

The Consequences of the Consequences: The Impact of the Environment on People With Aphasia Over Time

Robyn O'Halloran, Marcella Carragher, and Abby Foster

Understanding the impact of the environment on the participation of people with aphasia depends on one's perspective. A long-term perspective provides a unique insight into the myriad of ways in which the environment can influence the participation of people living with aphasia over decades. In this article, the authors present the real-life story of "Hank," who has lived with aphasia for more than 15 years. The authors consider how 2 different conceptual frameworks—the International Classification of Functioning, Disability and Health and the Social Determinants of Health—account for Hank's experience. The International Classification of Functioning, Disability and Health is useful to conceptualize the range of factors that influence living with aphasia at a particular point in time. In contrast, the Social Determinants of Health is useful to conceptualize the cumulative impact of living with aphasia on long-term health and well-being. Viewing aphasia as a social condition that impacts social determinants of health has potentially wide ranging implications for service design and delivery and the role of speech-language pathologists.

Key words: *aphasia, consequences, disability and health, environmental factors, international classification of functioning, social determinants of health*

THIS ARTICLE focuses on how the environment influences the ability of people with aphasia to communicate successfully. Aphasia intervention has traditionally focused on the language and communication of the individual and their close communication

partners. A new trend in aphasiology, informed by the World Health Organization's (WHO's) International Classification of Functioning, Disability and Health (ICF; WHO, 2001), recognizes the importance of the environment in enabling or disabling the functioning and participation of people with aphasia.

The ICF defines *Environmental Factors* as "those factors in the physical, social, and attitudinal environment in which people live and conduct their lives" (WHO, 2001, p. 10). Researchers have begun to identify how environmental factors influence the ability of people with aphasia to communicate (Howe, Worrall, & Hickson, 2008a, 2008b; O'Halloran, Grohn, & Worrall, 2012) and importantly, which environmental factors can be modified to improve communication and participation (Hux, Buechter, Wallace, & Weissling, 2010; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Rose, Worrall, & McKenna, 2003; Simmons-Mackie et al., 2007). These research endeavors inform the understanding of the kinds of environments that create

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barriers to or facilitators of communication for people with aphasia. However, this research is focused on understanding how the environment impacts the *present* communication and participation of people with aphasia. The chronic nature of aphasia necessitates that researchers and clinicians also consider how people's circumstances and, therefore, their communication needs and participation needs change over time. This, in turn, requires clinicians to consider the many different environments that impact the communication and participation of people with aphasia in the long term and the consequences on their future health and well-being.

The importance of exploring the interplay between aphasia, the environment, and long-term health and well-being was highlighted when the first author met Hank.¹ They were both members of a volunteer aphasia advocacy group that met once every two months to develop services and provide a support network for people living with aphasia. During the four years they worked together, Hank gave several presentations to community groups and to students about his stroke and living with aphasia. Through listening to these presentations, as well as through social conversation with Hank, the author got to know him well. His story raises important questions about the cumulative impact of the environment on the communication, participation, as well as health and well-being of people with aphasia over time. Hank's story may cause clinicians to reconsider how they conceptualize the impact of aphasia over time. Questions about long-term impacts of environmental factors are explored in detail later.

In Part 1 of this article, with Hank's permission, the first author recalls his story and how his life changed and evolved in the 15 years since the onset of aphasia. In Part 2, the authors explore how two different conceptual frameworks—the ICF (WHO, 2001) and the Social Determinants of Health model

(SDH; Commission on Social Determinants of Health, 2008)—account for the changes to Hank's health and well-being over time. Finally, Part 3 includes a review of the research literature to explore the evidence for a relationship between aphasia and the SDH.

PART 1: HANK'S STORY

Hank, a white Australian man, was in his 40s and married with four children at the onset of aphasia. He worked full-time for a large national company negotiating complex sales and contracts and his wife, Beth, worked part-time in retail. Although he often travelled interstate on business, he was working in his home town of Melbourne when he suddenly collapsed and was rushed to the nearest hospital. Subsequently, Hank was taken to one of the large publically funded tertiary hospitals that serve Melbourne's population of 4.5 million people.

His recollections of those days in hospital were vague; however, he recalled the doctors telling him that he had had three strokes in that first week. His only other memories were that he could hardly talk or walk. After several months of inpatient rehabilitation, he was discharged home. At the time, he had an expressive and receptive aphasia and a persistent right-sided weakness but was able to walk with a stick.

Despite the improvements he had made, his aphasia meant that he could not go back to his former job. As a result, he lost the enjoyment and challenge of work that he loved, he lost contact with work colleagues, and he lost his substantial income. The financial implications were serious. All four children were attending a private school. The eldest child finished her final year of high school, but the family could no longer afford the school fees for the younger children, who had to move to the local government-funded secondary school. Thus they lost contact with families they had known in the school community for years.

Hank reported that the stress of all the changes was terrible, and he and his wife separated within 2 years. Hank moved into

¹Pseudonym.

a private rental on his own. He was offered work through a disability employment agency, which entailed packing envelopes in a mailroom alongside people with intellectual disabilities. He reported attending for a while, but ultimately he found it too depressing, so he left.

