# 'Supported conversation for adults with aphasia~':
# Methods and evaluation

by

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'Supported conversation for adults with aphasia™':
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# ABSTRACT

This thesis reports the development and evaluation of a new intervention termed 'Supported Conversation for Adults with Aphasia™' (SCA™). The approach is based on the idea that the inherent competence of people with aphasia, an adult neurogenic language disorder, can be revealed through the skill of a conversation partner. The intervention approach was developed at a community-based aphasia center where professionally trained volunteers interact with individuals with chronic aphasia and their families.

Current evaluative tools focus exclusively on the person with aphasia and do not capture the impact of the conversational partner on communication. Two complementary evaluative instruments were therefore developed. One was designed to measure the skill of the conversation partner in providing conversational support to the person with aphasia. The second was designed to measure the aphasic individual's level of participation in conversation. Preliminary psychometric evaluation of these measures indicated that they were adequate for the purpose of an experimental study of the efficacy of SCA™.

The experimental study was designed to test a primary hypothesis related to the following question: Do volunteer conversation partners trained in SCA™ score higher than untrained volunteers on a 'Measure of Supported Conversation for Adults with

Aphasia™'? Secondary hypotheses related to the following two questions: a) Do adults with aphasia, in conversation with trained volunteers, score higher than those with untrained volunteers, on a 'Measure of Aphasic Adults' Participation in Conversation' and b) Are changes in volunteers' scores related to changes in the scores of their partners with aphasia?

The study (n=40 dyads) utilized a pre-post randomized control group design. Experimental volunteers received SCA™ training and control volunteers were merely exposed to people with aphasia. Results provide substantial support for the efficacy of SCA™ in training volunteer conversation partners. The methods also appear to be efficient in that training volunteers produced some positive change in the individuals with aphasia even though these individuals did not receive therapy. Implications for the treatment of aphasia and an argument for a social model of intervention are presented.

# ACKNOWLEDGEMENTS

I thank the Institute of Medical Science and Dr. Catharine Whiteside in particular, for allowing me to continue my position as Program and Research Director at the Pat Arato Aphasia Centre while pursuing the doctorate. While this has proved to be challenging at times, without daily access to people with aphasia and their families in an agency dedicated to providing long-term support, it would not have been possible to develop the approach described in this thesis, nor would it have been possible to access the number of participants required for the efficacy research.

I owe an enormous debt of gratitude to my supervisor, Dr. Sandra Black. Her initial enthusiasm for this work, fuelled by her dedication to her patients, was a key factor in my decision to register for a doctorate. She has been a solid rock of support throughout the process, consistently providing expert academic guidance and emotional support. This thesis is undoubtedly enriched by the interdisciplinary nature of my committee (Drs. Judy Duchan, Charles Lumsden, Lynn McDonald and Paula Square) and I consider myself

fortunate to have been the beneficiary of their wide range of expertise. Committee meetings held along the way were always stimulating, challenging and fun.

The Pat Arato Aphasia Centre has been a source of inspiration to me from the day I joined the staff. Pat Arato (the founder of the Centre and the Executive Director during the early stages of the PhD) set an example of 'dreaming big' and making things happen rather than waiting for the right moment. The Board of Directors and Executive Director (Helga Allan) have provided support on many levels and, partly as a result of work done for this PhD, have moved to incorporate research and education as part of the mandate of the Centre. For a community-based agency with on-going funding challenges, their commitment to research and education is remarkable.

My colleagues on staff over this period of time (Lynda Adler, Bea Bindman, Rochelle Cohen-Schneider, Linda Cream, Marcia Demchuk, Elaine Davis, Marlene Gagnon, Judy Hain-Cohen, Susan Jellinck, Lorraine Podolsky, Marc Roberts and Susan Rovillard) could not have been more generous or supportive. Their input at every stage of the research has been invaluable, with many ideas being clarified over lunch or around the coffee machine. Running the controlled trial had an impact on every facet of our program and I thank all concerned for their flexibility. The evolution of 'Supported conversation for adults with aphasia™' was also strongly influenced by interactions with Gillian Gailey (who co-authored one of the publications mentioned above) and Kathy Stiell of the Aphasia Centre of Ottawa-Carleton, and Ruth Patterson and Anne Wells of the York-Durham Aphasia Centre.

When I talk about this research being inspired by the Pat Arato Aphasia Centre, the people who deserve the most credit are our members with aphasia, their families, and

# TO YOU
# MEMBERS, FAMILIES, AND VOLUNTEERS
# AT THE
# PAT ARATO APHASIA CENTRE
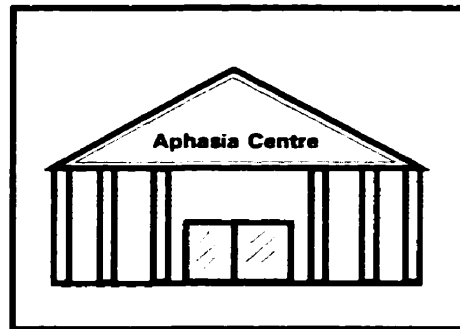


# THANK YOU FOR YOUR HELP
# WITH MY PhD.
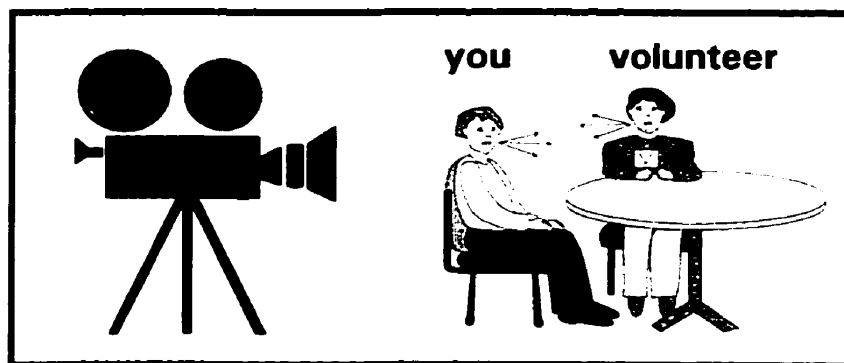


## YOU TAUGHT ME SO MUCH!!



## YOU HELPED ME GRADUATE!!

# LIST OF ABBREVIATIONS

| Abbreviation | Description |
| --- | --- |
| (M)SCA™ | Measure of 'Supported Conversation for Adults with Aphasia' |
| (M)APC | Measure of Aphasic Adult's Participation in Conversation |
| PCR | Pictographic Communication Resources |
| SCA™ | Supported conversation for adults with aphasia™ |
| SLP | Speech-language pathologist |
| WAB | Western Aphasia Battery (Kertesz, 1982) |
| WAB AQ | Aphasia Quotient portion of the WAB |

# NOTE REGARDING SPELLING

American spelling has been used throughout except for the word 'centre' when used as part of the name 'Pat Arato Aphasia Centre', also referred to as the 'Aphasia Centre'

**Supported conversation for adults with aphasia™: Methods and evaluation**

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## Chapter One

# INTRODUCTION

Aphasia can be defined as 'a language disorder that occurs in adults following focal brain damage, typically involving the language-dominant cerebral hemisphere' (Holland, Fromm, DeRuyter, & Stein, 1996). It is most commonly caused by stroke but can also be caused by brain tumors, infections, and head injury. The first written description of aphasia dates back to approximately 2800 BC, with treatment approaches varying through the centuries depending on conceptions of the nature of the impairment (Critchley, 1970; Eldridge, 1968; Howard & Hatfield, 1987). The field of clinical aphasiology as we know it today[1], emerged largely after World War II. Methods that were developed in response to the perceived treatment needs of young head-injured soldiers laid the foundation for many current treatment approaches for older adults with acquired neurogenic communication disorders (Lyon, 1997). Although the roots of modern aphasiology and the history of intervention are diverse and can be found in fields such as education and psychology (Howard & Hatfield, 1987), current practice is still largely influenced by a medical service delivery model designed to assess, treat and preferably cure, disease or impairment (Sarno, 1993).

Sarno (1993) distinguishes between the traditional biomedical approach and that of rehabilitation medicine (encompassing aphasia rehabilitation) which is not as narrow and 'deals with more open-ended goals and outcomes'. However, even in the rehabilitation medicine model, professional speech-language pathologists have traditionally focused most of their attention on restorative treatment to improve the language and/or cognitive impairments induced by injury to the brain (Simmons-Mackie, 1998a). Living with the long-term consequences of aphasia (the chronic stage) receives little professional attention

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[1] According to Crystal (1987), aphasiology is usually considered the 'research field' of aphasia.The field of clinical aphasiology encompasses a broad spectrum of clinical practice and research, including areas such as the neurological, linguistic, sensory, perceptual and motoric aspects of aphasia, as well as work in neuroimaging and pharmacology. In this thesis, however, the term 'clinical

despite the fact that many people are left with residual communication and psychosocial problems following treatment (Sarno, 1993). Nor has there been much attention paid to external factors such as environmental support or barriers that play a large role in determining the impact of the impairment (Parr & Byng, 1998).

Based on informal contact with clinicians and educators, it appears that academic curricula and clinical placements for many North American speech-language pathology students are in line with the focus on the acute and rehabilitation stages of aphasia, and are aimed at restoration or compensation for impairments in the period immediately following stroke. Public and private sector health coverage for aphasia follow the same pattern, with recent changes in health care in the USA resulting in an even shorter period of time allocated to rehabilitation (Elman, 1998).

In the past few decades, professionals have begun to recognize that this model of service delivery with its focus on impairment during the acute and rehabilitation stages of aphasia, has been too narrow. LaPointe (1978) describes the 'treat and hope for generalization' approach to intervention often assumed by clinical aphasiologists. However, as noted by Lyon (1992) improvement in treated language deficit areas based on linguistic and cognitive therapies has *not* easily generalized to better function in daily life. Influenced by the development of speech act theory which regards 'talking' as social action (Austin, 1962; Searle, 1969), and the field of pragmatics (Penn, 1988; Prutting & Kirchner, 1983; Schiffrin, 1988), experts in the field of aphasia began to study different uses of language in real-life contexts. This led to the development of functional communication methods based on the idea that context is important and that communication is more than verbal language (Holland, 1977; Lubinski, 1981). Many practitioners have since adopted these ideas when assessing and treating those who have aphasia. The approach is epitomized in the method

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aphasiology' will be used as described by Aten (1994), to refer to activities related to improving the communicative abilities of those with aphasia.

"Promoting Aphasics' Communicative Effectiveness" (Davis & Wilcox, 1981) where
participants are encouraged to get their message across by non-verbal as well as verbal
means, based on the maxims of cooperative conversation (Grice, 1975). In recent years,
speech-language pathologists with expertise in the field of augmentative and alternative
communication have used communication systems and techniques to incorporate broader
social parameters into intervention for aphasia (e.g., Fox & Fried-Oken, 1996; Garrett &
Beukelman, 1992). The approaches described above begin to take account of the level of
'disability' (based on the World Health Organization's (1980) model of impairment, disability
and handicap), but still do not take sufficient account of the personal experience of living with
aphasia (Simmons-Mackie, 1998a).

Aphasia has an impact on psychosocial areas such as identity, self-esteem, relationships,
and role (Herrmann & Wallesch, 1989; Lafond, Joanette, Ponzio, DeGiovani, & Sarno, 1993;
Sarno, 1986; Wahrborg, 1991; Wahrborg & Borenstein, 1989). Despite the fact that social
isolation is one of the most frequently reported consequences of aphasia (National Aphasia
Association, 1988), psychosocial intervention is not often considered to be the domain of
speech-language pathology (Byng, Pound, & Parr, in press; Simmons-Mackie, 1998a). Byng
et al. make a cogent case for working simultaneously in the communication and
psychosocial realm. They regard the emotional and social consequences of aphasia, *for all
those affected*, as legitimate areas for speech-language pathology intervention. Work on the
social role of communication (Brown & Yule, 1983; Goffman, 1959; Gumperz, 1982a;
Gumperz, 1982b; Schiffrin, 1987; Tannen, 1984), lends support to this argument.

Intervention in the field of aphasia does not belong solely to professionals. Individuals and
families affected personally by this disorder have also played an important role in the
creation of intervention programs. The Pat Arato Aphasia Centre in Toronto (hereafter
referred to as the 'Aphasia Centre'), is an example of an intervention that has been initiated

and organized by families[2]. The Aphasia Centre, a community-based agency utilizing the services of many professionally trained community volunteers and serving the long-term needs of individuals with chronic aphasia and their families, was the inspiration and testing ground for the doctoral research program that makes up this thesis.

In line with developments in the field in the 1980's, the communication program at the Aphasia Centre shifted from a focus on 'talking' to a focus on 'communicating'. Volunteers worked on strategies to help improve the functional communication skills of the members[3] of the Centre, and were asked to evaluate each activity in terms of the question: "Is this going to make a difference to his or her ability to communicate in the 'real' world?" Activities that did not relate to real-world needs were not encouraged. The outcome of this functional communication approach was evaluated informally in terms of members' independence in daily living, for example, shopping and choosing purchases on their own, or being able to indicate what they wanted to order in a restaurant.

A small pilot study was conducted to examine functional outcomes related to the above intervention (Kagan & Gailey, 1990). We experimented with the Communicative Effectiveness Index (CETI) (Lomas et al., 1989), and compared it to results obtained on the Western Aphasia Battery (WAB) (Kertesz, 1982). Part of the study involved administration of the above measures to eight people with chronic aphasia who attended the Centre. Although the absence of a control group did not allow for conclusions related to the efficacy of the intervention, results of pre- and post-testing over a 4-month period provided evidence of significant change in several of the 16 communicative situations assessed on the CETI; as expected, there was no change on the WAB.

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[2] The Aphasia Centre was founded in 1979 by Pat Arato, the spouse of a relatively young person with aphasia who had been discharged from therapy. Together with a small group of volunteers, she began a communication program for others in a similar position 'to give aphasic people hope; to help them to talk; to let them know that life had not come to an end and that there was still somewhere for them to go".
[3] The Aphasia Centre deliberately uses the term 'members' rather than 'patients'.

In discussion of this pilot work, we came to realize that the changes in perceived communicative effectiveness did not capture the more dramatic psychosocial changes in members that staff, families, and volunteers observed informally on a daily basis. For example, members who attended the program at the Aphasia Centre appeared to be more motivated, and showed increased confidence in their communication and social interactions, parameters which went beyond the confines of both language ability and functional communication skills measured on the CETI. All agreed that these psychosocial changes were even more important than changes in communication. This raised questions about the role of the speech-language pathologist. Were we running a purely social/recreational program? Was there a professional role for the speech-language pathologist in carrying out these activities, and if so, what exactly was it?

We had been attributing improvements in psychosocial functioning of our members to the general positive atmosphere at the Aphasia Centre, personal qualities of staff and volunteers, and the socialization that occurred *between* the 'communication' sessions; in other words, anything but professional intervention. Contact with Jon Lyon (1989), however, led us to examine the potential role of the speech-language pathologist in achieving psychosocial goals. Within this framework, we became increasingly aware that increased social interaction, always acknowledged as important, was also directly related to the type of communication program that existed at the Aphasia Centre. Through training by professionals, volunteers had acquired skills that enabled natural and spontaneous interactions to occur. The author's exposure to an interview with Emanuel Schegloff (1990) on the central role of conversation in everyday life, provided further insight into what was being observed in our members, namely, that it was the use of communication skills for the purpose of conversation and socialization that resulted in the psychosocial change. By offering *opportunities for conversation*, volunteers were functioning as a 'communication ramp' to normal social interaction.

The difficulty in interpreting the contribution of speech-language pathologists to improving social interaction can be understood in terms of the history of aphasia therapy and the training we receive as speech-language pathology students and professionals. The profession has generally focused on a particular role for speech-language pathologists, namely that of a 'fixer' of linguistic and/or cognitive aspects of communication deficits. In the context of aphasia, the shift in focus from language usage to functional communication, although striking in its impact on therapy goals, procedures, and criteria of evaluation has not essentially altered this 'fixer' role. Most speech-language pathologists still perceive their goal to be improvement in the communication skill of the person with aphasia (Simmons-Mackie, 1998a).

Our initial discomfort in using speech-language pathology expertise to provide those who have aphasia with opportunities for mutually satisfying conversation, was related to a move away from this traditional 'fixer' role. In offering conversational opportunities, the role of the speech-language pathologist expands to include deliberate attempts to reduce levels of frustration, with the aim of allowing the participants to 'forget' about the aphasia to the extent possible. We asked ourselves whether it was appropriate for speech-language pathologists to use their professional training in this way.

We concluded that a shift in focus was both appropriate and necessary. This came in part, through a reconsideration of functional activities within a real life context, for example, going out to a restaurant. For most of us, a visit to a restaurant is a social occasion, an opportunity to chat to friends while enjoying a meal. Although success in functional terms might be defined in terms of the ability to independently order from the menu, few of us would consider this to be the real purpose of eating out. The shift in focus is also supported by more recent research indicating dissatisfaction with traditional approaches to aphasia. For example, interviews with people who have aphasia (Le Dorze & Brassard, 1995; Parr, Byng,

Gilpin, & Ireland, 1997) highlight the fact that traditional treatment fails to address the social

consequences of the disorder (Simmons-Mackie, 1998a).

These insights led me to undertake the development and formalization of an approach to

aphasia entitled 'Supported conversation for adults with aphasia™' (SCA™) as a doctoral

project. SCA™ evolved in response to the needs of a particular population (individuals and

families living with aphasia), in a particular context (the Pat Arato Aphasia Centre). It also

draws on work in the field and is congruent with a small but significant movement toward

bringing a social perspective to aphasia intervention (Jordan & Kaiser, 1996; Lyon, 1992;

Parr, 1996; Parr & Byng, 1998; Simmons-Mackie, 1998b; Simmons-Mackie & Damico,

1996a; Simmons-Mackie & Damico, 1996b; Simmons-Mackie & Damico, 1995).

The social approach to aphasia involves a shift in thinking that moves from working solely on

the impairment of the individual, to examining the role of the environment and society in

creating barriers to life participation. This model anchors the SCA™ approach and is

discussed in more depth in chapter two.

The chapters in this thesis reflect the research program that evolved as several conceptually

related projects in the development of SCA™ concepts and applications. The projects

employed a combination of observational and quantitative research methods with the

following objectives:

- Creation of a conceptual framework for SCA™. This project is described in

  chapter two and presents the philosophical underpinnings and rationale for

  SCA™, with reference to the literature.

- Design of an intervention providing training for the conversation partners of adults with aphasia. Chapter three details SCA™ training methods and resources based on the conceptual framework outlined in the second chapter.

- Development of evaluation tools for examining efficacy and outcome of the intervention. Chapter four describes the psychometric development of clinical and research measures designed to rate conversation between adults with aphasia and their conversation partners.

- Design and conduct of an efficacy study. Chapter five provides the results of a randomized clinical trial designed to assess the efficacy of SCA™ methods.

Chapter six concludes with a discussion of the clinical applications of SCA™ and places SCA™ within the context of the most recent North American developments related to social approaches to aphasia.

# CONCEPTUAL FRAMEWORK UNDERLYING

# 'SUPPORTED CONVERSATION FOR ADULTS WITH APHASIA™'

Over fifty years ago, the World Health Organization (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1947). How does current practice in clinical aphasiology relate to the WHO concept of health? The scope of practice in this field has traditionally focused on neurological and linguistic/cognitive impairments or infirmity (Paradis, 1993; Peach, 1993; Rosenbek, LaPointe, & Wertz, 1989; Wepman, 1972). This is not surprising since the combination of 'focal brain-damage' and 'acquired language disorder' form the common denominator in most traditional definitions of aphasia. These definitions of the disorder give validity to the efforts of speech-language pathologists to restore and improve language abilities and performance and/or to help compensate for the language disabilities of those with aphasia. While many speech-language pathologists hold mental health and social well-being to be ultimate outcomes, practice remains largely impairment-based and narrower than the approach forwarded in 1947 by the World Health Organization.

Recent trends in the aphasia literature toward what has been described as a social model of aphasia are discussed below. These better reflect international trends in health rehabilitation set by the World Health Organization (ICIDH-2, 1997) because they attend *directly* to the importance of social outcomes of intervention. With the social model as context, the rest of this chapter consists of the presentation and elaboration of the core components of the conceptual framework underlying 'Supported conversation for adults with aphasia™' (SCA™).

## A social model of aphasia

The emerging social perspective on rehabilitation in aphasia recognizes, either implicitly or explicitly, that social outcomes such as increasing opportunities for participation in daily life involve more than focusing solely on the impairment or deficits of the person with aphasia. Theories, research and intervention programs have thus emerged that extend beyond the remediation of deficits (e.g., Bernstein-Ellis & Elman, 1999; Boles, 1997; Byng et al., in press; Hickey, Rogers, & Olswang, 1995; Jordan, 1998; Jordan & Kaiser, 1996; Kagan, 1995; Kagan & Gailey, 1993; Le Dorze & Brassard, 1995; Lyon et al., 1997b; Parr, 1996; Parr & Byng, 1998; Pound, 1997; Simmons-Mackie & Damico, 1996a).

The 'social model', as applied to aphasia, has two complementary frames of reference; *societal* and *communicative*. The *societal* perspective emphasizes the human rights issues involved in reducing barriers to communication and life participation (Parr & Byng, 1998). Work on the societal level has been influenced by the writings of members of the disability movement in the UK (e.g., Finkelstein & French, 1993; Oliver, 1996). This movement defines disability in terms of societal barriers and restrictions rather than in terms of an individual's inability to carry out normal activities (Byng et al., in press). The *communicative* perspective emphasizes social interaction within the context of conversation (Simmons-Mackie, 1998b) and takes into account the immediate environment of those affected by aphasia. Both perspectives support the notion of empowerment and of reducing the social consequences of aphasia. They also share the view that the person with aphasia should be treated as part of a social unit in a real-life context. There is an interest in "how the system copes, rather than on how the aphasic individual adapts in isolation" (Parr & Byng, 1998). In these terms, intervention has to be broader than addressing only the language disorder (or compensation for the language disorder) and should incorporate the dyad and/or group from the onset of aphasia through to stages where individuals are learning to live with aphasia in the long term.

In the North American context however, speech-language pathologists, like physicians (Roter & Hall, 1993), are generally not trained within a framework that allows them to connect their professional expertise to the achievement of long-term psychosocial goals for their patients (Lyon, 1992). Once the patient stops improving, usually evaluated in terms of scores on standardized language tests which tap traditional linguistic parameters such as syntax, semantics, and phonology or cognitive-linguistic parameters such as semantic memory, speech-language pathologists no longer have a defined role (Simmons-Mackie, 1998a). Treatment is terminated and the person who has not fully recovered is often labelled as having 'chronic aphasia'. By definition then, chronic aphasia is not regarded as a valid area for professional intervention. This is part of a larger issue affecting medical practice whereby chronic problems may be devalued or ignored because they lack 'the visibility and fascination of the [high-tech] dramas played out in acute care settings' (Jennings, Callahan, & Caplan, 1988, cited in Sarno,1993). Roter and Hall (1993) point out that although chronic problems might not be technically complex, they are extremely challenging in terms of requirements for life-style change and dealing with emotional distress.

Intervention that fails to take these issues into account is incomplete as many adults with aphasia remain socially isolated after discharge from therapy (Brumfitt, 1993; National Aphasia Association, 1988; Sarno, 1986; Sarno, 1993; Sarno, 1997). The nature and impact of this social isolation is not always fully appreciated. When applied to aphasia, the phrase 'social isolation' does not refer to merely having less social contact than one would like, or feeling lonely. People with *intact* language can experience social isolation to some degree. For many people with aphasia, however, the loss of language means social isolation in the most fundamental and devastating sense. It can mean the loss of one's place in society, ranging from the personal (e.g., one's place in the family or a relationship), to the sociopolitical (e.g., voting in an election). It can mean the loss of opportunity to participate in decision-making. Families of aphasic individuals are equally affected. For example, spouses

at the Aphasia Centre have told us of their overwhelming sense of loneliness while sitting in the same room as their partner with aphasia. Penn presents a poignant case in which an individual with mild aphasia committed suicide after completing what was felt to be successful treatment (Penn, 1993). This should alert us to the fact that we need to pay attention to the psychosocial impact of aphasia, whatever the stage of recovery, and whatever the degree of severity.

The importance of psychosocial factors is acknowledged in the aphasiology literature (e.g., Herrmann & Wallesch, 1989; Lafond et al., 1993; Sarno, 1986; Wahrborg, 1991; Wahrborg & Borenstein, 1989). However, speech-language pathologists who have made efforts to acquire appropriate skills in counselling and education are not always seen as working within their professional boundaries. In addition, Lyon (1992) points out that these interventions have been restricted to 'learning to cope' with the disability. In other words, work in the psychosocial area has focused more on the individual's responsibility (the 'psycho-' aspect) rather than on 'social-' aspects or responsibilities. The interpretation of 'psychosocial' suggested in this thesis, is of a different nature, and emphasizes the importance of understanding the social role that communication, and specifically conversation, play in everyday life. It implies a professional obligation to do something about social factors *outside the individual* in addition to helping him/her learn to accept or cope with the aphasia.

The social model provides a strong rationale for using the skills of speech-language pathologists as communication experts to work on enhancing life participation for the person with aphasia and *all those affected by aphasia*, particularly the family, throughout all stages of living with aphasia (LPAA Working Group, in submission). Work on increasing life participation includes:

- initiating and maintaining social connections

- increasing involvement in a broad range of life activities, and

- promoting internal well-being.

The development of 'SCA™' can be viewed within the above context.

## The conceptual framework for SCA™

The conceptual framework underlying SCA™ is based on an expansion of the traditional definition of aphasia as an acquired neurogenic language disorder, to include the idea that aphasia often masks inherent competence normally revealed in conversation. This expanded definition has implications for an expanded scope of professional practice. By requiring a focus on competence as well as deficit, and by targeting conversation, the key to accessing participation in everyday life, this definition of aphasia moves directly into the realms of mental health and social well-being suggested by the WHO definition of health.

These ideas are an extension and formalization of earlier work by the author and other speech-language pathologists in an agency that allows for unlimited access and continual exposure to a pool of hundreds of adults with chronic aphasia, family members, and volunteers, over many years (Kagan & Gailey, 1993). Central concepts first emerged informally, based on daily experience and exposure to the ideas of others in the field. Subsequently, an on-going cyclical discovery process that involved extensive observation of interactions between individuals with aphasia and speaking partners (volunteers and professional staff), followed by a search for emergent patterns or ideas, served to refine

concepts that formed the basis for the development of an intervention and methods of evaluation. Further detail regarding this process is provided in subsequent chapters.

The core conceptual components underlying SCA™ are illustrated in Figure 2.1 and are embodied in the following argument.

A. *Aphasia can be defined as an acquired neurogenic language disorder that may mask competence normally revealed in conversation* (Kagan, 1995). Many aphasic individuals find it hard to engage in conversation and reveal what they know, think or feel. They are often regarded and treated as incompetent as evidenced in studies by Le Dorze & Brassard (1995), and Parr (1997). Their 'decision-making capacity' may be questioned, or they may be regarded as incompetent in terms of 'knowing what is going on' or being socially adequate (Kagan, 1995). The fact that individuals with aphasia retain competence in many areas is not traditionally included in definitions of aphasia; neither is the mental health or psychosocial impact of the 'masking' of this competence (see review of definitions by Chapey, 1994; Rosenbek et al., 1989).

B. *Conversation is central to life participation.* Members of our society typically evaluate competence through conversational interaction with other people. In order to fully appreciate the impact of aphasia as defined above, it is important to recognize the central role that conversation plays in our lives. Schegloff (1990) describes the scope of conversation as follows: "In dealing with talk and interaction, we are dealing with the primordial site of human life. This is where the work of society gets done".

