOH and questioned their communication vulnerability. The purpose of the study was to investigate whether Emergency Preparedness Materials (EPM) were accessible to people who are Deaf and HOH and to analyze the readability of the materials. The authors found that only 23% of the community-based organizations in the study had EPM exclusively designed for Deaf and HOH individuals (Neuhauser et al., 2013). The authors concluded that there are limited materials available expressly targeting the needs and abilities of this population (Neuhauser et al., 2013).

The findings identified an important gap between the estimated health literacy abilities of these two populations [Deaf and Hard of Hearing] and the kind of emergency preparedness materials they can currently access from local CBOs [community-based organizations] and health departments. (Neuhauser et al., 2013, p. 10)

The authors also found that websites that did supply emergency information were not adapted to fit the literacy levels of Deaf and HOH individuals (Neuhauser et al., 2013).

Clearly, emergency information must meet the needs of Deaf and HOH individuals to save lives and to ensure access to other related sources. One solution to this problem has been a push towards creating "digital video-based articles" that are provided in American Sign Language (ASL) format rather than in a written text format (ASLized, 2015). The use of another

language modality, sign language, is an example of specialized communication accommodation that could give Deaf and HOH individuals the opportunities to access critical information that is needed to maintain their safety in their everyday lives.

However, one crucial difference between people who are deaf and HOH and other communication vulnerable adults is that as a population they are more likely to receive “reasonable accommodations” such as access to the services of an interpreter when compared to other groups (Blackstone et al., 2015). Other communication vulnerable populations are typically not given these types of accommodations. But even if the use of an interpreter is incorporated into health care settings and interactions, it may not always be sufficient and other considerations need to be made to ensure that information is being received accurately and efficiently (McKee et al., 2015). “Given the high proportion of inadequate health literacy among Deaf individuals, health providers and researchers should consider incorporating best practices to address poor health literacy and communication when caring and working with any of these individuals” (McKee et al., 2015, p. 98). Some general communication best practices include making sure you face the individual, not assuming that someone understands you, and using facial expressions and gestures to make your message clear (Shuler, Mistler, Torrey & Depukat, 2013).

### **People with Cognitive Impairment**

In the United States, there are more than 16 million people with a cognitive impairment (Center for Disease Prevention and Control, 2011). One group identified with problems in cognition is people diagnosed with Mild Cognitive Impairment (MCI) which is described as the zone between typical age-related cognitive decline and the disease dementia (Mayo Clinic Staff, 2016). The diagnosis of a mild cognitive disorder is associated with a deterioration of cognition (Han, Boyle, James, Lei, & Bennett, 2015). Symptoms can include difficulties related to

“memory, language, thinking, and judgement” (Mayo Clinic Staff, 2016). Individuals with MCI are at a greater risk for a communication breakdown because of their decreased literacy levels and decreased ability to think, judge, and remember information. Cognitive function has a direct effect on reading comprehension (Federman, Sano, Wolf, Siu, & Halm, 2009). In a study with 700 participants, it was found that people with MCI had lower performance on literacy tasks, including health literacy skills (Han et al., 2015). “These results suggest that MCI deleteriously affects literacy, a resource critical for health and well-being in old age” (Han et al., 2015, p. 1113).

Another group negatively affected by cognitive impairment are people diagnosed with intellectual disability (ID). Intellectual disability “is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association on Intellectual and Developmental Disabilities, n.d.). People with an ID are often excluded from health literacy research (Chinn, 2014). There has been a concern for the inequalities that people with ID face in securing the knowledge to improve their health (Chinn, 2014). Many health providers assume that people with ID are not individuals who are competent to make decisions and are thus are not included in research that studies health information and health literacy (Chinn, 2014).

It is unlikely that they [people with ID] will be offered opportunities to engage critically with health information if others lack confidence that these individuals are able to abstract from their own immediate experiences to think reflectively and critically and then move from individual reflection to social analysis. (Chinn, 2014, p. 258)

If health providers do not think individuals with ID are able to be involved in health-related research, then health practices cannot be adapted and appropriately adopted to fit their needs.

