

CHAPTER 2

SOME MAJOR CONTEMPORARY REHABILITATION ISSUES REGARDING THE INDIVIDUAL WITH A TRAUMATIC BRAIN INJURY

Rehabilitation ...is more than the mechanical application of technical procedures. In our judgement, it involves a commitment to enter the lives of people with disability, to create collaborative relationships with them and the everyday people in their lives, and to support them in part by serving as an ongoing source of optimism, creativity, flexibility, and enthusiasm in the face of the obstacles that often seem overwhelming.

(Ylvisaker & Feeney, 1998a, Preface, p. xi)

2.1 Introduction

The nature of contemporary intervention with adults with acquired communication disorders is shaped by, and reflects the influence of past and present social and health care models. The current research is aligned with the contemporary concept of society's obligation to individuals with disability worldwide to lessen their marginalization, reduce environmental and attitudinal obstacles, and enhance their participation in all aspects of life within their own capabilities (Alant, 2005b; Alant & Lloyd, 2005; Fox and Sohlberg, 2000; French, 1994; ICF (WHO, 2001); Kagan & LeBlanc, 2002; LPAA Project Group, Chapey et al., 2000; Pound, Parr, Lindsay & Woolf, 2001a, 2001b, 2001c; Sarno, 1986, 2001, 2004; Simmons-Mackie, 1998; Simmons-Mackie, Kagan, Christie, Huijbregts, McEwen & Willems (in press); Threats, 2002, 2003, 2004; Threats & Worrall, 2004).

This chapter examines the ability of the individual with a TBI to participate in society – in relation to the participation-based ICF model of the WHO (WHO, 2001). This conceptual framework advocates the removal of societal barriers, together with the provision of social supports and facilitators, thereby encouraging individuals with disabilities to integrate themselves and be more visible in society. In addition, an overview will be provided of the social and participation-based approaches (Alant, 2005b; Alant & Lloyd, 2005; French, 1994; Jordan, 1998; Jordan & Kaiser, 1996; Kagan, 1995; Kagan, Black, Felson Duchan, Simmons-Mackie & Square, 2001; Kagan & Gailey, 1993; Kagan & LeBlanc, 2002; LPAA Project Group, Chapey et al., 2000; Lyon, 1992; Parr, Byng, & Gilpin (with Ireland), 1997; Pound et al., 2001a, 2001b, 2001c, Simmons-Mackie et al., (in press); Sarno, 2004), which aim to remove the numerous

social environmental and attitudinal barriers that still exist for many individuals with disabilities, and in particular those with invisible communication disabilities, who are frequently stigmatized, facing a range of barriers including hostile, uncomfortable and even fearful reactions by society (Fine & Asch, 1988; Goffman, 1963a, 1963b; Lubinski, 1981, 2001; Sarno, 2001, 2004).

2.2 Traumatic brain injury (TBI) and cognitive-communication problems

TBI results from an external trauma to the brain (rather than disease) producing altered states of consciousness in the acute stage, and resulting in a range of diverse chronic cognitive-communication, physical and psychosocial problems (Togher, McDonald & Code, 1999b, 1999c; Togher et al., 2004; Ylvisaker & Feeney, 1996). Blunt head injuries are reportedly the most common type of head injury, caused by rapid acceleration and deceleration of the head occurring most commonly in a motor vehicle accident. The orbital and lateral surfaces of the frontal and temporal lobes are the most vulnerable in these injuries (Sohlberg & Mateer, 1989, 2001c; Togher et al., 1999c; Ylvisaker & Feeney, 1996; 2001) resulting in potentially debilitating problems with the regulation of cognitive, behavioural and social-communication functions which fall under the “umbrella term” of executive system impairments. (Ylvisaker & DeBonis, 2000; Ylvisaker & Feeney, 1996; Ylvisaker, Szekeres & Feeney, 2001a). The outcome may be a potentially varying range and degree of cognitive impairments including problems with attention; memory; new learning; impulsivity; self awareness; judgement; planning; problem solving; decision-making and self regulation of mood and emotional reactions (Sherer, Bergloff, Boake, High, & Levin, 1998; Sohlberg & Mateer, 1989, 2001c; Togher et al., 1999c; Ylvisaker & DeBonis, 2000; Ylvisaker & Feeney, 1996; Ylvisaker, Szekeres & Feeney, 2001a).

In the USA and Australia, the general incidence has been estimated at approximately 200-300 per 100 000 people per annum sustaining a severe brain injury, with the highest incidence occurring in the 15-24 year age group (McDonald, Togher & Code, 1999; Togher et al., 2004). Togher et al. (2004) note how these figures are on the increase, and with it a concomitant increase in social cost and burden. In South Africa, Nell and Brown (1990) reported the incidence of TBI being 316/100 000 (higher than the statistics more recently reported in the USA and Australia), while the Brain Injury Group (BIG) (retrieved May 15, 2004 from <http://www.headway-gauteng.org/brain-injury/statistics.htm>) reported approximately 80 000 new cases of TBI annually. D.A. Howitson (Chairperson, National Council for Persons with Disabilities) has noted that the South African Census 2001 reveals that there are 2 233 982 persons with disability in South Africa (5.07% of the population), with no specific information

being identified about individuals with a TBI (personal communication, May 3, 2004). Disabled People South Africa (DPSA) (2000) notes a “serious lack” of reliable information regarding the nature and prevalence of disability in South Africa for a number of reasons including the stigma attached to disability, as well as differing definitions of disability (retrieved May 2, 2004 from <http://www.dpsa.org.za/documentspocketguide.htm>).

2.3 Cognitive-communication problems following TBI

The American Speech-Language-Hearing Association (ASHA) (1988) defined the communication problem following TBI as a cognitive-communication disorder. In a recently updated position statement ASHA (in press) has stated that:

Cognitive-communication disorders encompass difficulty with any aspect of communication that is affected by disruption of cognition. Communication includes listening, speaking, gesturing, reading, and writing in all domains of language (phonologic, morphologic, syntactic, semantic, and pragmatic). Cognition includes cognitive processes and systems (e.g. attention, memory, organization, executive functions). Areas of function affected by cognitive impairments include behavioural self-regulation, social interaction, activities of daily living, learning and academic performance, and vocational performance.

The potentially widespread impact of this possible range of cognitively-based communication impairments has been extensively described and highlighted in the literature to include deficits that impact on the individual’s academic and work-related performance, social participation, and ability to resume their pre-traumatic roles in society (Coelho, 1999; Holland, 1982; Isaki & Turkstra, 2000; Larkins, Worrall & Hickson, 2004; Mentis & Prutting, 1987; Milton, Prutting & Binder, 1984; Penn, 2000; Penn & Cleary, 1988; Penn & Jones, 2000; Sherer et al., 1998; Sohlberg & Mateer, 2001a; Togher, 2001; Togher et al., 1999b; Watt & Penn, 2000; Watt, Penn & Jones, 1996; Ylvisaker & DeBonis, 2000; Ylvisaker et al., 2001a). Larkins et al. (2004) have further emphasized the impact of the cognitive changes on the individual’s communication interaction as not only creating a negative impression on friends or employers, but additionally impacting on their level of insight, as well as their adherence to acceptable social customs.