Figure 2.1 Schematic model illustrating core SCA ™ concepts and the
long-term psychosocial implications of aphasia (adapted with
permission from Kagan 1995).
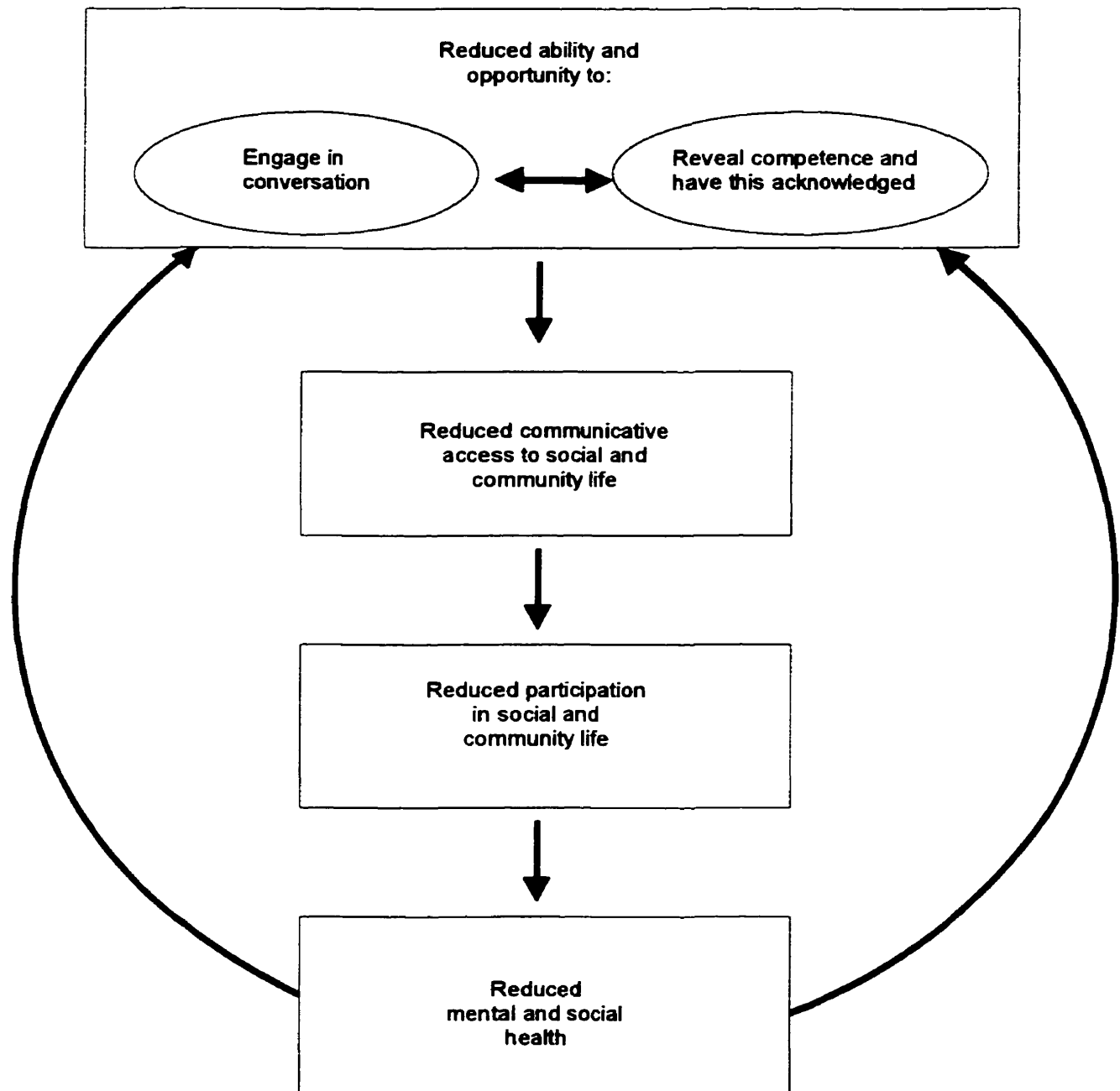
C. *There is an interactive relationship between perceived competence and opportunity for conversation.* When individuals with aphasia are perceived as incompetent, their opportunity to engage in conversation may be reduced. This view is supported by literature in the fields of communication in relation to aging (e.g., Ryan, Meredith, MacLean, & Orange, 1995), co-construction of competence and incompetence (e.g., Duchan, Maxwell, & Kovarsky, I999), perception of competence in medical settings (e.g., Robillard, 1994), and perceptions of competence related to the use of augmentative and alternative communication devices (e.g., Higginbotham & Wilkins, 1999).

D. *The ability and opportunity to engage in conversation and reveal competence lie at the heart of 'communicative access' to participation in daily life.* As adults with aphasia tell us in their own words, many are denied communicative access in situations such as participating in family events or discussions, interacting with the family doctor, or contributing to daily decision-making (Parr et al., 1997). Reduced communicative access has a direct impact on psychosocial well-being and quality of life.

E. *Competence of people with aphasia can be revealed through the skill of a conversation partner who provides a 'communication ramp' for increasing communicative access.* In order for conversation partners to function effectively, a new/additional set of skills is required.

Each element of the above argument will be elaborated below with reference to existing literature. This will be followed by a summary highlighting key SCA™ concepts developed by the author which are innovative in terms of the theory and practice of speech-language pathology.

### A. The concept of masked competence

Members of the Aphasia Centre have expressed that one of their greatest fears is being thought of as 'stupid'. Because of the communication difficulty associated with aphasia, many people are not aware of the inherent competence of aphasic adults, and do not intuitively know how to facilitate conversation with them, particularly when the aphasia is severe (Kagan, 1995; Kagan & Kimelman, 1995). For the purpose of this study, the term 'competence' refers to the ability of many aphasic adults to capitalise on premorbid cognitive and social abilities if given the opportunity.[4] As illustrated in the attached videotape (Kagan, Winckel, & Shumway, 1995a, see Attachment 1), such competence can easily be masked by aphasia. This affects the way that individuals with aphasia[5] are perceived and treated, and often results in additional barriers to life participation.

Weisstub (1990, p.27) notes that competence is a value-laden term - " a fluid notion, without basis in an absolute standard". Competence is interpreted in three ways in this thesis. The first reflects the common usage of the word. In this context, competence is seen as the ability to carry out tasks well, and to cope in complex situations. The concept of an 'active mind' is inherent in a judgement of competence - the idea that someone 'knows what is going on'. Second, from a medico-legal perspective, competence (or capacity) involves rational decision-making related to specific situations, and is based on the ability to understand information (Alexander, 1988; Weisstub, 1990). Examples of situations include financial management, making a will, and informed consent related to health care issues. The medico-legal perspective does not take a third view of competence into account, namely social competence – the ability to navigate social situations and interact meaningfully with other people. Social competence (and its perception by others) is central to the ability to fully

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[4] This does not necessarily imply fully intact cognitive functioning. The aphasiology literature reveals a diversity of views on the subject of cognition. For example, Chapey (1986), considers impairments in both language and cognition to be central, while Martin (1981) views impaired cognition, rather than language, to be at the heart of the problem.

participate in everyday life. The latter view is supported by Goffman's (1959) theory of 'dramaturgical selves' whereby assigned or assumed roles determine participation in life events, and by Duchan et. al.'s (1999) work on the evaluation of competence in the context of everyday interaction. Research in the field of traumatic brain injury lends further support to the importance of social competence to life participation. Individuals who have sustained traumatic head injuries are often left with residual difficulties in executive function and pragmatics (socially appropriate communication). These difficulties, even when subtle, have a dramatic impact on the ability to return to work and re-engage in life, despite the fact that the ability to receive and convey everyday information remains relatively intact (Ylvisaker & Szekeres, 1994).

Regardless of which specific interpretation is employed, *the ability to communicate, and specifically, to engage in conversation, is key to revealing competence in many instances.* The term 'communicative competence', first coined by Hymes (1972), is commonly defined in terms of the effectiveness and appropriateness of communication. When a person has difficulty in talking and understanding what is said, and doesn't sound appropriate, it is hard to 'see' the active mind; it is difficult to envisage the capacity to make life decisions; and it is difficult to think of the person as a competent social being. These perceptions affect the way the person with aphasia is likely to be treated, as illustrated by Tippett and Sugarman (1996) in their discussion of opportunities for those with aphasia to discuss advance directives under the patient self-determination act. The consequences of reduced ability and opportunity to reveal competence through conversation are best understood by realizing the pivotal role of conversation in everyday life[6].

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[5] Although the impact of masked competence is most dramatic when aphasia is very severe, individuals with mild aphasia are also significantly affected.

[6] Attitudes to conversation differ in different cultures. Based on their work with children, Crago and Cole (1991) suggest that factors such as conversation partners, verbal and non-verbal interaction, amount and duration of talk, and choice of topic are cultural dimensions to consider. The concept of conversation should therefore be interpreted judiciously in terms of cross-cultural application.

## B. The central role of conversation in everyday life

The focus on conversation draws on literature that regards ordinary *social conversation* as a primary communication genre in our society (Drew & Heritage, 1992; Goodwin, 1995; Schegloff, 1987; Schiffrin, 1988; Whurr, Lorch, & Nye, 1992). Schegloff's (1987) term 'talk-in-interaction' renders conversation in its broadest sense, encompassing almost every facet of human life. As applied to the practice of medicine for example, Roter and Hall (1993, p.3) refer to talk as "the main ingredient in medical care". This talk is more than social chat.[7] It includes case-history interviews, counselling, discussing treatment options and giving advice. In addition to the function of conversation in establishing rapport, and the therapeutic power of talk (White, 1988), Roter and Hall feel that even the technical side of medicine depends on being able to talk to the affected person. They give as an example the fact that when dealing with an unconscious patient, there is a need to supply what is missing by talking to family members/friends. Many aphasic individuals effectively find themselves in a situation similar to that of the unconscious patient.

Speech-language pathologists are most familiar with the term 'conversation' in the context of discourse analysis within a sociolinguistic tradition. Armstrong (1993) describes two main perspectives in clinical aphasiology: sociolinguistics where text or discourse is regarded as the basic unit of language, and psycholinguistics, which regards the word as the basic unit of language. In this thesis, however, the term 'conversation' is used in a broader context that goes beyond linguistics, to include social interaction, drawing more from the fields of sociology (e.g., Goffman, 1959; Goffman, 1974), anthropology (e.g., Gumperz, 1983; Hymes, 1974) and philosophy (e.g., Austin, 1962; Grice, 1975; Searle, 1969). Conversation analysis, an ethnomethodological approach that aims to uncover the recurring patterns of

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[7] Although a certain amount of medically unrelated social chat is positive, too much is regarded negatively by consumers of health services (Roter & Hall, 1993).

talk within a sociocultural context (Sacks, Schegloff, & Jefferson, 1974; Schegloff & Sacks,

1973), has considerably influenced the study of conversation in interaction (Mentis &

Thomson, 1991).

### Conversational transaction and interaction

Schiffrin (1988) highlights the dual nature of conversation; while it is a verbal activity, it is at

the same time "a vehicle through which selves, relationships and situations are socially

constructed" (p. 272). In a similar vein, Brown and Yule (1983) give this duality clinically

useful labels, namely transaction and interaction. *Transaction* involves the exchange of

content (in relation to information, opinions and feelings), while *interaction* involves social

connection. The transaction/interaction distinction has recently been employed by Simmons

in an in-depth ethnographic study of compensation in aphasia (Simmons, 1993; Simmons-

Mackie & Damico, 1995). She videotaped conversations with aphasic individuals and

interviews with therapists, family members and members of the public. Simmons (1993) re-

interprets situations which many speech-language pathologists would regard as a failure to

generalize compensatory strategies (e.g., not using a communication book). She suggests

that these 'failures' might instead indicate an acute awareness on the part of the individual

with aphasia that such strategies interfere with interaction in certain social settings.

Interactive aspects of communication have typically been neglected by speech-language

pathologists (Simmons, 1993; Simmons-Mackie, 1998b). In the field of augmentative and

alternative communication, for example, Light (1988) pointed out over a decade ago that

most researchers view the goal of interaction as the exchange of information, and do not pay

attention to the goal of developing 'social closeness'. There are at least three possible

explanations for this neglect. First, practice has been based on linguistic rather than social

theory. Second, on a concrete level, conveying information content is the 'stuff' of

conversation. Interaction is more difficult to capture, define and measure. Third, in the eyes

of many speech-language pathologists, aphasic individuals already have intact 'social' skills. Holland's well-known statement that aphasic individuals 'communicate better than they talk' (Holland, 1977) is supported by studies illustrating that pragmatic skills are superior to linguistic skills for adults with aphasia (Aten, Caliguiri, & Holland, 1982; Penn, 1988; Wilcox & Davis, 1977). However, the fact that *professionals* acknowledge that pragmatic skills are usually relatively intact, does not mean that individuals with aphasia are necessarily regarded as socially competent by society in general. In fact, based on what people with aphasia tell us, the opposite is often the case (Parr et al., 1997).

## The relationship between transaction and interaction

Social interaction is inextricably bound up with verbal content or transaction. It is therefore the *relationship* of transaction and interaction that is relevant, rather than a shift from a transactional to an interactional focus. Imagine trying to engage in 'small talk' without talking![8] In other words, even in conversations where there is little actual exchange of information (e.g.,, ritualised social greeting or 'getting to know you' talk), social interaction is almost always supported by what sounds like information exchange. The fact that this is so effortlessly achieved attests to the particular efficiency of the verbal medium. Achieving the goal of interaction when there is no longer automatic support by the verbal transactional process is possible, but challenging. Speech-language pathologists are frequently confronted with situations where the person with aphasia insistently indicates 'I want to talk', despite the fact that non-verbal message transaction may be successful. It is appropriate to acknowledge that much more than information transfer is lost when verbal transaction is diminished.

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[8] Sign language achieves the same goal as talking in terms of of its ability to simultaneously support transactional and interactional processes

Acknowledging the significance of verbal loss does not mean that non-verbal communication is regarded as secondary. Non-verbal communication is an integral part of normal communication. DiMatteo (1979), for example, talks about the impact of body language and tone of voice in the doctor-patient relationship. Non-verbal communication also plays an essential role in compensation for verbal difficulties in aphasia. However, in normal communication, there is a complex integration of non-verbal *and* verbal activity.

### C. The relationship between conversation and competence

The idea that there is a relationship between conversation and competence forms a cornerstone of the SCA™ approach and grew largely out of the author's experiences at the Aphasia Centre. It is based on the following line of thinking.

Prutting (1982) talks about pragmatics as social competence. As normal speakers, we constantly reveal our competence through conversational interaction and transaction. Competence is *implicitly acknowledged* by participants in the very act of the ongoing conversational activity. The use of humour is one example of the implicit acknowledgement of competence. Because 'getting a joke' is a sophisticated cognitive act, in its telling we are implicitly acknowledging this cognitive ability as well as giving an opportunity to all participants in the conversation to reveal social skill and demonstrate cultural membership. (This may be the reason that humour is such an effective social lubricant.)

There is clearly a set of conventions governing the complex relationship between conversation and acknowledging competence. We talk to others in a way that acknowledges their competence. If we fail to do this, we are accused of being patronising. When someone does not appear competent, we alter our way of speaking. Elderly and institutionalised patients, for example, are often spoken to in 'elderese' (Coupland, Coupland, & Giles, 1991; Ryan, Bourhis, & Knops, 1991; Ryan et al., 1995; Wood & Ryan, 1991). The problem is

endemic as indicated by the title of an international conference on communication in the elderly - "How are we today, dearie?" (International Conference on Communication, Aging and Health, 1994).

Reduced opportunity to engage in conversation affects opportunities for revealing competence which further reduces opportunities for conversation and interaction. This negative downward spiral erodes communicative access to participation in virtually all aspects of everyday life with profound psychosocial consequences. This is often not taken into account in traditional deficit or impairment-based interventions aimed at reducing communication difficulties (Simmons-Mackie, 1998a). Within these interventions, pinpointing deficits is deemed essential for planning treatments that improve the aphasic person's ability to manage independently in real-life situations where they do not receive support. However, we need to examine our success rate in helping those with aphasia feel competent in talking and interacting with others in these situations. Simmons (1993) describes a turning point in her approach to aphasia therapy when she observed that an individual who had done well with functional communication methods (conveying messages by whatever means) was unable to manage an interaction with a waitress at a lunch to celebrate his success in therapy. In other words, improving the communication of the person with aphasia is no guarantee of successful interactions in the world outside the therapy room. The responsibility needs to be shared with others in the environment who need to understand that the person with aphasia is inherently competent and that conversation is a possibility despite the apparent communication problem. Expanding the scope of traditional speech-language pathology practice to address issues such as these, requires a different way of thinking.

### D. Communicative Access

When the term 'access' is used in relation to disability, 'physical' access to life events is invariably stressed. There are, however, at least *two* essential access routes to life participation - physical and communicative. For example, while physical access to a building is essential to join in an activity at a local community centre, it is not enough. One also has to be able to communicate with instructors and others involved in the activity. Finding out about the activity, making enquiries about time and cost, often requires talk. Furthermore, conversation itself is frequently an integral part of the activity.

The disparity in approaches to physical versus communicative access is highlighted in rehabilitation practices. When patients with a physical disability such as hemiplegia following a stroke are discharged from therapy, those still unable to walk independently are given an aid to facilitate physical access. Practice with the aid is often incorporated into therapy. In addition to the aid, many communities recognize the importance of being as physically accessible as possible. The wheelchair ramp is one of the more obvious examples.

What happens to the patient with aphasia who is not able to participate independently in conversation at the time of discharge? There is currently nothing analogous to the wheelchair ramp that facilitates access for those with physical disability. Without a 'communication ramp', aphasic individuals are excluded to a greater or lesser extent, from participation in everyday life (Kagan & Gailey, 1993). Anything which impedes communicative access has potential psychosocial repercussions such as depression[9], which, in turn, lessen the desire to participate.

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[9] Depression following aphasia has been well documented (Starkstein & Robinson, 1988)

Aphasia can have an impact on communicative access to the very health professionals[10] who should be in a position to help deal with the host of challenges that arise. There are some studies examining the impact of psychosocial factors such as education, likeability, social class, gender and age on the medical visit (Roter & Hall, 1993), but investigation of the effect of communication disorders such as aphasia on interactions with health professionals is conspicuously absent. Many individuals with aphasia complain that their physicians ignore them and talk to their family members instead.

Intrinsic to the SCA™ approach is the idea that people with aphasia have a right to communicative access in the same way that they have a right to on-going physical access when therapy cannot restore normal function. In the case of aphasia, the 'communication ramp' takes the form of a skilled conversation partner, appropriate resource material and an 'aphasia -friendly'[11] environment (Kagan, 1993; Kagan & Gailey, 1993). This view is supported by the 'Communication Bill of Rights' (National Joint Committee for the Communicative Needs of Persons with Severe Disabilities, 1992) which states that 'All persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence".

### E. Conversational partnerships

The idea of training conversation partners is supported by well-accepted notions of the collaborative and co-constructed nature of conversation (Clark & Wilkes-Gibbs, 1986; Goodwin, 1995; Grice, 1975; Milroy & Perkins, 1992) which is exemplified by our intricate systems of conversational sequencing, turn-taking, and repair (Sacks et al., 1974; Schegloff, 1968; Schegloff, Jefferson, & Sacks, 1977). Goodwin (1995) vividly portrays the

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[10] The term 'health professional' is used to include physicians, nurses, occupational therapists, physical therapists and social workers as well as speech-language pathologists

[11] The term 'aphasia-friendly' was coined by Lorraine Podolsky, a speech-language pathologist at the Pat Arato Aphasia Centre

collaborative process of co-construction in his conversational analysis of everyday interactions between Rob, a man with very severe aphasia, his wife and his nurse. Through participation in a process of building context and meaning, Rob and his conversation partners negotiate their way through such ordinary events as making a decision regarding food. Because Rob only has three words at his disposal, this collaborative process is extremely time-consuming; however, as Goodwin points out, conversational interaction is achieved because both conversation partners treat Rob as a competent co-participant and assume that his few words and gestures are attempts to convey something meaningful.

In other words, the person with aphasia and the conversation partner should be regarded as being *jointly* responsible for maintaining the integrity of the conversational process. Co-construction can be viewed in many contexts. Holland (1998), Simmons-Mackie (1998b), and Parr and Byng (1998) refer to it in relation to meaning and conversation. Duchan, Maxwell and Kovarsky (1999) make a similar point in relation to competence, regarding it as co-constructed rather than an ability or abilities within the individual. Both meaning and competence co-construction are relevant to SCA™'s goal of revealing competence through conversation. From the co-construction perspective, there is less focus on independent transaction of messages and more emphasis on concepts of interaction and autonomy and what the dyad achieves collaboratively.

In the case of SCA™, the reduced emphasis on independence is often mistakenly assumed to be disempowering for the aphasic person, especially in situations where the aphasia is severe and the partner is providing a lot of support. While it is a given that those with aphasia also need to share the communication load, French (1993) and Sutherland (1981) point out that people with disabilities are often expected to cope in a way not demanded of society in general. They, like any of us, should be able to opt for more support in certain situations. In addition, Simmons (1993) warns us that communicating independently using non-traditional strategies such as gesture or written material, is not always received

positively by members of the public. Some people with aphasia might also therefore choose not to use these strategies in order to avoid negative reactions. Autonomy in deciding whether or not to use or ask for communicative support may be more important than the ability to communicate as independently as possible at all times. Using the analogy of physical disability, someone who is dependent on a great deal of physical support in order to be mobile, can, at the same time, be autonomous in making a decision regarding where he/she wants to go. In the same way, having a conversation that achieves social goals, may be valued more by the individual with aphasia, than conveying information independently.

Success within conversational partnerships can be conceptualized in terms of a conversational equation including the skill and experience of the aphasic partner, the skill and experience of the conversation partner, and the availability of appropriate resources (Kagan & Gailey, 1993). In order for conversational partnerships to work, training of the conversation partner and development of conversational resources warrant as much attention as working directly with the person who has aphasia. This is in line with the thinking of those who support a social model of aphasia.

**The novel contribution of concepts underlying SCA™**

Researchers and practitioners in areas related to aphasia have also recognized the value of examining the extent to which environmental factors interact with the individual to create or increase disability. For example, nursing professionals (e.g., Dawson, Wells, & Kline, 1993; Kayser-Jones, 1989) working with the elderly, the institutionalized, and those with Alzheimer's disease, draw on concepts such as 'environmental press' (Lawton, 1982) and models of person-environment interaction (e.g., Kahana, 1982; Moos, 1980) in developing their own concepts of 'excess disability' and 'enablement'. However, in these approaches as in the field of speech-language pathology, the role that ordinary face-to-face conversation

plays in explaining the social impact of disability is not an explicit focus of theorizing, research, or practice.

A unique contribution of the conceptual framework underlying SCA™ is that it explains the social consequences of aphasia in terms of its impact on the ability and opportunity to engage in conversation. As indicated earlier in this chapter, the notion of the centrality of conversation to life participation is recognized in other fields such as sociology, anthroplogy, and philosophy, but SCA™ is one of the first approaches to make it a pivotal focus in the area of speech-language pathology. SCA™ also introduces two original concepts in relation to conversation, namely, the concepts of masked competence and communicative access.

These concepts can be modified and applied to any disability involving communication, but are particularly relevant in situations where competence is better than language. This includes problems faced by speakers of English as a second language. The concepts are particularly relevant to aphasia where the underlying language disorder involves the *comprehension* of spoken and written communication as well as the more obvious communication difficulty relating to verbal expression seen, for example, in motor speech disorders.

Core SCA™ concepts and the interaction between them can generate many different interventions, evaluative tools and methods, as well as questions that result in testable hypotheses. As an example, the research program reported in this thesis describes an intervention that teaches conversation partners how to acknowledge and reveal competence through conversation; evaluative tools that examine skill in these areas and that look at conversational interaction and transaction as outcomes; and an efficacy study hypothesizing that it is possible to train conversation partners and that such training has some impact on the person with aphasia.

The conceptual framework described in this chapter allows for an analysis of what impedes communicative access to participation in social and community life for individuals with aphasia. By identifying the root of the problem, namely, the negative cycle of reduced opportunity to engage in conversation and to reveal competence, it also suggests potential solutions, such as focusing attention on the participation of skilled conversation partners. Marshall (1998) uses the analogy of dance to describe what a good conversation partner does. He says that in order to enjoy the dance, we need skill and practice so that we can forget about what our feet are doing. This is the goal of the training methods and resources for conversation partners described in the following chapter.

# THE INTERVENTION: PROVIDING OPPORTUNITIES FOR CONVERSATION

Recent trends in rehabilitation and intervention go beyond the traditional focus on lessening impairment to include goals of social participation. This shift is international as reflected in a recent version of the World Health Organization's Classification of Impairments, Activities and Participation (ICIDH-2, 1997). The field of aphasia rehabilitation has also seen the emergence of several intervention programs that extend beyond the remediation of deficits, including 'Supported conversation for adults with aphasia™' (SCA™), described in this thesis. The aim of this and other new approaches (Bernstein-Ellis & Elman, 1999; Hickey et al., 1995; Lubinski, 1994; Lyon, 1992; Parr, 1996; Pound, 1998a; Pound, 1998b), is to increase individuals' opportunities for participation in daily life, as well as to reduce or eliminate barriers to this participation.

As mentioned in Chapter Two, the conceptual framework for SCA™ can potentially generate many different interventions. The SCA™ intervention described in this thesis is a logical outgrowth of three of the main ideas, namely, that conversation is central to life participation, that competence is primarily revealed through the medium of conversation, and that a conversation partner can reveal competence by providing conversational support. The intervention comprises a workshop for training conversation partners accompanied by a motivational video, and pictographic material that provides support for conversation. These are designed to provide adults who have aphasia, and others affected by aphasia, with opportunities for interacting socially as competent adults within the context of natural conversation.

This chapter presents a rationale for intervention based on SCA™, as well as a description of the development and content of the intervention. This is followed by a discussion of

candidacy issues, the role of the person with aphasia, the challenge of inducing change in social variables and the concepts of independence versus autonomy.

## Rationale for training partners for adults with aphasia

The idea of training the partners of adults with aphasia originated in the early nineteen eighties as part of a general trend in speech-language pathology literature describing the impact of different partners on various aspects of communication (e.g., Gallagher, 1983). In many instances, the partners for adults with aphasia have been family members, usually the spouse. The value of involving the family of the person with aphasia has, therefore, been acknowledged for some time. Interest in families is demonstrated by early studies describing communication within family dyads from various perspectives. For example, Florance (1981) devised a method called 'Family Interaction Analysis' that evaluates facilitative and nonfacilitative behaviors of significant others. Larkins and Webster (1981) studied the use of gesture in dyads involving a person with aphasia and a stranger/spouse. Other studies include those by Flowers and Peizer (1984), Simmons, Kearns, and Potechin (1987), and Webster, Dans and Saunders (1982). Simmons et al. (1987) noted common practices used with families of those with aphasia that are still prevalent today. These interventions include offering counseling, giving written suggestions to improve communication, and modeling communication strategies. Several intervention studies also support the notion that direct training of family members and other partners can improve communication for both participants (e.g., Boles, 1997; Hickey et al., 1995; Lyon et al., 1997b; Simmons et al., 1987). Some of these studies, for example, Lyon et al. (1997), focus explicitly on social interaction and life participation as the goal, rather than improved communication per se. SCA™ is an intervention in the latter tradition.

The above studies involved individualized interventions for particular couples. While individualizing training in this way is desirable, it is also useful to have a more generic

approach for training, enabling partners (e.g., volunteers and/or health professionals) to interact with a variety of individuals with aphasia in different contexts.

The rationale for the development of the SCA™ intervention (i.e. training workshop, video and resource material, described below) was, therefore, twofold. First, it was based on the need to provide opportunities for conversation so that participants affected by aphasia can 'forget about the communication problem' and feel fully engaged in the interaction. Second, it was a response to the need for a generic training format.

## Development and description of the intervention [12]

The conceptual framework underlying SCA™ and ideas for the content of the intervention (workshop, video and pictographic resources) evolved concurrently from the observational process described in the previous chapter. At times, ideas or concepts guided observation, and at other times, the process of selecting and organizing behavioral targets for training, influenced the conceptual framework.

Observed behaviors contributing to skill in providing supported conversation ranged from concrete (e.g., using a marker) to more abstract (e.g., an encouraging manner). Initial organization of these behaviors of conversation partners included major categories already in use at the Aphasia Centre (Kagan & Gailey, 1993), namely, 'ensuring comprehension of the person with aphasia' and 'ensuring a means of responding'. The first subcategories included items such as 'linguistics', 'props', and 'adapted pragmatics'. These categories and subcategories were applied to the organization of subsequent observations, as well as in pilot versions of the training workshop. Alterations were made based on our experience in doing the observations and leading the workshops, as well as on feedback from workshop participants.

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The central concept of 'masked competence' was also further refined in this way. After approximately one year of observation and informal experimentation, two major categories ('acknowledging competence' and 'revealing competence') emerged as being clinically useful and theoretically consistent with SCA™. 'Ensuring comprehension of the person with aphasia' and 'ensuring a means of responding' were retained, but as subcategories under 'revealing competence'. A third subcategory, 'verification of what is being communicated', was added.

Table 3.1 and the subsequent text provide details of the development and final content of components of the intervention.

**Table 3.1. Details regarding the SCA™ training workshop, pictographic resource material and video**

| ITEM | DESCRIPTION | PEOPLE INVOLVED [a] | APPROXIMATE TIME SPENT ON DEVELOPMENT[b] |
|---|---|---|---|
| Training workshop | Purpose: To provide motivation, education and practice with SCA™ techniques<br><br>Length of workshop: Seven hours with breaks | Author<br><br>Research assistant<br><br>Educational consultant | 5 months<br><br>18 months<br><br>1 month |
| Pictographic Communication Resources | Purpose: To provide concrete support for conversations about complex topics with aphasic adults<br><br>198 pages of pictographs; 84 pages of instructional text | As above<br><br>+<br><br>Graphic artist | 10 months |
| Video | Purpose: To provide motivation and education<br><br>Running time: 26 minutes (color with black and white) | As above<br><br>+<br><br>Videographer | 1 month |

a     All besides the author were part of the grant acknowledged at the beginning of the thesis
b     Work done concurrently and spread over a two year period
SCA™   Supported conversation for adults with aphasia™

## A.    SCA~ Training Workshop and accompanying Video

The training workshop was piloted over a two-year period and adaptations were made according to the needs of the participant group (volunteers or health professionals). A total of eighteen workshops were piloted before arriving at the final version presented below.

The training program was designed with reference to a cognitive/ information processing theory of instruction (Braune & Foshay, 1983). This method is used for training performance within highly dynamic and complex environments. Competent performance is viewed as an on-going problem solving activity. Learners must develop increasingly sophisticated knowledge structures or 'schemata' with which to analyze given performance situations. A videotape (Kagan et al., 1995a, see Attachment 1) was developed to address entry-level knowledge and to encourage a positive affective dimension. Assessment of learning and satisfaction was carried out in early pilot versions of the training workshop and results were used to modify training. Training included a progression and broad range of problem-solving situations containing feedback. The final one-day workshop, conducted in a small group format, was based on experimentation with variations in length and methods of training, as well as participant feedback.

