APHASIA

2023 RESEARCH REPORT WITH GLOBAL PERSPECTIVE

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AphasiaAccess
Until Every Voice is Understood

IMPACT OF APHASIA ON PERSON, FAMILY, AND SOCIETY

Contents

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IMPACT ON THE PERSON WITH APHASIA

The direct result of aphasia is impairment of language processing; the language impairment in turn significantly disrupts communication. Since communication is at the core of most of one's daily life, aphasia has significant and far-reaching consequences. Negative social outcomes for people with aphasia such as social isolation, reduced participation in activities, and loss of friendships are frequently reported in the literature (Brown, Davidson, Worrall & Howe, 2013; Code, 2003; Code & Hermann, 2003; Cruice, Worrall, & Hickson, 2006; Parr, Byng, Gilpin, & Ireland, 1997; Sarno, 1997; Nätterlund, 2010a; Zemva, 1999). Likewise, emotional problems in people with aphasia are highly prevalent (e.g., Hilari et al. 2010; Kauhanen et al. 2000; Thomas & Lincoln, 2008). This chapter of the State of Aphasia report will describe the varied and distressing impacts of aphasia. These potential negative consequences associated with aphasia are summarized in Table 1 with the remainder of the section describing the relevant literature in more detail. Like the statistics on incidence and prevalence of aphasia, most of the research on the consequences of aphasia have been conducted in the stroke population. However, unlike the frequency data, information on the impact of aphasia is readily generalizable across etiologies. Thus, someone with aphasia because of focal trauma is likely to experience *similar* consequences as someone with aphasia due to stroke.

> “Most of us take for granted being able to read a bedtime story to our children. But for Scott, who acquired aphasia after a stroke in 2008, he lives with the challenge of trying to communicate and parent his boys.”

(http://www.aphasia.ca/people-with-aphasia-and-families/personal-stories/1/18/17)

> “I was desperate because I thought… my God… what about my job?”

(Parr et al. 1997, p. 15)

FIGURE 1: POTENTIAL NEGATIVE CONSEQUENCES ASSOCIATED WITH APHASIA

Impact	Examples of Potential Secondary Impacts
Aphasia diagnosis	Higher disability than stroke without aphasia Largest negative impact on quality of life
Higher likelihood of residential placement	Marginalization Social isolation & loneliness Adverse events/incidents Higher cost of care
Decreased participation in meaningful activities	Lower perceived quality of life Social isolation and loneliness Depression Negative impact on physical health
Low level of employment	Financial challenges Negative impact on identity Loss of social contacts Impact on well-being
Social Isolation	Lower marital satisfaction Poorer quality of family relationships Fewer friends Negative impact on physical health Poorer quality of life Negative impact on identity Depression
Loneliness	Increased rates of depression Higher morbidity and mortality Poorer physical health Higher frequency of disability Adverse medical events Higher medical costs
Depression, stress & anxiety	Lower quality of life Lower functional outcomes Poorer recovery Increased use of health care services Higher costs of care Higher mortality Suicide risk Negative impact on cognition
Negative sense of self/identity	Negative impact on communicative engagement Lower perceived quality of life
Less autonomy	Sense of helplessness Depression Fewer opportunities to make own choices
Negative impact on finances	Less positive outcomes associated with lower income Decreased ability to afford supports or rehabilitation
Negative impacts on caregivers	Changed relationship with person with aphasia Lower quality of life Increased roles and responsibilities Social isolation & loneliness Negative impact on intimacy Depression Negative physical health consequences Third-party disability Lack of involvement in rehabilitation
Higher costs	High health care costs More hospital readmissions Cost of lost wages Lost productivity Costs to family and society

Aphasia, Disability and Quality of Life

Although stroke, the most frequent cause of aphasia, is a leading source of serious, long-term disability (Centers for Disease Control, 2001, 2022; Tsao et al. 2022), among stroke survivors, aphasia is associated with greater disability compared to stroke patients without aphasia (Flowers et al. 2016; Gialanella et al. 2011; Wade et al. 1986). Ellis and Peach (2017) emphasize the negative impact of aphasia on life satisfaction. Aphasia has a significant adverse impact on quality of life (Cruice et al. 2003; Hilari et al. 2003; Hilari & Byng, 2009; Hilari, Needle & Harrison, 2012; Koleck et al. 2017; Ross & Wertz, 2003) with people with aphasia reporting lower quality of life than stroke survivors without aphasia (Hilari, 2011). **In fact, aphasia was reported as having the largest negative impact on health-related quality of life out of 60 diseases and 15 health conditions in a large cohort of individuals living in long-term care** (Lam & Wodchis, 2010).