One way of improving patient-provider communication for people with ID is to modify health instructions by using pictures and symbols to help the person recall health information (Chinn, 2017). It is likely that asking the health provider for clarification would facilitate communication between the communicators (Chinn, 2017). Additionally, increasing background knowledge on health could improve health communication for a person with ID (Chinn, 2017).

Individuals with MCI, ID, and other individuals who are cognitively impaired are more at risk of having limited health literacy skills (Apolinario, Mansur, Carthey-Goulart, Brucki, & Nitri, 2015). Specific cognitive abilities have a direct influence on health literacy, meaning that low cognition levels can influence the degree of health literacy a person can obtain (Apolinario et al., 2015). There is lack of observational data in the field of ID and health consultations (Chinn, 2017). The available research is based on assumptions of communication difficulties between people with ID and health care professionals, rather than of observed real-life health consultations (Chinn, 2017). More research on people with ID and other populations that are cognitively impaired is necessary to understand how to best modify the patient-provider communication interaction.

## **Culture**

Yet another group of people that are communication vulnerable are the more than one million people in the United States who speak one of six languages other than English (Blackstone et al., 2015). Patients who speak languages other than English need either an interpreter or health information translated in forms that allow them to understand the content (Blackstone et al., 2015).

Written materials have to be easy to read and culturally and linguistically appropriate. All too often, material developers do not pay attention to all 3 aspects. Materials translated for LEP [limited English proficiency] populations are rarely tested for cultural appropriateness or literacy. (Andrulis & Brach, 2007, p. 127)

Translation of written English materials into other languages is not enough because the translations can be inaccurate (Andrulis & Brach, 2007). There has been growing recognition that cultural diversity needs to be considered for effective communication to happen between a health care provider and a patient (Andrulis & Brach, 2007). “Culturally diverse individuals with limited literacy and limited English proficiency (LEP) are among the most vulnerable patients” (Andrulis & Brach, 2007, p. 123). Culture affects who will seek health care, report symptoms, and use treatment (Andrulis & Brach, 2007). If patient-provider communication is culturally competent it is able to address and appreciate that people with different cultures may think about health differently than the U.S. majority; providers are encouraged to learn patients' health belief systems to accommodate patients' health needs (Andrulis & Brach, 2007).

One way to meet patients health needs is a process called transcreation which allows for cultural concepts and language to be appropriate for all audiences (Andrulis & Brach, 2007). The materials are not strictly translated from English; they are adapted to fit the culture and writing for that specific language (Andrulis & Brach, 2007). As an example, one project adapted a health information booklet in English for adult cancer survivors into a booklet for Latino Spanish-speaking cancer patients. The authors used transcreation by translating the English text into Spanish and then adapting it to fit a Latino audience (Solomon et al., 2005). The influence of the Latino culture changed the context of the booklet because Latino cultural values may be different from those of African Americans and Caucasians (Solomon et al., 2005). The participants were

asked about the booklets “usefulness, readability, layout, amount of information, and cultural relevance” (Solomon et al., 2005, p. 408). They reacted positively to the Latino booklet and described the booklet saying it was “well written” and “well explained” (Solomon et al., 2005, p. 408). Improving translations by using transcreation would allow individuals who differ from the mainstream culture to have more access to health information and to participate in their health care decisions since culture plays a large role in influencing context (Solomon et al., 2005). If the context is more closely adapted to a person’s culture, the document will be more informative and understandable (Solomon et al., 2005).