Penn & Cleary (1988, p.3) consider the commonly-used adjectives to describe the characteristics of the expressive language of the individual with a TBI as including “confabulatory, tangential, irrelevant, non-specific, vague, digressive, fragmented and incoherent.” Penn and Jones (2000) noted that the following communication difficulties that have been found to interfere with successful return to work include “oral motor abnormalities, high level receptive difficulties,

expressive difficulties, difficulties in reading and comprehension and memory tasks, and slowed speed of verbal reasoning” (p.111).

Togher (1997); Togher and Hand (1999); Togher et al. (2004); and Togher, Hand and Code (1996, 1997a, 1997b, 1999a) have made more in-depth and complex examinations of the interpersonal functions of language in interactions between individuals with a TBI and various communication partners, across status and social distance, using a sociolinguistic framework, Systemic Functional Linguistics (Halliday, 1994), as well as a macrolinguistic generic structure potential (GSP) analysis (Ventola, 1979). These communication partners included family members, the police, and people working for the bus timetable information service. Their overall findings reveal how people with TBI were disadvantaged in their interactions with a number of communication partners, with reduced opportunity to provide information, and being less likely to have their contributions followed up by supportive comments. They were also more likely to be questioned regarding the accuracy of their contributions, and more likely to be asked repeatedly whether they had understood what had just been said. Togher and Hand (1999) noted how individuals with a TBI communicated more competently when in an information-giving role than in the less powerful information-requesting role. The conversation partner, on the other hand, was found, for example to change their communicative behaviour when speaking to an individual with a TBI (possibly compensating for their perceived deficits by, for example clarifying with the individual with a TBI whether they understood the intended message) (Togher et al., 1996), and also tended to use disempowering strategies for the individual with a TBI (Togher et al., 1997a). The implications drawn out by Togher and Hand (1999) included empowering individuals with a TBI by training them using different scripts and cues to “cognitively reorder that which is suggested to be deficient in TBI discourse” (p. 721), and in so doing, to be able to better anticipate and manage different communicative styles of interaction. Scripting as a form of executive system support for the individual with a TBI, has likewise also been widely advocated by Ylvisaker and Feeney, 1998f; Ylvisaker, et al., 2001b; and Ylvisaker, Wedel-Sellars & Edelman, 1998.

Armstrong & Togher (2001) have noted how service encounters account for a significant number of everyday communicative exchanges, and that focusing on these encounters “has the potential to have a significant impact on the communicative effectiveness of people with TBI” (p.6). Togher et al. (2004) advocate training larger numbers of individuals with a TBI, as well as service providers, to manage language choices and interactions across a number of different service encounters such as shopping, buying goods from a supermarket, banking, dealing with a

travel agent; and making enquiries in governmental departments such as the police. These researchers undertook a pilot 6 week training program with the New South Wales police, where the latter learned strategies to communicate more efficiently and satisfactorily with the caller with a TBI (making a telephonic police service enquiry), who likewise managed the communicative exchange more easily as a result. In so doing, more normal communication opportunities were created for people with a TBI.

Prutting (1982) has referred to appropriate communication as “social competence” since linguistic behaviour is the “vehicle by which one initiates, maintains and terminates relationships with others” (p.129). This understanding of competent communication being the product of the appropriate use of verbal behaviour together with nonverbal and paralinguistic behaviour within a context and a relational system (Prutting, 1982), underlies the reasoning offered by Prutting that one’s social identity (Goffman, 1963b) is often affected by having a communication disorder. This thinking demonstrates how the above range of cognitive-communication difficulties in the individual with a TBI could potentially impact on the perceived appropriateness and efficiency of their communication interactions generally, and specifically on their ability to independently manage a service encounter such as shopping (Mazaux et al., 1997; Mentis & Prutting, 1987; Milton et al., 1984; Togher et al., 1997a, 1997b; 2004; Ylvisaker et al., 2001a). More specific examples of the manner in which these cognitive-communication problems could potentially impact on such an individual’s being able to manage a retail interaction could include: difficulty reading labels and prices correctly; difficulty being understood by the sales assistant; working out how much money to give the cashier, and the change to expect when the transaction is completed; impulsive buying of unwanted items on the shopping list; asking relevant questions of the sales assistants regarding the required purchase; difficulty making decisions regarding items to buy if they don’t have enough money; over-familiarity with the sales assistant or other customers and chatting lengthily to them (possibly unaware of other customers in line, and creating anxiety and discomfort in these communication partners); feeling pressured by shoppers in the line or an impatient sales assistant in a busy shop, which could spark an outburst; eating or using items before they have paid for them; walking out of the shop without remembering to pay for items; and inappropriate behaviour and inability to deal with delays such as waiting in a line, or even while being served. Larkins et al. (2004) asked 5 stakeholder groups (comprising individuals with TBI and their families, health professionals working with individuals with a TBI, third party payers funding TBI rehabilitation programs; employers providing work; and also Maori community members in New Zealand) to consider a list of communication activities seen as particularly important for the individual with a TBI.

Some of the highest rated items identified by these groups included the same kinds of the above-mentioned cognitive-communication skills that would also be pertinent within the retail environment, including: initiating conversations, social greetings and basic conversation; focusing in a noisy environment; negotiating assertively; speaking slowly and clearly; asking questions and getting basic help.

In addition to the range of cognitive-based communication disorders described above, individuals with a TBI may also have impairments in speech (dysarthria); motor planning (apraxia) and / or language (aphasia) (Sohlberg & Mateer, 1989) which intrude upon the overall ease and efficiency of communicative interactions. According to Beukelman & Yorkston (1991) (cited in McDonald et al., 1999) dysarthria following TBI is reportedly one of the most persistent communication impairments impacting significantly on the individual's functional independence, and has been reported to occur in from 8% to 100% of patients with a TBI. Aphasia has been reported to occur in from 2% (Heilman, Safran & Geschwind, 1971 cited in McDonald et al. (1999)) up to roughly 30% (Sarno, 1980, 1988; Sarno, Buonaguro & Levita, 1987), with anomic aphasia reported as the most common aphasia type. Sarno, Buonaguro & Levita (1986, p.402) termed the aphasic-like symptoms "subclinical aphasia" in the less severely impaired individuals with a TBI. The discussion below highlights the controversy around this classification of the communication deficits following a TBI as a purely linguistic impairment, rather than reflecting underlying cognitive deficits (Holland, 1982; McDonald et al., 1999; Milton et al., 1984; Sohlberg & Mateer, 1989, 2001a).