However, quality of life is not dependent on the severity of the aphasic disability alone. In the general stroke population researchers have reported on the "disability paradox" – that is, a disconnect between a person's observed level of disability and their own self-rated quality of life or health (Araujo et al. 2019; Mavaddar et al. 2013, 2021). Mavaddar et al. (2021) interviewed stroke survivors and found that a sense of control, positivity, acceptance, and social engagement were associated with positive quality of life in the face of ongoing physical disability. These findings are similar to the research on living successfully with aphasia which suggests that a variety of factors might mitigate the language disability in some individuals with aphasia and enhance quality of life. For example, people with aphasia report that participating in life, meaningful relationships, support of others, positivity, and autonomy are important to successfully living with aphasia (Brown et al. 2010, 2011, 2012; Grohn et al. 2012; 2014). This does not imply that communication disability has no impact on quality of life; but rather, suggests that multiple factors in addition to language are important.

Gaps in Services Addressing Quality of Life

In an international survey of speech-language pathologists (SLPs), Hilari et al. (2015) found that 74% of respondents believe that improved quality of life is the primary aim of aphasia rehabilitation. However, aphasia therapists often do not evaluate or target quality of life during treatment. In a survey of SLPs Cruice and Ten Kate (2019) report that the majority of their respondents did not believe their training had adequately prepared them to manage quality of life issues in aphasia. Sherratt et al. (2011) interviewed Australian SLPs regarding their goals in aphasia treatment; no goals were reported that explicitly addressed quality of life. In addition, quality of life is likely to evolve over time as the person with aphasia experiences ongoing challenges of daily life. **Addressing the complex and varied issues involved in improving quality of life after the onset of aphasia may require a long-term approach to rehabilitation and support.**

Aphasia and Associated Deficits

Due to the language impairment, aphasia negatively impacts communication. But aphasia is often accompanied by coexisting disorders. For example, approximately a third to one half of individuals with aphasia have a chronic motor impairment such as weakness or paralysis of one side of the body (Coderre et al. 2010). People with aphasia might experience coexisting changes in body sensation (Dukelow et al. 2010) or visual perception. Motor speech disorders such as dysarthria or apraxia of speech often coexist with aphasia. The UK Sentinel Stroke National Audit Program found that 21% of acute stroke admissions presented with both aphasia and dysarthria (Mitchell et al. 2018). A follow-up analysis of a later UK Sentinel Stroke audit found that 28% of acute stroke admissions had both aphasia and dysarthria, 24% had dysarthria only and 12% had aphasia only (Mitchell et al. 2021). Flowers et al. (2013) found co-occurring dysarthria and aphasia in 15% of a patient sample, and dysphagia and aphasia co-occurring in 17% of the patient sample. Stipancic et al. (2019) found a lower frequency of co-occurring dysarthria and aphasia, reported as 4% of their sample of 100 inpatients, with co-occurrence of aphasia and dysphagia in 7% of their sample. Many people with aphasia also report fatigue. In fact, Bullier et al. (2020) found that fatigue has an important impact on quality of life in aphasia. Others report that fatigue is an often overlooked but important factor in stroke recovery (Staub & Bogousslavsky, 2001). These associated conditions complicate the impact of aphasia on daily life.