### **People with Low Health Literacy Skills**

Finally, because of low literacy skills, people may not understand their health condition or ways to improve their health. “American studies in the 1990s linked literacy to health, showing an association between low literacy and decreased medication adherence, knowledge of disease and self-care management skills” (Sorenson et al., 2012 p. 2). Limited health-literacy skills have negative health consequences, which demonstrates the importance of making health documentation more understandable for people with low literacy skills (Hironaka, & Passche-Orlow, 2008). “Without appropriate interventions, an individual’s limited health-literacy may compromise his/her ability to engage fully in healthcare interactions” (Hironaka, & Passche-Orlow, 2008, p. 431).

Experts acknowledge the interaction between low literacy and low health literacy skills. “Health literacy means the degree to which individuals have the capacity to obtain, process, and understand basic health information” (Blackstone et al., 2015, p. 15). It is not determined only by a person’s ability to read and comprehend written information (Andrulis & Brach, 2007). Health literacy is also the “product of individuals’ capacities and the demands that health information

places on individuals to decode, interpret, and assimilate health messages” (Andrulis & Brach, 2007, p. 123).

Only 12% of adults possess “proficient” health literacy (1 out of 10) (Blackstone et al., 2015). “Low health literacy is associated with poorer health outcomes and poorer use of health care services” (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011, p. 97). Research suggests that limited literacy skills and numeracy skills are factors for poor health (Kanj & Mitic, 2009). Literacy and numeracy skills are needed to understand medication and disease treatment; and without these skills, errors and misunderstanding can occur (Kanj & Mitic, 2009). A study conducted in England found that older adults with limited literacy were associated with a higher mortality rate (Bostock & Steptoe, 2012). As a result, the authors recommended that the design and delivery of health care need to be adapted to make services more accommodating for people with lower literacy (Bostock & Steptoe, 2012).

Identifying variables that could improve health literacy and health outcomes such as increasing health-related knowledge are important (Berkman et al., 2011). Two interventions that have the possibility of increasing health information in people with low literacy skills are the Ask Me 3 and Teach-Back Method (Ferguson & Roberta, 2011). The Ask Me 3 technique which was developed by the Partnership for Clear Health Communication is a way to improve health literacy (Six-Means et al., 2012). The method asks three questions, “What is my main problem? What do I need to do? Why is it important for me to do this?” (Six-Means et al., 2012, p. 183). By having patients focus on what they need to know and why, their engagement in care and improved health outcomes is promoted (Six-Means et al., 2012). Alternatively, the Teach-back method is a strategy that helps providers understand what the patient has learned by asking patients to repeat back what they said using the patient’s own words (MacLeod, Eastwood,

Struthers, Jennings, & Jodger, 2014). Both of these methods could improve health literacy and increase individuals' participation in their health care decisions and potentially in health care outcomes.

### **Aphasia: An Acquired Language Disorder**

#### **Defining the Disorder and the Population**

Another population that is considered communication vulnerable is people with aphasia. Aphasia is an acquired language disorder of neurological origin that impairs expression and reception of language (Hallowell, 2016). This language disorder usually occurs in adults who already have well-developed language (Hallowell, 2016). Having the ability to understand and use language, and then suddenly losing that ability has a profound and, most often, seriously debilitating effect on individuals and their lives. Given the often acute onset of the disorder, people with aphasia (PWA) are confronted with life-changing impairments.

Aphasia affects a person's ability to understand (reception) and produce language (expression) across all language modalities (Hallowell, 2016). Aphasia causes problems with a person's spoken language or auditory comprehension, reading comprehension, and understanding of sign language or gestures. Expressive language is also negatively affected in the ability to generate spoken, written, or signed language (Hallowell, 2016). In other words, aphasia may affect all modalities of language seriously impairing communication. Additionally, aphasia is specifically a language disorder and not "a sensory, psychiatric, or intellectual disorder" (Hallowell, 2016, p. 4). What this impairment means is that people with aphasia lose the ability to understand and express ideas, wants, wishes, desires, and needs.