The video designed to accompany the training workshop began with work on a script that was created to reflect the philosophy of SCA~ and motivate workshop participants to acquire skill in supported conversation (see Appendix 1)[13]. As with the workshop, principles of adult learning were applied. Video footage consisted of some material previously created by myself, as well as new footage involving staff, volunteers and members of the Aphasia Centre as actors in various scripted scenarios. Filming was done by a professional videographer. I was directly involved in script writing and the editing process of selecting

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[13]The video can also be used on its own as a motivational and educational tool

footage and matching it to the scripted narration. Feedback on preliminary versions of the video was obtained from diverse sources (staff, volunteers and members of the Aphasia Centre, as well as other speech-language pathologists, neurologists and social workers). Based on this feedback, additional scenarios were included to emphasize the impact that training has on the skill of the conversation partner.

The final version of the workshop developed and investigated in this thesis consisted of the following four modules described further below:

- Conceptual/motivational module (with accompanying video)

- Technical module

- Integrative role play

- Evaluation exercise

The workshop was designed to be led by a professional speech-language pathologist with extensive experience in SCA™.

## 1. Conceptual/motivational module (approximately one and a quarter hours)

This module introduces the notion of 'supported conversation' as well as basic information about aphasia for those unfamiliar with the disorder. The main purpose is to illustrate that the acquisition of skill by the conversation partner makes a dramatic difference to the potential for satisfying conversation with adults who have aphasia. Experiential role-play situations (in dyads of 'partner with aphasia' and 'conversation partner') as well as the motivational video (Kagan et al., 1995a, see Attachment 1), are used to give participants a taste of what it might be like to have aphasia. The twenty-six minute video introduces the key concepts of 'conversation', 'masked competence' and 'communicative access' in relation to aphasia. It contains real-life footage of an interview between a young doctor (a neurology resident) and an aphasic individual before and after the resident received training (see Figure 3.1). The video is not intended to be a primer on aphasia or the real-life stories of aphasic adults as these are available (e.g., Adair Ewing & Pfalzgraf, 1991a; Adair Ewing & Pfalzgraf, 1991b). Rather, it is intended to dramatize the impact of training on a conversation partner's ability to provide support for the person with aphasia. The role-play and video are accompanied by didactic teaching that follows a set script.

Figure 3.1    Illustrations of interactions between an individual with severe aphasia
              and an inexperienced conversation partner (a neurology resident) before
              and after the resident received SCA™training (excerpted from videotape
              with permission (Kagan, 1995a)).
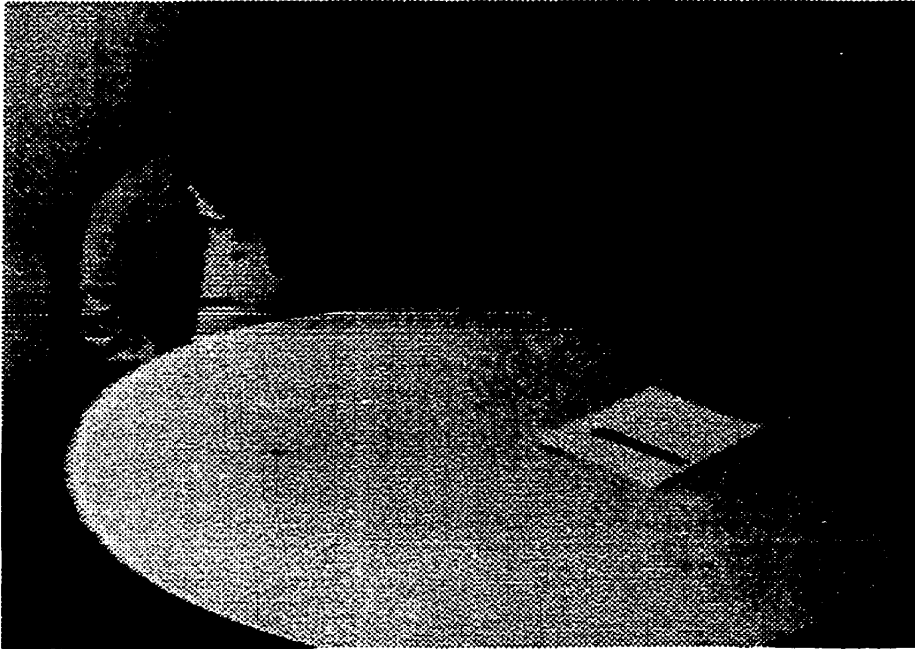


Before training



After training

SCA: "Supported conversation for adults with aphasia"™
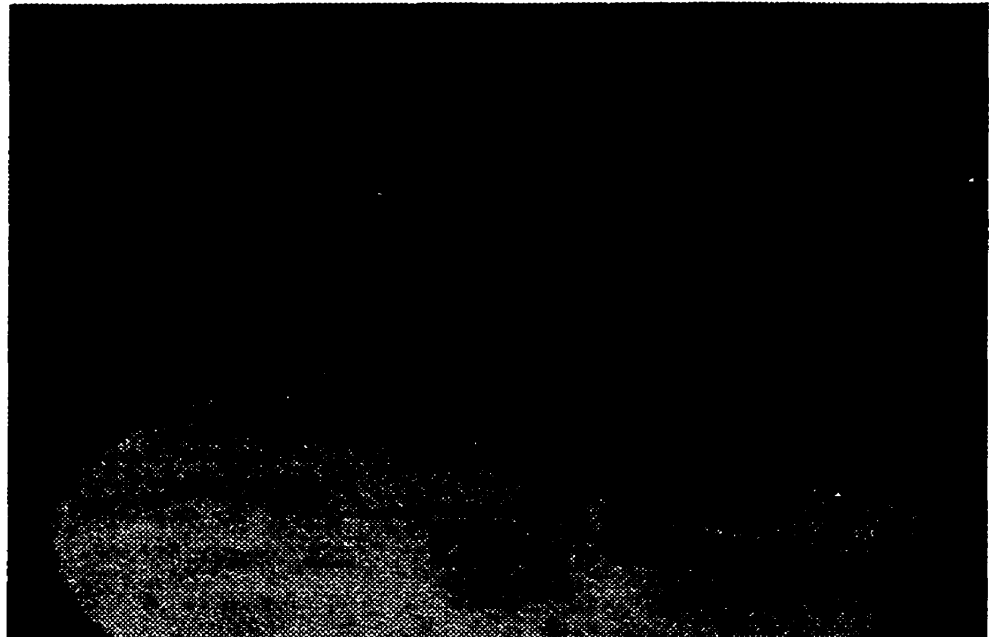
## 2. Technical module (approximately two hours)

During this module, participants are exposed to the two principal techniques used by conversation partners providing supported conversation: a) acknowledging and b) revealing, the competence of the person with aphasia.

Acknowledging competence is described as either implicit (e.g., using humor, appropriate tone of voice, and integration of verbal and non-verbal support in such a way that conversation sounds natural and adult), or explicit (e.g., verbally acknowledging the fact that the aphasic partner knows what he/she wants to say).

Revealing competence includes the following:

i)      ensuring comprehension (e.g., using gesture, writing key words, drawing, or utilizing resource material[14] to make the topic of conversation clear)

ii)     ensuring that the aphasic partner can respond and/or express what they think, know and feel (e.g., using skill in asking yes/no or fixed choice questions, providing appropriate response avenues, and giving the partner with aphasia time to respond)

iii)    verifying responses (e.g., using writing to reflect, expand or summarize what has been communicated). Techniques are taught through a combination of description, demonstration and role-play opportunities.

Throughout this module and the integrative role-play that follows (see below), the instructor stresses the *simultaneous use of techniques*. Timing is of the essence if gesture, written key words, drawing and use of resource material are to accompany talk in a way that enhances the *feel and flow of natural adult conversation*. As with many other clinical skills, the

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[14] This includes material from the Pictographic Communication Resource manual described below.

integration of these non-verbal supports into the flow of verbal conversation must be demonstrated and then incorporated through practice. Techniques are presented as tools to be used flexibly and creatively. Thus, although the goals of supported conversation remain constant, the means of achieving these goals varies.

The emphasis on natural-sounding conversation (even when the conversation partner is doing almost all of the talking and accompanying it with extensive use of techniques such as gesture, writing key words, drawing and using pictographic resources), is one of the features that differentiates the SCA™ approach and intervention from other similar-sounding approaches.[15]

## 3. Integrative role-play module (approximately one and a half hours)

In the third module of the workshop, role-play scenarios are specifically chosen to allow for integration of what has been presented earlier, as well as to illustrate specific points (e.g., situations where accuracy of information exchange is critical as compared to situations where information exchange is secondary to social connection or interaction)[16]. The content of role-plays includes introductions, giving information about an upcoming event, finding out what is upsetting the person with aphasia, and giving someone with severe aphasia the opportunity to initiate questions.

## 4. Evaluation module (approximately half an hour)

In order to encourage the concept of self-evaluation, the workshop concludes with an exercise in which participants practice evaluating the skill required by conversation partners

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[15] Even speech-language pathologists (including many with years of clinical experience) who have participated in the training, often find it a challenge to talk to severely aphasic adults in a manner that does not 'sound like therapy' or a question-answer session. This view is supported by Holland (1998), Simmons-Mackie (1998b), and Parr and Byng (1998).
[16] In a research context, the instructor plays the role of the aphasic person in order to maintain a level of consistency and to ensure coverage of all targeted areas. In other contexts, participants may work in pairs or groups, giving more opportunity for practice.

in a non-threatening situation. They view a video-taped interaction between an individual with aphasia and a conversation partner. Guided by the instructor, they then practice rating the conversation partner's skill in acknowledging and revealing competence on a 9-point numerical scale (see Chapter Four for detail regarding the scale).
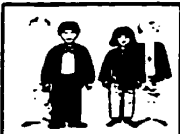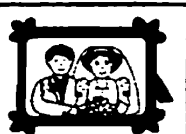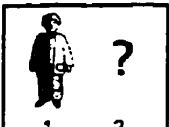
## B. Resource material to support conversation

According to Hux, Beukelman, and Garrett (1994), there are a large number of symbol systems in widespread use in the field of speech-language pathology. These include Blissymbolics, (Kates & McNaughton, 1975) and Picture Communication Symbols (Mayer-Johnson, 1981). Clinical aphasiologists (e.g., Darley, 1982) have long recognized the value of visual stimuli within the context of improving or restoring language function. As indicated by Fox and Fried-Oken (1996), however, there is a need for tools that enhance the ability of adults with aphasia to engage in conversation and 'talk' about topics of interest. Currently available picture dictionaries such as Picture Communication Symbols cited above, do not fulfil this need for several reasons. In some cases, the format is designed for children, or focused on the most basic wants and needs. In others, pictured items are organized in categories such as nouns or verbs rather than conversational topics. Sophisticated computerized programs such as the 'Computer-aided Visual Communication' system (Steele, Weinrich, Kleczewska, Wertz, & Carlson, 1987; Weinrich et al., 1989), designed to circumvent the language impairment of those with severe aphasia, are not conducive to creating the 'feel and flow' of conversation that characterizes SCA™. The Pictographic Communication Resource manual (PCR), an extensive collection of thematically organized pictographs (Kagan, Winckel, & Shumway, 1995b), was therefore created to give adults with aphasia increased opportunity to engage in conversations about relevant topics (see Figure 3.2 below; Appendix 2; and Attachment 2).
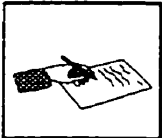
**Figure 3.2**     **Selected examples of pictographs from the Pictographic Communication Resources Manual**
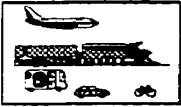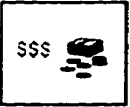


**I want to talk about...**

my children

my friend

my marriage / spouse

money

power of attorney

my medication

counselling

the future

risk of another stroke
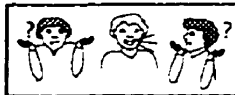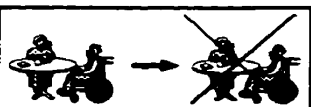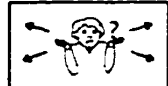
**BARRIERS**

What might prevent you from doing the activity?

● Communication problem?

speech problem

reading

writing

problem understanding what others say

making initial arrangements

● Other problems?

transportation

money

nervous about a new situation

**? ? ?**
**? QUESTIONS ?**
**? ? ?**

You may have many QUESTIONS...

The content and organization of the PCR were based on years of observation of conversational interactions at the Pat Arato Aphasia Centre, our familiarity with needs expressed by members with aphasia and their families, and SCA™ concepts related to conversation, competence, and communicative access. Artwork was created by a graphic artist based on concepts and/or layouts developed by me and by a research assistant. The page layout of the PCR was particularly important as it included key words as well as pictures. Wherever possible, the layout was created to anticipate potential directions that conversation might take.

On-going feedback was an integral part of this two-year project at all stages of development. For example, members, volunteers and staff at the Aphasia Centre were involved in choosing the generic face used in many items in the PCR. Various options were laid out on a table and people voted for the one they felt would be most suitable. Then, as material was developed, it was given to volunteers and individuals with aphasia participating in conversation groups at the Aphasia Centre. Adaptations were made based on their input and revised versions returned to them for further comment. As one example, groups were asked for feedback on the 'emotions' section. The emotions portrayed were largely negative, featuring pictographic illustrations such as 'depression' and 'anger'. We were asked by members with aphasia to include a picture of 'ok'. They also suggested that we include a picture of 'why me?'

The final version of the PCR combines pictures with selected key-words and phrases, organized within a structure that facilitates conversational interaction. The topics addressed include context-specific, relevant, and often complex issues facing adults with aphasia, going far beyond basic needs and wants. Adults with aphasia will derive maximum benefit from the PCR when their conversation partner possesses an understanding of the principles and techniques for supporting conversation. For example, the conversation partner should be

able to take a topic initiated by someone with severe aphasia and turn this into a mutually satisfying conversation. Initiation of topics is not necessarily an end in itself.

The PCR manual reflects a commitment to providing support for adults with aphasia who are often excluded from conversation on the basis of the severity of their language disorder. Speech-language pathologists or trained conversation partners can do this in two ways: first, by creating customized pictographic material as the manual is too bulky and complex to be a practical everyday resource for individuals with aphasia; and second, by creating materials for use by other conversation partners in relevant contexts. Retaining pictographic records of conversational interactions also enables the non-verbal individual to *refer back* to discussions or ideas. The detailed instructions and pictographic material can be used by speech-language pathologists for the purpose of in-services to other health professionals, particularly around the idea of giving people with aphasia the opportunity to participate in decision-making about their lives.

The manual consists of thematically organized sections, each with extensive instructional text. The first four sections (Basics e.g., yes/no, number and alphabet sheet; People e.g., various family combinations; Places e.g., maps, settings and buildings; and Time e.g., indicating past, present and future) contain generic material that is designed to be used in many conversational contexts. The fifth section (Health Assessment) provides material that can be used by either health care professionals, or by speech-language pathologists doing inservices for health care professionals such as physicians or nurses. Areas covered in this section include: Presenting complaint; History of complaint - pain or other; Past health history, Health Habits, and Plan. Section six contains examples of thirteen specialized topics arranged in alphabetical order. Examples include: Aphasia (a pictographic explanation of the disorder); Case-conference (emphasizing participation of the patient with aphasia) ; Decisions (about money or personal care); Social activities (including potential barriers to participation); and Informed consent (an example for consent to research that can be adapted to many situations). Users are encouraged to insert their own topics into this section

using cut-and paste techniques described in the manual. The final section ('I want to talk about..') embodies a distinguishing feature of the PCR, namely that in the hands of a trained conversation partner, it can empower the non-verbal aphasic partner to *initiate* discussion on complex topics or to raise questions by pointing to pictured choices. The conversation partner then uses the techniques discussed previously to turn this into a conversation. The 'I want to talk about...' section is deliberately placed at the end of the PCR so that it is more accessible.

The type of thematically organized resource material used in the PCR increases the opportunity for meaningful conversational interaction with people who have severe and moderate aphasia. Selected use of the material to support complex topics is appropriate for individuals with mild aphasia, particularly when reading comprehension is involved.

Development of the training workshop, video and pictographic resources took over two years and led to a theory grounded in experience, and an intervention with a strong theoretical underpinning. Questions regarding candidacy, the role of the person with aphasia, and the issue of independence are addressed below.

## Candidacy for conversational support

The intervention described in this chapter focuses on individuals with severe aphasia because this group generally requires the full range of SCA™ techniques (in contrast to moderate and mild aphasia where less and sometimes different support is necessary). In addition, it is important that conversation partners discover that it is possible to have conversations with adults who have severe aphasia. The severity of the language impairment often underlies exclusion from participation in life activities, extending in some instances to exclusion from traditional and non-traditional programs run by speech-language pathologists.

This emphasis on severe aphasia is not intended to minimize the often devastating psychosocial impact of mild aphasia (Parr et al., 1997; Penn, 1993). Individuals with mild aphasia also need opportunities for conversation so as to create contexts where they can forget about their communication difficulty. However, because their difficulties are of a more subtle nature, the conversation partner's skill lies at times in knowing when *not* to use particular techniques, knowing how to adapt techniques, and acquiring a sensitivity to the impact of mild aphasia as illustrated by Kiran, a participant in a study by Parr et al. (1997). Kiran talks about how he feels several years after his stroke. He is sufficiently verbal to give us insights into some of the fundamental and painful changes in his identity caused by aphasia in areas such as the speed of his wit and his way with words:

> *"Basically, I feel powerlessness. That is the hardest thing. And my language is all a part of the world. Even now, I get fed up with writing with my left hand...I'm annoyed with myself. I feel frustrated with myself for not spelling words correctly. My grammar is affected. I can only operate in my writing in simple sentences...My whole being is changed. I was always a performer and now I can't perform...I'm garrulous. I like to tell funny stories and it is hard for me to adapt."*

Candidacy for supported conversation should not, moreover, be limited to the chronic stage of aphasia. Simmons-Mackie (1998a) is critical of the prevailing treatment philosophy that focuses solely on the language deficit or compensation for it, with discharge being related to the stabilization of scores on language or functional communication tests, and psychosocial issues relegated to what happens after therapy. Implicit in the latter view is the belief that candidates for a social approach are those for whom traditional interventions have failed. Simmons-Mackie proposes that we change this treatment philosophy and give social aspects of aphasia validity by incorporating them from the start. Providing supported conversation is then relevant at any stage of aphasia, although the context for support will differ. Applications of supported conversation in different contexts and stages are described in Chapter Six.

Individuals with aphasia who benefit most dramatically from conversational support have relatively good comprehension and very limited expressive ability. The ability to indicate 'yes' and 'no' in some way, is essential. It may be necessary to do 'readiness' work with those who have difficulty indicating yes/no, but if there is no improvement, they are not good candidates for SCA™ intervention. However, based on experience at the Aphasia Centre, there are very few individuals with severe-moderate aphasia who are not able to engage in conversation at some meaningful level, with support. The few exceptions involve those who have serious cognitive deficits, or those with severe comprehension problems in verbal and non-verbal modalities.

The issue of candidacy also applies to the conversation partner. Preliminary research using conversational analysis, a qualitative methodology, was conducted on what constitutes a 'good' conversation partner (Simmons-Mackie & Kagan, in press). Results indicate that partners rated as 'good' by experienced and inexperienced judges, treated the person with aphasia as 'trustworthy, competent, interesting and sincere..' and structured their talk accordingly. For example, they were prepared to sacrifice accuracy at times in order to 'save face'. Further research is needed in this area.

**Completing the conversational equation**

At least three factors (skill of the conversation partner, skill of the person with aphasia, and the availability of supportive resources) play a role in maximizing opportunities for mutually satisfying conversation. These factors can be considered part of a conversational equation (Kagan & Gailey, 1993). The contribution of the factors may differ depending on context and circumstances. In other words, conversational success can be achieved in many different ways. Although this chapter describes training for conversation partners, and resources to support conversation, the skill of the person with aphasia, and the extent to which he/she

participates in co-creating the conversational interaction, also affects the balance of the equation. Severity of the language impairment does not necessarily prevent people with aphasia being effective communicators. As mentioned previously, Holland (1977) commented years ago that many individuals with aphasia communicate better than they talk.

Intervention with the person who has aphasia can be approached in two complementary ways. The first involves preparation for the many situations where there is little conversational support. Methods here may include working directly on the language impairment or compensating for it in various creative ways. As indicated by Byng et al., (in press), both of these are well established in our field. Some of these methods use conversation as the therapeutic medium, for example, conversational prompting (Cochrane & Milton, 1984), PACE therapy (Davis & Wilcox, 1981), and conversational coaching (Holland, 1991). However, the fact that conversation forms the context for therapy does not mean that these methods reflect the goals of the SCA™ intervention. The early work on conversational prompting by Cochrane and Milton (1984) is a good example because although the context is conversational, the desired outcome is specifically related to verbal output such as number and mean length of utterances. The interactions revealed in their written transcripts are not reflective of the breadth or depth of adult conversational topics or of the feel and flow of natural adult conversation.

A second way of approaching intervention involves preparation for situations where there is support. For example, this might include work on training dyads where both the person with aphasia and the conversation partner are explicitly trained to work collaboratively. This recent development of SCA™ is described in Appendices 10 and 11.

Practicing skills in any of the above situations should not be equated with providing actual opportunities for conversation. At the Aphasia Centre, for example, individuals with aphasia are offered both options. Volunteers facilitate conversation groups where opportunity for

social interaction and stimulating conversation is the goal. At other times, volunteers might also work with the group on activities directed toward compensating for the language impairment. In this case, improved communication is the primary goal. The fact that these activities are complementary, however, does not mean that their goals are equivalent.

Used within the context of SCA™, all these options can form part of an approach that incorporates the conversation partner from the start. For example, a speech-language pathologist might use pictographic material and written key-words to explain the above options to the person with aphasia and their speaking partner. Using SCA™, it is possible to facilitate a conversation that incorporates the person with aphasia as a decision-making partner in the process of rehabilitation.

**Social variables as a target for intervention**

One of the unique features of the intervention described in this chapter, when compared with traditional interventions, is the focus on interaction and its interrelationship with transaction or exchange of content. Trainees are encouraged to focus on interactional goals for themselves and for their partners with aphasia when engaging in conversation, but inducing change in social variables can be challenging. Based on our experience with volunteers at the Aphasia Centre, for example, it is difficult to change behaviors that are related to personality and attitudinal factors. However, the fact that it is more difficult to induce change in social variables related to conversation does not detract from their importance, nor does it imply that they should not be a focus of training.

**Independence versus autonomy.**

SCA™ helps to create a feeling of autonomy for the aphasic partner, rather than working towards the traditional therapeutic goal of communicative independence per se. The partner acts as a resource for the aphasic person and actively shares the communication load. Most

rehabilitation professionals, however, hold independence to be the goal of treatment and are wary of fostering dependence even though many individuals with aphasia are not, and may never be, 'independent' communicators as defined within the traditional medical model. If conversation is normally co-constructed as discussed in Chapter Two, interdependence is not only acceptable, but desirable. Providing access to mutual or inter-dependence for those with aphasia may have far more impact on well being than pursuing only the goal of independence.

## Conclusion

Viewing intervention in terms of support for communication as well as in terms of reduction of the communication deficit requires a change in our professional perspective that will be further elaborated in Chapter Six. Chapter Six will also provide a framework for speech-language pathologists that includes their role as conversation partners, as well as their role in training other conversation partners.

SCA™ can be seen as part of a larger shift in thinking related to intervention in aphasia. Approaches to evaluation of interventions need to undergo a similar shift. This is addressed in Chapter Four.

# Chapter Four

## MEASURES FOR EVALUATING CONVERSATION

With the mounting costs of our health care system, speech-language pathologists are increasingly required to demonstrate effectiveness and accountability in order to justify the provision of service to adults with aphasia. The fact that accountability is usually equated with quantifiable results leads Petheram and Parr (1998) to comment that "This can lead to the devaluing of therapeutic practices which are difficult to measure." At first glance, therefore, evaluation of social interventions such as SCA™ presents a challenge. Evaluative tools have to be sufficiently sensitive to social parameters that are often difficult to capture, while at the same time facilitating accountability in a health care system often driven by the marketplace.

This chapter describes the background and rationale for the development of a set of measures designed to take these issues into account. A description of the content of the measures and the scoring system is followed by a presentation and discussion of preliminary psychometric results. The chapter concludes with examples of clinical applications of the set of measures.

### Background

Standardized tests of language remain a commonly used method of evaluation in the field of aphasia, for example, the Boston Diagnostic Aphasia Examination (Goodglass & Kaplan, 1972 (rev. 1983)), the Western Aphasia Battery (Kertesz, 1982), the Porch Index of Communicative Ability (Porch, 1967), and the Minnesota Test for Differential Diagnosis of Aphasia (Schuell, 1965). Several of these tests focus predominantly on classification, and according to some authors, have limited clinical value (Byng, Kay, Edmundson, & Scott, 1990). Criticisms include the lack of clarity regarding the underlying disorder that the tests

purport to measure, insensitivity to changes over time, and the fact that insufficient account is taken of the complexities of language use (Byng et al., 1990; David, 1990; Martin, 1977; Weniger, 1990). In addition, as Simmons (1993) and Simmons-Mackie and Damico (1995) point out, aphasia tests provide information about potential communication behaviors of the person with aphasia rather than telling us what he/she actually does in everyday situations. As the focus of aphasia treatment has broadened to include communication and not just language, clinicians have required tools influenced by an appreciation of pragmatics (knowledge of who can say what, in what way, where and when, by what means and to whom) (Hymes, 1971, cited in Prutting, 1979). Over the past three decades, the evaluation of functional communication and 'functionality' has therefore also become increasingly important (Elman & Bernstein-Ellis, 1995). Examples of broader tools that take real-life communication into account include 'Communicative Abilities in Daily Living' (CADL-2), (Holland, Frattali, & Fromm, 1999); 'Communicative Effectiveness Index' (Lomas et al., 1989); 'Profile of Communicative Appropriateness' (Penn, 1988);'Pragmatic Protocol' (Prutting & Kirchner, 1987); and the 'Functional Communication Profile' (Sarno, 1969). Most recently, the American Speech-Language-Hearing Association (ASHA) has expended considerable effort on the development of a functional communication measure – the ASHA Functional Assessment of Communication Skills (Frattali, Thomson, Holland, Wohl, & Ferketic, 1995).

Functional and pragmatic assessment tools have produced important new ways to look at aphasia by rating communication in a more natural context, and/or using events or categories that are presumed to be relevant to everyday communication. In order to achieve standardization, some of these measures require the use of pre-set procedures such as role-play, and tend to sample a limited range of activities. Lomas et al. (1989) also comment that in some cases, functional tools correlate so well with existing language measures that they are probably tapping the same dimensions. In regard to the latter, the fact that correlations are high should not necessarily devalue the usefulness of both sets of measures. Height and weight, for example, are highly correlated, but information on both can be useful.

The introduction of functional and pragmatic tools has considerably broadened the approach to assessment in aphasia. Despite these advances, evaluative tools remain limited in that they do not evaluate critical *social* aspects of communication in relation to aphasia (e.g., co-construction of conversation) highlighted by methodologies such as conversation analysis (Boles, 1997; Ferguson, 1996; Oelschlaeger & Damico, 1998; Simmons-Mackie & Damico, 1999). Literature in the field of augmentative and alternative communication increasingly emphasizes the importance of determining outcomes of social relevance (e.g., Beukelman & Mirenda, 1992; Calculator, 1997; Fox & Fried-Oken, 1996). Yet, the effectiveness of aphasia intervention is rarely evaluated in these terms (Simmons-Mackie, 1998a). The development of evaluative methods appropriate to the social model of aphasia is therefore timely.

### Rationale for development of new measures to evaluate conversation between people with aphasia and their conversation partners

Current methods of evaluating communication fall short in several areas:

- There is a one-sided emphasis on the person with aphasia rather than the social unit or dyad incorporating the communication or conversation partner

- Scoring or rating the person with aphasia is done without providing formal contextual information as to the degree of support provided by the environment

- There has been an almost exclusive preoccupation with what can be termed *transaction* (content of conversation), as opposed to giving *interaction* (social connection) equal weight (Kagan, 1995; Simmons, 1993) based on terms introduced by Brown and Yule (1983) and Simmons-Mackie (1998a).

These are gaps related to the scope of evaluation, but methodological issues must also be considered. In the early stages of this century, the evaluation of the efficacy of aphasia treatment was largely based on single cases that examined whether specific approaches worked for specific types of aphasia (Howard & Hatfield, 1987). Methods of assessing communication disorders and evaluating intervention were often descriptive. In later decades

(primarily post World War II), methods of assessment and evaluation, influenced by positivist thinking and experimental research, shifted to a more quantitative focus. Experimental methods, requiring standardized tools, stand in contrast to qualitative methods that are designed to capture events or perceptions of events as they naturally occur.[17] Experimental group studies have tended to examine 'whether aphasia therapy *in general* benefits aphasics *as a group*' (Howard & Hatfield, 1987). Although qualitative methods are often more suited to capturing essential components of SCA™, such as what the dyad constructs collaboratively in a specific context, in terms of the current health care climate, it is wise to also include valid and reliable instruments that yield the type of data that make sense to administrators and funders. The interests of those affected by aphasia are probably best served by a broad array of evaluative methods and tools within a process referred to by Elman (1995) as multi-method research.