With only a disability pension as income, Hank found living on his own too expensive, so he moved into accommodations where the costs of rent and bills are shared. He said he did not like living in a shared house, and the house was not adapted to suit his needs, as there were no rails on the stairs or in the bathroom. Furthermore, he said his aphasia made it difficult for him to find the right person to live with, and he was worried that his housemate would take advantage of him. As he was living on a disability pension, he was eligible for public housing. He was looking forward to having his own place but there was a five-year waiting list. Around that time, Hank was diagnosed with depression.

In talking about how he managed every day, Hank said that he was okay but that he still needed occasional help with communication. For example, when his car needed to be fixed, he reported that he did not really understand what the mechanic was talking about; therefore, he did not really know what the problem was with his car and was worried that he had been charged too much to get it fixed. He also said he needed help with his computer; his e-mail often did not work and he could not work out how to fix it.

After Hank did not attend the aphasia group for two months, the author learned that he had fallen on the stairs at home and broken his ankle. He was admitted to hospital and had another short period of inpatient rehabilitation. Back in his share house, he said his mobility was worse but he was now the highest priority on the public housing list. The following month, he moved into his own single-level, one-bedroom unit.

Reflecting on the events that occurred in the 15 years following Hank's stroke provides a unique insight into one Australian man's experience of living with aphasia. The

immediate consequences of his stroke and aphasia, such as being unable to return to his former job, would be familiar to clinicians and researchers. But Hank's story suggests that there are long-term consequences of aphasia. In other words, there are secondary consequences of the initial consequences of aphasia that are not immediately apparent. In Hank's case, one could speculate that the stroke and aphasia contributed directly to his economic challenges and indirectly to the demise of his marriage, both of which, in turn, contributed to his depression. Furthermore, it is probable that his financial difficulties and separation meant Hank had to live in a shared house where he felt unsafe. One could even surmise that these consequences contributed to the deterioration of his health, culminating in his broken ankle.

Hank's story is unique, but it is not an isolated example. It raises questions that have broader implications, including the essential question addressed in this article: Is there a conceptual framework that can explain the sequence of challenging events that can follow stroke and aphasia in cases like Hank's? In the following sections, the authors explore how two different conceptual frameworks could account for Hank's story and the implications each might have for reducing barriers to long-term health and participation for people with aphasia.

PART 2: APPLYING DIFFERENT CONCEPTUAL MODELS TO HANK'S STORY

Applying the ICF to Hank's story helps to understand the current consequences

The ICF is a biopsychosocial framework of health and health-related conditions (WHO, 2001). It has been used in speech-language pathology to describe communication and swallowing disability (Ma, Threats, & Worrall, 2008; Threats & Worrall, 2004). The ICF consists of four components: Body Functions and Structures (Impairments), Activities and

Participation (Activity Limitations and Participation Restrictions), Environmental Factors (Barriers and Facilitators), and Personal Factors, all of which contribute to a person's experience of functioning, disability, and health (WHO, 2001).

The ICF provides a way to conceptually understand the different factors that influence a health condition such as aphasia. A speech-language pathologist (SLP) working with Hank could apply the ICF to Hank's situation to capture the wide-ranging factors influencing his aphasia. For example, the clinician could describe his language deficits (the Impairment) or describe the consequences of the language deficits in terms of his communication Activity Limitations and Participation Restrictions. These might include the range of communication Activity Limitations related to his interpersonal relationships, such as difficulty expressing feelings, difficulty understanding intent, and difficulty adjusting to a change in topic (Frattali, Thompson, Holland, Wohl, & Ferketic, 1995). Furthermore, the SLP could consider how these different communication Activity Limitations combine to result in Participation Restrictions, such as difficulty in maintaining his spousal relationship.

The ICF framework also provides a useful framework to think about how the commu-

nication environment might be creating barriers to or facilitating Hank's ability to communicate and participate. Consideration of environmental factors might prompt the SLP to wonder if Hank's important communication partners, such as his wife and daughters, have the knowledge and skills to communicate with Hank. Finally, the ICF's Personal Factors component might prompt the SLP to consider if Hank's personality, his knowledge of stroke and aphasia, and his ability to cope with such a dramatic loss might also be influencing his ability to communicate. Some of these factors are depicted in Figure 1. The ICF framework can be applied to explore the factors influencing Hank's aphasia at any point in time after his stroke. Figure 2 provides a hypothetical example of the factors that may have influenced Hank's experience of aphasia many years after his stroke.