The type and degree of severity of aphasia depends on where in the brain the damage occurred and how much of the brain was damaged (ASHA, n.d.). For example, when a stroke



damages a large section of the left hemisphere of the brain, PWA may completely lose the ability to understand and to produce spoken and written language (Hallowell, 2016). In instances of more discrete brain damage, milder forms or less impairment in an isolated language modality may occur such as occasional difficulty in finding/retrieving specific words (Hallowell, 2016).

Aphasia has neurological causes, meaning it is “a loss of language due to some type of neurological event or condition that leads to a loss of language ability” (Hallowell, 2016, p. 44). Examples of neurological events causing aphasia could be strokes, traumatic brain injuries, tumors, or other disorders or diseases that negatively affect the brain in the left hemisphere. The most common cause of aphasia is a stroke or cerebrovascular attack (CVA) (Hallowell, 2016).

Approximately 795,000 people each year in the United States have a stroke (“Stroke Facts,” 2016). Of those people approximately 33% of them have aphasia (Pederson, Jorgenson, Nakayama, Raaschou & Olsen, 1995). The disorder is more common than cerebral palsy, muscular dystrophy, and Parkinson’s Disease and can arise from any injury or disease that affects the brain regions that support language (National Aphasia Institute, n.d.) such as traumatic brain injury, tumor, infectious disease, or metabolic disorders (ASHA, n.d.). Although aphasia is most commonly seen in older adults, it can occur in individuals regardless of age, race, or gender (National Aphasia Association, n.d.).

### **Describing the Effects of Aphasia**

Regardless of the cause, type, or severity of aphasia, no one disputes the seriousness of its effects on communication. Aphasia can cause a person to be unable to read, write, produce and understand language (ASHA, n.d.). People with aphasia have difficulty finding, retrieving and speaking words that convey meaning. They may produce jargon (meaningless words) and be unaware of the lack of meaning in their speech. They may misunderstand what people say,

misunderstand jokes, have difficulty differentiating between speech that is literal or figurative, or have a difficulty understanding speech with background noise (ASHA, n.d.).

People with aphasia may also have difficulty comprehending written material, spelling, and understanding number concepts such as telling time and counting money (ASHA, n.d.). As a result, one of the residual disabilities of aphasia is reading impairment (ASHA, n.d.). For example, people with aphasia may not have the ability to read forms, pamphlets, books, or other written materials (ASHA, n.d.). These impairments may interfere with a person's ability to use and understand health-related information and forms in a medical setting. If PWA do not have access to health-related documents or have the ability to comprehend the material, they may withdraw from participating in their health care, which could impact their quality of life and their access to health care and information. (Brennan, Worrall, & McKenna, 2005).

### **Aphasia-Friendly**

Aphasiologists have addressed the problem of accessing text and making health information available by applying content and design principles to make text more understandable by people with aphasia. The term aphasia-friendly is used to describe a style of presentation. Although there is not an exact definition of "aphasia-friendly" it is a term often used in the research literature. Rose, Worrall, and McKenna (2003) acknowledged that "aphasia-friendly" is not a new term, but that there is not a specific operational definition of the term or a delineated list of criteria.

### **Aphasia-Friendly Content Characteristics**

Content characteristics such as simplified vocabulary and syntax, the use of high frequency words, and addition of graphics can be used to make documents aphasia-friendly. Simplified vocabulary and syntax can be used to make the content of documents more aphasia-

friendly. The participants in the Rose, Worrall, Hickson, and Hoffman (2011) study showed their dislike in documentation that contained a large amount of only text. The participants expressed their gratitude to read only single words and short phrases (Rose et al., 2011). Brennan et al. (2005) found that participants comprehended the most written material when simplified vocabulary was incorporated. The authors simplified the text by shortening long sentences and simplifying syntax such as making passive sentences active (Brennan et al., 2005).

High frequency words, which are words that are more frequently occurring in a language, are more likely to be understood by people with aphasia and can also help with adapting content (Aleligay, Worrall, & Rose, 2008). DeDe (2012) concluded that people with aphasia may have difficulties processing sentences that have low frequency words and that sentence comprehension is influenced by the word frequency. This finding shows that people comprehend less information when they read low frequency words compared to high frequency words.