Based on the above, a set of measures was developed for use in research and clinical contexts (see Appendix 3[18]):

1.  A support measure entitled the 'Measure of skill in providing Supported Conversation for Adults with Aphasia™' ([M]SCA™) - designed to evaluate the skill with which the conversation partner supports the person with aphasia (see Appendix 3, p.7)

2.  A participation measure entitled the 'Measure of the Aphasic Adult's Participation in Conversation' ([M]APC) - designed to capture the extent to which the person with aphasia participates in conversation (see Appendix 3, p.1)

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[17] Using the term 'experimental' is more useful than the term 'quantitative' as the latter implies that qualitative methods do not involve quantification.
[18] Appendix 3 contains score sheets, information for raters, summary and detailed versions of behavioral guidelines, and examples of rating anchors, for both measures.

## Development of the measures and description of content

The final versions of both measures have a simple format but the process of their development was complex and took almost two years. The two major categories in each measure are closely tied to concepts outlined in previous chapters.

The (M)SCA™ (support measure) rates the **skill** of a conversation partner in:

- **acknowledging competence** of the person with aphasia, and

- **revealing competence** of the person with aphasia, using supported conversation. 'Revealing competence' is further broken down into three areas:

    - ensuring that the person with aphasia understands what is being communicated (getting the message IN)

    - ensuring that the person with aphasia is able to express him/herself (getting their message OUT) and

    - verifying to ensure that the conversation partner has correctly received the message.

The (M)APC, on the other hand, rates the **level of participation** in conversation by the person with aphasia in the areas of:

- **interaction**, or social connection, and

- **transaction**, or content related to the ability to exchange information, opinions, and feelings.

The intention was to create measures that could be used to evaluate any conversation between speaking partners and adults with aphasia in any context, including, for example, social chat between friends, case-history interviews in medical settings, conversation about consent to treatment or placement, and family discussion around important issues. The measures were designed to capture elusive social aspects of conversation and at the same time yield data that would be useful within an experimental framework. To this end, work began as described in previous chapters, with categories emerging from, as well as influencing, the observation of behaviors. As new versions of the measures developed, they were immediately field-tested by various individuals including staff at the Aphasia Centre and speech-language pathologists from outside the Centre. The methodology involved rating of videotaped conversational interactions and obtaining feedback regarding ease of use of the measures, clarity of categories/constructs, minimum amount of observation required, and reliability. Modifications were made on the basis of feedback from these rating sessions. Originally, it was anticipated that behaviors selected as indicative of a particular construct such as 'revealing competence' would be scored individually, with total or average scores used to represent the category. However, pilot work led in a different direction as explained below.

### Selection of major categories and subcategories

#### Support measure: (M)SCA~

From the start, analysis of lists of behaviors led to categories representing the content of conversation (information exchange) and the relational aspect of conversation. Thus for example, in one early version, content categories such as getting the message 'IN' and getting the message 'OUT' were accompanied by a category called 'establishing rapport'. Borrowing from the theorizing of Brown and Yule (1983) as applied by Simmons (1993),

subsequent versions began employing the terms 'transactional' and 'interactional' for the main categories. As theoretical constructs relating to masked competence were refined through observation, the phrases 'acknowledging competence' and 'revealing competence' were attached as descriptors to 'interaction and 'transaction'. In the final version, the latter phrases were adopted as labels for the main categories, with the relationship to interaction and transaction remaining implicit.

Subcategories and their breakdown into specific behaviors also went through several stages. Subcategories under 'acknowledging competence' included 'natural talk' and 'sensitivity to partner'. Although these categories were useful in guiding observation, scoring them separately proved to be challenging. Raters had little difficulty in using the subcategories and underlying behaviors to arrive at a total score for 'acknowledging competence', but scores assigned to the subcategories individually were not reliable, probably due to overlap. The concepts were retained for the purpose of training and are still evident in the raters' guide described below, but are not scored separately.

Early versions of the 'reveal competence' category listed areas such as 'support for talk' (which included the use of non-verbal modalities), 'response to cues given by the person with aphasia', and 'verification', before arriving at the final three subcategories (getting the message IN, helping the person with aphasia to get their message OUT, and verification). In contrast to the subcategories discussed under 'acknowledging competence', these subcategories appeared to be relatively independent of each other, and raters found it easier to reliably assign separate scores.

*Participation measure: (M)APC*

The development of major categories for this measure followed a similar path to the development of categories for the (M)SCA™. Initially, there was an attempt to use parallel

categories that emerged from observation for rating both conversation partner and adult with aphasia, in order to reflect the conversational partnership and equal responsibility. Taking the preliminary category of 'response to cues' as an example, behavioral guidelines for the conversation partner included such items as 'giving enough response time'. In the case of the person with aphasia, the behavioral guidelines included items such as 'giving an indication of intact competence when appropriate', for example, pointing to the head and gesturing 'I'm ok'. However, adhering rigidly to this process proved to be cumbersome. In addition, when the categories of 'acknowledging' and 'revealing' competence were adopted for the (M)SCA™, they clearly did not apply to the person with aphasia, despite their implicit relationship to 'interaction' and 'transaction'. The latter terms were therefore chosen as explicit labels for the main categories of the (M)APC.

As with the category of 'acknowledging competence' on the (M)SCA™, the categories of interaction and transaction were initially broken down into subcategories (e.g., verbal/vocal and non-verbal, the latter further subdivided into gesture, writing, drawing and use of resources). However, as described above, scoring these subcategories proved to be difficult despite the fact that the concepts were useful for guiding observation.

### Use of specific behaviors

Individual behavioral items within each category/subcategory were initially intended to form the basis for rating, following the usual protocol for scale development (Streiner & Norman, 1992). However, although the *range* of behaviors contributed to rating the overall category or construct, individual items relating to the specifics of verbal and non-verbal communication were not found to relate directly to the overall construct reflected by the categories. Scoring of these individual items proved to be frustrating. For example, raters argued about how to score a conversation partner who achieved the goal of ensuring that the person with aphasia understood the topic, but did not make use of a particular modality such as drawing. If each

item is scored separately, the conversation partner must be penalized for this, despite the fact that he/she achieved the overall goal.

In addition, any one behavior, such as using gesture to point, might be either transactional (e.g., indicating a topic) or interactional (indicating that it's the partner's turn to talk), or may achieve both goals simultaneously. These behaviors are often not 'good' or 'bad' in themselves, but must be judged in context (Simmons-Mackie, personal communication). For example, touching the person with aphasia may contribute to a higher score under 'acknowledging competence' for a conversation partner if this appears to provide reassurance, but would be penalized if it is overdone or appears patronizing.

### Move to more global categories and subcategories

In the next phase of development, 'ends' or goals were scored irrespective of the specific individual behaviors or techniques used to achieve the goal. Behavioral indicators were still used, but in the sense of guiding the observation (see Appendix 3, pp. 3-5 and 9-12 for summary and detailed rating guidelines for both measures). This process, when used by raters familiar with the conceptual framework underlying SCA™, made it easier to achieve reliability, and proved to be far more successful in capturing constructs of interest.

The problem with broad categories is that it is easier to get agreement between raters, but reliability, defined as the ability to differentiate among people, decreases. In other words, there is a loss of power and discriminating ability (Suissa, 1991). Agreement for its own sake *is* meaningless. What was, therefore, most important was the raters' perception that the broader categories based on behavioral guidelines were better able to capture the category or construct under consideration in terms of differentiating between people. Further psychometric analysis, therefore, concentrated on overall issues of reliability and validity rather than specific procedures such as behavioral item-analysis.

Use of global categories and a behavioral rating guide rather than individual behavioral indices fits in with the original purpose of the measures which was to capture elusive elements of conversational interaction between adults with aphasia and various conversation partners in various contexts. Although the scoring categories may appear simple, the final score is a result of a complex analysis of behavioral interactions within the mind of the rater, based on his/her understanding of the construct under consideration. The reasons for employing any particular behavioral strategy are complex and can be influenced by a myriad of personal and contextual variables. Capturing this complexity and interaction is difficult within a reductionist process. A broad approach to analysis is consistent with the intervention component of SCA™ where participants in the training workshop are discouraged from rigid adherence to a behavioral recipe and are encouraged to think about interactive use of techniques in achieving the goals of supported conversation.

The measures were designed to be used together, as a set. Scores reported in conjunction with one another give a picture of the dyad, while still allowing for a focus on either the conversation partner or the person with aphasia. This, as well as the possibility of examining the relationship between the two major categories *within* each measure, add further depth to the measures. The (M)SCA™ gives information about the conversation partner's skill in acknowledging competence, in relation to his/her skill in revealing the competence of their partner with aphasia. In similar vein, the (M)APC gives clinically useful information about transaction in relation to interaction for the individual with aphasia. These features allow the measures to do more than merely categorize 'good' versus 'poor' communicators.

The use of global categories is not meant to supplant more detailed behavioral analysis for clinical and research purposes. However, it is suggested that the latter (i.e. behavioral analysis) be individualized, taking into account relevant personal and contextual variables.

While retaining a qualitative flavor that takes the complexity of the endeavor into account, the measures also provide scores that can be used for statistical purposes as illustrated by the efficacy study reported in Chapter Five.

## Scoring system

Scoring can be done in real time or on videotaped interactions. Feedback from raters during the pilot phase indicated that 10-15 minutes of observation are usually sufficient. Categories are scored on a 9-point numerical scale (see Figure 4.1 below). The scale is presented as a range of 0 – 4 with 0.5 intervals for ease of scoring.

Rating anchors or reference points for scoring are important in order to create a common standard when using the measures. In developing rating anchors, it is useful to think of scores in terms of 'concern for the person who will be the partner'. Thus, in the context of the Aphasia Centre, knowing that someone with aphasia scores '2' on interaction, even when talking to an unskilled partner, means that there is no concern about leaving him/her alone with a new volunteer. Similarly, if a volunteer scores '2' on revealing competence, we are not concerned for the person with aphasia because we know that the volunteer will be able to get some transaction going. The rating anchors presented in Appendix 3 (pp.6 and 13), describe scores in terms of clinically significant differences based on the above considerations. Although the specific descriptions of the rating anchors need to reflect the context in which the set of measures is being used, the general numerical scoring system is designed to hold across contexts. Thus, for example, in another setting, the conversation partner might not be a volunteer, making issues related to the amount of supervision required irrelevant, but a '2' should always be 'adequate'.

**Figure 4.1**   Numerical scales used for rating the (M)APC and the (M)SCA™



**M(APC)**

| 0 | 0.5 | 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4 |

No Participation          Adequate          Full  Participation

**M(SCA)**

| 0 | 0.5 | 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4 |

Very Poor          Adequate          Outstanding
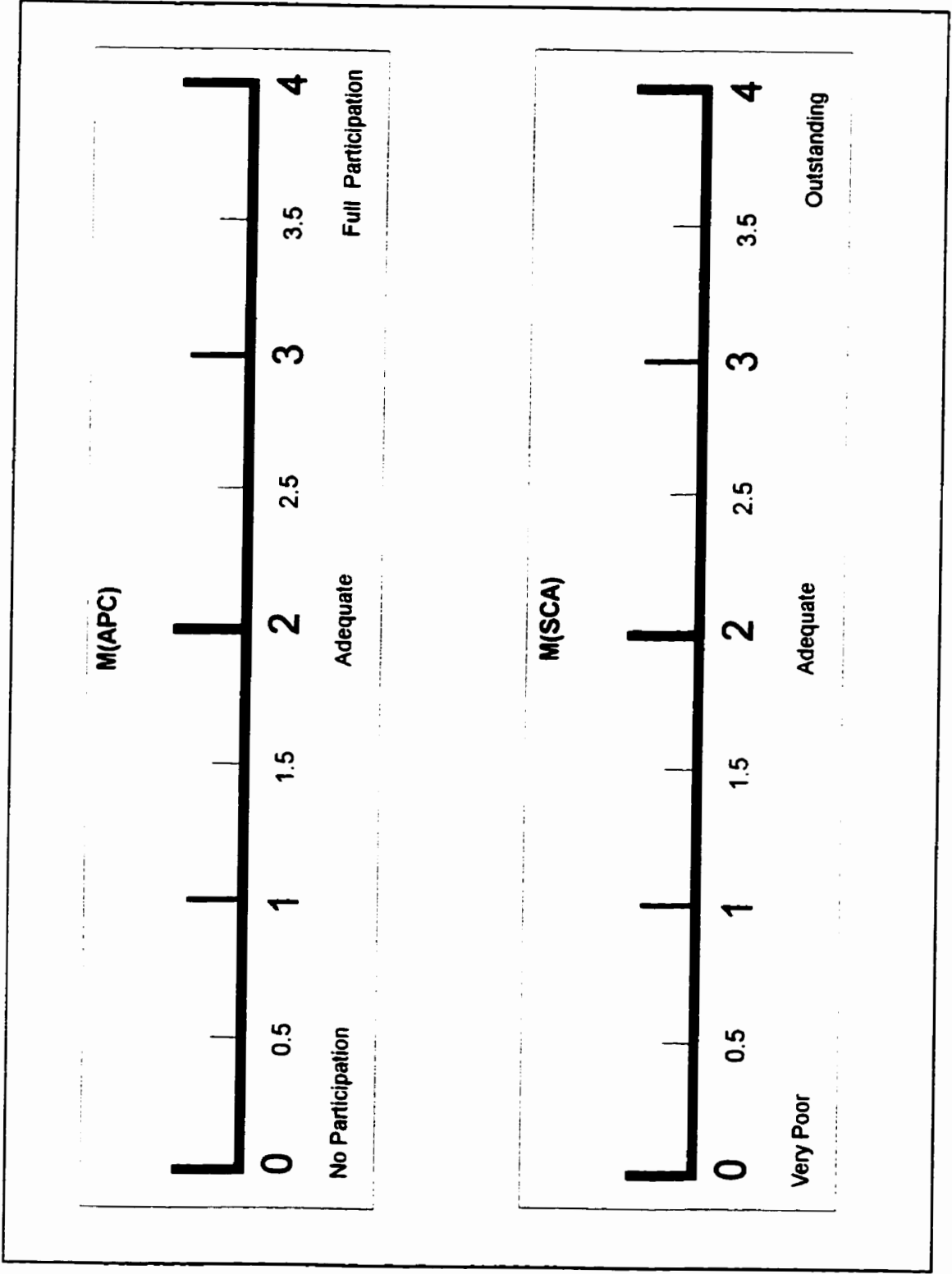
M(APC):     Measure of Aphasic Adult's Participation in Conversation
M(SCA):     Measure of Conversation Partner's skill in providing 'Supported Conversation for Adults with Aphasia.'

The initial version consisted of a 9-point scale presented as a range of 0 – 8; however, raters found it difficult to keep rating anchors in mind. The scale was then reduced to a range of 0 – 4, but this was not sufficiently refined; raters wanted to rate 'in-between' points on the scale. The range of 0 – 4 with .5's was a compromise. Raters found it easier to keep five rather than nine rating anchors in mind, and the scale retained the flexibility of 'in-between' rating points. The (M)SCA™ scale ranges from '0' (totally inadequate) through '2' (adequate), to '4' (outstanding), in relation to the conversation partner's skill in providing supported conversation. The (M)APC scale ranges from '0' (no participation), through '2' (adequate participation), to '4' (full participation in conversation). Raters use rating guidelines and rating anchors to assign a score to each of the major categories and subcategories: interaction, transaction, acknowledging competence, and revealing competence, the latter being broken down into three subcategories.

To facilitate the joint use of the measures, the score of the person with aphasia is always placed on the scoring sheet of the conversation partner. More importantly, the score of the conversation partner should be indicated on the scoring sheet of the person with aphasia, because this indicates how the aphasic person participates in conversation with a particular level of support. This simple method ensures that both elements of the dyad or social unit are kept in mind, even when the focus is on only one of the participants.

Initially, the score of interest for both measures was thought to be the overall or total score. However, this was not found to be clinically useful. For example, two people with aphasia could have scores of 2 on the (M)APC that derive from very different configurations of interaction in relation to transaction. One might be outstanding interactionally, but very poor in terms of exchanging information, while the second person might be adequate in both areas. Similarly, two conversation partners might each have a total score of 2 on the support measure ((M)SCA™) derived from entirely different profiles. It is more useful to use a combined index for clinical purposes. An index of 3/1.5, for example, means that the partner

is doing very well in acknowledging competence but is not quite adequate in revealing it. This has obvious clinical implications, but is also valuable for research. For example, in relation to the (M)SCA™ we might be interested in whether or not there is a difference in the two sub-areas in terms of potential for change with training.

While these measures were developed for use with individuals with moderate-severe aphasia and their conversation partners[19], scores on the (M)APC (participation measure) are not necessarily related to traditional levels of severity. In other words, it is possible for someone with very severe aphasia to score at the top of the range on the (M)APC.

**Psychometric evaluation**

Two pilot studies were carried out to evaluate inter-rater reliability and construct validity[20] for both the (M)SCA™ and the (M)APC (see Table 4.1 for an overview of the methodology for both studies). Study #1 examined inter-rater reliability, and study #2 examined construct validity (while also providing additional inter-rater reliability data).

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[19] People with mild aphasia need to target different behaviors, and their conversation partners need to acquire a different skill set - one not reflected in these measures.

[20] This thesis refers to a unified concept of validity as opposed to the concept that validity should be divided into many different types. According to Messick (1994), assessment validity is best thought of as a unified whole because 'the appropriateness, meaningfulness and usefulness of score-based inferences are inseparable'. 'The unifying force behind this integration is the trustworthiness of empirically grounded score interpretation' namely, construct validity.

Table 4.1.    Summary of methodology for two psychometric studies evaluating the

(M)SCA™ and (M)APC

| STUDY | MEASURE | METHODOLOGY | NO. OF SUBJECTS AND RATERS | OBJECTIVES |
|---|---|---|---|---|
| Pilot study #1 (Reliability) | (M)SCA™ | Five dyads (conversation partners and aphasic adults) were videotaped in a semi-structured conversation before and after the conversation partners received training. Three SLP's independently rated participants on the measures | Conversation partners: N = 5 Raters: N = 3 | To determine inter-rater reliability (intraclass correlation). |
| | (M)APC | As above | Aphasic adults: N = 5 Raters: N = 3 | As above |
| Pilot study #2 (Validity) | (M)SCA™ | Two SLP's used clinical judgement to select ten volunteer conversation partners who represented a range from good to poor. Two other SLP's independently rated the ten volunteers on the measure. | Conversation partners: N = 10 Raters: N = 2 | To determine whether or not there was a correlation between the measures and informal clinical judgement (Spearman Rank Correlation). To determine inter-rater reliability (intraclass correlation). |
| | (M)APC | Two SLP's used clinical judgement to select ten adults with aphasia and ranked them as good to poor communicators based on informal clinical judgement. Two other SLP's independently rated the ten aphasic adults on the measure. | Aphasic adults: N = 10 Raters: N = 2 | As above |

Key

(M)SCA™ = Measure of skill in providing Supported Conversation for Adults with Aphasia™

(M)APC = Measure of the Aphasic Adult's Participation in Conversation

SLP = Speech-language pathologist

Inter-rater, rather than intra-rater reliability was examined because it is by definition a more conservative estimate (Streiner & Norman, 1992). The statistic of choice for evaluating inter-rater reliability in all studies was the intraclass correlation. An intraclass correlation was chosen because it takes into account both agreement and association and is, therefore, a more conservative statistic. Intraclass correlations achieve the same result as the weighted kappa (Streiner & Norman, 1992, p.95).

According to Streiner and Norman (1992), validation can be seen as a process of hypothesis testing, with the ultimate definition of a valid scale being "one that allows us to make accurate inferences about a person" (p.115). The construct validity study presented in this chapter is based on the understanding that establishing construct validity is an on-going process involving many studies that either add support to, or detract from, the validity of the measure. The results of construct validity potentially lend support to the underlying theory or constructs as well as the validity of the measuring tool. If the findings are negative, the problem could lie with either the theory or the measure. The statistical procedure used for the validity study was the Spearman Rank Correlation.

Raters for both studies were speech-language pathologists with at least one year of experience at the Aphasia Centre, and extensive experience in the area of aphasia in general (ranging from 12-24 years). Conversation partners were volunteers at the Centre. Depending on the study design, they were either newly recruited (study # 1), or experienced (study #2). Participants with aphasia were recruited from among the members of the Pat Arato Aphasia Centre. (See details below).

### Study #1: Reliability

The purpose of this study was to determine inter-rater reliability of three raters on both measures using pre-post training videotapes.

### Participants

A convenience sample of five volunteer conversation partners and five adults with moderate-severe aphasia, from the Aphasia Centre, were recruited as participants based on their willingness to participate. Volunteers were new recruits to the Centre who had not had previous exposure to adults with aphasia. The raters were three speech-language pathologists from the Aphasia Centre, including the author.

### Methodology

Ten semi-structured interviews between volunteer conversation partners paired with aphasic adults were videotaped; five before and five after the volunteers received training as described in Chapter Three. The three raters used both measures and independently rated all ten randomly presented tapes. Raters were trained to achieve consensus. Training consisted of viewing a range of videotapes (different from the tapes used in the study), rating them, discussing scoring differences and jointly deciding on rating guidelines to be used as criteria for scoring.

### Results

Intraclass correlations for the three raters on the two measures were uniformly high ($r$ ranged from between .73 to .9, $p<.001$), (see table 4.2). Results are discussed below.

**Table 4.2.      Inter-rater reliability results on the (M)SCA™ and the (M)APC for study #1**

| MEASURE | INTER-RATER RELIABILITY<br>Intraclass correlations (r) for 3 raters, p<.001 |
|---------|------------------------------------------------------------------------------|
| (M)SCA™ | Acknowledge Competence:      0.83<br>Reveal Competence:              0.89 |
| (M)APC  | Interaction:      0.85<br>Transaction:      0.73 |

<u>Key</u>

(M)SCA™ = Measure of skill in providing Supported Conversation for Adults with Aphasia™
(M)APC = Measure of the Aphasic Adult's Participation in Conversation

### Study #2: Construct validity (comparison with experienced clinicians' judgements)

The main purpose of this study was to determine whether there was a correlation between scores on the measures and the informed judgements of clinicians regarding the effectiveness of volunteers and the communication abilities of aphasic adults. In addition, the study examined inter-rater reliability on the (M)SCA™ and the (M)APC.

## Participants

A convenience sample of ten volunteers and ten adults with moderate-severe aphasia were selected as participants, again based on their willingness to participate. In contrast to the first study, these volunteers had experience in facilitating conversation groups at the Aphasia Centre. The raters were four staff speech-language pathologists, one of whom participated in Study #1.

## Methodology

Two of the raters (in their capacity as staff speech-language pathologists) were asked to jointly compile a list of ten volunteers and, based on informal clinical judgements, rank them from 'very poor' to 'outstanding', taking care to ensure that both ends of the continuum were represented. They were specifically asked to make a snap judgement regarding volunteers who came immediately to mind. The volunteers were ranked in relation to each other and not according to any pre-set scale. This list was then given to the two other raters who independently rated the volunteers on the (M)SCA™. The ratings were done in real time, with the two staff members observing each volunteer with a person who had severe aphasia, chatting about current events, for approximately ten minutes. The score of each rater was correlated with the joint ranking given on the basis of informal clinical judgement.

The same basic procedure was followed for ten individuals with aphasia. The same four raters participated, but exchanged roles i.e. those who did the independent rating on the measures for the volunteers, now compiled a list of ten members with aphasia based on informal clinical judgement and ranked them as communicators from 'very poor' to 'outstanding'. The two other raters then independently rated the members on the (M)APC.

Two groups of five aphasic adults were videotaped in conversation with the same volunteer. Ratings were done from the videotapes rather than in real-time. Use of the group setting rather than one-on-one interaction was related to the need to keep the volunteer constant in order to avoid variation in skill level. Asking a volunteer to do the same thing ten times was felt to be an undue imposition. Although the dynamics of conversational interaction do differ in group settings, the raters focused on the level of participation of each individual rather than on the group dynamics and interaction.

## Results

*Relationship between scores on the (M)SCA~ and (M)APC and experienced clinical judgement*

There was a significant positive correlation between informal clinical judgement and scores on all categories of the measures for both raters ((M)SCA™: rho ranged from between .83 – .95, p<.01-.001; (M)APC: rho ranged from between .76 to .93, p<.01-.003) (See Table 4.3).

*Inter-rater reliability*

Data collected from this second study yielded highly significant positive correlations (r ranged from between .91 to .96, p<.001, see Table 4.3).

**Table 4.3.** **Inter-rater reliability and construct validity results on the (M)SCA™ and the (M)APC for pilot study #2**

| MEASURE | INTER-RATER RELIABILITY<br><br>Intraclass correlations (r) for 2 raters, p<.001 | CONSTRUCT VALIDITY<br><br>Spearman Rank correlations (rho) for 2 raters (correlating scores on measures with informal clinical judgement) |
|---|---|---|
| (M)SCA™ | Acknowledge competence:  0.91<br>Reveal competence:  0.96 | <u>Rater 1</u><br><br>Acknowledge competence:  0.95 (p<.01)<br>Reveal competence:  0.87 (p<.01)<br><br><u>Rater 2</u><br><br>Acknowledge competence:  0.87 (p<.001)<br>Reveal competence:  0.83 (p<.003) |
| (M)APC | Interaction:  0.93<br>Transaction:  0.94 | <u>Rater 1</u><br><br>Interaction:  0.93 (p<.01)<br>Transaction:  0.91 (p<.01)<br><br><u>Rater 2</u><br><br>Interaction:  0.84 (p<.003)<br>Transaction:  0.76 (p<.01) |

<u>Key</u>

(M)SCA™ = Measure of skill in providing Supported Conversation for Adults with Aphasia™

(M)APC = Measure of the Aphasic Adult's Participation in Conversation

### Overall discussion of studies

Inter-rater reliability scores for both studies on both measures were in the range of .8 and above and statistically significant. This indicates that raters who are familiar and experienced with SCA™ (Supported Conversation for Adults with Aphasia™) agree on scoring of the measures to an acceptable degree. Although reliability scores of .8 are conventionally regarded as adequate, Streiner and Norman (1992, p.89) comment that recommendations regarding how much reliability is 'good enough' are arbitrary.

The validity of both measures was supported by results of study #2, lending support to both the conceptual framework underlying supported conversation and the validity of the measures. There was a significant positive correlation between informal clinical judgement and scores on all categories of the measures. Correlations of this magnitude might indicate that the measures are unnecessary because scores can be predicted by informal clinical judgement. However, there are two points to consider. First, staff at the Aphasia Centre are very familiar with the concepts underlying SCA™. This same study done in another agency might have had less significant results. Second, the informal clinical rating does not give a breakdown of areas for comparison. On the support measure ((M)SCA™), for example, scores differentiated skill in acknowledging versus revealing competence that were of clinical interest. One of the volunteer conversation partners who is experienced as a facilitator of groups consisting of adults with mild aphasia, had only recently started working with more severe groups. Her score in acknowledging competence was very high, but her score in revealing competence, while adequate, was not yet in the same range. The measure could be used to assess her current level of skill, suggest areas requiring attention, and create goals.

In its final form, the set of measures deliberately assesses aspects of communication on a macro or global level. However, as discussed previously, there is a danger in focusing

exclusively on more global measures (Gordon, 1997). Depending on the purpose of evaluation, the measures should be supplemented by more detailed microanalyses that capture different aspects of communication, for example, conversation analysis (Damico, Simmons-Mackie, & Schweitzer, 1995; Simmons-Mackie & Kagan, in press), pragmatic analysis (Penn, 1988), and cognitive neuropsychological approach (Byng et al., 1990).

This project focused on conversational interaction but there are many other areas to evaluate when working within a social model. One of the most concrete outcomes is an increase in social participation, for example, the number and frequency of relevant activities or participation in life events. As Penn (1998) states, it is essential to include measures examining quality of life as the ultimate outcome. Literature in the field of alternative and augmentative communication also increasingly emphasizes the importance of determining outcomes of social relevance (e.g., Beukelman & Mirenda, 1992; Calculator, 1997; Fox & Fried-Oken, 1996).

In addition, as stated earlier, the evaluation of conversation as described in this chapter is one of many potential methods that can be used to clinically evaluate or research conversational partnerships in aphasia. Qualitative approaches increase in-depth understanding of underlying patterns and processes (e.g., Damico et al., 1995). There is a range of rigorous qualitative methodologies available to research conversation, for example, phenomenological research that can be used to capture the experiences of individuals with aphasia; and ethnographic research that can be used to describe the 'culture' of aphasia by observing and examining the way it manifests. Combining the SCA™ measures with approaches such as these will provide a richer picture than using only one evaluative method.

**Examples of direct clinical applications of the set of measures**

*Reporting on level of function with, and without support*

Writing or receiving reports that include information about how the person with aphasia does with and without support is valuable. For example, a person might score 2/1 (interaction/transaction) with an unskilled partner, but 3/3 with a skilled partner. The potential for intervention with the aphasic person, as well as a conversation partner, is immediately apparent. This gives a much broader picture than a score or severity label derived solely from a standardized language test. Thus, ideally, in addition to the traditional information available on someone with aphasia, we could also give his or her potential level of participation in conversation with poor/average/good conversational support. At the Aphasia Centre, the concept of giving scores in relation to the partners' scores is also used in a more generic sense to describe, for example, a particular volunteer's overall skill when paired with aphasic individuals with high as opposed to low participation ((M)APC) scores.