2.4 Differences between TBI and aphasia

While both acquired aphasia (following a stroke) and TBI potentially impact on the interactional style and conversational roles of the individual, an examination of the literature highlights numerous differences between the aphasic and TBI populations. Darley's original definition of aphasia (cited in Davis (2000)) has been re-defined by Davis as being "a selective impairment of the cognitive system specialized for comprehending and formulating language, leaving other cognitive capacities relatively intact" (p.16). With regard to the TBI population, Ylvisaker et al. (2001a) have emphasized the heterogeneity of this population in terms of pre-injury variability and variety of pathophysiologic mechanisms (related, for example to site of impact), so that "constellations of communication-related strengths and weaknesses potentially associated with the TBI are extremely varied, depending on the nature, location, and severity of the injury, as

well as the characteristics of the individual who is injured and post trauma supports” (p.752). Ylvisaker et al. (2001a) have further noted that:

although symptoms of aphasia are often present early in recovery, and in some cases specific language impairment does persist, aphasia defined in terms of the classical syndromes is relatively uncommon after TBI. ... generalized and persistent expressive and receptive language impairment is generally associated with widespread diffuse injury that also produces global cognitive deficits (p.754).

With specific reference to pragmatic competencies, Milton et al.(1984) noted that “communication may be disrupted in this population in ways which are qualitatively different from the stroke patient we label as aphasic” (p.114). Furthermore, in relation to Holland’s (1977, p.173) observation that “aphasics probably communicate better than they talk,” Milton et al. (1984, p.114) noted that “the reverse seems true for head injured individuals. This population appears to talk better than they can communicate.” Holland (1982, p.345) emphasizes this difference most emphatically by stating that:

if the language problems seen in closed head injured patients don’t look like aphasia, sound like aphasia, act like aphasia, feel, smell or taste like aphasia, then they aren’t aphasia. Further, they will not be terribly responsive to the traditional methods by which we have come to treat aphasia.

In addition to the impact of the above-described cognitive-communication difficulties on the ability of the individual with a TBI to resume pre-traumatic roles and functions, Togher (2001); and Togher et al. (1996; 2004) have extended this notion further by emphasizing the importance of assessing the real barriers faced by individuals with a disability in real life situations, and the need to take cognisance of the broader role played by societal skill and attitude in facilitating, or interfering with the ability of the individual with a TBI specifically to resume their role in society as for example, a parent, student or employee. With reference to the therapeutic process specifically, Togher et al. (1996) refer to disability in relation to society’s response, and the need to change the stereotype within the therapist-patient interaction to a more equal dyadic one. In addition (in support of Fine and Asch, 1988), they note the awareness of the role played by the individual with a TBI in the community, and the importance of modifying the attitudes and response of the community displayed towards such individuals in these broader contexts. Thus, for example, Togher et al. (1996, 1997b; 2004) advocate the need to improve communication in Governmental agencies and in private organizations dealing directly with the general public. They emphasize the importance of training programs “for the uninformed sections of the

community” (1997a, p.502) (such as the police) to enhance interactions when dealing with customers with a TBI. By changing their communication behaviours, the person with a TBI “could assume the role of the primary knower more often in service counter interactions” (Togher et al., 1996, p.565), thereby empowering them to take a more equal role in the conversation.

Sarno (1986, 2004) has repeatedly referred to “society’s ignorance and lack of awareness of aphasia” (2004, p.23) and in recent personal communication (M.T.Sarno, May 24, 2004) has confirmed how her philosophy regarding aphasia, public ignorance and the impact of the invisibility of communication disorders extends beyond aphasia to other acquired communication disorders. Within the field of acquired brain damage specifically there has been a growing endeavour to tackle the stigma and disability (barriers) associated with aphasia in particular through the use of public surveys (Parr & Byng, 1998). Elman, Ogar and Elman (2000) reviewed the top 50 newspapers in the USA for stories referring to disabilities, and found that the word aphasia was used least frequently as compared with other conditions. These writers conclude the need for advocacy in individuals with aphasia to increase awareness and “give aphasia a name” (p.459). Code et al. (2001) surveyed an unselected group of 929 shoppers in England, USA and Australia to determine their awareness concerning aphasia. Despite some cultural variation, their findings overall highlighted a generally low percentage awareness of aphasia in the general public, as compared with respondents who were professionals. Garcia, Laroche & Barrette (2002) used three focus groups (comprising consumers across 6 categories of communication disorders (including stuttering, voice disorders, aphasia and dysarthria), employers, and SLP’s and Audiologists) to examine the awareness of barriers to integration specifically perceived to exist within the workplace for individuals in Canada with a range of communication disorders. They concluded that “there appear to be perceivable psychosocial and environmental factors that contribute to the integration of persons with communication disorders in the workplace” (p.206). Difficulties associated with the communication disorder itself comprised some of the barriers identified. Other factors consensually identified as barriers included self esteem, noise, and attitudes of colleagues, with the latter reportedly a “major barrier for many groups” (p.206).

2.4.1 Consumerism

Parsons, Elkins and Sigafos (2000) have noted how one of the most valued social roles in Western society is that of the customer/consumer and how in spite of this (with specific

reference to individuals with intellectual disabilities), “surprisingly few investigators have examined the views of business communities towards such customers” (p.244). They refer to research in the United Kingdom by Saxby, Thomas, Felce and De Kock (1986) who interviewed a small number of employers in businesses (cafes, pubs and retail shops) used by customers with intellectual disabilities, and concluded how exposure to such customers may result in more accepting attitudes by the business community. Parsons et al. (2000) extended this research by examining the views of a larger sample of business owners and employers across Queensland, Australia, looking specifically at their attitudes; experiences and perceptions related to interacting with such customers. Their results overall suggested that while business people appeared to exhibit “few special concerns about having people with intellectual disabilities as customers” (p.250), nearly half of the businesses surveyed verbalized concern about the appearance of such customers, who “often acted differently” (p.249). Parsons et al. (2000) emphasize the importance of further research to “assess the acceptance of such individuals in today’s highly commercial society” (p.251). With regard to this issue of community barriers for Augmentative and Alternative Communication (AAC) users specifically, Alant (2005b) addresses the “onerous task” faced by AAC interventionists to create opportunities for greater community participation, and highlights the importance of increased visibility of such individuals in everyday life activities. This will facilitate greater awareness and understanding by the community of both disability and diversity. Alant (2005b) stresses the need to build community capacity to accommodate and integrate individuals with disability in society, and in so doing, for the latter’s level of participation to deepen with more sustainable long-term outcomes. Furthermore, Alant (2005b) highlights the mindshift that will be necessary for communities to become prepared to change their priorities and work in partnership with professional services in accommodating individuals with disability. She adds that such a process will be empowering for everyone. Bedrosian, Hoag, and McCoy (2003) undertook the first in a series of investigations looking at sales clerks’ attitudes towards AAC users, by having 96 sales clerks look at 12 scripted videotapes involving AAC customers (actual AAC users using a Liberator) dealing with a clerk (an actor) at a bookstore checkout counter. The messages of the AAC users were manipulated according to, for example, relevance and speed of delivery. Videos were made from behind the clerk so that only the AAC user’s face was visible. After viewing the videotapes the clerks completed a questionnaire assessing their attitudes toward the AAC users. Results revealed that AAC users were rated more highly under slowly delivered message conditions than under any other condition, and the researchers conclude that these findings are valuable in the endeavour not only to facilitate greater independence for the AAC user, but also their inclusion and acceptance in society.