In summary, the ICF (WHO, 2001) provides a conceptual framework to describe Hank's functioning and disability at a particular moment in time. However, it does not provide a way to conceptualize how current level of functioning and disability, such as difficulty participating in relationships or difficulty reading complex information, may influence health and well-being over time. Is there another conceptual model that

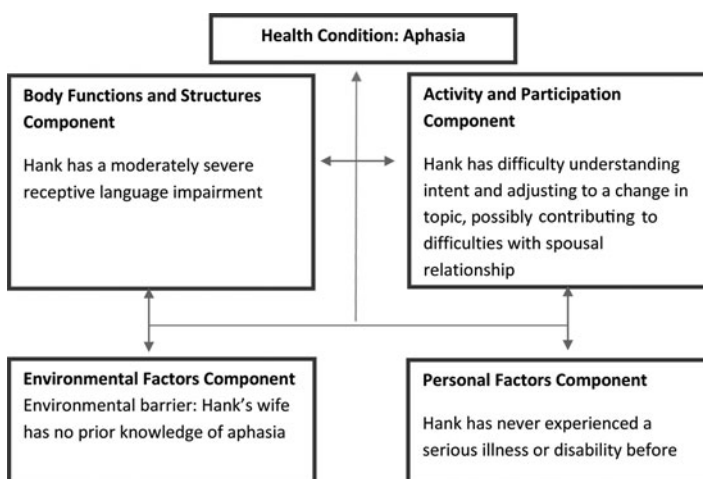


Figure 1. The factors hypothesized to influence Hank's communication activity and participation in the months after his stroke as conceptualized by the ICF. Adapted from *International Classification of Functioning, Disability and Health*, by World Health Organization, 2001, Geneva, Switzerland: Author.

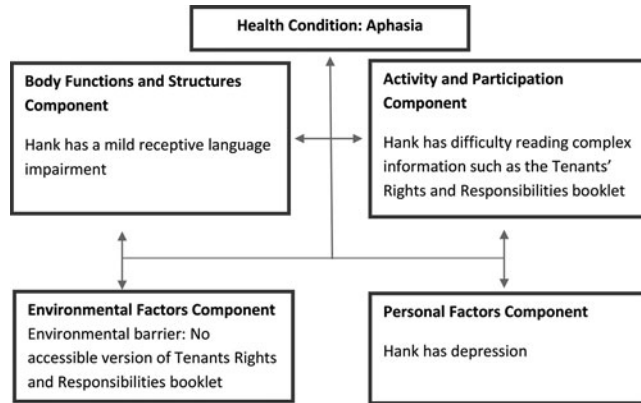


Figure 2. The factors hypothesized to influence Hank's communication activity and participation many years after his stroke as conceptualized by the ICF. Adapted from *International Classification of Functioning, Disability and Health*, by World Health Organization, 2001, Geneva, Switzerland: Author.

offers guidance in regard to potential long-term consequences?

Applying the SDH to Hank's story helps determine the possible long-term consequences

The social determinants of health

The SDH model provides a different conceptualization of health: one that identifies the social factors that influence health and well-being in the long term (Solar & Irwin, 2010). The SDH may provide a better account of the factors contributing to Hank's dramatic change in circumstances from being a successful executive, living with his wife and children with financial means and several social networks, to being an unemployed recipient of a disability pension, living in shared accommodations where he does not feel comfortable or safe. The SDH model, as depicted in Figure 3, states that social factors (such as the socioeconomic and political context, and a person's subsequent social position) directly influence a person's material, social, psychological, and biological circumstances, which in turn influence a person's health and well-being (Solar & Irwin, 2010). According to the SDH, it is not simply that disease or injury causes poor health and well-being; rather, it is the complex interplay of social factors that determine the likelihood that an individual will

experience disease or injury that leads to poor health and well-being.

A wealth of evidence world wide demonstrates how different social factors influence population health and well-being (Commission on Social Determinants of Health, 2008). For example, mortality rates for both men and women steadily increase as poverty increases; this pattern is evident both within individual countries and across different countries (Commission on Social Determinants of Health, 2008). Mortality rates are related to ethnicity, education, and income. For example, indigenous Australians live approximately 16 years less than non-indigenous Australians (Commission on Social Determinants of Health, 2008). In the United States, men with a low education live on average 6.5 years less than men with university degrees (Davidson, 2015). Similarly, women on low incomes live on average 5 years less than affluent women (Davidson, 2015). As Davidson (2015) states, some differences in population health, such as health differences due to genetic factors, may be unavoidable. These differences are called *health inequalities*. However, if the variations are avoidable, like the variations in health described earlier, then they are no longer considered to be health inequalities but *health inequities* (Davidson, 2015). Health inequities occur because of the way society is structured and the