*Using the breakdown of sections within each measure to give feedback to conversation partners and individuals with aphasia*

The support measure (M)SCA™ can also be used to give concrete feedback to a conversation partner. For example, a volunteer can be told that they are doing well with getting their message in, but that they need to work on helping the aphasic person to get their message out, and specifically, that using written key-words would make all the difference. In similar vein, the participation measures ((M)APC), can be used as a basis for giving feedback to the person with aphasia.

### Dyad/family training

The measures can be used as a starting point for dyad or family training. For example, a person with aphasia who scores poorly in social interaction but adequately in transaction or information exchange, might be encouraged to focus on 'making the conversation partner feel good' about communicating with him/her. In one such example, intervention supported by the measures focused on encouraging a man with severe aphasia to concentrate on social interaction rather than on transaction, because his insistence on getting every detail across was demoralizing and exhausting his spouse to the point that a potentially good communication environment was not effective. Lyon (1997a) has developed scales to evaluate both participants' perception of communication. This type of evaluative tool complements the behavioral rating scales described in this chapter.

### Making feedback less 'personal'

Data in the form of a measure might serve to 'depersonalize' awkward interpersonal situations to some extent. For example, it has been suggested (Simmons-Mackie, personal communication) that the (M)SCA™ is potentially useful for rating student performance in a way that analyzes behaviors rather than 'personality'. This would be relevant to students in any discipline where there is likely to be interaction with individuals who have aphasia e.g., medicine, nursing, medical social work, physical therapy, and occupational therapy. The framework of acknowledging and revealing competence can also be adapted for different communication problems, by making relevant changes to the specific techniques included under these headings.

## Conclusion

This chapter presented a preliminary psychometric evaluation of a set of two new measures intended to provide a simple method for capturing essential broad elements of conversation. Their use for both clinical and research purposes was described. Initial psychometric data yielded satisfactory results thus suggesting that these are adequate tools for conducting a study to evaluate the efficacy of training conversation partners to use SCA™, and to evaluate the soundness of the underlying conceptual framework. This project is described in Chapter Five.

# SUPPORTED CONVERSATION FOR ADULTS WITH APHASIA™:
## A CONTROLLED TRIAL

Evaluation of 'Supported conversation for adults with aphasia™' (SCA™) can be approached from both a qualitative and quantitative perspective. Although qualitative research is ideally suited to investigating the complexities of conversation, these methods are not necessarily well understood or appreciated by administrators and funders. Using evidence based on more traditional methods to provide support for SCA™ is especially important because the approach itself falls outside the realm of traditional interventions in the field. For this reason, experimental methods were used for the first study examining SCA™.

In a recent meta-analysis of clinical outcomes in the treatment of aphasia, Robey (1998) found a total of 55 studies that qualify as at least quasi-experimental in that they used random allocation of subjects (Cook & Campbell, 1979)[21]. Of these, only twelve studies had more than forty subjects, and only six focused on severe aphasia. In terms of a social model of aphasia, the scope of existing studies is limited in that they have mainly examined interventions for language impairment, with a few studies looking at communication ability of individuals with aphasia. Many of these studies have methodological shortcomings. As no previous experimental study has specifically targeted the conversation partner, the following section analyzes studies that have used randomized controlled methodology in assessing traditional aphasia treatment.

A detailed literature search revealed two large studies that fit the criteria of being both randomized *and* controlled. The paucity of controlled trials relates to ethical problems arising

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[21] Two of the most well-known efficacy studies in aphasia (Wertz et al., 1981; Wertz et al., 1986) were omitted because they lacked certain mathematical details

from the inclusion of a 'no-treatment' group[22]. In most aphasia efficacy studies, control groups comprise a self-selected group of people who either cannot or choose not to receive treatment. This compounds the problem of heterogeneity of population endemic to group efficacy studies of aphasia treatment. The first of the two studies referred to above (Lincoln et al., 1984), compared a treatment (N=163) and no-treatment group (N=164) and concluded that speech-language therapy is not effective. Treatment was described as 'standard clinical practice in many speech therapy departments'. The second (Wertz et al., 1986) compared treatments, one of which was stimulus-response therapy delivered by a speech-language pathologist that allowed for adaptation to individual needs. The treatment group (N=38) was compared with a 'deferred-treatment' group (N= 40) that functioned as a no-treatment group for the first phase of the study. (Forty-three subjects were assigned to a second treatment group where treatment was administered by volunteers, but this is only relevant to the issue of comparison of treatment.) The authors concluded that therapy is effective. Both these studies can be criticized on methodological grounds as described below.

*Selection criteria*

The Lincoln study was particularly poorly designed. Selection criteria for acute stroke patients were purposefully minimal so that the population would resemble that which would normally be admitted to hospital in the UK, but so little information is given about the subjects that it is difficult to judge the potential for biased outcome. The drop-out rate was approximately 50%, but there was no 'intention-to-treat' analysis. No statistics are given on the differences between groups in terms of attrition, thus potentially negating the benefits of any initial randomization. The Lincoln group did not provide confidence limits for their negative statistical finding and also did not do a power analysis to determine whether the N was large enough to show a difference should it really exist.

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[22] The ethical dilemma of a no-treatment group can be partially resolved by providing treatment to the latter after a fixed period of time as is the case in the Wertz (1986) study.

In the Wertz study on the other hand, the selection criteria were so stringent that they excluded almost 93% of the population screened, making it highly unlikely that the sample resembles a real-life clinical situation. However, the study does provide relevant subject characteristics.

## Measurement in relation to selection criteria

The Lincoln study used tests such as the Porch Index of Communicative Ability (Porch, 1967) to diagnose aphasia. Although such tests are highly sensitive in that they detect most instances of aphasic language disturbance, they can end up including people with other/additional problems such as multi-infarct dementia. The Wertz study included neurologically based selection criteria for aphasia (e.g., single, left-hemisphere focal infarct) in addition to using aphasia test batteries.

## Specification of treatment

Neither study gives sufficient detail about treatment to allow for a replication of the study, although the Wertz study is better in this regard. This is another significant problem that all aphasia research has in common. Howard and Hatfield (1987) point out that "...it is axiomatic to every school of treatment that the tasks a patient is asked to do should be determined by his/her particular aphasic symptom complex."

## Specification of clinical significance

Lincoln did not specify a criterion for clinically significant difference beforehand. Wertz did make this specification (15 percentile units on the PICA), although as Brookshire (1994) comments, no-one knows what this means in terms of functional communication or quality of

life. Neither study included quality of life measures but Lincoln did incorporate a functional communication profile and questionnaire for families.

According to Brookshire (1994) an important difference between most randomized clinical trials in medicine, and group efficacy studies in aphasiology, is that standardized aphasia test scores (primary outcome measure in efficacy research in aphasia) are not intuitively meaningful to the medical profession, health care financing agencies, and the public, whereas medical outcome measures are generally accepted as reasonable and appropriate. There is little research on whether differences of a given magnitude on the tests represent meaningful changes in communicative ability in daily life, and whether these changes are worth the effort and cost. No major study has employed a standardized test of functional communication such as Communicative Activities of Daily Living (Holland,1980), as a primary outcome measure.

Randomized group trials derive their form and methodology from clinical drug trials and are not necessarily regarded as the optimal method for evaluating the efficacy of aphasia treatment (Howard & Hatfield, 1987). However, as Brookshire (1994) points out, consumers (patients, families, physicians, and funding agencies) often look to such trials and large group studies for evidence of the effectiveness of treatment.

The present study is the first of its kind to assess the efficacy of an intervention targeting a social unit that comprises a communication partner as well as the person with aphasia. Because the intervention is directed toward volunteer conversation partners and not the person with aphasia, the study is able to overcome some of the critical methodological problems described above, for example, specification of treatment. It also overcomes the ethical issue of withholding treatment.

Professional training and supervision of community volunteers as conversation partners has increased (Coles & Eales, 1999; Kagan & Cohen-Schneider, 1999; Kagan & Gailey, 1993; Lyon et al., 1997b; Patterson, Paul, Wells, Hoen, & Thelander, 1994). This is particularly relevant as cost-saving measures in the current health care atmosphere require all health professionals to 'do more with less'.

The purpose of this study was, thus, to investigate the efficacy of SCA™, with the primary aim of determining the feasibility of training volunteer conversation partners, and the secondary aim of assessing the impact of such training on those with aphasia.

The following research questions were asked: 1) Do volunteers trained in SCA™ score higher than untrained volunteers on a 'Measure of Supported Conversation for Adults with Aphasia™'; 2) Do adults with aphasia, in conversation with trained volunteers, score higher than those with untrained volunteers, on a 'Measure of Aphasic Adults' Participation in Conversation'; and 3) Are changes in volunteers' scores related to changes in the scores of their partners with aphasia?

# METHOD

### Design

The study, conducted at the Pat Arato Aphasia Centre, utilized a single-blind, randomized, controlled, pre-post design. The Aphasia Centre forms a logical first testing ground for SCA™ because the approach was developed on the basis of experience gained in this setting.

### *Participants*

Eighty participants (made up of forty dyads each consisting of a volunteer conversation partner and an adult with aphasia), were recruited to the study. This allowed 20 dyads in the experimental group and 20 in the control group. Sample size was loosely based on a sample size estimation using data from a study described in Chapter Four (study #1)[23].

### *Volunteer participants*

Volunteers were recruited from applicants accepted for training at the Aphasia Centre. They had, therefore, been through the routine screening process conducted by the coordinator of volunteers. The process of recruiting volunteers for the study was identical to that normally followed for volunteer recruitment at the Centre, except for the fact that those who had previous experience with a neurogenic population or any program similar to that of the Centre were excluded. Volunteer subjects were also required to be proficient English speakers such that English was their mother tongue or the primary language used at work or in the home.

As is typical of the volunteer population at the Aphasia Centre, a large proportion of the 40 volunteers were women (87%), less than 30 years of age (75%), and students (28). All had completed high school, with 45% having an undergraduate degree and 7.5% a masters degree.

Five volunteers (4 women and 1 man) chose not to participate. Reasons given included 'preferred not' (n=2), 'too nervous' (n=2), and 'busy schedule (n=2). These volunteers were

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[23] At the time the power analysis was carried out, the experimental hypotheses for the efficacy study were based on the total score for the (M)APC (participation measure) and the (M)SCA (support measure). Using an effect size based on the data, with ratings of the three raters averaged, an $\alpha$ level of 0.05 and a $\beta$ level of 0.2, sample size was calculated to be N=26 for the (M)APC and N=12 for the (M)SCA. The final sample size of N=20 per

older than those who agreed to participate (two over 60 and two between 50 –60 years of age).

## Participants with aphasia

Recruitment of the participants with aphasia was facilitated because of the availability of a pool of approximately 150 members with varying severity levels actually attending day-programs at the Aphasia Centre. Inclusion criteria, especially that of moderate-severe, preferably severe aphasia [based on the Aphasia Quotient on the Western Aphasia Battery (WAB AQ) (Kertesz, 1982), and the clinical judgement of a speech-language pathologist at the Aphasia Centre], reduced the available pool. This resulted in most people who fit the criteria being approached to participate. Other inclusion criteria included: the ability to engage in conversation at some level with a skilled conversation partner (speech-language pathologist at the Centre) using some/all of the following modalities – verbal/gestural/written/pictured or drawn; at least one year post-stroke; clinically verified focal lesion/s; and, premorbidly competent in English. Exclusion criteria for the study included deteriorating neurogenic disorders such as dementia; severe behavioral or psychiatric problems; and progressive aphasia.

The 40 participants with aphasia were predominantly men (63%) with a mean age of 70 years (standard deviation (SD) = 11). The most common etiology was stroke. With two exceptions, all participants had left hemisphere strokes (one bilateral at onset and two with subsequent right hemisphere strokes). Two participants had right hemisphere strokes causing aphasia, despite being right-handed. Only one participant was left-handed. According to CT reports available on 39 of the 40 participants the following brain regions were damaged either alone or in combination: frontal (62%), parietal (74%), temporal (59%) and occipital (5%). In terms of subcortical structures, basal ganglia damage was present in

group took these figures into account, as well as guidelines regarding procedures for inferential statistics (Cohen,

48% of scans in which this information was available, and thalamic damage in 2%. In all but two participants, the stroke was in the middle cerebral artery territory. Based on their WAB AQ scores (mean = 28; SD = 15) and profiles, the breakdown of aphasia types was as follows: severe Broca's type aphasia (75%), global aphasia (15%), Wernicke's type aphasia (5%) and conduction and transcortical aphasia (2.5% each). Mean time post-onset was 58 months (SD = 40 months; range 12-178 months) and mean length of attendance at the Aphasia Centre was 42 months (SD = 46 months; range 1-210 months). The majority were either hemiplegic or hemiparetic (93%) and had accompanying motor speech problems (93%). Mean level of education was 13 years (SD = 4 years).

Five members (2 women and 3 men) chose not to participate in the study. The reasons given were 'not interested' (4), and 'too soon after participation in another research project' (1). Mean age was 72 years (SD = 8.7 years). Severity of aphasia based on the clinical judgement of speech-language pathology staff ranged from severe (3) to moderate-severe (2).

### Group assignment

After a specified date, all volunteers applying to work at the Aphasia Centre and fitting the selection criteria were asked if they were willing to participate in the study. The Centre has a constant flow of volunteer applications, but these do not normally accumulate within one time period in the numbers required for this study. Four blocks of ten volunteers were, therefore, recruited over a period of one year. As soon as ten volunteers had agreed, they were randomly assigned by the coordinator of volunteers (an administrative person) to two groups. The coordinator of volunteers was not involved in the study and did not know which of these groups was experimental versus control. Four blocks of ten volunteers each were recruited and assigned in this way.

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1988).

### Dyad assignment

At the same time, participants with aphasia fitting the subject selection criteria were randomly assigned to volunteers. In a few instances, changes were made on the basis of the availability of transportation in order not to inconvenience subjects unnecessarily. Strictly speaking, this is quasi-randomization; however, as there was no pattern for selection of aphasic participants assigned to experimental versus control group in terms of differences between days or programs attended, the study can be described as 'randomized' for practical purposes (Streiner, personal communication).

### Tests for randomization

Participants with aphasia

In order to ensure equally representative groups, tests for randomization were carried out on the following key variables: severity of aphasia based on the WAB AQ score, time post-onset, and experience based on length of time at the Aphasia Centre. Randomization for participants with aphasia was effective in all cases except the WAB AQ, in which there was an 11 point difference between groups, with the experimental group (WAB AQ= 22) being more severe than the control group (WAB AQ=33), [$t$(38)=2.483,$p$= 0.018]. Correlations between WAB AQ scores and pre-scores on the dependent variables were calculated. WAB AQ scores were significantly correlated with one of the dependent variables (the level of transaction of aphasic subjects prior to intervention) ($r$= 0.374, $p$<.05). For these reasons, as well as the fact that severity of aphasia was felt to be clinically important, the WAB AQ was included as a covariate when analyzing results (see data analysis section). It should be noted however, that there was no difference between groups on the comprehension section

of the WAB ($t(38)= 0.793$, $p= 0.433$). Comprehension ability was felt to be more important to participation than the total WAB AQ score.

## Volunteer participants

Randomization for volunteer participants was effective for sex ($\chi^2 = 0.23$, $p>0.999$) and student status ($\chi^2 = 4.29$, $p=0.082$). Groups differed on age ($t(36)=-2.154$, $p=0.038$), with the experimental group being an average of seven years older. This difference was partly driven by three volunteers over age 50 who happened to be in the experimental group. Volunteer age was not covaried as in our experience at the Aphasia Centre, we had not found age per se to make a difference to the skill level of volunteers.

### Informed consent

Informed consent to participation was obtained from all participants (see Appendices 2 and 4). The informed consent process for participants with aphasia differed from the traditional process in that information about the research was presented in a pictographic format accompanied by key words [24]. As suggested by Kagan and Kimelman (1995), the document was presented using techniques of supported conversation including verbal and non-verbal adaptations that aided comprehension, gave opportunity to express opinions, and ensured verification of key issues before asking for a signature. Paying attention to the *process* of informed consent in this manner meant that even participants with severe aphasia were able to give consent themselves rather than asking their families/significant others to do this for them.

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[24] The University of Toronto has set a precedent in recognizing this form as a legal document in its own right rather than as a supplement to the traditional informed consent document.

**Procedures**

Data were collected in blocks of ten dyads at a time. Once ten volunteer participants were available, they were randomly assigned to either the experimental or control group. Pre-training interviews were videotaped. Experimental dyads were videotaped in a semi-structured interview situation both before and after the volunteer received SCA™ training in supported conversation. (See below for details regarding interview and methods.)

Control group dyads were videotaped in the same way but volunteers in the control group did not receive training between the two tapings. They were 'exposed' to aphasia by watching a video that tells the stories of five aphasic adults and their families (Adair Ewing & Pfalzgraf, 1991b). They were also given an opportunity to interact with aphasic members at the Aphasia Centre so that exposure to individuals with aphasia would be comparable to that of the experimental group. This process continued until there were 20 dyads per group.

<u>Description of conversational interview</u>

The conversational format selected for the study was a semi-structured interview (see Appendix 5). The choice of this format for the pre- and post-training videotapes (as opposed to more flexible and open-ended conversation) was influenced by requirements of the experimental design. For example, the videotaped conversations had to allow for comparison between dyads as well as comparison of the same dyad at two different points in time. Semi-structured interviews allow for such comparison as topics follow a pre-selected agenda. Furthermore, this type of conversation is frequently encountered by individuals with aphasia when interacting with health professionals.

The semi-structured interview used in the study was specifically designed to provide opportunities for social interaction as well as information exchange. Therefore, it consisted of some predominantly interactional and some predominantly transactional components[25]. Choice of topics was constrained by the time available for the interview. To counterbalance the fact that the interview format puts the volunteer in the position of asking questions, an additional section was added where the volunteer is instructed to ask the participant with aphasia whether there are any questions that he/she would like to ask the volunteer. The interview was piloted numerous times to ensure that questions allowed people with severe aphasia to participate and that, at the same time, it was sufficiently challenging for those with less severe aphasia. The structure of the second interview was identical to the first except that the volunteers in the second were asked to re-introduce themselves at the beginning, and after that, to try and refrain from referring back to the first interview in any way (see Appendix 5 for specific instructions given to volunteers).

## Procedure for interviews

Three staff members served as research assistants for the interviews (see Appendix 6 for research assistants' instructions). Prior to each interview, volunteers had time to read through their instructions and prepare for the interview. They were seated at a table with standardized content and layout of resource material (see Figure 5.1), and told that they could take whatever they wanted with them to the interview, which was conducted in a different room. They were not given any time constraint for the preparation period, but preparation time was noted.

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[25] Although components of the interview have been described as 'predominantly' transactional or interactional, as discussed in Chapter Two, conversation usually achieves these goals simultaneously. For example, Roter and Hall (1993) talk about the fact that information conveyed by physicians to patients carries emotional content.

When they indicated that they were ready, volunteers were taken to a second room and introduced to the aphasic person with whom they would be chatting. (The research assistant had already conducted a brief pre-interview with the aphasic participant to see whether or not there had been any change in personal circumstances that might influence results (see Appendix 7)). A tripod-mounted Panasonic SVHS AG-455 video camera with Shure SM58 Dynamic microphone was used for videotaping and was set up so that both participants were clearly visible. Videotaping equipment was controlled from an adjoining room by research assistants who monitored the entire interaction in case of undue distress by participants (see Figure 5.2)[26]. Materials available in the interview room included some written and pictographic resource material from sources other than the PCR manual, and magazines. All material was displayed in a consistent manner for each interview. The layout was designed so that it would not be immediately apparent to a rater that the interview was the first versus second or experimental versus control. All written/drawn material was kept for later analysis.

Volunteers were told that they could have approximately 15 minutes for their interview. In practice, interviews were not stopped until all sections had been attempted. In some cases, the research assistant had to interrupt the interview if the conversation was clearly straying too far from the assigned topics. The length of each interview was noted.

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[26] There were no instances where research assistants felt the need to intervene.

**Figure 5.1**     Layout of preparation room for volunteers prior to interview



Extracts from 'Pictographic Communication Resources' Manual

Globe

Information Resources

Dictionary

Local Maps

Canadian Atlas

Large letter Atlas

Fashion
Technology
Transportation

Magazines

Scissors   Tape   Pencils   Pens   Markers   Glue   Scrap Paper

Pictographic Resources

**Figure 5.2    Set up for interviews**



Interview Room (3.33m x 4m)

Observation Room

One way mirror

Controls

Monitor

Video camera control button

Microphone

Volunteer

Participant with aphasia

Magazines

Pictographic materials

Months of the year

World map

1.66m round table

Video Camera

Cornelia Simpson '97

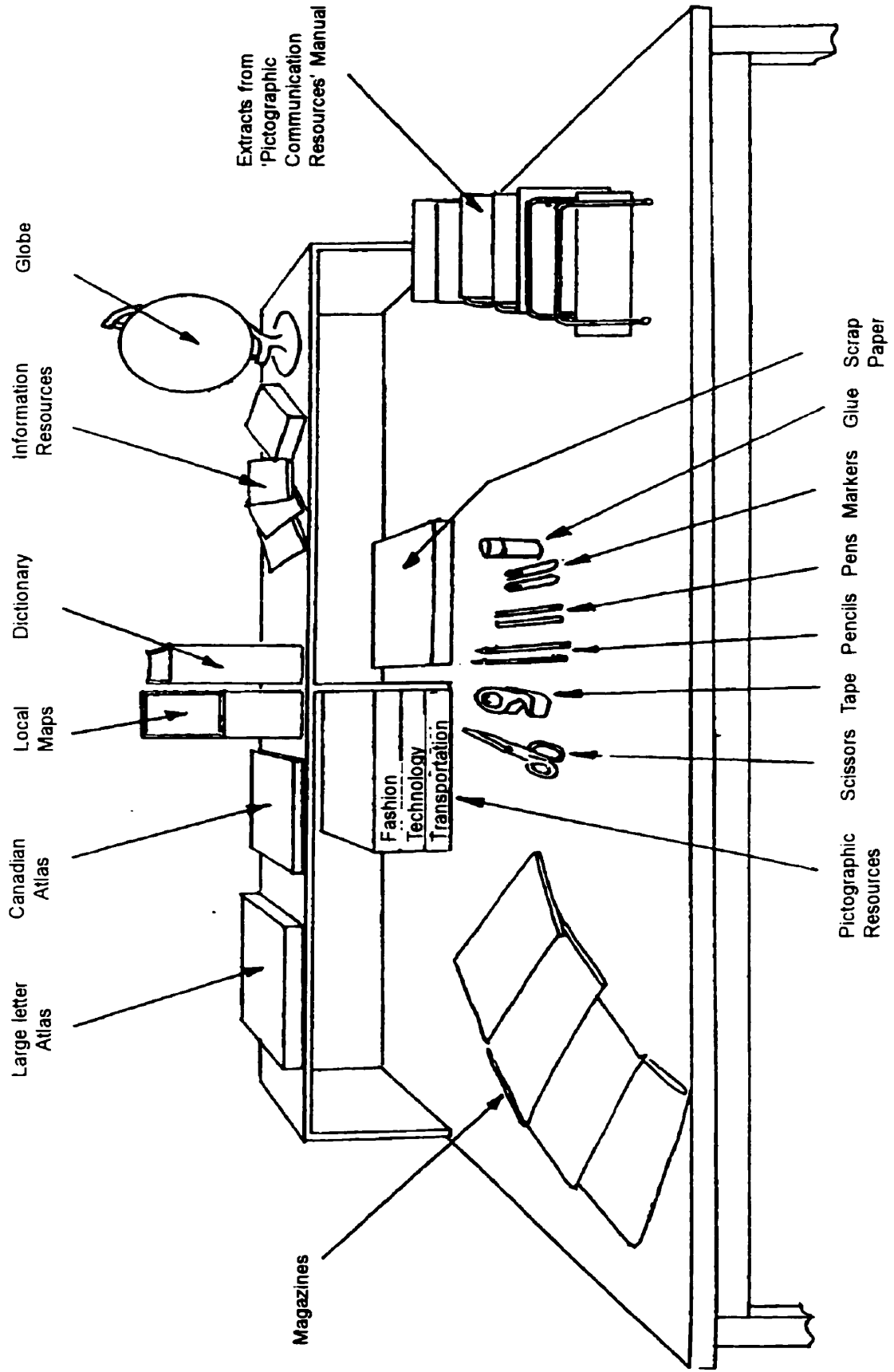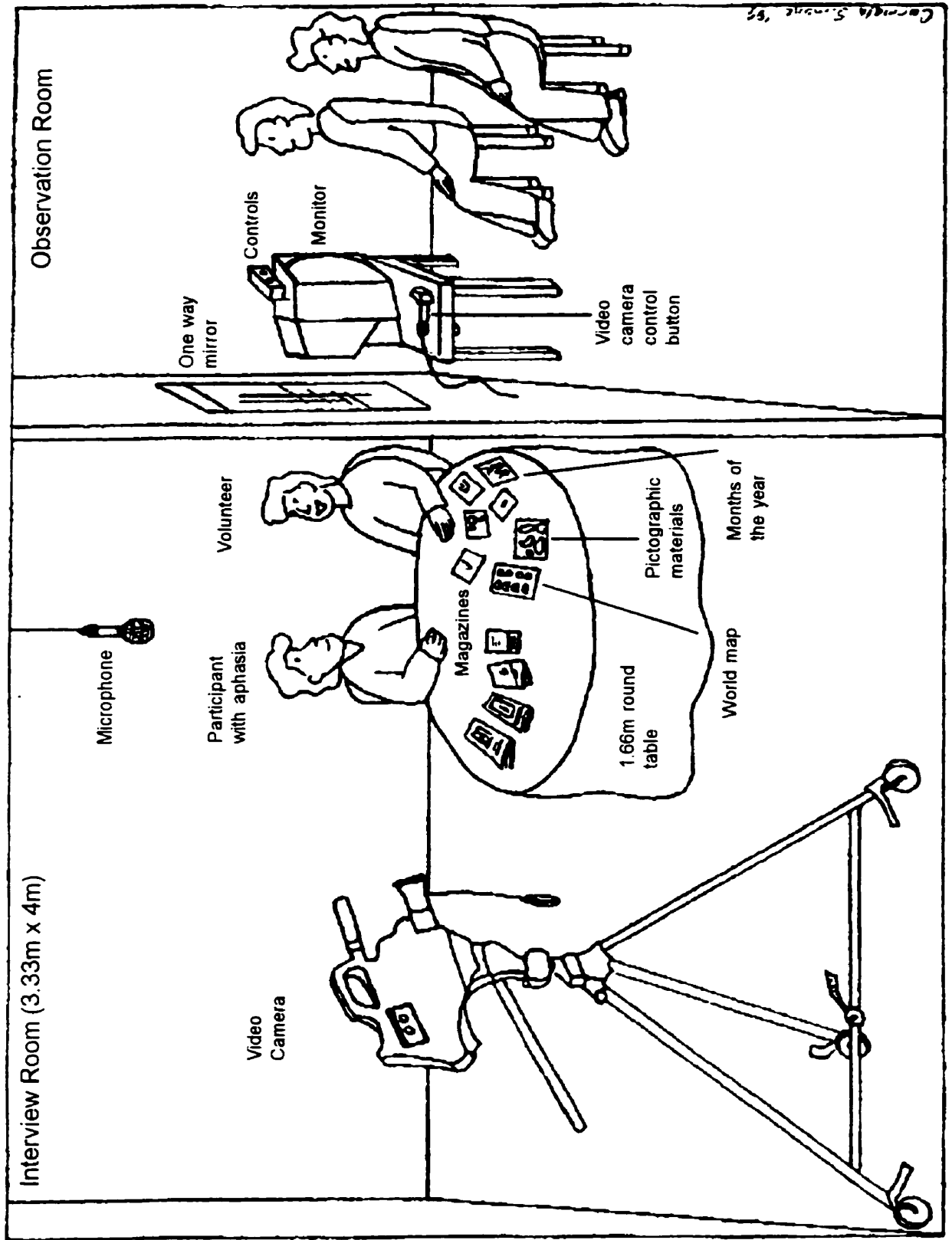**Training procedures**

Within two weeks of the first interview, experimental volunteers were given formal training in how to acknowledge and reveal the competence of adults with aphasia through supported conversation. The training procedures followed the SCA™ instructional protocol described in Chapter Three. Training groups included volunteers not participating in the study, but numbers did not exceed ten. I conducted the training workshops[27] and followed a pre-determined script. During this one-day workshop, participants were exposed to didactic and experiential methods illustrating both the 'why' and 'how' of SCA™. The workshop modules have been described in Chapter Three.

The one-day workshop was followed by a 1 ½ hour hands-on session within a two week period where volunteers in the experimental group worked with a group of aphasic individuals other than the person they had interviewed. They had the opportunity to practice some of what they had learned in the workshop under the supervision of a speech-language pathologist at the Centre (see Appendix 8 for instructions to speech-language pathologists). Procedures used to rate the performance of volunteers and participants with aphasia are described below.

**Instrumentation and Measurement**

The set of measures used in the study included a support measure (Measure of skill in providing Supported Conversation for Adults with Aphasia™ ([M]SCA™)) and a participation measure (Measure of the Aphasic Adult's Participation in Conversation ([M]APC)). As described in Chapter Four, the measures were designed and are currently being used for evaluating conversation between adults with aphasia and speaking partners in various

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[27] In order to avoid bias, I was not directly involved in situations where there was potential to influence results (e.g., videotaping where observers could interrupt the interview if it was too 'upsetting' for participants)

contexts at the Aphasia Centre and not just for the purpose of the study undertaken in this thesis (see Chapter 4 for a detailed description). The rater for the study was experienced in the use of both these measures.