Aphasia and Living Situation

Most people look forward to going home from the hospital. They look forward to familiar surroundings, daily routines, and interaction with family members and pets. However, many patients post-stroke are not discharged home. Many people are at risk for being discharged to nursing facilities due to shorter hospital stays (Edwards et al. 2017) and estimates suggest that one in five stroke patients are discharged to long-term care from inpatient rehabilitation (Nguyen et al. 2015). The statistics for people with aphasia are even worse: people with aphasia are less likely to be discharged home from inpatient settings than stroke patients without aphasia (Bersano et al. 2009; Ellis et al. 2012; Flowers et al.2016). Gialanella et al. (2011) found that 77% of patients with aphasia and 91.6% of patients without aphasia returned home after inpatient rehabilitation. Others have also reported that people with aphasia are more likely to be discharged to long-term care settings (e.g., Dickey et al. 2010; Gialanella & Prometti, 2009). In a study by Gonzalez-Fernandez and colleagues (2013) auditory and reading comprehension and oral spelling to dictation deficits were significantly associated with discharge to a setting other than home. Among inpatients with aphasia, variables that helped predict discharge home included better functional motor status, absence of dysphagia, and unimpaired nonlinguistic cognitive functioning (Ginex et al. 2022).

> Home…I can get better.
> Wife…dog…yes…I like home.”

(Simmons-Mackie, Unpublished data)

Implications: Does Living Situation Matter?

When people with aphasia are discharged to institutional or residential settings a constellation of factors can result in poorer quality of life. Life in an institutional setting can limit opportunities for participation in meaningful and fulfilling activities resulting in feelings of loneliness and boredom, as well as lower well-being. Research has documented that people with aphasia in institutional settings are often marginalized and socially isolated (Hartwell, 2015; Parr, 2007; Simmons-Mackie et al. 2007).

Staff of nursing homes and other care facilities tend to be the primary communication partners of residents. Living among unfamiliar people can be especially challenging for someone with a communication disability. Staff often lack knowledge and skills necessary to communicate with people with communication disabilities (Hartwell, 2015; Parr, 2007; Simmons-Mackie et al. 2007). In a study of nursing homes, Hartwell (2015) reported lack of communication support, little understanding of aphasia and lack of staff training regarding aphasia and communication. In addition, common co-morbidities (e.g., hearing loss, paralysis) further restrict the person's ability to communicate needs, wishes and feelings (Forsgren, Ake & Saldert, 2022). Nursing home staff often focus on physical "task oriented" activities such as bathing, rather than social or personal activities (Azios, Damico & Roussel, 2018). In a study of nursing home communication Saldert, Bartonek-Åhman and Bloch (2018) reported that the main proportion of staff interaction (78%–90% of time spent) included talk related to the nursing task at hand. Such interactions limit relationships to superficial interactions that fail to fulfill the need for social connectedness and a sense of belonging. Forsgren, Ake and Saldert (2022) reiterate that long-term care facilities provide limited possibilities for communication outside of care routines. The resulting loneliness and social isolation are associated with a range of physical and emotional consequences. In addition, staff turnover negatively impacts the ability of staff to become familiar with individuals and practice relevant communication strategies (Azios & Damico, 2020; Long, Azios, & Richings, 2019; Page & Rowles, 2016).

The absence of people with whom a resident can communicate is not only socially crippling, but also a significant safety issue. Poor understanding of aphasia and communication can lead to medical errors, adverse events, and personal suffering. A study by Barlett et al. (2008) found that people with communication disability were six times more likely to have adverse events than people without communication disability in inpatient settings. Hemsley, Werninck and Worrall (2013) found that poor communication resulted in adverse events such as falls, bed wetting, swelling of a limb and vomiting (p. 711). Among people who had a stroke in inpatient settings, O'Halloran, Worrall and Hickson (2012) found that over half of those with communication disorders had difficulty communicating their healthcare needs to staff. In addition, discharge to higher levels of care such as nursing homes increases the cost of health care services.

Not only is institutionalization difficult for people with aphasia, but also relocation to different home locations is challenging. For people with aphasia who move to new home locations (e.g., to live with adult children), negative impacts on social networks can result from physical distance from friends and familiar activities. Loneliness, social isolation, and depression can be a consequence of moving away from one's friends and neighbors (National Academies of Sciences, Engineering & Medicine, 2020).