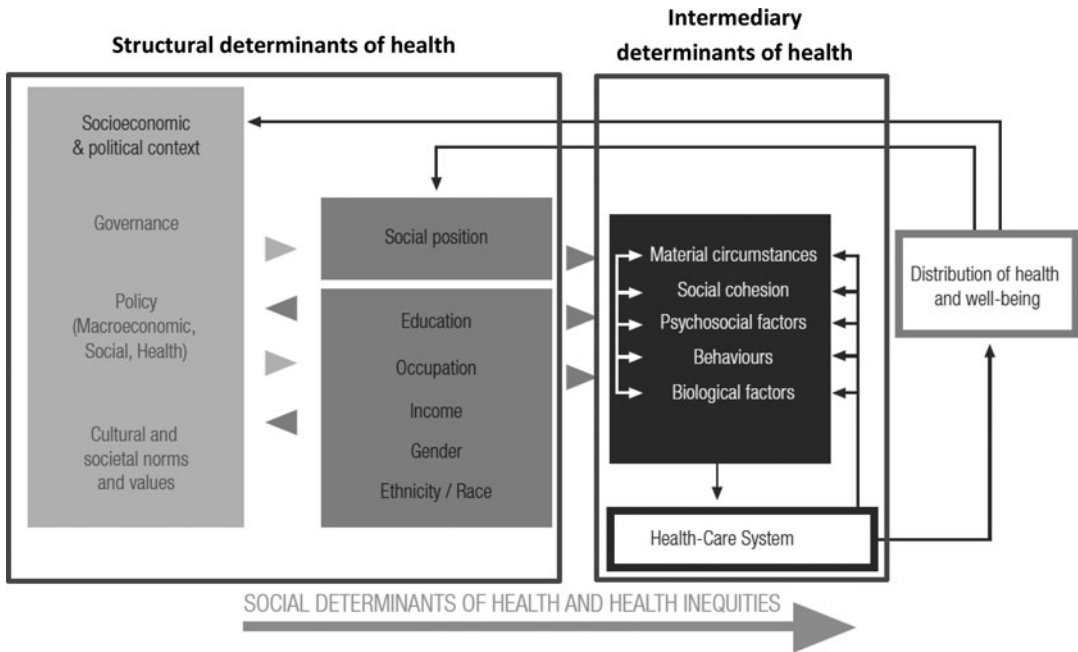


Figure 3. The Social Determinants of Health model. Amended from Solar & Irwin (2007). Reproduced with permission from *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health*, by Commission on Social Determinants of Health, 2008. Final report of the Commission on Social Determinants of Health. Geneva, Switzerland: Author.

way in which resources are distributed within society (Commission on Social Determinants of Health, 2008).

The SDH model proposes that there are *structural determinants of health* such as the socioeconomic and political context that influence social position in society. The socioeconomic and political context is proposed to influence a person’s access to education, income, and occupation. The socioeconomic and political context may also have differential impact on people, depending on their gender and ethnicity. These structural determinants are hypothesized to effect *intermediary determinants of health* such as a person’s material circumstances, psychosocial factors, and behaviors. The health system in which an individual finds himself or herself is also considered an intermediary determinant of health because it influences a person’s access to health services, such as the specific criteria around access to health care and health care resources (Solar & Irwin, 2010). Apart from an

individual’s behaviors and biological factors, all the other factors in the SDH model are environmental factors. Some factors such as material circumstances and psychosocial networks are part of a person’s immediate environment, whereas factors such as the socioeconomic context, the political context, and the health care system are part of a person’s broader environment. Can the SDH model be applied to individuals such as Hank, to explain the series of events that occurred to him after his stroke and aphasia?

Applying the SDH to Hank’s story

The SDH is a cyclical model that depicts how an individual’s health and well-being are influenced by structural and intermediary determinants of health. Therefore, in applying the SDH to Hank’s story, the authors acknowledge that there were structural and intermediary determinants of health already operating that had influenced Hank’s health and well-being prior to his stroke. These included

the prevailing Australian socioeconomic and political context at the time (e.g., Australia is a stable democracy; it is a wealthy, developed nation; free public health care is available), as well as Hank’s prestroke social position (e.g., white male, high school educated, high status occupation, and high income), his preexisting material circumstances (e.g., whether or not he could afford safe comfortable housing, healthy food, adequate clothing), the degree of social cohesion (e.g., the safety of his neighborhood), psychosocial circumstances (e.g., his social networks, his stress levels), behavioral circumstances (e.g., the extent to which he ate well, slept well, and exercised), and biological factors (e.g., his preexisting medical conditions). The application of SDH to conceptualize the consequences of aphasia over time begins at Hank’s discharge from formal rehabilitation services approximately 3 months after his stroke and consider the possible interplay of social determinants of health from this time on. Although all social determinants influence health and well-being,

the particular social determinants thought to play a key role in influencing Hank’s health and well-being are highlighted in Figure 4.

How might structural determinants influence Hank’s long-term health and well-being?

The SDH leads to reflection on how structural determinants of health may have influenced Hank’s health and well-being after his stroke, subsequent aphasia, and reduced mobility. That is, were there any factors in the environment related to government and reflected in Australian macroeconomic, social, and/or health policies that impacted Hank’s health and well-being? Did Australian cultural and societal norms and values regarding stroke and disability affect Hank? Two structural determinants that influence a person’s social position, income, and occupation are considered later.