### Scoring

Both performance measures rate behaviors on a 9-point numerical scale ranging from 0 (indicating poor performance) to 4 (indicating a high level of performance), with intervals of 0.5. Scores on the measures reflect the level of skill in achieving a particular goal, rather than the means for achieving it. For example, a score was given for skill in 'revealing competence', rather than skill in using a specific technique.

### Inter-rater reliability and validity

As described in Chapter Four, preliminary studies support the validity and reliability of the measures. Inter-rater reliability was repeated in the current study. Twenty videotapes were randomly selected from the pool of eighty tapes, balancing experimental and control groups, pre- and post conditions, and data blocks[28]. Intraclass correlations were performed on independent ratings by the experimental rater (see below for details) and myself. As with the preliminary studies, there was a moderate-high positive correlation for all categories on both measures (acknowledge competence, $r = 0.86$; reveal competence, $r = 0.96$; interaction, $r = 0.65$; transaction, $r = 0.84$; $p<.001$ in all cases). Agreement on interaction, while acceptable, was lower than agreement on the other categories. Possible reasons for this will be discussed further in a subsequent section of this chapter.

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[28] Data was collected in four blocks of ten dyads each.

## Data collection procedures

The eighty videotapes were coded within each block and ordered randomly for rating purposes. Ratings were done in two stages: Blocks 1 and 2 and then blocks 3 and 4. The tapes were rated by an independent rater, JW (see Appendices 9a,b for instructions to the rater). JW was a previous staff speech-language pathologist who had moved to another city before the start of the experimental study. She was one of three raters who participated in the inter-rater reliability study conducted prior to the experimental study.

Prior to rating, I reviewed the videotapes and noted all references that could reveal to the rater that she was watching a first versus a second interview, for example, phrases such as "this is my first time at the Center" or "remember I met you a few weeks ago..". These references were then edited out by the videographer, in my presence. Editing was done on copies of the videotapes so as to preserve the original versions in their entirety. Both the edited tapes and the original tapes are preserved at the Pat Arato Aphasia Centre, and can be made available for viewing by specific arrangement.

Data corresponding to the experimental hypotheses was collected as follows:

- Volunteer participants were rated on the two components of the M(SCA™): skill in acknowledging competence, and skill in revealing competence of the person with aphasia. They received a score of between 0 and 4 for each section. The score for revealing competence was an average of scores for a) ensuring that the person with aphasia understood the topic; b) ensuring that the person with aphasia had a way to express him/herself, and c) using a process of verification to ensure that the conversation was on track from the perspective of the aphasic partner.

- Participants with aphasia were rated on the two components of the M(APC): level of participation in conversational interaction and level of participation in conversational transaction with their conversation partner. They received a score of between 0 and 4.

To examine the effectiveness of blinding, the rater was asked to guess whether she was watching a first or second interview, and in the case of second interviews, whether the volunteer was trained or untrained. Degree of certainty in the rating was indicated by a score on a scale of 0 – 4 with '0' indicating 'not certain at all' through '2', 'fairly certain' to '4', 'absolutely certain'. This procedure was followed for the final two blocks (i.e. forty videotapes).

## Data analysis

The first two hypotheses (primary hypothesis and first of the secondary hypotheses) were tested using an analysis of covariance (Ancova) with the criterion for significance set at $p < 0.05$. Ancova can handle groups or factors as well as continuous variables. It is, therefore, a sensitive test for assessing treatment effects because it enables the researcher to control for baseline characteristics. Ancova was chosen in preference to a two-tailed t-test for unpaired samples because of its increased sensitivity [see \Norman, 1994 #284]. In the Ancova analysis, the dependent variables were the post-training scores, with pre-training scores as well as WAB AQ scores, as the covariates. Covarying the pre-scores was important because volunteer participants and participants with aphasia came in to the study with different skill levels and different levels of participation respectively. The WAB AQ was covaried because as described in the section on randomization, the experimental group differed from the control group on this measure. Although age of volunteer participants did differ significantly between groups as described previously, this was not covaried because it was important to avoid including too many covariants [Norman, 1994 #284] and age was thought to be the

the least clinically significant of the potential covariates. The third hypothesis was tested

using a Pearson Correlation.

**RESULTS**

To recapitulate, the research addressed the following hypotheses:

- Primary hypothesis: Volunteer conversation partners who are exposed to SCA™

  training (Supported Conversation for Adults with Aphasia™) will score higher on a)

  the 'acknowledging competence' section and b) the 'revealing competence' section

  of the (M)SCA™ (Measure of Supported Conversation for Adults with Aphasia™) than

  those who are not exposed to training, as judged in ratings of videotaped

  conversations by a rater trained in the evaluative measures

- Secondary hypothesis a): Aphasic adults talking with volunteer conversation partners

  who are exposed to SCA™ training (Supported Conversation for Adults with

  Aphasia™) will score higher on a) the 'interaction' section and b) the 'transaction'

  section of the (M)APC (Measure of Aphasic Adult's Participation in Conversation')

  than those whose partners are not exposed to training, as judged in ratings of

  videotaped conversations by a rater trained in the evaluative measures

- Secondary hypothesis b): Changes in (M)SCA™ scores of volunteers will correlate

  with changes in (M)APC scores of their partners with aphasia as judged in ratings of

  videotaped conversations by a rater trained in the evaluative measures.

Results will be presented first followed by a discussion.

## 1. Assessing the effectiveness of 'blinding' of rater

Table 5.1 presents the rater's guess and degree of certainty as to whether observed interviews were time one versus time two, and if time two, whether the volunteer was trained or untrained. The rater was correct in 31 of 40 ratings (77.5%) and confident in 28 instances (70%). The 9 errors (22.5%) included mistaking one untrained for a trained volunteer.

**Table 5.1.** **Rater's guess (and degree of certainty) regarding status of observed interviews**

| Actual Condition | Rater's Guess | | Degree of confidence | |
|---|---|---|---|---|
| | Correct | Incorrect | Not confident (rated <2 on confidence scale [a]) | Confident (rated ≥ 2 on the confidence scale) |
| INTERVIEW #1 (N = 20) | 17 | 3 | 5 | 15 |
| INTERVIEW #2 (Untrained) (N = 10) | 4 | 6 [b] | 7 | 3 |
| INTERVIEW #2 (Trained) (N = 10) | 10 | 0 | 0 | 10 |

a     This scale is described earlier
b     In 5 cases, rater guessed interview #1 instead of interview #2.
      In 1 case, she guessed 'trained' rather than 'untrained'.

## 2. The effect of SCA™ training on the performance of volunteer conversation partners

Table 5.2 presents the means and standard deviations for volunteer subjects in the experimental and control group for acknowledging and revealing competence. Overall, volunteers in the experimental group scored higher on these dependent measures in the second interview when compared with the first interview. Volunteers in the control group did not change much. Analysis of covariance indicates that the training effect was statistically significant for both acknowledging competence (F= 19.1(df=1), p< .001) and revealing competence (F= 159.0,(df=1), p< .001).

**Table 5.2.     Scores (means and standard deviations) for acknowledging and revealing competence for volunteers pre- and post-training** [a]

|  | Experimental Group Scores | | Control Group Scores | |
|---|---|---|---|---|
|  | Time 1 | Time 2 | Time 1 | Time 2 |
| (M)SCA™ Acknowledge competence | 1.9 ± .6 | 2.6 ± .7 * | 1.7 ± .8 | 1.5 ± .8 * |
| (M)SCA™ Reveal competence | 0.7 ± .4 | 2.7 ± .6 * | 0.6 ± .3 | 0.7 ± .4 * |

(M)SCA™     Measure of Supported Conversation for Adults with Aphasia™
a           Numbers refer to mean ± standard deviation
*           Significant difference between experimental and control group on post-training scores (Ancova; p<.001)

## Pre-interview preparation time

Volunteers in both experimental and control group gave more time to pre-interview preparation prior to the second interview as compared to the first interview (see Table 5.3). The difference between the experimental and control group was not statistically significant prior to the first interview, but there was a significant difference between groups for preparation time prior to the second interview with the experimental group taking longer ($t= 4.67$, $p < .001$). Paired t-tests also indicate that differences in preparation time prior to the first as compared to the second interview, were statistically significant for the experimental group ($t= 4.26$, $p < .001$). Differences were not significant for the control group.

**Table 5.3.** **Scores (means and standard deviations) for preparation times for interviews and duration of interviews, for volunteers pre- and post-training** [a]

| | Experimental Group Scores | | Control Group Scores | |
|---|---|---|---|---|
| | Time 1 | Time 2 | Time 1 | Time 2 |
| Preparation time in minutes | $5.5 \pm 1.9$ [*,c] | $9.0 \pm 3.3$ [*,b,c] | $4.9 \pm 1.5$ | $5.1 \pm 1.8$ [*,b] |
| Duration of interview in minutes | $8.5 \pm 3.9$ [*,c] | $13.4 \pm 4.0$ [*,c] | $10.5 \pm 4.4$ | $11.4 \pm 5.1$ |

a    Numbers refer to mean $\pm$ standard deviation
*    Significant difference ($p<.001$)
b    Significant difference between experimental and control group (t-test)
c    Significant difference between pre- and post training scores (paired t-test)

<u>Duration of interview</u>

Similarly, the duration of the interview was longer the second time for both the experimental

and control group (see Table 5.3). The difference between experimental and control group

was not statistically significant for the first or second interview. However, paired t-tests

indicate that differences in duration of the interview between the first and second sessions

were statistically significant for volunteers in the experimental group (t= 7.39, p <.001), but

not for the control group.

### 3. The effect of training conversation partners on the performance of participants with aphasia

Table 5.4 presents the means and standard deviations of participants with aphasia in the

experimental and control group for interaction and transaction. Overall, subjects with aphasia

in the experimental group scored higher on these dependent measures in the second

interview, compared to subjects with aphasia in the control group. Analysis of covariance

indicates that the training effect was statistically significant for both interaction (F= 5.7(df=1),

p<.023) and transaction (F= 17.6(df=1), p <.001).

**Table 5.4** **Scores (means and standard deviations) for interaction and transaction for participants with aphasia for first and second interviews (untrained versus trained volunteers respectively) [a]**

|  | Experimental Group | | Control Group | |
| --- | --- | --- | --- | --- |
|  | Time 1 | Time 2 | Time 1 | Time 2 |
| (M)APC Interaction | 2.2 ± .9 | 2.6 ± .9 * | 2.3 ± .9 | 2.2 ± .9 * |
| (M)APC Transaction | 1.9 ± .9 | 2.7 ± .8 ** | 2.0 ± .8 | 2.0 ± .8 ** |

(M)APC      Measure of Aphasic Adult's Participation in Aphasia
a             Numbers refer to mean ± standard deviation
*            Significant difference between experimental and control group on post-training scores
                  (trained versus untrained volunteers respectively), (Ancova; $p<.023$)
**         As above ($p<.001$)

*4. Relationship between changes in volunteer scores on acknowledging and revealing competence, and changes in the scores of their partners with aphasia on interaction and transaction*

Correlations between changes in volunteer's scores on acknowledging and revealing competence, and changes in the scores of their partners with aphasia on interaction and transaction were moderately positive and statistically significant ($p<.01$, Bonferroni corrected

for 4 comparisons: $\alpha$ = 0.05 / 4). The strongest correlation was between revealing competence and transaction ($r$ = 0.64 ) as compared to acknowledge competence and interaction, r = 0.45; acknowledge competence and transaction, $r$ = 0.59; and reveal competence and interaction, $r$ = 0.39).

A post-hoc analysis was conducted after obtaining the above results to examine the impact of exposure and experience on the performance of volunteer participants and participants with aphasia.

## 5. *Impact of exposure and experience on the performance of volunteer participants and participants with aphasia*

Table 5.5 presents an analysis of subjects in relation to whether or not they did the same, better, or worse in the second interview compared with the first interview. A larger proportion of control subjects did the same or worse the second time around as compared with experimental subjects. Results of a chi square analysis indicate that the differences were statistically significant ($p$'s ranged from <.05 to <.001).

**Table 5.5.    Numbers of subjects in the experimental and control group who received better, same, or worse scores on the dependent measures in their second interview**

| | | Acknowledge competence | Reveal competence | Interaction | Transaction |
|---|---|---|---|---|---|
| Experimental | Better | 17 | 20 | 15 | 17 |
| | Same | 1 | 0 | 2 | 2 |
| | Worse | 2 | 0 | 3 | 1 |
| Control | Better | 3 | 8 | 4 | 5 |
| | Same | 9 | 6 | 9 | 11 |
| | Worse | 8 | 6 | 7 | 4 |
| Chi-Square test results | | $\chi^2 = 19.80$ $p<0.0001$ | $\chi^2 = 17.14$ $p<0.0001$ | $\chi^2 = 12.42$ $p<0.002$ | $\chi^2 = 14.58$ $p<0.001$ |

## DISCUSSION

### *Statistical significance*

These results provide substantial support for approaches that emphasize the training of communication partners for adults with aphasia.[29] In addition to providing support for the efficacy of SCA™ in training volunteer conversation partners, the methods also appear to be efficient in that training volunteers produced some positive change in the individuals with

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[29] Based on experience at the Aphasia Centre, results might have been even better if volunteers had had the opportunity to practice their skills and receive feedback.

aphasia even though the latter did not receive specific training other than their regular attendance at the Aphasia Centre.[30] Note that although there was a wide range in length of attendance at the Centre for participants with aphasia, and no difference between the experimental and control groups on this variable, it may still have impacted results. For example, those with experience may have been better able to use the supports given by the trained volunteers. However it is also worth noting that participants with aphasia came in to the study with scores of approximately 2 on interaction and transaction which gives less room for dramatic improvement (see Table 5.4). Future research needs to examine the impact of conversation partner training when participants with aphasia have had no previous experience with supported conversation.

The statistically significant correlations between changes in the scores of volunteer participants, and changes in the scores of participants with aphasia, lend further support to the idea that the target of intervention in aphasia therapy should be a social unit, rather than a sole focus on the individual with aphasia. This is in line with related research in the area of child language that demonstrates the possibility of inducing language change in children by working with their parents (Girolametto, Pearce, & Weitzman, 1996). Although SCA™ differs from the latter in that it does not target language problems, it does share the common focus of targeting someone other than the 'identified patient'.

### Effectiveness of rater blinding

Effective blinding of raters is difficult to achieve in clinical trials, particularly when dealing with a strong treatment effect. I did, however, make concerted efforts to ensure blinding of the rater in this study, as described in the methodology section. Although the rater was usually correct and confident in rating the forty videotapes (see Table 5.1), the fact that she

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[30] Duration of attendance at the Aphasia Centre did not differ between those assigned to the experimental versus the control group.

was wrong in 9 instances (including mistaking one untrained for a trained volunteer) and uncertain in 12 instances, indicates that these efforts to blind the rater were at least partially successful.

### Clinical significance

As described in Chapter 4, the rating anchors for the numeric scales used in both the (M)SCA™ and the (M)APC were specifically designed to be clinically significant. A difference of 1 point on the 9-point numeric scale employed in both measures (translating into a 0.5 on the 0 – 4 scale) is regarded as a small, but clinically significant, difference by speech-language pathology staff at the Aphasia Centre. Using '0.5' as a criterion, the differences between post-test scores for the experimental versus control group are clinically significant for dependent variables except for interaction (see Tables 5.2 and 5.4). The difference between experimental and control volunteers was 1.1 for acknowledging competence and 2 for revealing competence. The differences for participants with aphasia were smaller with post-test differences being clinically significant for transaction (0.7) and not clinically significant for interaction (0.4).

Differences between the first and second interview for the experimental versus the control group followed a similar pattern (see Tables 5.2 and 5.4). The difference between the first and second interview was clinically significant for the experimental volunteers on both dependent measures (acknowledge competence 0.7, and reveal competence 2) but not for the control group (acknowledge competence –0.2, and reveal competence 0.1). The difference in transaction scores between the first and second interview was also clinically significant for participants with aphasia in the experimental group (0.8) and not in the control group (0). The difference in interaction scores between the first and second interviews was not clinically significant for either group, but moved in a positive direction for the

experimental group and in a negative direction for the control group. The challenge of inducing and capturing change in variables such as social interaction is discussed below.

### *Differences in preparation time and duration of conversational interview for the experimental and control groups*

One of the noticeable differences between the groups was the fact that the experimental group took significantly longer to prepare for the second interview. Experienced conversation partners at the Aphasia Centre know that preparation is critical when wanting to chat about a topic in depth with an individual who has severe aphasia. The fact that dyads in the experimental group were also able to sustain conversation for a significantly longer time in the second interview when compared to the first is probably related to a combination of increased expertise and the fact that they had prepared more material to support conversation. There was no significant difference between the groups at the time of the first interview, thus this finding is unlikely to be attributable to some chance differences in the characteristics of the experimental group.

### *The challenge of inducing and capturing change in 'social' variables*

Although overall the results were statistically and mostly clinically significant, the impact of training on 'social' variables was noticeably weaker than results for variables that focus more directly on the content of conversation. For example, results on acknowledging competence were weaker than those for revealing competence (volunteers) and results for interaction were weaker than for transaction (participants with aphasia). Inter-rater reliability results for 'interaction', while felt to be acceptable, were also lower than for the other dependent variables, indicating that it is harder to induce and accurately capture change in this area using a quantitative methodology.

These findings are in line with our experience at the Aphasia Centre where we find it much more challenging to induce change in areas relating to interpersonal skills than technical skills. As described in Chapter Three, volunteers' ability to acknowledge competence is probably related to inherent personality traits and learned attitudes. In fact, it was surprising to obtain significant results in any of these areas after such minimal training and with no real opportunity to practice and refine skills in a more relaxed context. Based on our observation, we also do see marked changes in level of participation related to interaction on the part of individuals with aphasia, but these changes occur slowly over time. Weaker results in relation to inducing and/or capturing social variables in this study should not therefore be taken to mean that it is not possible to induce change in these areas. In relation to ideas for future research, it would be worthwhile to examine outcomes on all dependent measures, but particularly the social variables, after volunteers have had a few months of experience. Results indicating that some volunteers did very well on acknowledging competence with no previous exposure to aphasia or training (21 out of 40 volunteers received scores of '2' or more on acknowledging competence in their first interview), also bears further investigation.

### *Performance in the second interview*

In designing the study, all participants were expected to do better the second time because of the opportunity for exposure and experience (however limited). This was one of the reasons for including a control group. It was therefore surprising to note that a number of volunteers and aphasic participants did not improve at all after their first encounter and even more surprising to find that a number actually did worse the second time around (see table 5.4). The majority of the latter were in the control group. A tentative explanation for the two volunteers in the experimental group who did worse on acknowledging competence post-training relates to 'over enthusiasm' in the use of techniques. Based on what we have learned about volunteer training at the Aphasia Centre, additional experience and feedback

tend to eliminate the negative impact associated with 'over enthusiasm' or overuse of trained strategies.

The fact that so many participants in the control group did worse in the second interview is of interest. For approximately one third of the volunteers, exposure to individuals with aphasia when no training was provided, was not only 'neutral' but negative in its impact. Those of us in clinical roles as hospital speech-language pathologists have observed unfortunate interactions between physicians and patients with aphasia. Based on the findings of this study, it may be that a negative first experience with a patient who has aphasia and does not appear to be competent, has a negative impact on subsequent interactions. If this is so, and with nurses, other health professionals and family members often looking to the physician for a role-model, the ripple effects on the way aphasic individuals are treated within the health care system are not surprising. Providing SCA™ training for medical students in how to acknowledge and reveal the competence of their patients would be valuable in counteracting this situation.

### Ideas for further research

Several additional ideas for future research arise directly from this study. First, the outcome measures used in the study were designed to capture specific aspects of conversational interaction. Subsequent studies evaluating the efficacy of approaches such as SCA™ need to use a far broader range of outcome measures (Worrall, personal communication). It would also be useful to include Lyons' suggestion that we score the dyad as a unit in itself, as well as looking at outcomes such as mutual confidence, satisfaction, and enjoyment within the context of conversational interaction and the relationship (Lyon, 1997a, personal communication).

Second, future research needs to address more complex issues than those addressed in the current study, for example, providing evidence for the concept of masked competence. Data from the current study can be used to examine whether or not factors such as the skill of the conversation partner and level of participation of the person with aphasia, in isolation or in combination, have an impact on the way the aphasic partner's competence is perceived by others. For example, large numbers of health professionals could rate randomly selected videotapes designed to balance different levels of skill of conversation partners and different levels of participation of individuals with aphasia.

Simmons-Mackie (1998b) also suggests studies to examine whether perceptions of competence have a bearing on opportunities for conversation and communicative access, and to determine what other factors potentially interact with perceptions of competence. In this vein, Parr and Byng (1998) call for research on how 'different attitudes and beliefs' impact on the ability to acknowledge and reveal competence.

Third, following a recent qualitative study by Simmons-Mackie and Kagan (in press), many ideas emerge in relation to a qualitative examination of the data derived from the efficacy study. These ideas include detailed analyses of taped interactions in order to further investigate the following:

1.  Use of 'verification' as a technique. Even slight overuse or misuse of verification detracts from the feel of natural adult conversation. It would be interesting to examine whether teaching of this technique sometimes makes a conversational interaction worse rather than better.

2.  Characteristics of dyads who got worse after training or who improved with no training.

3. Patterns in qualitative comments made by the trained rater of the videotaped interactions.

4. Different perspectives on the videotaped interactions from people with no experience of aphasia, people with aphasia, and speech-language pathologists unfamiliar with the study.

Fourth, the common practice of encouraging family members to observe therapy sessions is worthy of investigation. Personal experience indicates that observation of therapy sessions by family members can have a negative impact on natural conversation, with family members taking on the role of 'teacher' rather than 'conversation partner'. Current research indicates that direct training of family members is critical (Hickey et al., 1995; Simmons et al., 1987). Future research could examine the impact of direct training of conversation partners, versus observation.

Finally, as described earlier, the use of volunteers in the area of aphasia is becoming more widespread. The results of this study demonstrate that it is possible to provide effective training for volunteers. Marshall (1998) comments on potential concerns of speech-language pathologists in regard to the use of volunteers, citing for example, the fact that some professionals see volunteers as a threat to their livelihood. Data from this study support the professional role of speech-language pathologists in the training of volunteer conversation partners. Future research, however, needs to examine a more representative range of volunteers. The volunteer participants in this study were largely highly educated and motivated students. The current study can therefore be regarded as a validation of the SCA™ approach and methods under optimal conditions, with conversation partners who have willingly volunteered. Future research might examine what happens with conversation partners such as family members who are thrust into situations that are not of their choice (Rubin, personal communication). The training described in this study is geared toward

groups of volunteers who need generic skills that will help them in their interactions with many different individuals with aphasia. Additional research is also needed to investigate the efficacy of generic SCA™ training for other conversation partners such as health professionals, as well as a more individualized training approach for family members.

## CONCLUSION

In conclusion, training volunteers as conversation partners using a one-day workshop and two hours of hands-on experience can be effective in improving the communication of volunteers and their partners with aphasia, even when the aphasic participants receive no direct intervention. In this study, the lack of skill of untrained conversation partners poses a barrier to effective communication, and increasing skill through training increases communicative access to opportunities for conversation for the person with aphasia. These results provide experimental support for social approaches that emphasize the professional obligation to reduce social communication barriers for those affected by aphasia. As clinicians we often face situations where our clients are 'all dressed up with nowhere to go' (Podolsky, personal communication). SCA™ training provides a vehicle for increased participation so that there is opportunity to go places.

## OVERALL DISCUSSION AND CONCLUSION

The preceding chapters report on four interrelated projects, each representing a different facet of the development of 'Supported conversation for adults with aphasia™' (SCA™). This final chapter begins with a discussion of the overall strengths and limitations of the SCA™ research program, followed by applications of SCA™ for speech-language pathologists working within the current health care system. The chapter concludes with a look toward the future and incorporating SCA™ into a different system of service delivery attuned to the social needs of those affected by aphasia.

### A. Overall strengths and limitations of SCA™ and the SCA™ research program

As discussed in previous chapters, SCA™ builds on years of experience and exposure to hundreds of adults with aphasia, their family members and volunteers who, together with professional staff, work to improve quality of life for all those affected by aphasia. The research program began by articulating some core concepts grounded in this experience. The concepts included: a focus on revealing competence rather than deficit; the equal contribution of both conversational partners – the speaking partner as well as the individual with aphasia; the importance of conversational interaction as well as transaction; and the use of professional speech-language expertise in communication to directly enhance access to life participation in addition to working on communication as something that requires 'fixing'. These concepts formed the basis for the subsequent development of an SCA™ intervention, evaluative measures, as well as an efficacy study. The fact that the development of SCA™ was so firmly rooted in daily experience is seen as a strength of the research program.

This thesis highlights the need for a shift in professional focus in the treatment of aphasia. In the current health care climate, any such shift will be challenged in terms of accountability and reimbursement issues. The availability of methods and tools to assess outcome, and data to demonstrate the efficacy of 'Supported conversation for adults with aphasia™' (SCA™), as described in Chapters Four and Five, is an important first step in addressing this challenge. The two SCA™ measures, for example, provide a simple numerical scoring system for capturing elusive social elements of conversation. The psychometric data presented in Chapter Four, however, can only be regarded as preliminary in that it was accumulated as part of the initial development of the measures. Further research is needed in the form of a full-scale psychometric study examining reliability and validity in other settings, and using raters less familiar with SCA™.

The efficacy study reported in the previous chapter is one of the few controlled trials that have been conducted in our field and is the first within a social model of aphasia. In terms of subjects, it is one of the largest single center studies on aphasia and also one of the few studies to include large numbers of individuals with severe or global aphasia (see Chapter Five for a description of the two other large randomized controlled studies in our field). The informed consent process for participants with aphasia, based on SCA™ principles and methods, has since been used by several other researchers in the field (e.g., Kimelman, 1999; Kimelman, under review; Rochon, in progress). There are, however, several limitations to the efficacy study. The main one relates to the limited generalizability of results because the study was conducted within a single center. Multicenter research would be the next logical step. In addition, although participants were randomly allocated, they were not randomly selected as this was not possible for logistic reasons. Lack of random selection characterizes most research in our field.

Generalizability of results also needs to be discussed in relation to the type of conversation employed in the study. As discussed in Chapter Five, a semi-structured interview was

chosen based on requirements of the experimental design. This conversational genre or format differs from free-flowing social chat in that topics are pre-selected (in this case, fairly concrete topics such as the date of the stroke, and nature of activities participated in at the Aphasia Centre). Although social variables such as interaction are by definition a part of any conversation, whatever the format (see Chapter Two for a description of the dual nature of conversation), interviews appear to be predominantly transactional because of the explicit focus on exchange of information. In evaluating social variables, therefore, context must be taken into account. For example, in this case, (as with any semi-structured conversation such as a case-history interview), the 'interviewer' should not be penalized for asking most of the questions. The issue should be framed in terms of whether or not the interaction is appropriate to the particular context. In addition to examining whether other conversation partners, for example, health professionals, can be trained to improve their skills within the context of a semi-structured interview, future research should also examine whether results of the current study hold for different conversational contexts. These contexts might include less structured conversations and more abstract topics.

The issue of mild aphasia, referred to in previous chapters, deserves further mention as generalization of the usefulness of SCA™ techniques for this population should not be assumed. In certain situations, the adaptation and/or judicious use of SCA™ techniques is appropriate. Other situations require a different framework and set of techniques. For example, one might work on awareness, giving those with mild aphasia and their conversation partners a deeper understanding of the role of conversation in maintaining identity and social relationships. Framing difficulties in this way might make it easier to understand why things start to fall apart whenever there is even a subtle change in what Tannen (1984) calls conversational style, and might allow for the development of specific techniques. Further research is thus required to establish guidelines for conversation partners of those with mild aphasia. Such research also needs to take into account the difference between moderate-mild aphasia and very mild aphasia.

Although there are distinct advantages to the experimental design and the accumulation of efficacy data to support SCA™, use of a quantitative, standardized research paradigm does not allow for the insights gained through a more qualitative study of conversational interaction. The study by Simmons-Mackie and Kagan (in press), mentioned in Chapter Five, provides an example of the application of qualitative research methods to SCA™. The aim of the study was to examine the communication strategies used by 'good' versus 'poor' conversation partners of individuals with aphasia. Using data collected in the efficacy study, a detailed conversation analysis was performed on randomly selected pre-training videotaped conversational interactions. The results of this analysis support the idea that conversational interaction is as important as transaction. For example, 'good' partners often used strategies that attributed competence to their partner with aphasia and, at times, sacrificed transactional goals to allow for 'saving face'. The results of this qualitative study have implications for SCA™ methods in that '...speaking partners who believe that people with aphasia are competent, trustworthy people are more likely to structure their talk to reflect this belief'. This view is supported by a nursing model (Swanson, 1993) that examines the relationship between beliefs about the competence of others and actions that support well-being after illness.

The need to adapt SCA™ techniques to different contexts is not necessarily a limitation, but is an important caution. The intervention is only a tool for giving people with aphasia the opportunity for genuine conversation and interaction as a means of increasing their communicative access. It does not specify the conversation partner, the topics of conversation, the exact content of resource material, or the parameters for defining life participation. As Penn (1998) comments, these must of necessity differ within and between sociocultural systems (including healthcare systems) and/or geographical areas. However, although the form might vary, what remains constant is the central role that the speech-

language pathologist can play in giving the aphasic individual communicative access to their own community.