Lastly, the use of graphics could also be used to modify content and benefit people with aphasia. Rose et al. (2011) found that a majority of participants in their study who were asked what characteristics facilitated comprehension indicated that graphics were very useful. They reported that graphics helped make the information interesting, more understood, easier and quicker to read, and helped add humor and enjoyment to the text (Rose, et al., 2011). But at the same time, the type of graphic must be carefully considered. Rose et al. (2003) showed that the participants with aphasia felt that use of commercial clipart images and line drawings were disrespectful. The participants in the Rose et al. (2003) study showed that there were mixed opinions about the use of pictures in the brochures analyzed. Some participants perceived they were not being respected since they received information with illustration, yet other participants commented that the use of pictures helped them remember the information provided (Rose et al.,

2003). Rose et al. (2011) studied the use of graphics alone in health information for people with aphasia; it was reported that “both participants with and without aphasia correctly comprehended more paragraphs in the set with photographs” (p. 1592). The authors mentioned how important it was for creators of health materials to incorporate other features, such as shorter sentences, to increase comprehension because photographs would not be enough to increase understanding (Rose et al., 2011). Adaption of content characteristics such as simplified vocabulary and syntax, the use of high frequency words, and the addition of graphics are important to make health documentation aphasia-friendly.

### **Aphasia-Friendly Form Characteristics**

The use of larger font, larger amounts of white space, and different font styles can be added to forms to make them aphasia-friendly and help PWA better understand documentation. Rose, Worrall, Hickson, and Hoffman (2014) explored text formatting preferences from 40 PWA and concluded that 14-point font was easier to read for PWA. Brennan et al. (2005) also concluded that people with aphasia were able to comprehend more information when the text was in larger print. Brennan et al. suggested that increasing white space may be helpful for people with aphasia (2005). White space can be increased by using wider line spacing and larger margins. Varying font style may also be beneficial to PWA but it must fit a person’s needs. “Regardless of what group studies may reveal, it would be ideal to try out varied font size and style with a particular individual where possible to optimize personalized written material” (Hallowell, 2016, p. 415). The use of larger font, more white space, and different font styles are aphasia-friendly form characteristics that could be used to make documentation more understandable by PWA.

### **PWA Response to using Aphasia-Friendly Products**

People with aphasia have been asked to respond to aphasia-friendly formats and content options. Rose et al. (2014) intended to, "explore the text formatting preferences of people with aphasia by asking participants to consider what makes written patient education materials easier and harder to read." Forty adults with aphasia were surveyed on their preferences. The authors concluded that the current practice in health education is not meeting the needs of people with aphasia (Rose et al., 2014). Eighty-eight percent of the participants explained how no one else had ever asked them about how to format documents to make them more accessible (Rose et al., 2014). Personal preference related to formatting is crucial to PWA because every person has unique needs, abilities, and how information presented can be most accessible.

"Although aphasia-friendly materials are designed with the intention of enhancing transaction of information, the benefits of doing so may be questioned if the recipient feels degraded and disrespected" (Rose et al., 2003, p. 960). Clinicians must use caution when creating aphasia-friendly documents in respect to the formatting. Worrall et al. (2011) asked *What People with Aphasia Want* and surveyed PWA to assess their goals. The majority of the participants stated that activities and participation were very important to them (Worrall et al., 2011). People with aphasia want to be included in everyday activities (Worrall et al., 2011). They also want to fully participate in their healthcare decisions. By creating and using aphasia-friendly health documents, PWA may more fully participate in their healthcare and not rely on others to make decisions or choices.