Hank’s stroke, aphasia, and reduced mobility meant that he could no longer participate

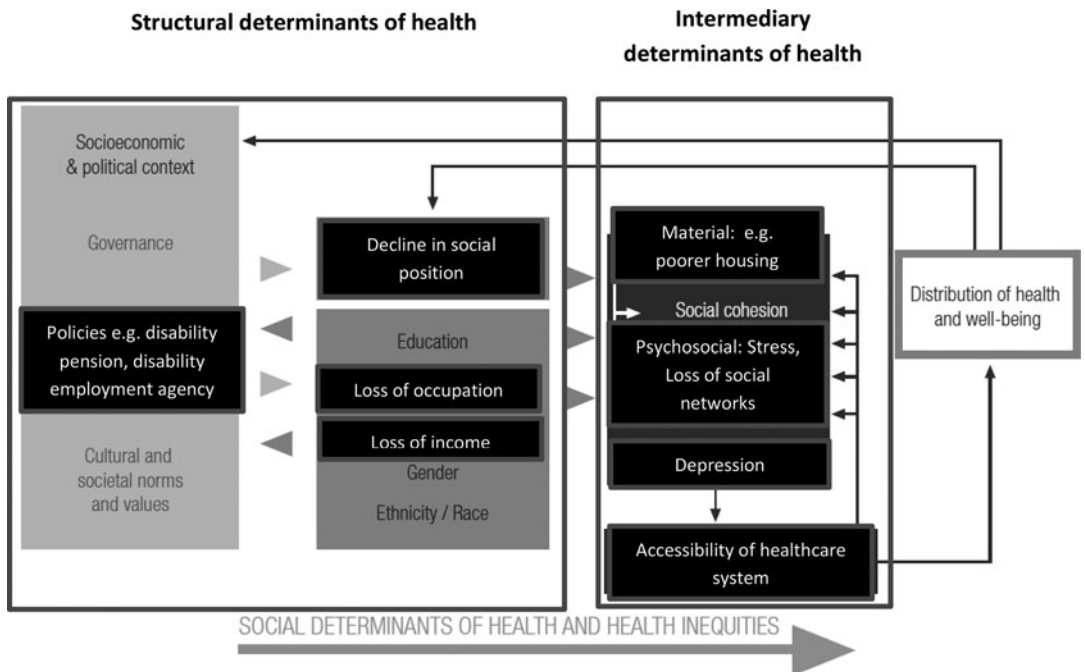


Figure 4. Some of the factors hypothesized to influence Hank’s participation as conceptualized by the Social Determinants of Health. Adapted from Solar & Irwin (2007).

in a high-status, high-income job. His inability to resume his prestroke occupation had many consequences, including a dramatic reduction in income. However, government policy did play a role. Although considerably less than the income he had previously received, Hank received some income through a government-funded disability pension. This pension also entitled him to a concession on the cost of some essential services, such as electricity. The overall value of this pension would determine the extent to which it served as a protective factor for Hank's health and well-being.

There was also a government service to support people with acquired disabilities to find employment. However, it is important to consider whether there were any environmental factors operating within these government services that created barriers for Hank, given his aphasia. Specifically, did the people responsible for finding Hank employment after his stroke understand what aphasia is? Were they able to communicate with him in a way that revealed his competence (see Kagan, 1995)? It is unknown if the disability employment staff had an understanding of aphasia and provided Hank with a supportive communicative environment or not. Instruction in aphasia and supportive communication may have benefited their assessment of his capabilities and the work opportunities he was offered.

How might intermediary determinants influence Hank's long-term health and well-being?

The SDH proposes that social position, indicated by occupation and income, has a direct bearing on intermediary determinants of health such as psychosocial factors, material circumstances, and access to health care. The SDH may be useful when considering the long-term impact of these environmental factors on Hank's health and well-being. The authors aim to initiate a conversation within aphasiology regarding the long-term impact of aphasia that can inform future research,

service planning, and delivery, and resource allocation.

Psychosocial factors

The SDH model suggests that the fall in Hank's social position as a result of his loss of occupation and income may have resulted in a range of negative psychosocial consequences. These might include living with the stress of debt, the loss of his work-related social network, the loss of the school social network, and the breakdown of his marriage. It is also important to consider the interactions among aphasia, the environment, and these psychosocial consequences. Whereas the environmental supports provided to Hank were unknown, the SDH can prompt clinicians to consider what they might need to be. For example, if there were a communicatively accessible financial counselling service, Hank and his wife would have been able to get financial advice and support in a way that Hank could understand. This support might have been in the form of supporting Hank to continue to be involved in making financial decisions and/or giving him the opportunity to be involved in appointing someone to assist with these decisions.

Similarly, as Hank and his wife experienced their relationship deterioration, communicatively accessible relationship counselling services might have meant that they would have been able to get the psychological and emotional support that they needed. The consequences of losing his job and his income also meant that Hank lost important social networks. Environmental factors related to the knowledge, skills, and attitudes of family, friends, school colleagues, as well as work colleagues become critical. Having communication partners with the skills and knowledge to support a person with aphasia in conversation (Simmons-Mackie, Raymer, & Cherney, 2016) and having opportunities to develop new social networks (see Howe, this issue) may have provided Hank with a communicatively supportive social network. The loss of social networks alone can be detrimental to feelings of belonging and overall health and

well-being (Dalemans, de Witte, Wade, & van den Heuvel, 2010).