To increase sensitivity to the issue of context in evaluation of interventions based on SCA™, the use of criterion-referenced assessment, a concept advocated in the area of child language, might help speech-language pathologists and those affected by aphasia to decide whether or not designated goals have been met (Anderson, Brown, Shillcock, & Yule, 1984). Assessment is carried out in relation to the individual's needs rather than making judgements in relation to peers or norms. This method's use of goals or intervention targets as the criteria for assessment is practical and allows for in-depth evaluation of communication. Criterion referenced procedures can be 'informal and naturalistic' or 'formal and clinician-directed' (Paul, 1995).

A more fundamental concern relates to whether or not professionals working in the field see SCA™ as a viable approach. The concern is valid because not only is the approach non-traditional, but it was developed within a setting that differs from that within which most speech-language pathologists work. In contrast to agencies such as the Aphasia Centre, where there is a long-term commitment to the quality of life of those affected by aphasia, many speech-language pathologists treating aphasia either work in medical settings or train students to work in acute, subacute and rehabilitation settings where there is a pressure to treat and discharge. Direct applications of SCA™ may therefore not be readily apparent. The next section provides a framework for addressing this concern.

**B. SCA™ framework for use by speech-language pathologists working in diverse settings**

There are at least three different ways in which speech-language pathologists can create communication ramps and reduce barriers to life participation in contexts including hospitals,

rehabilitation clinics, or home care organizations. These applications are described in detail in Appendices 10 and 11.

1.  The speech-language pathologist can serve as a conversation partner for an individual/s with aphasia

2.  The speech-language pathologist can train other partners to converse with a particular aphasic person or group

3.  The speech-language pathologist can work on creating a generic infrastructure of communication ramps that can potentially benefit many individuals with aphasia in an agency, in the community, and/or in society at large.

The three different ways of creating communication ramps should not be seen as related to any particular chronology or stage in therapy. Work can be done in some/all of the three areas at any one time as illustrated in examples of case-conference scenarios in Appendix 10.

## C. Changing the system: A broader social approach to aphasia

Service delivery models for those affected by aphasia are changing in both the USA and Canada. This makes it timely to provide new options to those responsible for training future professionals, as well as those already working in the field. Table 6.1 highlights some of the contrasts between traditional individual approaches to aphasia and social approaches such as SCA™. The table is presented not only as a reaction to current reality, but also as one way of more effectively addressing the needs of those affected by aphasia.

The potential role for approaches such as SCA™ is clearly outlined in Table 6.1. If

communication and conversation are viewed as the currency of life participation, providing

support necessary for engaging in conversation is central to achieving the social goals

considered by the World Health Organization to be an essential component of health (ICIDH-

2, 1997; World Health Organization, 1947).

**Table 6.1. Contrasting traditional approaches to aphasia with social approaches such as SCA™**

| | Individual/traditional approaches | Social approaches such as SCA™ |
|---|---|---|
| **Focus** | *Individual with aphasia.* Family members may be involved (e.g., observing therapy or working at home), at the discretion of the speech-language pathologist (SLP) | Individual with aphasia as part of a *social unit* including for e.g., family members, friends, wider community, society |
| **Responsibility for planning and implementing approach** | The SLP is primarily responsible for the process of therapy. Person with aphasia and family may be given choices and opportunity to actively plan treatment but this is at the discretion of the SLP. | The SLP is responsible for initiating the process of increasing life participation, but sharing this responsibility with the *person with aphasia* and *relevant 'partners'* (e.g., family, friends, volunteers, other rehabilitation specialists) is a core value. There are many times when the person with aphasia and relevant social partners take over the process |
| **Assessment** | Goal of assessment is to *reveal deficits*, i.e. SLP assesses how person with aphasia does *without support*. | Impairments taken into account, but interested in revealing the person's *competence* i.e. SLP equally interested in how person with aphasia does *with support*. Assessment focuses equally on *socially relevant partners*. |

## Table 6.1. Contrasting traditional and social approaches to aphasia cont.

| | Individual/traditional approaches | Social approaches such as SCA™ |
|---|---|---|
| **Response to perceived needs** | Work involves minimizing *language deficit* and/or compensating for it. | Language deficits may be main focus at certain times but work involves addressing *social sequelae of* impairment by *reducing barriers* and *increasing access* to life participation. |
| | Person with aphasia and family may receive counseling to help cope with *psychological reaction to the impairment* | Providing *social support* in addition to psychological support seen as a valid part of professional practice e.g., building social connections |
| | *Life participation* implicit *long-term goal*, resulting from *generalization of treatment*. | *Life participation* is *immediate, explicit goal*, resulting from *direct work in this area* |
| **Nature of SLP's specialty in communication** | SLP is a *specialist in communication disorders*. Communication is *perceived as the problem* to be addressed | In addition to being a specialist in communication disorders, SLP is an *expert communication partner*. From the onset of the injury, (supported) conversation with the SLP and other skilled partners is an *integral part of the solution* to the life-altering repercussions of aphasia |
| **Evaluating success (outcome)** | Evaluated in terms of language and/or communication *skill acquisition*. | Evaluated in terms of *quality of* life and degree *of engagement in life* |
| | Great value attached to ability to communicative *independence* | Value of *interdependence* recognized. |
| **Context for intervention** | Usually medical settings (e.g., acute care and rehabilitation centers or clinics) | May include medical settings but applicable to life events in many other contexts e.g., home, work, community |

Although reviewers of social approaches such as SCA™ are generally supportive of underlying ideas (Holland, 1998; Parr & Byng, 1998; Penn, 1998; Simmons-Mackie, 1998b), some question what is actually achievable given the enormous societal barriers that exist, and the challenges for documentation of outcome. Parr and Byng query the feasibility of making a difference in the lives of aphasic people without a change in infrastructure - change that might not be viable given the shrinkage in time and money allocated for the treatment of aphasia. The experiences of people with aphasia (Parr et al., 1997) teach us just how far we still have to go and how enormous the challenges are. Issues of physical access for those with physical disabilities must have looked equally insurmountable in past decades. Communicative access is even more challenging, because it is more difficult to see and understand. However, system-wide change might be the only way to ensure the existence of meaningful services for those affected by aphasia.

In response to this challenge, a small group of speech-language pathologists (including the author) is presenting a rationale for practical alternatives to current North American practice in our field (LPAA Working Group, in submission). Similar proposals have been put forward in the UK by Byng et al., (in press).

**Conclusion**

SCA™ has influenced and been influenced by the development of the broader social approach to aphasia described above. However, change in daily practice does not necessarily have to await system-wide change. For example, each person who acquires SCA™ skills makes a difference. A physician or nurse who knows how to acknowledge and reveal the competence of an aphasic patient may influence other physicians, nurses, social workers, family members, or anyone else who routinely observes his/her interactions. Such incremental empowerment can help to restore the dignity of those with aphasia. These small

concrete steps in conjunction with larger scale development of new models of service delivery for aphasia begin to extend the scope of practice in an era that emphasizes outcomes that have meaning in the real world. A real, albeit abstract, outcome is that of 'membership'. Ferguson (1994, p.10) writing from the perspective of special education for children, asks "Is communication really the point?" She answers by arguing that 'what we really seek is not 'socially effective communication repertoires' at all, but *membership*, specifically participatory, socially valued, image-enhancing membership'. SCA™ provides a means of enhancing membership in the context of family, community and society, for many individuals affected directly and indirectly by aphasia.

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# Appendix 1

# Video Script

from

## *Supported conversation for aphasic adults: Increasing communicative access*

by

Kagan, A., Winckel, J., & Shumway, E. (1995)
Toronto, Canada: The Aphasia Centre – North York©

| <u>VIDEO</u> | <u>AUDIO</u> |
|---|---|
| **Supported Conversation for Aphasic Adults** | Music |
| **Narration by Dr. Roberta Bondar Canadian Astronaut and Neurologist** | |
| Marg | <u>Marg</u>: I have a friend, aphasia, he can't speak, but we have a lovely conversation. |
| Freeze on Marg | <u>Dr. Bondar</u>: This is Marg. She has aphasia. As you may already know, aphasia is a language problem that results from brain injury, usually a stroke. |
| Dr. Bondar on screen | Hello. I'm Dr. Roberta Bondar. As an astronaut and a neurologist, I really do understand the importance of communication. But I also know that unless one has actually experienced what its like to have difficulty talking and understanding what others say, it is hard to truly appreciate the central role that communication and conversation play in our lives. The video you are about to see is designed to give you more insight into the experiences of people with aphasia and to suggest some specific ways to help. This is relevant for any of us who interact with aphasic individuals, whether we are friends, family, volunteers or health professionals.

But lets get back to Marg. |

| | |
|---|---|
| Marg talking | **Marg:** I always come and say, "hello, how are you?" And that's important for them, and for me, too. |
| Freeze on Marg | <u>Dr. B.</u>: Marg was talking about a friendship that developed |
| Shots of Aphasia Centre | here at the Aphasia Centre - North York, a community centre designed to meet the long-term needs of adults with aphasia. |
| scenes to be specified | With the help of professional staff and trained volunteers, aphasic members of the Centre are encouraged to participate in social and community life ranging from personal discussions with friends or family, to participating in local politics. |
| scenes to be specified | When Marg said 'that's important for them and for me too', she was referring to the social connections that she and others with aphasia have made at the Centre. To truly appreciate why this is so important, we need to understand the role of conversation in everyday life and the way that this is disrupted by aphasia - a language problem. |
| Dr. B. | But what exactly is a language problem and how can a language problem affect a person's life? When we think of language, most of us think of speaking - but speech and language are not the same thing. The difference will become clearer as you watch the following clip of a hearing-impaired woman who is also aphasic. Before her stroke, she used sign language to communicate. But once she became aphasic, she struggled to find the right signs, just as other aphasic people struggle to find the right words. |

| | |
|---|---|
| McGreevy clip | **Mom, brother, drive....** |
| Dr. B. | <u>Dr. B.</u>: So aphasia is a language problem that occurs here, at the level of the brain, not here, at the mouth. This is why people with aphasia have difficulty in reading and writing as well as talking, and understanding what others are saying. |
| | But let me help you to feel what it might be like to have aphasia. Imagine not being able to fully understand what people are saying to you. Let's try this out. Imagine that you are sitting in your family doctor's office and she obviously has something serious to discuss with you. Try your best to understand her. |
| Cut to Fariba | "...." |
| Dr. B. | <u>Dr. B.</u>: How much did you understand? Although your mind was working normally, you probably found it hard to understand what she was saying, unless you speak Persian. In other words, you have experienced a language barrier. Add to this, additional language problems related to aphasia, such as difficulty in speaking, reading and writing and you may just begin to appreciate how incredibly frustrating aphasia can be. How would you feel if this was your reality all day, every day? |
| Cut to Tume | <u>Tume</u>: Hospital, no speech, nothing, doctor: "hi, how are you...oh". I know, but, um, frustrated. |
| Dr. B. | <u>Dr. B.</u>: So far, you've had some exposure to what it might be like to have aphasia. Now, lets have a look at this in more depth. We are going to view a series of conversations with Gerry, a 60 year old man with severe aphasia. |

| | |
|---|---|
| Freeze on Gerry and Lorraine | In the first clip we will see Gerry talking with a skilled conversation partner, a Speech-Language Pathologist from the Aphasia Centre. They are discussing the 1992 World Series. As you will see, Gerry is a keen baseball fan. Take note of the communication techniques that the conversation partner is using. |
| Gerry and Lorraine | [Gerry and Lorraine talking] |
| Freeze on Gerry and Lorraine | Dr. B.: Does Gerry look like he was participating in that conversation? Does he seem to know what went on in the game? |
| Dr. B. | Would you say that Gerry looks like he might be capable of making major life decisions, for example participating in drawing up a will or deciding whether or not to have surgery? Most people who have seen this video feel that there is a good chance that Gerry could do these things. But let's look now at what happens when Gerry is talking with a conversation partner who has had no special training. |
| Freeze on Gerry and resident | We will see Gerry being interviewed by a young doctor who volunteered to help the Aphasia Centre develop their training program. |
| Gerry and resident | [Gerry and (untrained) resident talking] |
| Freeze on Gerry and resident | Dr. B.: Quite a difference! The video tapings were made at about the same time, but Gerry doesn't seem to be the same person. |

| | |
|---|---|
| Freeze on Gerry and Lorraine | In the first segment, Gerry looked like he knew what was going on and could communicate. |
| Freeze on Gerry and resident | In the second, we're not sure that he understands. Even if he does, he certainly doesn't seem to be able to convey his thoughts. He doesn't look like someone who is able to participate in making life decisions. |
| Dr. B. | Dr. B.: Why the difference? We believe that it's the skill of the aphasic person's partner. We use the term "supported conversation" to describe the techniques for helping an aphasic person participate in conversation.<br><br>To highlight the difference training can make, here once again is Gerry and the same doctor, after the doctor had participated in the training program. |
| Gerry and resident | [Gerry and the resident talking] |
| Freeze on Gerry and resident | Dr. B.: Once again why is it that Gerry looks so much more competent when he is interacting with a trained conversation partner? |
| Dr. B. | We believe that specific training in the techniques of supported conversation has improved the doctors ability to acknowledge and reveal Gerry's inherent competence. |
| scenes to be specified | The Aphasia Centre has developed a training program to help people become skilled in the Supported Conversation Approach. |

| | |
|---|---|
| scenes to be specified | It's important to remember that people with aphasia could speak and understand like you or I before their stroke. Although brain injury may affect thinking skill at some level, people with aphasia know what's going on around them. They can call upon cognitive and social abilities which were well established prior to the onset of aphasia. |
| scenes to be specified | However, we shouldn't underestimate how difficult it is for people with aphasia to reveal their inherent competence. |
| scenes to be specified | You and I normally reveal our competence through conversational interaction. |
| scenes to be specified | But for someone with aphasia, the language problem often acts as a barrier, making it hard for others to see what's below the surface. |
| scenes to be specified | Aphasia tends to affect the way people with aphasia are perceived. When we meet someone for the first time, we quickly make decisions about them, about how intelligent and socially appropriate they are -- and we do this mainly through conversation. When people with aphasia are perceived as being less competent they are unfortunately treated as though they are less competent, as Kassie will tell us. |
| Cut to Kassie | Kassie: The dentist, you know, disaster. I, you know, um, hello, hello, excuse me, you know, forget it. |

| | |
|---|---|
| Freeze on Kassie | **Dr. B.**: Without the ability to talk and engage in conversation the way she used to, it's difficult for Kassie to appear competent in the eyes of others. Her competence is hidden or 'masked by the aphasia.' |

**Aphasia Can Mask
Inherent Competence**

| | |
|---|---|
| Close up of Don | For example, when a person has aphasia, it can be hard to see the active mind. |
| Don scene starting, audio down | Let's look at Don, who still retains his lifelong interest in politics. Watch how, in this next conversation, his wife and friend don't even ask his opinion, and consequently exclude him from the conversation. |
| Don scene, three on the couch | **Actors**: You know we worked hard and we really put a great effort into the campaign. But sometimes, no matter how hard you work, it just doesn't click. The polls made a big mistake. |
| Close up on Don, looking sad | Thank goodness, it was a great victory. |

Dr. B.

Dr. B.: If Don's conversation partners had been trained in the skills of supported conversation, Don may have been able to participate in this conversation and show that he does have opinions about the election topic being discussed.

As shown in the previous scene, the presence of aphasia can make it difficult to see the active mind. It can be equally difficult to imagine the capacity to make life's decisions. In the next interaction, Stella and her husband are facing a major decision: whether or not to move out of their family home. Stella is aphasic. Note her obvious frustration at not being included.

Jack wheels Stella into the doctor's office

They sit down at the desk and Jack takes Stella's hand

Stella: Yes

Jack: We made it that time, mother.

Stella: Yes

Doctor comes in

Dr.: Hi, how are you both this morning? So, Stella, how are you?

| | |
|---|---|
| Stella looks exasperated | **Jack:** I'm afraid you're right. And as much as I hate to admit it, I think, maybe, that's the way I should be thinking. |
| Close up on Stella | **Dr.:** Yes |
| Dr. B. | **Dr. B.:** Once again, training of both the physician and Stella's husband in the techniques of supported conversation might have given Stella more opportunity to participate in the decision at hand. |

We've used the term 'conversation' a great deal so far, but what exactly do we mean? Conversation is more than just social talk. It underlies almost everything we do. People with aphasia have reduced opportunity to engage in all of these conversations – and the combined psychological effects can be devastating.

Most of us take for granted our participation in social and community life, activities as ordinary as:
chatting with friends
or
playing games

We believe that aphasia limits the opportunity to engage in conversation and reveal competence, Aphasic individuals are denied access to participation in social and community life.

**Communicative Access**

| | |
|---|---|
| Person in wheelchair at bottom of steps, no ramp | **Dr. B.:** To better understand the concept of access, let's first think about physical access. If someone has a physical disability following a stroke, they receive treatment. If they still can't walk independently following treatment, they are provided with physical aids, for example a walker or a wheelchair. Our buildings are designed with special ramps to facilitate physical access. |
| Dr. B. | **Dr. B.:** But what happens to the person who still can't communicate independently after a stroke – the person with aphasia? What do we do to ensure communicative access in the same way we ensure physical access? What is the aphasic person's equivalent of the wheelchair ramp? Let's look at an activity as apparently simple as getting to see your family doctor. Ted will show us what can go wrong. |
| Ted and his wife are sitting on the couch. Ted picks up the phone. | **Dr. B.:** Let's think about the steps required to make an appointment with a health care professional. |
| Ted dials the number | First you must telephone for an appointment and make yourself understood. |
| Ted begins to talk | **Ted:** How are you, uh, OK. |
| Ted hands the phone to his wife, and she says | **Ted's wife:** I'd like to make an appointment for my husband. |
| Cut to the receptionist | **Receptionist:** and what's your husband's name? OK, OK, let me just check my appointment book. |
| Cut to ted approaching Wheeltrans bus, driver waiting. | **Dr. B.:** You may have to talk to someone about transportation. |
| Cut to Ted walking down the hall toward the receptionist. | Then, you need to talk to the receptionist and you may be asked to fill out a form. |

| | |
|---|---|
| Interaction between Ted and the receptionist. | R: Hi<br>T: Hello, how are you?<br>R: I'm fine, how are you?<br>T: OK<br>R: It's nearly 1:00, so you must be Ted.<br>T: Yes<br>R: You are. I have just one thing to fill out. If you could just fill this application out for me, that would be really helpful.<br>T: OK |
| Cut to facing Ted, trying to fill out application | T: Gosh, I, I, no<br>R: You're having trouble with the application, the information.<br>T: Yea, yea, and, and, sigh |
| Ted's face on screen, talking to receptionist, no sound. | Dr. B.: For the aphasic person, even when they can manage to this point, true communication is often blocked when they need to communicate with the health care professional. |
| Cut to Doctor | Doctor: So, Ted have you been having any problems since your last visit? |
| Cut to Ted | Ted: Sigh, uh, uh, Christ, nope. Laughs. But, yes, and no, but. |
| Ted looks exasperated | Doctor: Yes and no. Can you tell me what kind of problems? |
| Freeze on Ted | |
| | Dr. B.: For the aphasic person, even when they can manage to this point...true communication is often blocked when they need to communicate with the health care professional. |
| Shot of person in wheelchair going up a ramp | Dr. B.: Can we provide a "communication ramp" in the same way that we provide wheelchair ramps for physical access? |

| | |
|---|---|
| Gerry and the trained neurology resident | Yes, we believe we can. You, as a skilled conversation partner are essential to providing this ramp. Acquiring these skills does make a difference, as we can see in this second version of Ted's interaction with his family doctor, where she is providing supported conversation. |
| Doctor's face | Doctor: So, Ted, I haven't seen you for a little while.<br><br>Ted: Yea<br><br>Dr.: Yes, it's been awhile. |
| Ted and the Doctor | Ted: Yea<br><br>Dr.: So, how've you been feeling, Ted<br><br>Have you had any problems since your last visit?<br><br>Ted: Sigh, uh |
| Doctor takes out pen and paper | Dr.: OK, let me help out here. Let's do a bit of writing. Problems, Ted. Can you tell me if you've had any problems, since your last visit? |
| Doctor writes and points | Dr: Just show me yes or no. |
| Ted points | Ted: um, yes<br><br>Dr.: OK, can you tell me Ted, what kind of problems? Can you show me? Show me where the problem is? |
| Ted gestures to head | Ted: um<br><br>Dr.: Give me a clue. Your head. Um, let's see what kind of problem it is. I think we have some pictures here that will be helpful., |

| | |
|---|---|
| Doctor takes out resource book and points | **Ted**: OK. Do you have a pain? Do you have a pain in your head? Just show me yes or no. Is it a pain? No? |
| Ted points and shakes his head no | **Dr.**: No? Not a pain? |
| | **Ted**: No |
| | **Dr.**: OK, let's try something else. Are there any pictures here that describe how you feel? Anything wrong with your ears? |
| Ted shakes his head no | **Ted**: No |
| | **Dr.**: No. Are you feeling dizzy? |
| | **Ted**: No |
| | **Dr.**: A headache? |
| | **Ted**: Uh |
| | **Dr.**: Not a headache? OK, let's look a little further. Is there anything here? How about this one? |
| Ted looks at the material and points | **Ted**: Yes |
| | **Dr.**: This? |
| | **Ted**: Yes |
| | **Dr.**: This shows a problem with sleeping. |
| Ted points and nods | **Ted**: Yes |
| | **Dr.**: OK, this is what you have a problem with. |
| | **Ted**: Yes |

Appendix 1.14

| | |
|---|---|
| Doctor gestures 'sleeping' and Ted imitates | Dr.: Sleeping, is hard? Sleeping? Ok, let me just verify that Ted. Sleeping. |
| Doctors writes 'sleeping' and shows Ted, who points | Ted: Sleeping |
| | Dr.: Is hard? |
| | Ted: Yes |
| | Dr.: OK, alright, alright. OK, that's good, that's given us somewhere to start. Now let's see if we can find out why that's happening. |
| | Ted: Oh, boy, nope |
| | Dr.: Don't worry, don't worry, we'll find out what the problem is. OK. |
| Doctor takes Ted's hand and freeze | |
| | Dr. B.: Ted's experience ended well. But people with aphasia experience many instances of knowing much more than they can say. It's really important to acknowledge this explicitly. |
| Aura clip | [Aura and member talking] |
| freeze | Dr. B.: The phrase 'I know you know' underlies our training philosophy. |
| Joanne's training clip | Dr. B: The Aphasia Centre's training is especially designed to teach you how to provide conversational support. I invite you, whether you are a professional, a family member, a friend, or a volunteer, to join us |

Appendix 1.15

collage of close-ups on
faces of members looking
pleased

I invite you, whether you are a
professional, a family member, a
friend, or a volunteer, to join us
in creating communication ramps and
in increasing communicative access.

You can make a difference.

Address of Aphasia Centre,
and additional information
for contacting regarding
materials and training

For more information, please contact
the Aphasia Centre - North York.

Credits, etc.

Music

*Appendix 2*


**Extract from the**
**'Pictographic Communication Resources' Manual:**
**Informed Consent**

# An Example of

# INFORMED CONSENT
# for

# RESEARCH
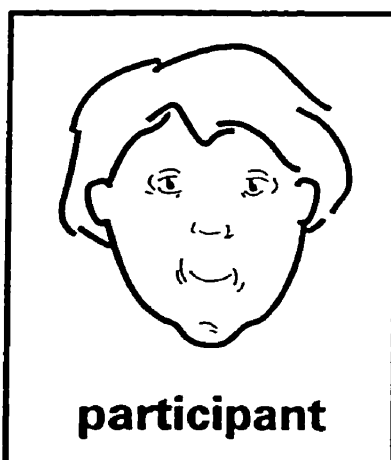


**participant**

# Participant :_____

# Investigator: Aura Kagan, M.A.
(416) 226-3636

# Project Title: Training Volunteers:  Does it work?

Appendix 2.2

### 53 The Links Road
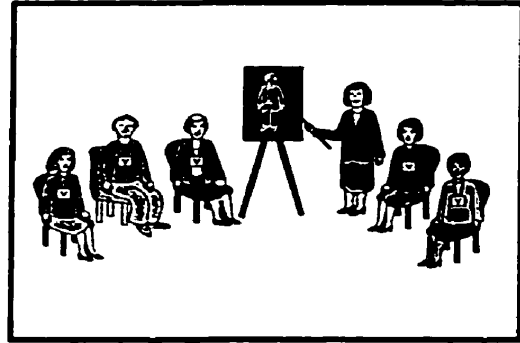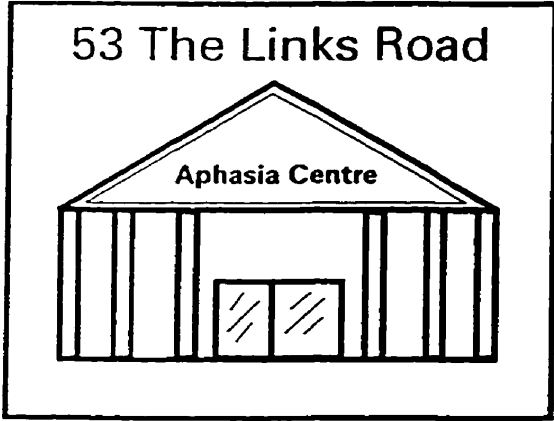
**Aphasia Centre**

At the **Aphasia Centre** we train many **volunteers.**

We want to know if our
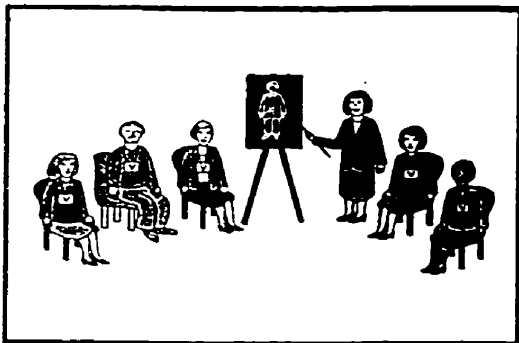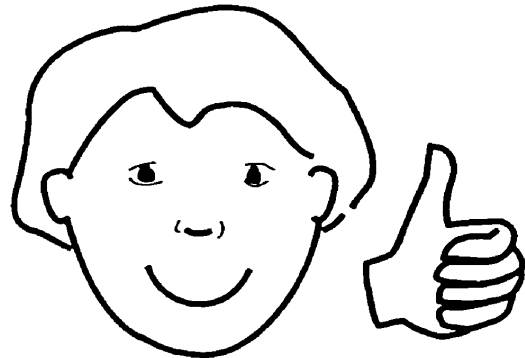
**training** **is** **good?**

Does it work?   **YES** 👍   **NO** 👎
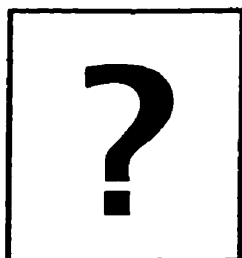
# what  **?**  can you expect?

## Potential Benefits:

✔ This **will help** research!

✔ This **will help** the **Aphasia Centre** and others with aphasia!

✗ This is **not** speech or language therapy.
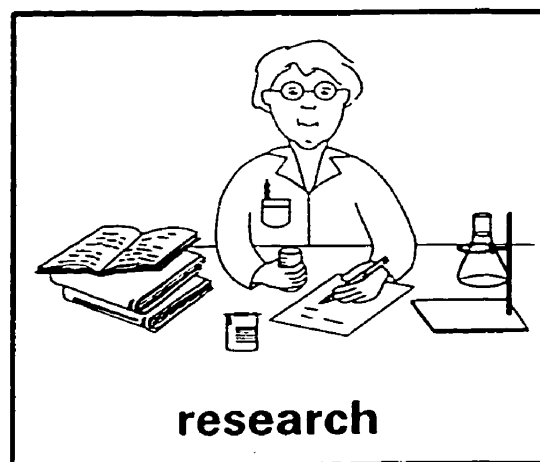
**research**

Will this **help research**?  | YES | 👍

Will this **help you** to **talk** better?  | NO | 👎

# where?

**where?**

**participant**

**You**

**at the** →

## 53 The Links Road

Aphasia Centre

# Aphasia Centre

# when?

S M T W T F S
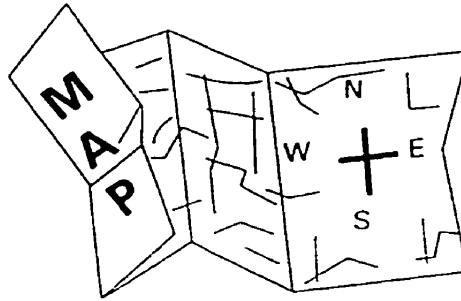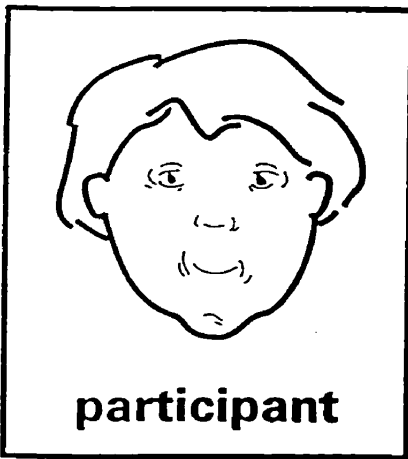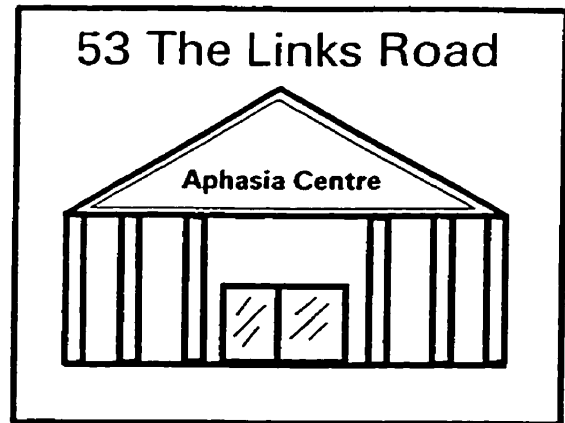
→ **to be arranged**
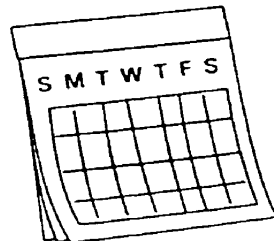
# how often?