The use of aphasia-friendly principles is a helpful tool that can improve comprehension for those with aphasia and other communication vulnerable adults (Rose et al., 2011). Even though aphasia-friendly materials can be beneficial, not all PWA will benefit from its use (Worrall et al., 2005). Multiple formats or individualized accommodations should be more

available to PWA and other communication vulnerable adults. Improvements at the policy level could lead to system change in which everyone is offered equal access to communication (Worrall et al., 2005). Applying aphasia-friendly principles to health-related documents could give PWA greater access to their health care and increase participation in their lives (Brennan et al., 2005).

### **Aphasia-Friendly Advocacy Groups**

In addition to recommendations from the research literature, aphasia-advocacy organizations and consumer support groups offer additional resources or guides to make information accessible by using aphasia-friendly communication techniques, strategies, and tools. AphasiaAccess is an organization that supports speech-language pathologists and other providers of social and community programming for PWA ([www.aphasiaaccess.org](http://www.aphasiaaccess.org)). The group maintains a website which offers this information and serves as a source for examples of aphasia-friendly documents and forms. Its goals are to educate individuals about aphasia and to supply resources and education (“Our History and Mission,” 2016.). For example, the website features free training videos that demonstrate the utility of the Life Participation Approach to Aphasia (“Our History and Mission,” 2016.). AphasiaAccess members share “aphasia-friendly” products such as examples of forms used for consent-to-treat and photo-consent forms. AphasiaAccess has provided a repository for documents to be easily shared – thus promoting the accessibility and the use of aphasia-friendly documents to providers.

Another organization that promotes the use of accessible information is the American Speech-Language-Hearing Association (ASHA). ASHA provides tips to make materials health literate. General advice suggests understanding who your audience members are and what they need to learn so they are able to comprehend the most information (ASHA Health Literacy, n.d.).

The organization advises health providers to be clear and to engage the audience as much as possible (ASHA Health Literacy, n.d.). Yet even with the advice and instruction of professional sources, evidence-based guidelines for designing effective materials for people with aphasia and other communication vulnerable adults remains lacking and implementation system-world or nation-wide is absent. (Rose et al., 2011).

### **Implications for Practice and Policy**

#### **Examples from other Nations**

There are other sources of information about accommodating language disabilities such as aphasia and improving access to communication in health settings. In Australia, the Centre for Clinical Research Excellence (CCRE) in Aphasia Rehabilitation developed the Best Practice Statements for aphasia care targeting 82 best practices in total. The statements are intended to serve as a guide for improving the care for people with aphasia. The statements formed the Australian Aphasia Rehabilitation Pathway (AARP) which is a set of standards for aphasia management” (“Australian Aphasia Rehabilitation Pathway,” 2014.). This Pathway is intended to guide speech-language pathologists in creating the best care possible for PWA.

Two of the best practice statements are directly connected to increasing communication with PWA about their health and about participation in their lives. The best practices statements declare that “People with aphasia should have support material available to enable them to participate in communication” and “Communicatively accessible environments should be provided for people with aphasia” (Clinical Centre for Research Excellence in Aphasia Rehabilitation, 2014). The use of aphasia-friendly principles could give people with aphasia the support materials needed to allow them to communicate in their healthcare, their everyday lives, and in their communities or society. The authors of the Australian Aphasia Rehabilitation

Pathway intend to change health care practices in their nation by adopting these best practices. Through education of speech-language pathologists, engagement of primary health providers, and by empowerment of PWA and their families, a system change for an entire population of communication-vulnerable adults is underway.

In Canada, the Aphasia Institute, headed by Aura Kagan, was founded and remains centered around the Life Participation Approach to Aphasia (<http://www.aphasia.ca/>). The "Life Participation Approach to Aphasia" (LPAA) is a consumer-driven service-delivery approach that supports individuals with aphasia and others in achieving their immediate and long term life goals (Chapey et al., 2000). It places the life concerns of the PWA at the center of all decision making (Chapey et al., 2000). The LPAA revolves around five core values that guide treatment of PWA (Chapey et al., 2000). The core values include:

1. The explicit goal is enhancement of life participation
2. Everyone affected by aphasia is entitled to service
3. Success measures include documented life enhancement changes
4. Both personal and environmental factors are intervention targets
5. Emphasis on availability of services as needed at all stages of aphasia. (Chapey et al., 2000, p. 4)

The goals of enhancement of life participation are to assess the extent to which the PWA is able to achieve life goals, and how the aphasia obstructs these goals (Chapey et al., 2000). The Aphasia Institute, comprised of researchers and clinicians, clearly understand the importance of reengagement in life for PWA. They study, produce, and disseminate communication support materials which use aphasia-friendly principles portraying topics widely ranging from conducting conversations with the doctor, clergy, and therapists to supporting the



communication surrounding making life decisions on housing, personal counseling, and family relationships (Aphasia Institute, 2015).

On a global level, Aphasia United is an organization working to change and increase knowledge about aphasia and advance opportunities for services to PWA throughout the world (<http://www.aphasiaunited.org/>). The organization grew out of the need to address the prevailing unawareness of aphasia and the resulting communication problems faced by PWA. Advancing services for PWA worldwide is a second goal (“About Aphasia United,” 2016). Aphasia United intends to connect people globally and increase the visibility of aphasia and the people that support them (“About Aphasia United”, 2016). The organization represents the voice of already existing aphasia organizations throughout the world (“About Aphasia United,” 2016). It aims to represent the aphasia community at a global level, create networks with people living with aphasia, promote global research, and encourage best practices (“About Aphasia United,” 2016). The essential belief in supporting communication is the foundation in building a framework for care available to PWA worldwide.

### **Improving Patient-Provider Communication**

Rao (2011) described effective patient-provider communication as “an important risk-management issue, cost-containment factor, and essential component of quality of health care and patient safety” (p. 17). When patient-provider communication and care is successful, it results in better health care outcomes, lower costs of health care, and better self-management of diseases (Blackstone et al., 2015). Blackstone and colleagues (2015) stress the importance of good communication which “could lead to better outcomes because it increases the chances of a correct diagnosis and the development of an appropriate treatment plan” (p. 40). Good communication can result in a plan that fits the patient’s needs and address psychosocial health,

only when be health care providers are trained and educated to communicate competently (Blackstone et al., 2015).

To improve patient-provider communication it is imperative that healthcare organizations train employees to use effective patient-provider communication techniques (Patak et al., 2009). For example, communication boards have been developed and used in facilities to accommodate the needs of some communication vulnerable patients (Patak et al., 2009). The use of aphasia-friendly materials could also help improve patient-provider communication by bridging the gap between providers and communication vulnerable populations. The American Health Information Management Association requires health care systems to “provide patients access to information that is important and useful for them when they need it” (Dimick, 2011). A way to provide patients with information that is understandable is by creating resources in a way that is accessible to all communication vulnerable patients using aphasia-friendly principles.

It is also critical to identify people who are communication vulnerable by screening all patients for their communication vulnerability (Blackstone et al., 2015). By identifying communication vulnerable patients, providers can accommodate their needs and make communication as successful as possible. Communication supports should be in place and readily available for providers and patients (Blackstone et al., 2015). It is essential that all communication vulnerable people are able to communicate about their health needs and participate in decision making.

### **Changing Practice and Policies**

In the United States, communication access for patients is mandated through accreditation standards for health care institutions; and, as a result, health care professionals need to develop a better understanding of what it takes to successfully provide information to their

patients (Blackstone et al., 2015). The Joint Commission on Hospital Accreditation is an independent not-for-profit organization whose vision is to create the highest quality health care for everyone (The Joint Commission, 2017). Its mission is to improve health care for the public by inspiring organizations to excel in their quality of care (The Joint Commission, 2017). Among its many requirements for accreditation are expectations for effective and consistent communication between health-care providers and their patients.