Aphasia and Participation

Most people living with aphasia report that they had interests, hobbies, and meaningful activities prior to the onset of aphasia. However, such engagement often disappears with the challenges of communication disability and resulting identity and confidence problems. While meaningful participation and preferred roles are individually defined (Foley et al. 2019; Manning et al. 2021), most people with aphasia experience diminished participation in personally relevant activities and roles (Chiou & Yu, 2018; Wallace, 2010). Reduced life participation is often a long-term consequence of aphasia (Niemi & Johansson, 2013).

> “Most days, Tom [age 38] lay in bed till noon, then watched TV, lying on the sofa with a cigarette in one hand and the remote control in the other.”
>
> **(Parr, 2007, p. 106)**

> “Jean was very reluctant to leave the house, even to go on an outing with her husband. He felt she was frightened and expressed his own frustration at being couped up.”
>
> **(Parr, 2007, p. 111)**

> “I talk to everybody in the church, but outside you can't do that, people don't do that...”
>
> **(Souchon et al. 2020 p. 6)**

> “Awful, because sitting there, and then? Home, and then?”
>
> **(Woelders et al. 2018, p. 1500)**

Stroke survivors in general report significantly fewer leisure and recreation activities than before the stroke, and those leisure activities in which they do engage are often sedentary and lonely activities such as watching television and reading (Winstein et al. 2016). In a study of activity and participation at six months post stroke, Mayo et al. (2002) found that 72% of their study participants lacked activities to fill their day. In a study of participation in chronic, community dwelling stroke survivors, Foley et al. (2019) found that more than 20% of pre-stroke activities had been given up by participants.

People with aphasia tend to experience even greater restrictions in participation than the general stroke population. Hilari (2011) reported that people with aphasia in their study participated in fewer activities than stroke survivors without aphasia. Dalemans and colleagues (2010) found that aphasia negatively impacts social participation as measured on the Community Integration Questionnaire. Davidson, Worrall and Hickson (2003) found that older adults with aphasia engaged in less frequent communication interactions and storytelling than healthy older adults. Boden-Albala et al. (2005) found that aphasia is associated with decreased participation in activities favored prior to onset. Chiou and Yu (2018) compared life participation pre and post onset of aphasia and found significantly diminished participation in home and community life after aphasia onset. Lee et al. (2015) found that home and social integration, productive activity, time outside the home and social contact were significantly decreased among participants with aphasia compared to a non-aphasic control group. In a comparison of aphasic and nonaphasic study participants, Cruice, Worrall and Hickson (2006) found that the types of activities that each group engaged in were different; people with aphasia reported never participating in activities such as museum visits, indoor games (e.g., cards), community or society meetings or classes or lectures; rather, people with aphasia tended to watch television and attend family parties. The researchers concluded that people with aphasia tended to participate in activities that either involve no other social partners or involve family members, while healthy older individuals are more likely to participate in social activities involving other members of the community. In a qualitative study involving ten people with aphasia, 80% of participants "preferred spending time with family members or close friends, as opposed to meeting new people or attending larger social events" (Souchon et al. 2020, p. 5).

The United Nations General Assembly (2007) declared that participation was the ultimate aim of rehabilitation; however, research continues to document poor life participation of people with aphasia. Despite these repeated findings of low levels of participation, people living with aphasia would like to be engaged and "doing things" that are meaningful and comfortable. For example, in an investigation of the perspectives of people with aphasia and their families across seven countries, participants reported that essential treatment outcomes included "opportunities to communicate" and "to participate in family, community and pre-stroke roles" (Wallace et al. 2017b, p. 21). In a comparison of people with aphasia to a non-aphasic group (standard elderly peers), Cruice, Worrall and Hickson (2006) found that almost 58% of people with aphasia would like to be doing more activities when compared to only 16% of the non-aphasic group. People with aphasia are able to identify goals that are individually meaningful and relevant; for example, Guhacai and Hildebrand (2022) found that people with aphasia participating in an Intensive Comprehensive Aphasia Program identified goals within physical leisure activities and sports in addition to communication.