Cottrell (2001) likewise examined the attitudes and perceptions of employees working in a supermarket in England towards individuals with communication disorders, by interviewing them using both an individual and focus group format. She showed the employees video clip footage of individuals with aphasia, dysarthria and other communication disorders, and after a discussion, gave them a questionnaire to complete. Her findings revealed that people's beliefs about communication disability are varied and complex and are influenced by numerous factors, including for example, personal experience, as well as policy within the workplace. In addition, Cottrell (2001) suggests that there may be a hierarchy of general awareness in the public consciousness, with communication disabilities far lower down than physical and visual disabilities. When people meet others with communication difficulties they approach the individual with a wide range of pre-conceived ideas and ideals which may be rigidly adhered to and difficult to modify and which need to be taken cognisance of when developing relevant training programs for communication partners. Cottrell (2001) noted how, when unsure about this person, people tended to react in one of two ways: either through a process of "normalization" (treating them like any other person), or by perceiving them as different, and stereotyping them into an "other" category (such as "they, people like that").

In relation to the Disability Discrimination Act (DDA) (in the UK), Cottrell (2001) observed that discrimination in the workplace is probably occurring as a result of attitudinal barriers caused "unwittingly" (p.88) through a lack of awareness, and that the removal of these attitudinal barriers in order to facilitate greater access is by no means straightforward. In addition, she refers to the apparent lack of communication disability modules evident in disability training programmes to date, and stresses the many existing challenges remaining for the development of suitable training programs, as well as for the creation of more communication-friendly environments. These challenges exist for a number of reasons, such as that people with communication impairments have difficulty complaining about the discrimination against them because of their communication problem, and because service providers are mostly unconscious of this discrimination owing to their lack of awareness. In addition, Cottrell (2001) suggests that training programs will need to take cognisance of how communication disabilities are highly varied and complex, as well as of how to teach individuals to deal with people with differing kinds of communication disabilities and communicative needs. She concludes that "there is a need for wide-ranging and increased training and awareness-raising among the general public about communication disability" (Cottrell, 2001, p.102).

From the above it is clear that the impact of a cognitive-communication disorder on the individual's life can be widespread, and the following discussion will consider models identified by the current researcher as useful in examining this impact further.

2.5 The evolution of the classification of communication disabilities using the World Health Organization schemes

Since 1980, the World Health Organization (WHO) has published a number of classification schemes that have been revised from time to time. The first scheme, namely the International Classification of Impairment Disability and Handicap (ICIDH) (WHO, 1980), used the categories of impairment, disability and handicap. These terms, which reflected “a consequence of disease classification” with negative connotations (WHO, 2001, p.4), were replaced in 1997 by body, structure and function, activity in the revised Beta 1 and Beta 2 drafts (ICIDH-2) (WHO, 1997), aiming to help clinicians shift from a strictly medical impairment-orientated understanding of how to help individuals with chronic impairment, to a social, participation-and-support-orientated paradigm (Holland & Hinckley, 2002; Ylvisaker, 2003). The most recent version in the evolving family of WHO classifications, the ICF (WHO, 2001) is the WHO's current framework for health and disability, to be used internationally as a unified and standard language and framework across disciplines and sectors (WHO, 2001). It is based on a biopsychosocial approach allowing clinicians and researchers to document a wide range of human functioning from biological, individual and societal perspectives (Threats, 2002). Threats, Shadden, Vickers and Lyon (2003) have noted that the ICF (WHO, 2001) is significantly improved in relation to previous versions of the WHO classification. Amongst other things it contains operational definitions for all items, environmental factors; as well as a social model orientation, highlighting the recognition given in this classification scheme to the role of the environment as either facilitating functioning or creating barriers for the people with disabilities. In 2001 the American Speech-Language Hearing Association's Legislative Council (ASHA, 2001) voted for a new Scope of Practice for the profession, stating that the ICF (WHO, 2001) is the chosen framework for the field, reflecting ASHA's “present and future need to broaden our view and demonstrate that the profession makes an important impact on the lives of our clients and the health of the nation” (Threats, 2003, p.4).

The ICF's (WHO, 2001) classification scheme reflects the multiple interactions of the person with the environment, and provides one with a means of organizing measures of function, activity, participation and environmental context. The latter “make up the physical, social and

attitudinal environment in which people live and conduct their lives” (WHO, 2001, p.22) and include aspects external to the person’s control which can have either a positive (facilitative) or a negative (barrier) effect on their functioning.

Numerous criticisms have been lodged in the past against the WHO family of classification schemes, and more recently regarding the ICF (WHO, 2001). Hurst (2003), as a disability rights activist and a member of the World Council of Disabled Peoples’ International, has criticized the earlier versions of the WHO classification schemes (WHO, 1980; 1997) as being formulated by “non-disabled experts...who perpetuated the concept of disability being another word for incapacity, impairment or lack of functioning” (p.573). In contrast to these earlier versions, Threats (2004) has noted how the ICF (WHO, 2001) “represents an advocacy approach to disability...designed to empower persons with disabilities and organizations that are trying to ensure the right of persons with disabilities to be fully integrated into society ” (p.5). Threats and Worrall (2004) have emphasized how the details of the ICF (WHO, 2001) continue to be “work in progress” (p.56), attempting to deal with numerous limitations and practical issues including considerable ambiguity and overlap of codes that are complex and require training to use properly (Simmons-Mackie, 2004; Threats & Worrall, 2004). Despite these limitations, and the ongoing need for clarification and usability of the codes, Threats (March, 2003) has commented that “Using the ICF codes will take time....ICF must be thought of as a constitution, which sets the rules and framework. It’s the ingenuity of individuals to use it and make it really grow and prosper” (retrieved May 21, 2004 from <http://www.cdc.gov/nchs/data/icd9/Threatspot.pdf>). Threats (2002) has furthermore noted how the ICF (WHO, 2001) provides a common language between clinicians and researchers, thereby advancing the quality and quantity of clinical research, and enhancing our understanding of the relationship between Body Structure/ Function and the Activity /Participation domains; as well as the role of Environmental Factors and Personal Factors in the rehabilitation process. Specifically, with reference to the Speech Language Pathology (SLP) profession, Threats & Worrall (2004) maintain that the ICF (WHO, 2001) promotes systematic examination of the environmental barriers for individuals with disabilities, emphasizing the importance of a facilitative and barrier-free environment to enable individuals with disabilities to function optimally.