Material circumstances

Another important intermediary determinant of health is a person's material circumstances, such as housing (Solar & Irwin, 2010). This prompts a number of important questions around how a range of environmental factors, such as the accessibility of legal services and the availability of advocacy services, may have contributed to Hank's financial situation and the quality of his housing. Although Hank did not mention it explicitly in his story, thinking about the relationship between aphasia and the social determinants of health may prompt clinicians to consider what, if any, communicative support Hank received during the complex, legal process of divorce and how this might have affected the amount of money he received as part of the financial settlement. This is important because it would have had implications on many aspects of his life, including the quality of rental accommodation he could afford. A better financial settlement might have made the difference between living in a place where he felt safe or in a place where he did not feel safe.

Another environmental factor relates to the presence of advocacy services. There are no advocacy services for people with aphasia in Melbourne. If Hank had had access to an advocate, he might have been able to find affordable and acceptable accommodations for himself. Alternatively, an advocate might have been able to help him find a shared house where he felt both physically safe and psychologically comfortable. An advocate might also have supported Hank when more complex communication situations arose such as understanding his rights and responsibilities as a tenant, negotiating with his housemates on bills, negotiating with the landlord about getting stair-rails in place, and negotiating car repairs with the mechanic.

The health care system

Another intermediary determinant of health is the health care system itself (Solar &

Irwin, 2010). The SDH provides a way of explaining how access or a lack of access to the health care system can serve to protect a person's health or further compromise it. Health care policies determine who is able to access health care and the cost of this access. Given that Hank was in receipt of a disability pension and living in Australia, he would have received free transport to hospital, free hospital care, and free inpatient rehabilitation. A publically funded health care system facilitates access for all Australians to basic health care. However, on his admission to hospital with a broken ankle, the SDH model prompts clinicians to consider whether there were any environmental factors that could have influenced Hank's access to this health care given that he had a preexisting aphasia.

A recent metasynthesis of the environmental factors that influence health care for people with communication disabilities based on observations in Melbourne hospitals (O'Halloran et al., 2012) identified that there are no systems in place to detect patients with preexisting communication disabilities, and there are no systems in place to equip health care providers with the knowledge, skills, and resources to support people with communication disabilities to participate in their health care. It is possible that health care staff were not aware that Hank had aphasia, that the SLPs were not aware of Hank's admission, and that staff did not modify the information they provided him about the assessment and treatment of his broken ankle. Ineffective communication might have placed Hank at risk of a preventable adverse event in hospital (Hemsley, Werninck, & Worrall, 2013) and might have undermined an optimal recovery (Street, Makoul, Arora, & Epstein, 2009).

In summary, the SDH model prompts consideration of the effect of aphasia and the environment beyond communicating in a particular activity or participating in a certain event. It encourages consideration of how aphasia, as a chronic condition, may make an individual more vulnerable to a set of conditions, such as poorer housing and fewer social supports, which, in turn, place him or her at

greater risk of poorer health and well-being over time. For clinicians and researchers, the SDH identifies some environments that may be particularly important to target in order to enhance and protect the long-term health and well-being of people with aphasia. These include government policies, employment, income, education, psychosocial networks, and health care environments. The SDH also prompts new questions in terms of how aphasiologists define and measure the success of aphasia interventions. Finally, it highlights the need for support services for people living with aphasia when life circumstances change. Below, the authors review the research evidence to explore the relationship between aphasia and the structural and intermediary social determinants of health.

PART 3: IS THERE EVIDENCE OF A RELATIONSHIP BETWEEN APHASIA AND SDH?

This section provides an overview of the research evidence in relation to aphasia, the communicative environment, and SDH. The authors have not identified any studies that apply the SDH model to aphasia and its consequences. However, as described later, some literature exists examining aphasia and these health and well-being determinants.

Exploring the structural determinants of health and aphasia

Within the SDH model, structural determinants of health refer specifically to “interplay between the socioeconomic–political context, structural mechanisms generating social stratification and the resulting socioeconomic position of individuals” (Solar & Irwin, 2010, p. 28). As such, the authors begin by discussing the evidence regarding the citizenship experiences of people with aphasia, and the environmental factors that influence their access to government services. The structural determinants of health both influence and are influenced by an individual’s socioeconomic position. The most important indicators for socioeconomic position are occupational sta-

tus, level of education, and income level (Solar & Irwin, 2010). To further illustrate the impact of aphasia on these indicators of socioeconomic position, the following provides an overview of the literature in relation to the influence of aphasia and the environmental factors that influence access to education.

Aphasia, civic engagement, and access to government agencies

Citizenship is “a concept which encompasses connection to wider society, rights and responsibilities, and the capability for exerting power and influence” (Mackenzie, Bennett, & Cairney, 2011, p. 187). People with aphasia largely define citizenship in terms of community involvement, although some suggest a broader definition involving dealing with government agencies (Mackenzie et al., 2011).

Findings from interviews with people with aphasia suggest that their desire for civic involvement is driven by a wish to engage in activities beyond the home, and by a desire to act as agents for change for both themselves and others in the populations they represented (Mackenzie et al., 2011). An investigation by Howe et al. (2008a) found that the environmental factors that influenced the community participation of people with aphasia included (a) awareness of aphasia; (b) opportunity for participation; (c) familiarity; (d) availability of extra support for communication; (e) communication complexity; (f) message clarity; and (g) time available for communication. However, little is known about the relationship between environmental factors and participation, or the impact of environmental level interventions on the participation of people with aphasia.