Failure to participate appears to relate to a variety of factors for individuals with aphasia. Parr et al. (1997) discussed the socially constructed barriers that make it difficult for people with aphasia to engage in community life such as time pressures, negative attitudes, or lack of public knowledge of aphasia. Code (2003) found that the severity of aphasia was a significant predictor of the amount of time spent outside of the home. Environmental factors, both physical and social, markedly influence participation (Brown et al. 2006; Foley et al. 2019; Howe, Worrall & Hickson, 2008; O'Halloran, Grohn, &Worrall, 2012). Social support appears to be an important mediator of participation among stroke survivors (Foley et al. 2019; Niemi & Johansson, 2013; Souchon et al. 2020). People with aphasia tend to participate in activities that feel comfortable, safe, and supportive (Souchon et al. 2020). For example, a study by Garcia and Connor (2011) found that poor understanding of aphasia affected how people with aphasia were treated by others and these attitudes affected participation in meaningful activities and routines. A qualitative study conducted in Africa found 70% of participants identified familiar and supportive faith-related contexts, such as attending church or bible study groups, were the primary form of social participation outside of family (Souchon et al. 2020). Wunderlich, Newesely and Reheis (2023) suggest that people with aphasia might encounter significant difficulty participating in interactions with employees of public authorities. This could limit access to public services (e.g., government funding agencies), involvement in voting and policy making, and encounters with police.

In a review of articles on living successfully with aphasia 81% of the articles found that "participation of PWA [people with aphasia] is facilitated by opportunities and supportive, enabling environments" (Manning et al. 2019, p. 10). Howe et al. (2008) found several key factors that influence community participation for people with aphasia including: other people's awareness of aphasia, opportunities for participation, familiarity of other participants, availability of communication support, complexity of required communication, and time available for communication. Personal factors such as fear or avoidance can also be barriers to participation (Le Dorze et al. 2014). However, not all factors carry equal weight. Factors differ in the degree to which they influence an individual's participation either positively or negatively (Magasi et al. 2015). Some environmental factors might totally curtail participation of people with aphasia despite the presence of other facilitating environmental factors (Howe, 2017; Magasi et al. 2015). For example, availability of aphasia-friendly materials might not be enough to encourage someone with aphasia to join a club if negative attitudes of other participants are obvious. 'Doing things' is important to people with aphasia; however, when people with aphasia feel marginalized, misunderstood, or unsupported then participation can be frustrating, depressing and tiring (Dalemans et al. 2010; Howe, Worrall & Hickson, 2008; MacKenzie, Bennett & Cairney, 2011; Niemi & Johansson, 2013).

With recent evidence that stroke is significantly increasing among younger adults (e.g., Krishnamurthi et al. 2015), attention to working-aged individuals with aphasia is important. In this population perceptions of restricted participation may differ as compared to older or retired adults with aphasia (Manning et al. 2021). Neurologically healthy working-age adults may be engaged in a wider variety of activities compared to older adults (Pike, Kritzinger & Pillay, 2017); thus, participation limitations can be more extensive. Working-aged adults with aphasia frequently encounter loss of employment, changing financial situations, and impacts on parenting roles (Manning et al. 2021). Many working-age adults with aphasia want to re-integrate within the community, employment, education, domestic life, social and leisure activities (Pike et al. 2017). However, reintegrating into work, varied social situations, parental roles and spousal roles can be challenging; failure to incorporate pre-onset roles can result in restricted participation and social isolation (Alaszewski, Alaszewski & Potter, 2007; Alaszewski & Wilkinson, 2015; Törnbom, Lundälv & Sunnerhagen, 2019).

In addition, younger adults are likely to live longer with the effects of aphasia, resulting in greater expectations of financial and social independence and shifting needs over time (Ntsiea, Van Aswegen & Olorunju, 2013).

Implications: Does Participation Matter?