Although the importance of environmental factors for individuals with communication disorders has been recognized in the SLP literature for many years (as referred to by, for example, Lubinski, 1981, 1995, 2001; McCooey, Toffolo & Code, 2000; Sarno, 1969; Van Riper, 1939; Wepman, 1968 (cited in Avent, 2004)), Threats and Worrall (2004) note how policy development

to date has paid much attention mostly to the physical environment (resulting in initiatives such as wheelchair-accessibility for public buildings). Since communication depends heavily on a physically-and-attitudinally-facilitative environment, the ICF (WHO, 2001) provides a broader framework from which to view barriers relevant to individuals with communication disabilities, so that policies addressing these barriers will in the future create “more accessible and communication-friendly environments for all language-impaired people” (Threats & Worrall, 2004, p.59). In promoting systematic examination of such environmental barriers, and in emphasizing the centrality of a facilitative environment for the optimal functioning of individuals with disabilities, the ultimate goal will be the improvement in the person’s actual life of the activities he or she finds important (Hirsch & Holland, 2000; Lubinski, 1981, 2001). T. Threats (personal communication, April 30, 2003) has further stressed his belief that it is the SLP’s responsibility “to reduce the environmental barriers for our neurogenic clients with communication disorders, and their moral obligation to advocate for creating environmentally and communication friendly places for all persons with communication disorders.”

2.6 Shifting from the medical to the social model

As with the above-described shifts within the evolution of WHO classification schemes (WHO, 1980, 1997, 2001), there has, over the past decade, likewise been a philosophical shift regarding intervention with the adult with acquired neurogenic communication disorders (including TBI and aphasia), from the traditional medical model (focusing on the impairment and viewing these individuals as ‘patients’ with an illness that will recover with treatment), to a social model of intervention, promoting an individual’s participation in a social world with reduced barriers, in which the chronicity of the communication impairment is acknowledged. This conceptual model, in a sense, reflected the maturation of Sarno’s thinking (Sarno, 1969, 2004; Sarno, Silverman & Levita, 1970), who for over 4 decades has advocated the need for SLP’s to examine the impact of a communication disorder on the lives of the individuals for whom they provide therapy. Numerous authorities have described the concept of living with aphasia from a long-term perspective, with services viewed along a continuum as the needs of the individual evolve over time (Parr et al., 1997; Pound et al., 2001b; Simmons-Mackie, 2000). This concept is particularly pertinent in the TBI population - the majority of whom are young when the injury occurs, and who still have many years of living, working and socializing ahead of them (Larkins, Worrall & Hickson, 2000; McDonald et al., 1999; Snow & Douglas, 1999; Ylvisaker & Feeney, 1996).

When presenting this social model of disability with specific reference to the field of acquired neurogenic disorders, it will become clear that the literature related to individuals with aphasia is far more extensive than that related to the individual with a TBI. Personal discussions with numerous authorities in the field including Holland (2004); Kagan (2004); Pound (2004); Sarno (2004); Sohlberg (2004); Togher (2004) and Ylvisaker (2004) (*Appendix 1A*), reflect the consensual belief that the issues pertaining to the individual with aphasia can be relevantly extrapolated to the individual with a TBI. C. Pound has likewise noted how the “the social model approach would seem to me to be equally applicable across any disability group since the principle of change lies more in the barriers in the social environment (attitudes; lack of training and attention to access etc.) than anything to do with the specific nature of the impairment” (personal communication, May 28, 2004). M.T. Sarno has likewise affirmed (as is the case with aphasia) that, “The need for all who come in contact with individuals who have communicative disorders secondary to TBI to be sensitive to their feelings, needs, impairments and disabilities, and versed in how to accommodate them into the human community at all levels, is considerable and essential to their wellbeing (and to our functioning as a caring, benevolent society)” (personal communication, May 24, 2004).

The social model of disability emerged within British disability theory, first published in the late 1970's, which challenged the medical model about misleading people to view disability as a disease process and a personal tragedy. According to this model, disability did not arise from the functional limitations of the individual, but rather the failure of society and the physical environment to take their needs into account, thereby creating a role of dependency and disempowerment (French, 1994; Jordan & Kaiser, 1996; Oliver, 1996). Pound et al. (2001b) have identified two key concepts as reflecting the essence of this model: disabling barriers; and the concept of disability and identity. Oliver (1996, p.33) powerfully highlights the former by stating that:

“All disabled people experience disability as social restriction whether these restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign language, the lack of reading material in Braille, or hostile public attitudes to people with non-visible disabilities”.

Oliver (1996) emphasizes a diverse range of disabling barriers confronting such an individual, including environmental, informational, and attitudinal barriers. These barriers were construed as being created by a society bounded by non-disabled assumptions, filled with attitudinal stereotypes and institutional discrimination. The second concept, namely disability and identity,

is likewise stressed by Oliver who challenges “the dominant social perceptions of disability as a personal tragedy and the affirmation of positive images of disability through development of a politics of personal identity” (1996, p.89). Tregaskis (2000) refers to the social model of disability as being “an emancipatory concept in the lives of many disabled people” (p.343), and she observes how disabled people in Britain have begun to “reclaim control of their lives” (p.344). Initiatives such as the establishment of the Independent Living Movement, which started in the United Kingdom, and the formation of Disabled Peoples’ International represented the birth of the international disability rights movement worldwide (Disabled People South Africa (DPSA), 2000). These disability movements have constituted powerful lobby groups that continue to pressurize various governments worldwide to implement changes and to gradually erode the stigma of disability. The message conveyed by these groups has been to acknowledge the right of the disabled to be both equal and different – rather than to try and hide their disability (French, 1994). In South Africa specifically, the foundation of the disability rights movement was laid in 1981 – the year designated by the United Nations as the International Year of Disabled Persons. According to the DPSA (2000), the South African Government did not recognize this year, but despite that, disabled activists came together to discuss their marginalization, which, in the context of a racially-segregated South Africa at the time, strengthened their goal to eradicate discrimination on several levels. People with disabilities then started to organize themselves into local groups and in 1984 disabled activists came together in South Africa to form DPSA (2000), which today is a democratic cross-disability umbrella body of organizations of people with disabilities in South Africa, aiming to unite people with disabilities across type of disability, race, gender, language, religion and socio-economic group. Furthermore, through consulting with people with disabilities countrywide, the Integrated National Disability Strategy (White Paper) was formulated in 1997, providing a blueprint for inclusion and integration of disability into every aspect of government in South Africa, and highlighting the challenge of the transformation of attitudes, perceptions and behaviour towards people with disabilities at all levels of society (DPSA, 2000).