The ability of people with aphasia to engage with government agencies has been reported to be fraught with challenges. As an example, people with aphasia have been found to experience difficulties accessing services through Centrelink (Booth, 2012), the public interface of the Australian Government’s Department of Human Services responsible for the provision of social security payment to, among

others, people with disabilities. In interviews about their experiences with this government agency, people with aphasia reported that additional time, accessible interactions, information and processes, and service relationships with individualized approaches were needed to facilitate their engagement, but that none of these things was currently being provided.

Aphasia and access to education

The notion of access to education is important in addressing both equity within the education system, and opportunities that seek to grant equal opportunities in employment beyond course completion (Santiago, Tremblay, Basri, & Arnal, 2008). There has been very little research on the environmental factors that influence access to education for people with aphasia. The number of people with aphasia who make the decision to either enter or return to higher or further education following the onset of aphasia is unknown.

Existing literature on the experiences of people with aphasia in the educational sector describes both experiences in which the challenges of trying to access education lead to withdrawal (e.g., Parr, Byng, Gilpin, & Ireland, 1997) and those in which academic success was achieved despite these challenges (e.g., Bruce, Parker, & Renfrew, 2006; Parr et al., 1997). That is, in addition to the person's language impairment, the findings reported in the literature revealed environmental barriers experienced by people with aphasia in the educational setting. These barriers can grossly be categorized into two areas: (1) poor awareness of aphasia and its consequences within the education sector and (2) a lack of responsive and flexible systems to support the needs of people with aphasia in educational settings. These categories are explored in further detail later.

Poor awareness of aphasia and its consequences within the education sector

To meet the needs of people with aphasia in an educational context, their needs must

first be understood clearly by the educational provider. When staff have a lack of awareness or understanding about a student's disability, students are more likely to have negative educational experiences (Holloway, 2001). Facilitating an understanding of aphasia within educational settings is likely to be made difficult by a poor public awareness and understanding of the aphasia in the community (Code et al., 2016). The "invisible" nature of aphasia may mean the obligation of disclosure and seeking accommodations lies with the student with aphasia (Mullins & Preyde, 2013), a process that has been reported as difficult for individuals with a variety of disabilities and may be made more difficult for people with aphasia as a result of their linguistic deficits.

Lack of responsive and flexible systems to support the needs of people with aphasia in educational settings

Because of the high-level language demands in educational settings and the communication difficulties inherent to aphasia, people with aphasia may be limited in their capacity to participate in formal education without learning support (Bruce et al., 2006; Parr et al., 1997). Aphasia can restrict a person's ability to engage with the process of education, which is normally conducted in the spoken and written language modalities, including their ability to meet linguistically focused outcome assessment requirements.

Parr et al. (1997) identified a number of specific teaching methods that contribute to educational success for people with aphasia. However, it has been reported that these methods are not commonly employed. Exploration of education service provision to people with aphasia by Jordan and Kaiser (1996) in the United Kingdom identified a number of small-scale examples of collaboration between SLP services and adult education providers to meet the needs of people with aphasia; however, challenges related to conflicting philosophies were identified. Despite this, the value of collaborations between SLPs and academic staff was also identified by Bruce et al. (2006). They suggest that the

model and location of SLP services should enable people with aphasia to seek support from SLPs as their educational circumstances and needs change.

Exploring the intermediary determinants of health and aphasia

The structural determinants of health for people with aphasia, as discussed earlier, operate through a series of intermediary determinants of health. Those structural determinants can be considered to influence these intermediary determinants. The main categories of intermediary determinants of health as outlined in the SDH model are material circumstances, social cohesion, psychosocial factors, behaviors, and biological factors. The following section reviews the evidence regarding environmental factors that influence access to interpersonal relationships for people with aphasia and access to the health care system for people with aphasia.

Aphasia and interpersonal relationships

Without the speed or ease of prestroke verbal output, are people with aphasia able to maintain and create new social relationships? Language has been described as the “currency” of relationships (Parr et al., 1997, p. 44). Thus, the loss of language with aphasia deprives the individual of one of the fundamental ways to maintain relationships (Hilari & Northcott, 2006). There is substantial evidence to support the assertion that aphasia has a profound impact on interpersonal relationships, described as a psychosocial factor within the SDH. The effects of aphasia have been described in regard to many different kinds of relationships, including intimate relationships, relationships with children, and relationships with friends.

There are no data available on the number of marital relationships that break down following one person acquiring aphasia. There are some limited studies on the perceptions and experiences of spouses of people with aphasia that suggest that aphasia impacts spousal relationships in positive and nega-

tive ways (Michallet, Le Dorze, & Tétreault, 2001; Michallet, Tétreault, & Le Dorze, 2003). Recent research also indicates that many spouses of people with aphasia experience third party disability that may further compromise their ability to support the relationship. For example, family members of people with aphasia are at risk of developing depression (Grawburg, Howe, Worrall, & Scarinci, 2013a, 2013b), deterioration in their own health (Grawburg, Howe, Worrall, & Scarinci, 2014), changes to their own social relationships (Gillespie, Murphy, & Place, 2010), and recreational activities (Le Dorze & Signori, 2010).