Clearly people with aphasia are less likely to engage in meaningful activities. In turn, diminished participation in meaningful activities, events and life situations has markedly negative implications for health and quality of life. Howe (2017) advises that a lack of communicatively supportive opportunities for social participation is a critical barrier for many adults with aphasia. Quality of life is significantly impacted by the resumption of previously valued activities after stroke (Robison et al. 2009). Similarly, Mayo et al. (2014) report that after a catastrophic health event, participating in personally relevant and meaningful activities is highly correlated with life quality. In a study of the impact of traumatic brain injury researchers found that greater community participation was related to higher quality of life (Huebner et al. 2003). Social participation affects physical, mental, social and role functioning along with one's perception of well-being (Almborg et al. 2010). Qualitative interviews with people with aphasia revealed that "doing things" or engagement in meaningful activities is a vital component of living well with aphasia (Brown et al. 2010, 2011, 2012; Grohn et al. 2012, 2014). Conversely, lack of meaningful engagement has been associated with depression (Ahern & Hendryx, 2008; Angeleri et al. 1993). Engagement in leisure and recreational pursuits is considered an important component of good health (Winstein et al. 2016). In a systematic review of articles about living successfully with aphasia Manning et al. (2019, p. 9) found that **"restricted ability to take part in and to enjoy previous activities impacted negatively on well-being, hope, quality of life and sense of self."** The failure to participate in activities also has a negative impact on relationships (Northcott & Hilari, 2011). In studies of other neurologically impaired groups less frequent social contacts and lower levels of participation are associated with declines in global cognition, processing speed, executive function, and visuospatial abilities (National Academies of Sciences, Engineering & Medicine, 2020).

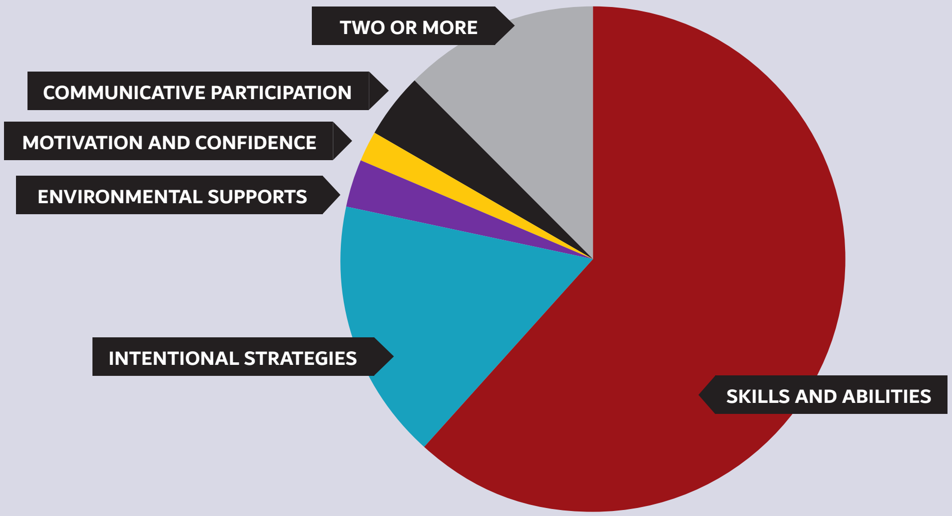
There appears to be a significant need for participation opportunities for people with aphasia. However, research suggests that simply making activities available is insufficient; participation in activities must be perceived as positive and satisfying. Researchers have reported that the quality of social activities and participation is more important than the quantity of activities (Dalemans et al. 2010; Howe, 2017; Niemi & Johansson, 2013; Souchon et al. 2020).

Gaps in Services Addressing Participation

Given the marked relationship of participation, health, and quality of life, it is imperative that participation assessment and goals are included in aphasia rehabilitation. However, gaps continue to exist in participant-oriented research and service delivery for aphasia.

- In commenting on the current issues in aphasia, Enderby and Sutton (2020) reported that the majority of aphasia research continues to focus on changes in the aphasic impairment (e.g., word finding).
- Results of a focus group study in Canada suggested that aphasia therapy practices are anchored in a traditional medical model focused on treating the language impairment (Laliberté et al. 2016). SLP "participants expressed that it was not a priority to work on social participation" (p. 1123).
- SLPs appear to mistakenly believe that inpatient rehabilitation is too early to focus on participation (Laliberté et al. 2016). Furthermore, SLPs often mistakenly believe that participation-oriented therapy will not be funded by payors.
- Many health care settings and university curricula appear to fail to support practices required to follow a social participation-based model in aphasia (Laliberté et al. 2016). None of the SLPs in the Laliberté et al. study "had received training for improving participation, indicating that university curricula [in many countries] are still mainly based on re-educating language" (p. 1126).
- Haley and Cunningham (2019) collected 609 goal examples from ASHA certified SLPs in the USA. As can be seen from the pie graph in Figure 2, the overwhelming majority of goals addressed language skills & abilities.