A Roadmap for Hospitals on "Advancing effective Communication, Cultural Competence, and Patient- and Family-Centered Care" created by the Joint Commission is used to instruct managers in addressing all aspects of care and in integrating standards and best practices for communication into their organizations (The Joint Commission, 2010). The Joint Commission created a checklist to "Improve Effective Communication, Cultural Competence, and Patient and Family-Centered Care Across the Care of Continuum" (The Joint Commission, 2010). Some of the bullets are as follows:

- Identify whether the patient has a sensory or communication need
- Identify if the patient uses an assistive device
- Develop a system to provide language services
- Address patient communication needs during assessment, treatment, end-of-life care, and discharge and transfers
- Address the communication needs of patients with sensory or communication impairments
- Provide discharge instruction that meets patient needs
- Ask the patient if there are any additional needs that may affect his or her care
- Incorporate health literacy strategies into patient discussion and materials

- Develop a system to collect patient language information
- Incorporate the issues of effective communication...into new or existing staff training curricula. (The Joint Commission, 2010, p. 5-6)

These directives from the Joint Commission on Hospital Accreditation may serve as the point of entry for aphasia-friendly practices and communication supportive procedures to become standardized and institutionalized for PWA and for communication-vulnerable patients.

Not only can aphasia-friendly practices benefit people with aphasia, but these practices can serve as model accommodations for other communication vulnerable populations. Both content and form accommodations that are used to make documents aphasia-friendly can be directed toward other communication vulnerable populations. These accommodations may provide greater access to health documentation, for example people who are blind or have low vision can increase access through changes in print materials (Warren, 2013). A form adaption that could be applied to make documents more accessible is increasing white space by widening margins and double spacing between paragraphs (Warren, 2013). For individuals who have a cognitive impairment, the use of content adaptations can be used to format documents by inserting graphics to make them more accessible. Simplified language, syntax and vocabulary, can be used in documents, such as high frequency words, to allow for greater understanding of materials (Chinn, 2017). Aphasia-friendly form and content design principles can be used to benefit other communication vulnerable adults and not only people with aphasia.

Accessible documents alone do not suffice for effective communication with people who are considered communication vulnerable. Providers also need to have the ability to be flexible in their interactions with patients and communicate with them in ways that remain respectful. All patients will be different with their communication needs, and providers must demonstrate

flexibility to accommodate individual patients' needs allowing for effective communication to take place. Individuals will benefit from their health visit if providers are aware of ways to communicate effectively and if they take the time to understand their patient's needs.

Changing professional practices and policies to enhance patient-provider communication by providing aphasia-friendly health materials is an ultimate goal of advocates for PWA. Blackstone et al. (2015) generated five steps to foster and implement change in the health care system related to patient-provider communication. The first step is leadership, in that it is important to have an internal advocates to help lead and develop the implementation (Blackstone et al., 2015). Next, it is important to identify which patients are communication vulnerable (Blackstone et al., 2015). One way to identify who is at-risk for communication failure or who is communication vulnerable is to instigate and implement screenings that identify people with communication disorders and vulnerabilities (Blackstone et al., 2015). Another step is the actual implementing of communication supports, such as communication tool kits, for both the patient and the provider (Blackstone et al., 2015).

Teamwork is also needed from professionals representing all levels of employee groups in health care facilities (Blackstone et al., 2015). If all employees are supportive of changing an organization's communication with its patients and clients, then large support systems for communication vulnerable patients become available (Blackstone et al., 2015). Lastly, additional research is needed to guide policy development and implementation so as to ensure effective and efficient patient-provider communication ultimately resulting in heightened health outcomes (Blackstone et al., 2015).

All people, but especially people who are communication vulnerable, may have the opportunity for improved health outcomes when health literacy is addressed sufficiently and

appropriately. Professional organizations and their leaders are recognizing that health literacy needs to be addressed for a successful patient-provider communication, and patient-centered health interactions are associated with better health outcomes (Yin, Jay, Madness, Zabar, & Kalet, 2015). When health organizations and their employees change the health care system, PWA and other communication vulnerable adults will broadly benefit from improved communication.

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