Positive and supportive intimate relationships are a powerful contributor to living successfully with aphasia (Brown, Worrall, Davidson, & Howe, 2012). Access to supportive and meaningful relationships was one of the seven themes identified in a qualitative meta-analysis of interview data from people with aphasia, family members, and SLPs (Brown et al., 2012). The authors concluded that their study reinforced “the idea that living successfully with aphasia can only occur within the context of love, acceptance, friendship, and support from others” (p. 146). This research supports the idea that access to and participation in meaningful personal relationships may serve to buffer people with aphasia against some of the negative impacts of aphasia.

Relationships with children appear more resilient to the impact of aphasia. In a study of 83 people with chronic aphasia, 71% reported that they had the same amount of contact with their children following the stroke (Hilari & Northcott, 2006). This is in keeping with evidence from the broader stroke population (e.g., Astrom, Asplund, & Astrom, 1992). However, less is known about the relationships between younger children and their parents, when parents still have caring responsibilities (e.g., Harlow & Murray, 2001).

Outside family relations, evidence suggests that aphasia affects the nature and quality of interactions between people with aphasia and their friends (Parr et al., 1997). This manifests in reduced social networks and/or

reduced quality of social relationships (Cruice, Worrall, & Hickson, 2006; Davidson, Howe, Worrall, Hickson, & Togher, 2008; Davidson, Worrall, & Hickson, 2003). Hilari and Northcott (2006) found that 64% of 83 people with aphasia interviewed reported reduced interactions with friends and 30% reported having no close friendships whatsoever. This loss of friendship is uniquely attributed to the presence of aphasia rather than the stroke more generally. A survey of people with aphasia in the United States found that 75% felt others avoided them because of their communication difficulty (Sarno, 1997). The evidence to date creates a picture of shrinking social networks, while the nature of aphasia further restricts opportunities and ability to seek emotional and informational support (Davidson et al., 2008). It is still possible for people with aphasia to develop and maintain friendships, but this requires the “two way hard work of friendship” as well as creativity and resourcefulness (Pound, 2013, p. 354).

Aphasia and access to health care

Recent research has addressed the factors that influence the success and failure of communication between patients (including those with aphasia and other communication disabilities) and health care providers across the continuum of health care (Blackstone, Beukelman, & Yorkston, 2015). When patients and health care providers manage to establish shared meaning, positive health care outcomes are likely (Blackstone et al., 2015). Conversely, communication breakdowns within the health care sphere lead to negative health outcomes, increased length of hospital stay, higher rates of readmission, increased costs, an increase in negative events, and a reduction in patient satisfaction (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; The Joint Commission, 2013).

Without access to appropriate and relevant communication support, people with aphasia may experience a reduction in their capacity to express their health care needs and actively participate in decisions regarding their own health care (O'Halloran, Worrall, & Hickson, 2012). Poor communicative

access within health care can lead to damaging and negative experiences for people with aphasia, including a reduction in the reported satisfaction with the health care experience (Tomkins, Siyambalapatiya, & Worrall, 2013), an increased risk of inappropriate or inadequate service provision (Hemsley et al., 2013), and an increased likelihood of the occurrence of adverse events (Bartlett et al., 2008).

CONCLUSION

The SDH model offers clinicians and researchers a way to conceptualize the cumulative effect of inaccessible environments on the long-term health and well-being of people with aphasia. The authors are not suggesting that Hank's story is typical for people who acquire aphasia, nor is his story rare. Aphasiologists have much to learn regarding how SDH can enrich approaches to aphasia assessment, decision making around the aims and type of the interventions offered, and measurement of intervention effects.

For SLPs, the SDH may challenge traditional views of the clinician's role in the lives of people with aphasia. Viewing the impact of aphasia decades after the onset emphasizes the importance of understanding the impact of many different environments on people with aphasia. The SDH suggests that SLPs need to work beyond the level of the individual with aphasia in formal rehabilitation settings, to address the vast range of systems, services, and policies that have the potential to damage or enhance the long-term health and well-being of people with aphasia (see McAllister, Wylie, Davidson, & Marshall, 2013).

Hank's life following the onset of aphasia is one example of how many different facets of the environment appeared to influence his health and well-being for the long term. His story illustrates the disconnect between how an individual might present initially in a health care setting (e.g., with a clinical diagnosis of aphasia) and the foreseeable and unforeseeable impacts that aphasia may have on that person's health and well-being in the future. Indeed Hank's story serves to highlight the powerful (at times devastating)

domino effect that can result from changes in one aspect of the model (i.e., biological factors), which turns a present-day health condition into a long-term social problem that impacts all aspects of life. Given the chronic nature of aphasia and that limited public health care resources are typically front-

loaded to acute care and rehabilitation within the first year poststroke, the SDH poses interesting questions on how clinicians might serve the needs of people with aphasia by recognizing and reducing the environmental barriers to full participation in life to optimize health and wellbeing for the long term.

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