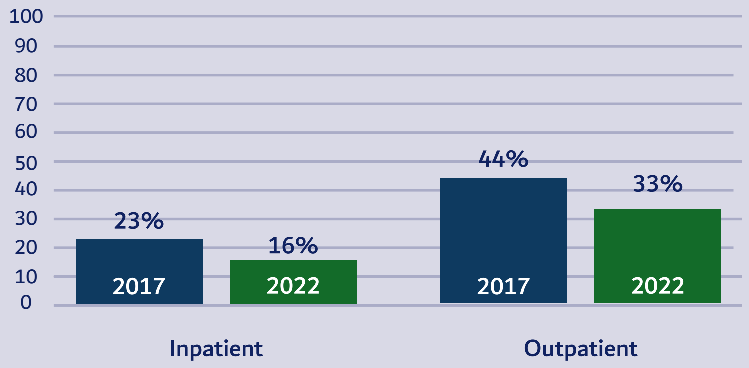
FIGURE 2 **DISTRIBUTION OF GOAL CONTENT FROM 609 GOALS COLLECTED FROM SLPS IN THE USA**



Haley & Cunningham, 2019; reprinted with permission

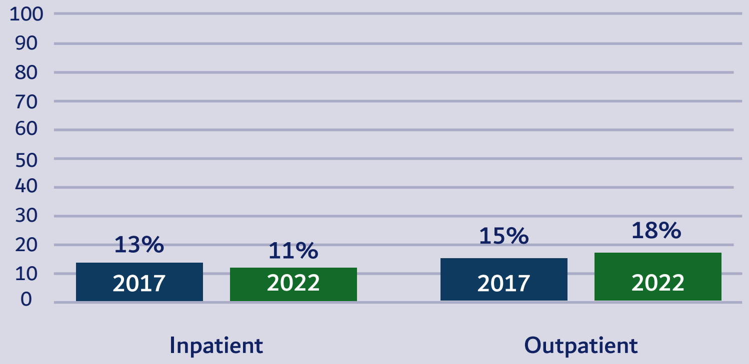
- An international survey with 257 respondents (including Africa, Asia, Australia, Canada, Europe, Middle East, New Zealand, South America, USA) revealed that participation-oriented assessment and intervention remain scarce (Simmons-Mackie & Azios, 2022). For example, only 16% of SLPs reported routinely assessing participation for inpatients and 33% of SLPs reported assessing participation for outpatients with aphasia. Moreover, these statistics were lower than those reported in a similar US survey in 2017 (Simmons-Mackie, 2018) (see figure 3). Similarly, the average time spent on participation-oriented activities in aphasia therapy remains low with 11% of therapy time in inpatient and 18% of therapy time in outpatient focusing on participation in aphasia (see figure 4). According to these survey results little has changed in participation-oriented aphasia assessment and intervention in the past five years.

FIGURE 3 PERCENTAGE OF SLP RESPONDENTS WHO REPORTED ROUTINELY ASSESSING PARTICIPATION IN A 2017 SURVEY COMPARED TO A 2022 SURVEY



Simmons-Mackie, 2018; Simmons-Mackie & Azios, 2022

FIGURE 4 AVERAGE PERCENT OF APHASIA THERAPY TIME SPENT ON PARTICIPATION IN A 2017 SURVEY COMPARED TO A 2022 SURVEY



Simmons-Mackie, 2018; Simmons-Mackie & Azios, 2022

Despite greater publication and research attention to participation in aphasia, there remains a pressing need for greater attention to participation outcomes in aphasia rehabilitation services. Since "social participation is a key determinant of successful and healthy aging, participation is therefore an important emerging intervention goal for health professionals" (Levasseur et al. 2020, p. 2141). "Speech–language pathologists (SLPs) need to use their unique expertise in communication and aphasia to play a key role in ensuring that people with aphasia have opportunities for social participation" (Howe, 2017 p. 39).