Clearly this social model has endeavoured to increase self determination, personal responsibility, self advocacy and participation for the individual with a disability, advocating that the true experts are those who experience the disability firsthand, so that, for example in the case of TBI, the personal reactions and experiences of the individuals and their partners are central to understanding the meaning of living with a TBI. Professionals and individuals with disabilities have since begun to collaborate and share their respective expertise in the endeavour to identify and ultimately remove disabling environmental barriers (Finkelstein, 1991). In the late 1980’s

the consumer movement for individuals, specifically with acquired brain injuries, began to flourish in the USA, resulting in the establishment of the National Head Injury Foundation and the National Aphasia Association (NAA) (Sarno, 1986; Sohlberg & Mateer, 2001b). Sarno (1986, p.23) celebrated the formation of the NAA, adding that although each disability group considers itself a unique minority, “the special problems of the aphasic community transcend those of most disabled groups because the very faculty which gives each of us a voice, the power to communicate, is impaired.” Holland (2000) has noted the following combined group of factors leading to limited self determination for individuals with aphasia including: a) the language impairment itself – making it difficult to advocate on behalf of one’s causes and beliefs; b) society’s unease with brain damage and regarding how to interact with such individuals; and c) until recently the relative lack of advocacy for people with aphasia, resulting in both public ignorance and apathy, which, according to Holland (2000); and Pound et al.(2001b) have recently shown an increase, with support programs flourishing worldwide. As A. Holland has commented (personal communication, June 2, 2004), “My own sense is that it extends beyond aphasia and even TBI to most neurologically-mediated communication disorders Disablement is a societal response to difference as well as a problem to the individual who possesses a disability.”

2.7 Approaches to training communication partners of individuals with neurogenic communication disorders

Shifts within the WHO classification schemes (WHO, 1980, 1997, 2001), together with alterations within the models of intervention, from the medical to the social model of disability, have clearly resulted in the endeavour to extend the view of the individual with a communication disorder from a narrow patient perspective, to that of a “consumer” of society, whose perspective needs consideration (Parr, 1996) in their endeavour to resume their role in society. These shifts have likewise been reflected in the consideration of the facilitators and barriers in the individual’s environment, encompassing the role of the possible range of communication partners within the environment. The training of conversation partners to enhance life participation is consistent with the framework of the ICF model (WHO, 2001), as well as with the social approach to disability. The importance for individuals, that they can participate as valued members of a more facilitative society, is likewise reflected in the literature, where studies by numerous authorities working with individuals with acquired communication disorders such as aphasia , and cognitive–communication disorders (following a TBI) have called for environmental accommodations, contextualized cognitive supports, and the training of

as wide a range of communication partners as possible to communicate more easily and satisfyingly with these individuals (including Coelho, De Ruyter & Stein, 1996; Cottrell, 2001; M.Cruice (personal communication, October 18, 2002); Cruice, Worrall, Hickson & Murison (2003); Elman et al., 2000; Jordan, 2001; Kagan & LeBlanc, 2002; Lubinski, 1981, 2001; Lyon, 1989; Lyon et al., 1997; Pound et al., 2001b, 2001c; Racino & Williams, 1994; Simmons-Mackie & Kagan, 1999; Sohlberg, 2002; Threats, 2002; Togher, 2000, 2001; Togher & Hand, 1999; Togher et al., 1997a, 1997b; 2004; Worrall & Yiu, 2000; Ylvisaker, 2002; Ylvisaker et al., 2003; Ylvisaker, Feeney & Urbanczyk, 1993). In so doing, they will “restore their membership in the human community” (Sarno, 2004, p.29), and impact positively on the quality of life of both the individual with a disability (who will feel more respected and in control of their own lives), as well as their communication partner.

Kagan (1995); Kagan and Gailey (1993); Kagan and LeBlanc (2002) and Kagan et al. (2001) have acknowledged the influence of the earlier writings of Sarno (1993, 1997) in their endeavour repeatedly to highlight the reduced opportunities that individuals with aphasia have to participate in conversation, which in turn “reduces opportunities for revealing competence” (Kagan, 1995, p.17). Kagan and Gailey (1993), in providing a rationale for the need for training conversation partners to create access to conversation for individuals with aphasia, note the absence of anything analogous to wheelchair ramps for these individuals, and advocate the need to create “communication ramps” (1993, p.204). In 2000, Kagan together with Chapey, Duchan, Elman, Garcia, Lyon and Simmons-Mackie joined to form the Life Participation Approach to Aphasia Project Group (LPAA, Chapey et al., 2000). This advocated a consumer-driven model of intervention reflecting 5 core values making real life differences, and minimizing the consequences of the disease or injury. The first of these values is to work towards enhancement of life participation for the individual. Within this framework, Kagan et al. (2001); Kagan and LeBlanc (2002), and Simmons-Mackie et al. (in press) report on programs undertaken under the auspices of the Aphasia Institute, Toronto, where volunteers are trained to use an approach, ‘Supported Conversation for Adults with Aphasia’ (SCA), as a tool for communication partners, providing the necessary communicative support for individuals with aphasia. Kagan et al. (2001, p.634) noted how “the lack of skill of the untrained conversation partners can pose a barrier to effective communication” and advocated training to provide the communication partner with the skill to both acknowledge and reveal the inherent competence of the individual with aphasia. Results provided experimental support for the efficacy of this training in improving such partners’ skills, and Kagan et al. (2001) concluded that the brain injured partners, though not specifically trained, also reportedly improved significantly. Kagan and Shumway (2003a,

2003b, 2003c, 2003d, 2003e, 2003f) have recently developed a series of pictographic resources for various healthcare professionals including chaplains, counsellors and doctors in the ongoing endeavour to empower both the individual with aphasia as well as the communication partner in society, and thereby to lessen barriers. Kagan and LeBlanc (2002), and Simmons-Mackie et al. (in press) use their data to motivate for infrastructure change within the healthcare services in Canada. Such change would aim to provide individuals with aphasia and their families truly client-centered care along with relevant support to enable them to participate in society. Alant and Lloyd (2005) likewise advocate a change of training paradigm for professionals, with an emphasis on focusing on developing support systems to build community capacity for enhancing the participation of individuals with a disability across the range of culturally and socio-economically diverse contexts. In the same vein, Simmons-Mackie et al. (in press) similarly advocate that long-term sustainable changes in communicative access for individuals with aphasia are achievable through programs training different sectors of society to provide communicative supports to these individuals, and in so doing, to increase access and participation. Given the “little information about intervention and outcome related to improved communicative access within the larger realm of society or systems” (Simmons-Mackie et al. (in press)), these clinician-researchers developed the Communicative Access Improvement Project (CAIP). This targeted the training of individuals within the health care systems where people with aphasia face ongoing decisions regarding e.g. menu choices; agreeing to surgery; and decisions re living situations once out of hospital.

More specifically in the area of individuals with AAC needs, Alant (2005a) has referred to the concept of participation as being comprised of levels – and that interventionists need to consider whether the client is participating at a more tacit (more obvious) or deeper level (Seligman, 2002). For sustainable intervention to take place, Alant (2005a) advocates the necessity of a dynamic relationship between participation and skills. Alant (2005b), and Alant and Lloyd (2005) have likewise urged the formation of collaborative partnerships beyond the individual with a disability and their family members, to include the broader community, and in so doing, to facilitate deeper, more sustainable participation for the individual with AAC needs. Despite this call for greater community integration and participation by individuals with disability, with specific reference to the individual with a TBI, Togher et al. (2004) have noted how there are only a few documented cases where community agencies have been trained regarding how to create more normal and respectful communicative opportunities for such individuals through partner training (Holland & Shigaki, 1998; Togher et al., 2004; Ylvisaker et al., 1993).

Table 2.1 identifies research by Togher and her colleagues (Togher, 2000; Togher and Hand, 1999; Togher et al., 1997a, 1997b) who carried out in-depth examinations of the communication interactions of individuals with a TBI, as an emerging rationale for her police officer training program (Togher et al., 2004). In addition, Table 2.1 presents an overview of the published volunteer and communication partner training programs, as well as of programs aimed at training and empowering the individuals with aphasia and TBI themselves, which aim ultimately to facilitate greater community integration for individuals with aphasia and TBI. Closer examination of Table 2.1 reveals the dearth of published research evaluating the effects of training on communication partners of individuals with TBI specifically (noted by Togher et al. (2004), emphasizing the need for such research. More specifically, Togher et al. (2004) note the surprising lack of descriptions of training programs that could be appropriate for training community groups who might interact with individuals with a TBI, in spite of community reintegration being frequently suggested as the primary aim of the rehabilitation of an individual with a TBI (Coelho, et al., 1996; Ylvisaker & Feeney, 1998d).

Table 2.1 Research reflecting published partner training programs of individuals with aphasia and TBI

RESEARCHER	GOAL OF RESEARCH	OUTCOME AND RECOMMENDATION
Lyon, J.G., Cariski, L., Keisler, J., Rosenbek, J., Levine, R., Kumpula, J., Ryff, C., Coyne, S. & Blanc, M. (1997).	Developed a treatment model, Communication Partners, using trained community volunteers to train 10 communication pairs (consisting of patient with aphasia; and caregiver) with effective communication skills both in the clinic, as well as in the home and community twice weekly over a total of 20 weeks.	No significant gains on standardized Aphasia test batteries, but all participants noted statistically significant gains in the aphasic adults' sense of well being, and increased ability to participate in life.
Togher, L., Hand, L. & Code, C. (1997b).	Examined communicative exchanges of 5 individuals with a TBI and 5 matched controls across 4 speaking situations including speaking to a therapist, the police, the bus timetable information service, and their mothers.	Examined disempowering strategies used by partners on the telephone dealing with individuals with a TBI. Urge training individuals to deal more competently with individuals with a TBI in service encounters such as requesting bus timetable information and licenses, and in so doing, to learn how not to disempower the communication partner with a TBI.
Togher, L., Hand, L. & Code, C. (1997a).	Examined and compared the communicative abilities of an individual with a TBI and his brother during 4 communicative interchanges.	Individuals who have sustained a TBI may be compromised in social interactions. Society generally, as well as the individual with a TBI specifically, needs education about interacting more equally and competently.

Table 2.1 (continued). Research reflecting published partner training programs of individuals with aphasia and TBI

RESEARCHER	GOAL OF RESEARCH	OUTCOME AND RECOMMENDATION
Sohlberg, M.M., Glang, A., & Todis, B. (1998).	Trained caregivers using single subject experiments to provide appropriate cognitive support to 3 individuals with a TBI in their natural living environments.	All 3 subject/caregiver groups demonstrated improvement in the target behaviour during the baseline period before intervention commenced. The act of measuring the performance of the subjects and support persons was considered to change the behaviours of the support persons.
Togher, L. & Hand, L. (1999).	Looked at interactions of 7 individuals with a TBI and their matched controls in 2 conditions: speaking to two 16 year olds about driver education; and requesting information from the 2 researchers.	Individuals with a TBI become disempowered when requesting information, versus giving information. Recommend the need to train individuals with a TBI about expected structure and scripts of interactions in order to be more effective.
Booth, S., & Swabey, D. (1999).	Ran a group communication skills program for carers of adults with aphasia over 6 weeks (2 hours at a time), teaching skills, and modifying perceptions about aphasia.	Advice and information about aphasia improved perceptions of caregivers regarding their relatives' aphasia.
Simmons-Mackie, N., & Kagan, A. (1999).	Examined videotapes of good and poor communicative skills of 10 volunteer non-aphasic partners interacting with 10 individuals with aphasia.	Partner training needs to target both communicative skills, and attitudes towards aphasia. The "good" partners judged the individual with aphasia as more competent; interesting and sincere than the "poor" partner.
Worrall, L., & Yiu, E. (2000).	Trained 15 volunteer conversation partners for 2 hours each about stroke and aphasia, and demonstrated a structured functional communication therapy program to use with individuals with aphasia in their homes over a 10 week period. The program focused on 10 general daily communication domains such as banking and using the telephone.	Volunteer training made small (clinically significant) changes in everyday communication of individuals with aphasia, reducing their isolation in society.
Togher, L. (2000).	7 subjects with TBI were compared with 7 matched control subjects across 2 communicative conditions.	Using the tenets of functional linguistics, Togher suggests democratization of discourse via: a) empowering individuals with a TBI by teaching them various discursive skills with various partners (as they appear to communicate better when in a more reciprocal or powerful linguistic interaction); and b) equalizing power relationships with people communicating with individuals with a TBI, training them, e.g. to be less controlling.

Table 2.1 (continued). Research reflecting published partner training programs of individuals with aphasia and TBI

RESEARCHER	GOAL OF RESEARCH	OUTCOME AND RECOMMENDATION
Kagan, A., Black, S., Felson Duchan, J., Simmons-Mackie, N. & Square, P. (2001).	In an effort to increase the social participation of individuals with aphasia (by reducing barriers to effective communication), this study evaluated the efficacy of Supported Conversation for Adults with Aphasia (SCA) which taught conversational techniques to 20 volunteer participants using a 1 day workshop and 1.5 hours of hands-on experience within a 2 week period. 20 other control volunteers were not trained but exposed to people with aphasia only.	SCA training of volunteers increased access to opportunities for conversation by reducing barriers for the person with aphasia. Empirical evidence of positive social and communicative outcomes of training communication partners. Their partners with aphasia also improved significantly even though they did not receive specific training.
Cottrell, S. (2001).	Examined attitudes, perceptions and beliefs of 13 lay people working in a British supermarket towards individuals with communication difficulties following aphasia. Looked at videotaped interviews with an individual with aphasia, and used focus groups and individual interviews to access information.	Noted a varied range of beliefs about communication disability as a result of differing pre-conceived ideas that may not be easily modified. Attitudes of communication partners a key component in attempting to remove barriers and facilitate access.
Togher, L., McDonald, S., Code, C., & Grant, S. (2004).	Trained 10 police officers over a 6 week period to determine whether training these communication partners would enable them to deal more effectively with telephonic service inquiries from individuals with a TBI.	Trained police improved their conversational skills involving individuals with a TBI, thereby enabling such individuals to communicate more appropriately and to resume some of their social roles in the community. Advocate replication of the study using a larger trial to train a range of service providers interacting with individuals with a TBI.
Feeney, T.J. & Ylvisaker, M. (2003).	Collaborated with teachers and parents of 2 children with challenging behaviours resulting from a TBI in order to reduce their challenging behaviours in the classroom and at home. Behavioural, cognitive and executive behaviour supports were implemented.	Reduction of behavioural problems reported in both children, through the use of a support-oriented intervention combining cognitive and behavioural components, with the collaboration of the team and everyday people in the children's environment.

Table 2.1 (continued). Research reflecting published partner training programs of individuals with aphasia and TBI

RESEARCHER	GOAL OF RESEARCH	OUTCOME AND RECOMMENDATION
Braga, L.W., Campos da Paz, A., & Ylvisaker, M. (2005).	Used 2 groups: First group trained parents of children with TBI aged between 5 - 12 years in an intensive 2 week program to work on cognitive and physical abilities within the child's home environment. Weekly follow-ups with the professional team over a year period to work with their children. Second group, the direct clinician-delivered group, received conventional cognitive-physical rehabilitation 2 hours a day 5 days a week over a year period.	Although both groups demonstrated improvements in physical and cognitive functioning, the family-supported intervention group demonstrated statistically significant and clinically important improvements in these 2 outcome domains. Family-supported intervention advocated.
Simmons-Mackie, N., Kagan, A., Christie, C.O., Huijbregts, M., McEwen, S., & Willems, J. (in press).	Implemented the Communicative Access Improvement Project (CAIP) to train teams (including managers, aides, housekeepers as well as professionals) working in an acute care, rehabilitation, and long care health facility with knowledge and skill in providing communicative supports and access to decision-making for people with aphasia. Training took place over 2 days, with a follow-up 4 months later.	The CAIP succeeded in improving communicative access to communication, as well as the decision – making of people with aphasia, thereby increasing their participation. This project considered a useful way of targeting systems level change, and removing barriers within healthcare facilities.

In the area of cognitive rehabilitation specifically (which aims to rehabilitate individuals with cognitive impairments (such as individuals with a TBI)), attention has likewise shifted increasingly towards a consideration of barriers existing within the social environment. Sohlberg & Mateer (2001b, p.3) note how:

“Although some of the fundamental goals of improving and compensating for cognitive abilities continue to be the mainstays of rehabilitation efforts with this population, the last 25 years have allowed a richer appreciation for the influence of contextual variables, the personal, emotional, and social impacts of brain injury; and their interactions with cognitive function”.

These authorities stress how empowerment principles guide rehabilitation efforts so that the rehabilitation should not only build strengths within the individuals and their families, but should also, through a coaching process, assist these people to become involved in planning the intervention, setting goals, participating and evaluating its outcome.

Sohlberg et al. (1998); Ylvisaker and Feeney (1996, 1998b, 1998d, 1998e, 1998f, 2001); Ylvisaker and Holland (1985); Ylvisaker et al. (2001a; 2003) likewise advocate a collaborative brain injury intervention approach for the rehabilitation of individuals with chronic cognitive behavioural and communication impairments after brain injury, using an apprenticeship or ‘supported participation’ model (Ylvisaker et al., 2003, p.9). In this functional and richly contextualized approach, everyday people collaborate with, and provide ongoing supports for the individual with a TBI to participate within the context of their everyday routines (such as in the home, work and school environment). Collaboration ranges from, for example, providing in-service information to relevant everyday people, to situational coaching of both the individual with a TBI and the relevant person in that particular environment (e.g. the teacher, parent, therapist, aide, employer) about ways to use positive behaviour supports and become “facilitative conversationalists” (Ylvisaker et al., 2001a, p.787) in the endeavour to elicit positive, respectful communicative interaction from, and enhanced participation for, the individual with a TBI (Ylvisaker, 2002; 2003). In addition, these authorities advocate the use of projects - taking the form of, for example, collaboratively produced self-advocacy videos (Ylvisaker & Feeney, 1998b, 1998c, 2000; Ylvisaker et al., 2001b), ideally creating an expert role for the person with a disability, which is empowering for the individual, as well as empowering for the targeted individual/s who in turn gain more competence in interacting with that person.

In addition, through working repeatedly on goal setting, planning and monitoring with support by others in everyday contexts, practice becomes increasingly automatic and strategies become increasingly internalized (Ylvisaker & DeBonis, 2000; Ylvisaker et al., 2003). This helps the individuals succeed at levels “beyond those predicted by their degree of neurologic impairment” (Ylvisaker & Feeney, 1996, p.223). Not only has this collaborative/supported participation approach within the individual’s own culture and context been viewed by Ylvisaker and Feeney (1998c); and Ylvisaker et al. (2003) as working towards the goal of a more meaningful and ultimately satisfying life for the individual, but with reference to the ICF (WHO, 2001) this approach can be conceptualized as removing social barriers and improving their ability to participate more deeply and in a more sustainable way in their everyday communities (Alant, 2005a, 2005b; Alant & Lloyd, 2005).

2.8 Summary

The purpose of the current chapter was to describe the conceptual framework of the ICF (WHO, 2001), and the social disability model, specifically in relation to the individual with a TBI. The

chapter began with an overview of TBI and the possible range of cognitive-communication impairments that may result. A more in-depth look at TBI research and the interpersonal functions of language in the interaction between individuals with a TBI and various communication partners was undertaken. Differences between aphasia and TBI were also highlighted. The views of society towards individuals with a communication disorder generally, and with a TBI specifically, were examined, reflecting a general lack of awareness, with an environment concomitantly filled with informational and attitudinal barriers and a resultant marginalisation of the individual in society. The ICF (WHO, 2001) and the social model of disability are used to examine this impact further, and to emphasize the need to create environmentally-and-communication-friendly places for all individuals with communication disorders. One of the ways to achieve this is through communication partner training programs, and the literature reviewed reveals a dearth of published research reflecting such programs using communication partners of people with a TBI. The need for such training (incorporating broader social systems) with skills to provide support, lessen barriers, and empower both the individual with a TBI and their partners, (thereby potentially enhancing life participation), is suggested.