## 2 Sessions
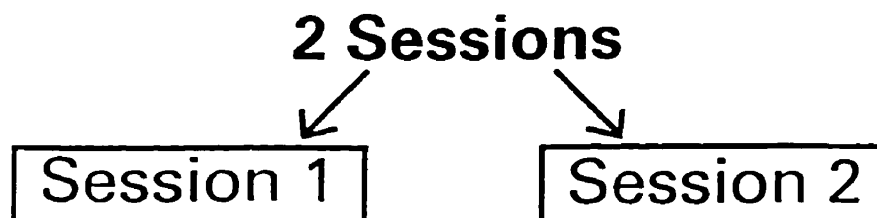
| Session 1 | | Session 2 |

## BUT

# If you get **tired** we will **stop** and **start** again on another day.



tired



stop
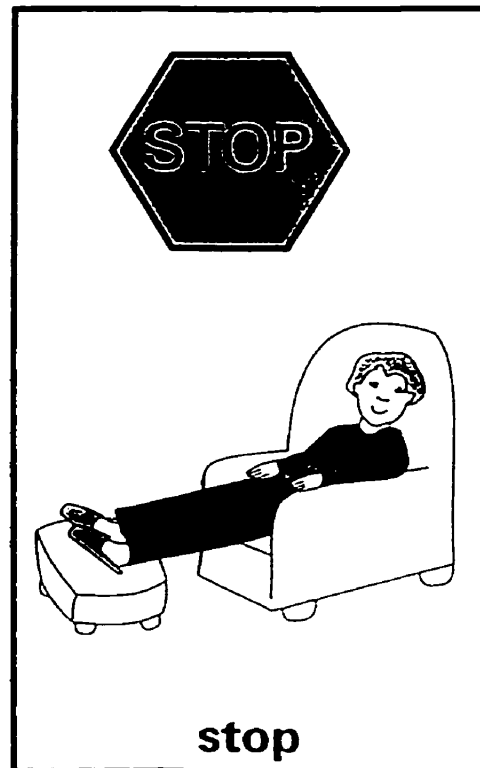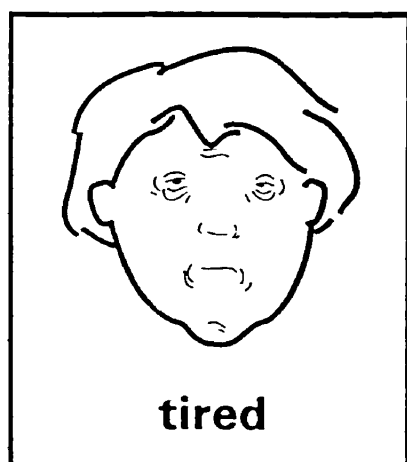
# how long?

## Session = 15 - 30 minutes
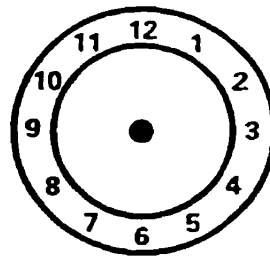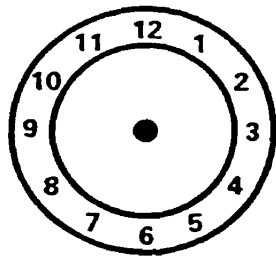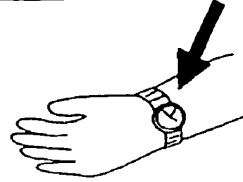
from _____    to _____

# Videotape

We want to make a **videotape** of **you** with a **volunteer**.

you

volunteer

you
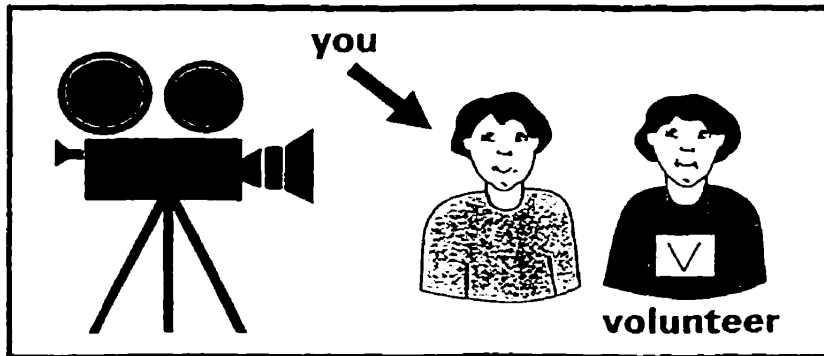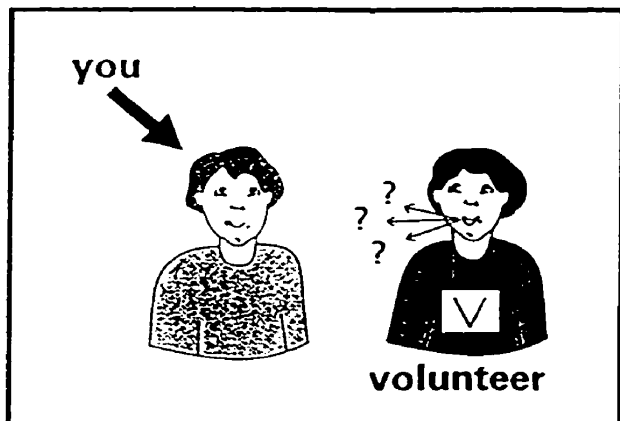
volunteer

The **volunteer** will **talk**
to **you** and **ask** you
questions.

you
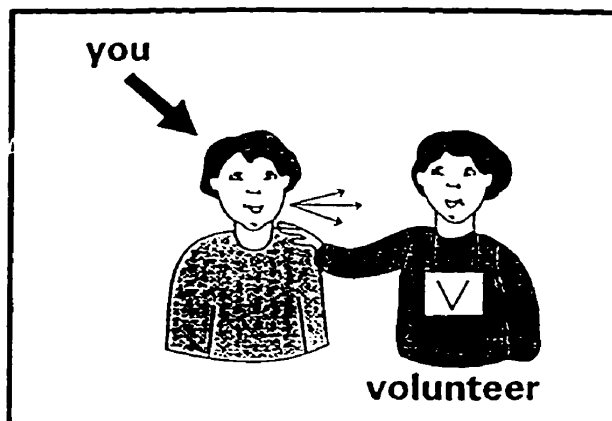
volunteer

The volunteer will try to
**help you** to **answer**.

you
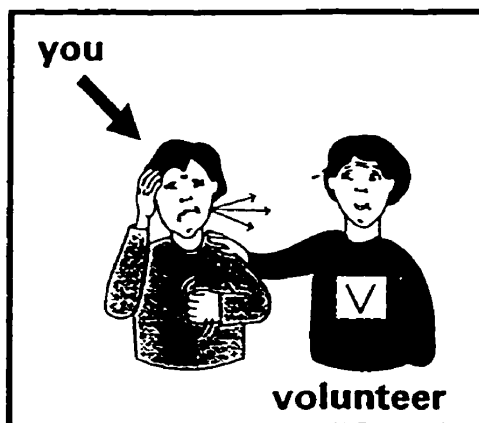
volunteer

The **volunteer** will **try hard** but
the interviews
**may be frustrating**.

you    volunteer    staff person
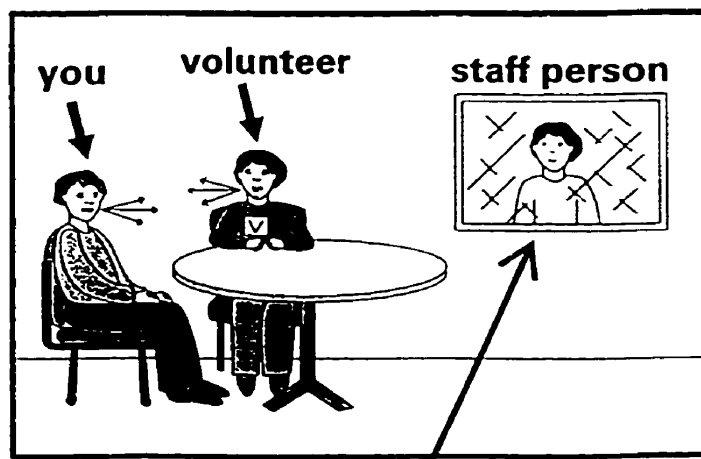
A staff person will observe the session
through a **one-way mirror** to make
sure everything is okay.

# We will make **2** videotapes of you with the **same volunteer**.

## **2 videotapes**
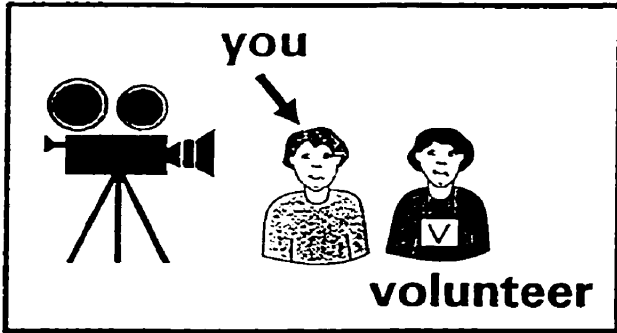


**Session 1**
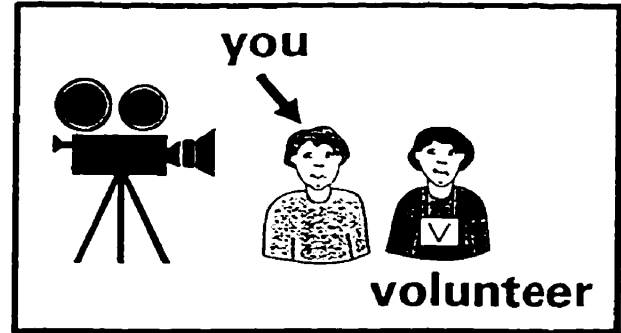


**Session 2**

## **Right to Withdraw:**

✔ You **can stop** at any time.

✔ It is **your choice**.

✔ It is **ok** to quit.



**quit**
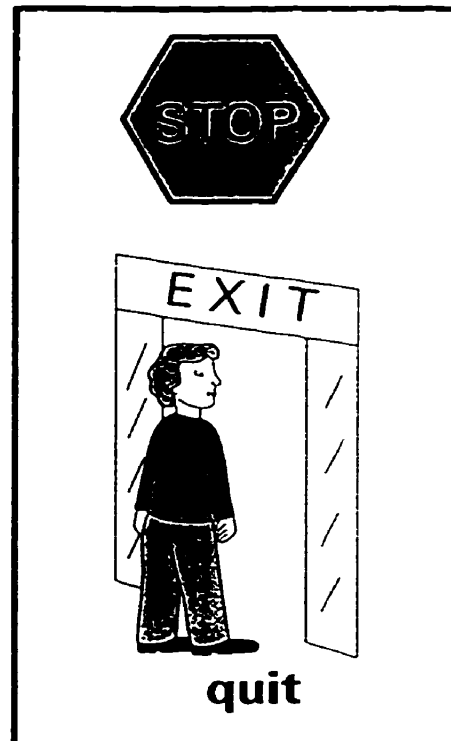
# Potential Risks:

**X** There is **NO** danger
in participating in this study.
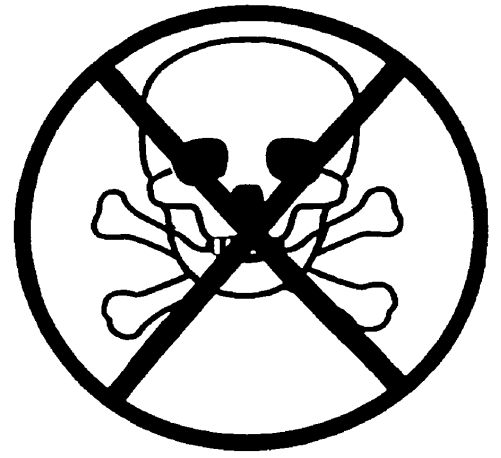
**no danger**

✔ Everything is **confidential**.

Shh

**confidential**
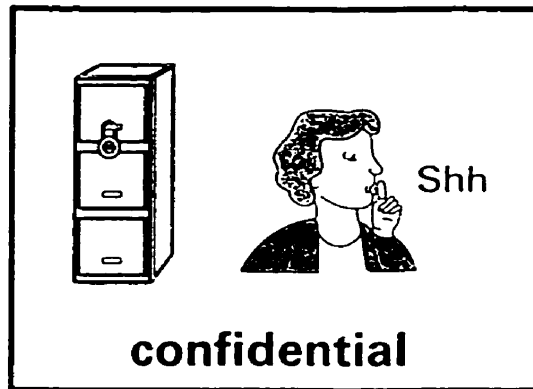
Will this **harm** you?   | **NO** |

# Project Consent:

The information presented on the previous pages has been **explained** to me.

| YES | 👍 |

____

I **agree** to participate in this research project.

**agree**
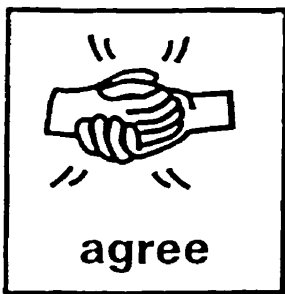
| YES | 👍 | | NO | 👎 |

____                    ____

I have been given a **copy** of this form.

copy
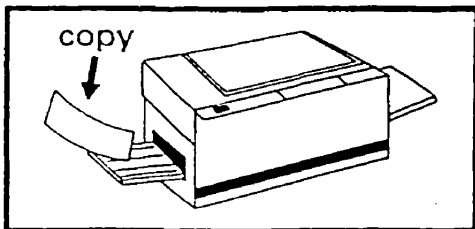
| YES | 👍 | | NO | 👎 |

____                    ____

_____        _____
Signature of Participant                                Date


_____        _____
Signature of Witness                                    Date

# Appendix 3

## Set of Observational Measures for Rating Conversation

## (Between an Adult with Aphasia and his/her Partner)

Appendix 3.1

# Table of Contents

## Measure for Rating Aphasic Adult's Participation in Conversation [(M)APC]

## Measure for Rating Conversation Partner's skill in providing 'Supported Conversation for Adults with Aphasia' [(M)SCA]

Appendix 3.2

# (M)APC

### Measure for rating Aphasic Adults' Participation in Conversation

Name: _____

Date: _____

Rated By: _____

M(SCA)
(Skill of Conversation Partner)

Acknowledges Competence _____

Reveals Competence _____

|  | | Score |
|---|---|---|
| **A.** | **Interaction** | |
| | 1.  Verbal / Vocal | |
| | 2.  Non-Verbal<br>Gesture<br>Writing<br>Drawing<br>Resources | |
| **B.** | **Transaction** | |
| | 1.  Verbal / Vocal | |
| | 2.  Non-Verbal<br>Gesture<br>Writing<br>Drawing<br>Resources | |

Appendix 3.3

# (M)APC
## INFORMATION FOR RATERS

1. This measure is designed to be used by trained raters familiar with SCA™ (Supported Conversation for Adults with Aphasia).

2. The concept of appropriateness in relation to participation in conversation is key. AP's do not necessarily need to be verbal, or respond in all non-verbal modes in order to achieve the highest rating.

3. Experienced AP's will generally be better able than non-experienced AP's to use whatever conversational support is provided by the CP. However, without a skilled CP, even experienced AP's might not be able to reveal their competence to participate in conversation.

4. Use behavioural guidelines and rating anchors when assigning scores. Note: Behaviours listed are meant to guide observation rather than being used as 'behavioural indices.'

5. When scoring, think of the level of <u>participation in conversation</u> by person with aphasia:

---

**Numerical Rating Scale for M(APC)**

| 0 | 0.5 | 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4 |
|---|-----|---|-----|---|-----|---|-----|---|
| No Participation | | | | Adequate | | | | Full Participation |

---

# (M)APC
# BEHAVIOURAL GUIDELINES: SUMMARY

## A. INTERACTION

Verbal/Vocal

Non-Verbal

- Does AP share responsibility for maintaining the feel and flow of conversation (including appropriate affect)?

- Does AP initiate/maintain interaction with CP or make use of supports offered by CP to initiate/maintain interaction?

- Does AP indicate communicative intent?

- Is AP pragmatically appropriate?

- Does AP ever acknowledge the frustration of the CP or acknowledge their competence /skill?

- Behaviours might include:

    appropriate eye contact, use of gesture, body posture and facial expression, use of writing or drawing in any form, use of resource material, use of verbalization/vocalization in any form.

## B. TRANSACTION

Verbal/Vocal

Non-Verbal

- Does AP maintain exchange of information, opinions and feelings with CP?

- Does AP ever initiate transaction?

    - introducing or referring back to a previous topic?

    - spontaneously using a compensatory technique?

- Does content of transaction appear to be accurate? (depending on context and purpose of rating, rater would have more/less access to means of verification of information)

- Does AP use support offered by CP for the purpose of transaction? This might include:

    using a gesture modelled by CP; pointing to key-words or pictured resources, collaborating with CP around a drawing.

---

| Key | AP: | Aphasic Partner |
|-----|-----|-----------------|
|     | CP: | Conversation Partner |

Appendix 3.5

# (M)APC
# BEHAVIOURAL GUIDELINES: DETAILED VERSION

## A. INTERACTION (Includes verbal/vocal/non-verbal behaviours)

Does AP help to maintain the feel and flow of conversation with either verbalizations/ vocalizations (V's)/ non-verbal behaviours of any sort? Do these occur appropriately most of the time e.g., in response to questions/at appropriate breaks or pauses in conversation? Does AP ever spontaneously initiate interaction with CP or make use of supports offered by CP to initiate/maintain interaction? Is affect appropriate? Is there 'intent' to communicate?

### Interactional non-verbal behaviours:

GESTURE (includes body posture and facial expression)
Does AP use gesture to interact e.g. smiling, leaning forward, maintaining eye-contact, appropriate touching?

WRITING
Does AP interact with CP's writing e.g. showing interest or paying attention to it?

DRAWING
Does AP interact with CP's drawings e.g. showing interest or paying attention?

RESOURCES
Does AP interact with resource material e.g. showing interest or paying attention?

| Key | AP: | Aphasic Partner |
|-----|-----|-----------------|
|     | CP: | Conversation Partner |

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# B. TRANSACTION (includes verbal/vocal/non-verbal behaviours)

Does AP use verbal/vocal/non-verbal behaviours to answer questions, or to comment e.g. 'ya' with rising intonation to indicate 'really'? Does AP use these behaviours to initiate transaction e.g. ask questions/ indicate feelings/give information or an opinion on a new or earlier topic?

## Transactional non-verbal behaviours:

### GESTURE
Does AP use gesture to give information/express opinions and feelings? Does AP use CP's gestures as models to aid transaction? Does AP respond to CP's requests for gesture? Does AP spontaneously use gesture to maintain or initiate conversation or to return to a previous topic?

### WRITING
Does AP maintain CP's attempts to use writing as a transactional tool by responding to written material provided by CP e.g. using it to indicate choice? Does AP respond to CP's requests for written responses by attempting to write letters/parts of words/more? Does AP ever write spontaneously? Does AP use writing to initiate a topic, or search for 'old' sheets of paper to refer back to a previous topic? Does AP ever indicate that he/she wants a pen and paper if these are not readily accessible?

### DRAWING
Does AP maintain CP's attempts to use drawing as a transactional tool by responding to drawn material provided by CP e.g. pointing to it to respond? Does AP respond to CP's requests for drawings e.g. start to draw, or do something more complete? Does AP ever draw spontaneously? Does AP use drawing to initiate a topic or to refer back to a previous topic? Does AP ever indicate that he/she wants a pen and paper if these are not readily accessible?

### RESOURCES
Does AP maintain CP's attempts to use resources as a transactional tool by responding to resource material provided by CP e.g. pointing to it to respond or to indicate choice? Does AP ever ask for or use resource material spontaneously? Does AP use resource material to initiate a topic or to refer back to a previous topic? Does AP ever indicate that he/she wants a resource if this is not readily accessible?

Appendix 3.7

# (M)APC
## EXAMPLE OF RATING ANCHORS FOR PARTNER WITH APHASIA
### (IN THE CONTEXT OF THE PAT ARATO APHASIA CENTRE)

|  | Interaction | Transaction |
|---|---|---|
| 0 | No participation at all. No attempt to engage CP or respond to interactional attempts. Would be very concerned for the volunteer. Would definitely not feel comfortable to leave the volunteer (CP) alone with this member (AP) unless volunteer is highly skilled. | No evidence of being able to understand or get a message across. Would be very concerned for the volunteer. Would definitely not feel comfortable to leave the volunteer alone with this member unless volunteer is highly skilled. |
| 1 | AP beginning to take some responsibility for interaction. Still concerned about the volunteer, and would feel obliged to observe frequently and provide support, unless volunteer is highly skilled. | AP beginning to show evidence of being able to understand and convey content. Still concerned about the volunteer, and would feel obliged to observe frequently and provide support, unless volunteer is highly skilled. |
| 2 | Clear attempts to be part of the conversation. Feel ok to leave this member with the volunteer, but would need to check in. | Evidence of ability to understand and get a message across in some way at least 50% of the time. Feel ok to leave this member with the volunteer, but would need to check in. |
| 3 | AP taking increased responsibility for interaction. Very little concern for volunteer, but would still check in from time to time eg: 1 x per term (4 months) | Able to understand and convey content most of the time. Very little concern for the volunteer, but would still check in from time to time (eg: 1 x per term (4 months). |
| 4 | Full and appropriate participation. Takes responsibility for conversational interaction. Full confidence in the member - no concerns at all for the volunteer. | Able to understand and get a message across. Full confidence in the member - no concerns at all for the volunteer. |

Appendix 3.8

| Key | AP: | Aphasic Partner |
|---|---|---|
|  | CP: | Conversation Partner |

# (M)SCA

### Measure for rating conversation partners' skill in providing
### 'Supported Conversation for Adults with Aphasia' ™

Name: _____

Date: _____

Rated By: _____

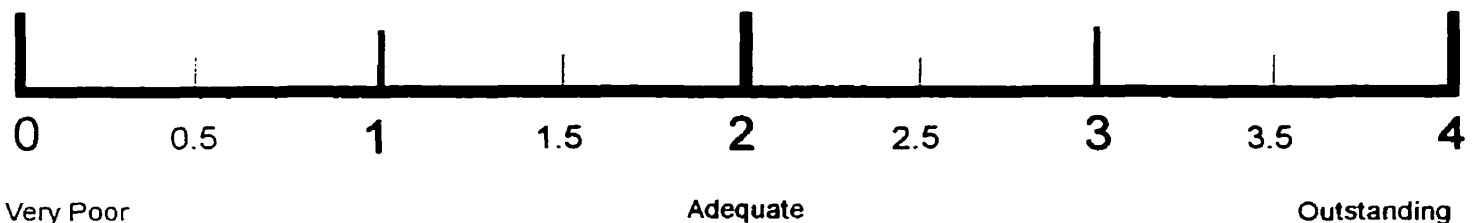|  | Score |
|---|---|
| **A.  Acknowledges competence** |  |
| **B.  Reveals Competence**<br><br>1. Ensures that AP understands<br><br>2. Ensures that AP has a means of responding<br><br>3. Verifies | * <br><br> * Average of B1, B2 and B3 |

**Key**  AP:  Aphasic Partner
CP:  Conversation Partner

**Appendix 3.9**

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# (M)SCA
## INFORMATION FOR RATERS

1. This measure is designed to be used by trained raters familiar with SCA ™(Supported Conversation for Adults with Aphasia).

2. The concept of 'appropriateness' is key. Techniques that are well executed but inappropriately used (e.g. overused) would result in a lower score under 'Acknowledging Competence'.

3. Use behavioural guidelines and rating anchors when assigning scores. Note: Behaviours listed are meant to guide observation rather than being used as 'behavioural indices'.

4. When scoring - Think in terms of skill of conversation partner in 'providing support'.

5. To score section on 'reveals competence', score B1, B2 and B3 separately and then average these scores

---

**Numerical Rating Scale for M(SCA)**

| 0 | 0.5 | 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4 |
|---|-----|---|-----|---|-----|---|-----|---|

Very Poor            Adequate            Outstanding

---

Appendix 3.10

# (M)SCA
# BEHAVIOURAL GUIDELINES: SUMMARY

## A. ACKNOWLEDGING COMPETENCE

| | |
|---|---|
| **Natural Adult Talk Appropriate to Context*** | • Feel and flow of natural adult conversation appropriate to context e.g. social chat vs interview; respectful approach to verification (verifying that the <u>conversation partner</u> has understood rather than verifying that <u>AP</u> knows what they want to say; not over verifying)<br><br>• Not patronizing (loudness, tone of voice, rate, enunciation)<br><br>• Appropriate emotional tone/use of humour |
| **Sensitivity to Partner*** | • Incorrect/unclear responses handled respectfully<br><br>• Sensitive to AP's attempts to engage in conversation<br><br>• Encourage when appropriate<br><br>• Acknowledge competence when AP is frustrated/upset e.g. "I know you know what you want to say"<br><br>• "Listening attitude"<br><br>• Taking on communicative burden as appropriate/making AP feel comfortable |

## B. REVEALING COMPETENCE (How much support is provided relative to what's needed?)

| | |
|---|---|
| **1. Ensures that AP understands**\*\* (e.g. topic, questions) | • Verbal (e.g. short, simple sentences; redundancy; Is there some verbal adaptation?)<br>• Non-verbal<br>   Gesture       Meaningful; slightly exaggerated; Used to emphasize or clarify<br>   Writing        Clear and visible; Appropriate key words<br>   Resources/   Used only when necessary (would something simpler suffice?)<br>    Drawing     Simple and clearly presented<br>• Response to Communicative Cues (e.g. reacting to facial expressions that indicate lack of comprehension) |
| **2. Ensures that AP has a means of responding**\*\* | • Verbal   (e.g. use of Fixed Choice / Yes/No Questions)<br>• Non-verbal<br>   Gesture      Models response mode (e.g. pointing, thumbs up/down)<br>   Writing      Provides choices for pointing; Clear and visible; Appropriate key words<br>                  Encourages writing (e.g. makes sure that AP has paper and pen)<br>   Resources/ Provides something so that AP can point to it, encourages use of reources<br>   Drawing     Encourages drawing<br>• Response to Communicative Cues (e.g. giving enough time to respond) |
| **3. Verification**\*\* (Accuracy of AP's response not automatically assumed) | • Verbal (e.g. "So let's see if I've got this right . . .") - reflecting and expanding<br>• Non-verbal<br>   Gesture      Model desired response for clarification<br>   Writing      Reflecting, summarization<br>   Resources/ As appropriate<br>    Drawing<br>• Response to Communicative Cues (e.g. appropriate handling of inconsistant yes/no response)<br><br>*NOTE: Verification often involves checking in <u>another</u> modality* |

---

\*   Although these two areas are not scored separately because of considerable overlap, they are useful in guiding observation

\*\*  B1, B2 and B3 are scored separately and then averaged to give the score for 'revealing competence'.

| Key | AP: | Aphasic Partner |
|---|---|---|
| | CP: | Conversation Partner |

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# (M)SCA
# BEHAVIOURAL GUIDELINES: DETAILED VERSION

## A. ACKNOWLEDGING COMPETENCE

### Natural Adult Talk Appropriate to Context

Does talk keep the feel and flow of natural <u>adult</u> conversation? Is the type of talk appropriate to the context e.g. question and answer format for interviews but not for social chat? Are verbal adaptations/ non-verbal techniques integrated into natural talk? Is loudness, rate and tone of voice appropriate? If verbal adaptations/non-verbal support are used to introduce topics, is this appropriately embedded in natural talk? Patronising talk should be heavily penalised in this section.

Is adapted questioning (see below) embedded in natural-style questioning so that it maintains the feel and flow of conversation, e.g. by appropriate use of open-ended and rhetorical questions?

### Sensitivity to Partner and Context

Is CP sensitive to the conversational partnership in context to the type of conversation being engaged in? Is affect appropriate to context?

Is CP sensitive to AP's attempts to engage in conversation? Is CP sensitive to the conversational partnership in terms of facilitating opportunities for initiation and turn-taking by AP? When AP is experiencing difficulty/ is frustrated in terms of expressing him/herself, does CP explicitly acknowledge competence and frustration, e.g. 'I know you know'/I can see how frustrating this is for you' - accompanied by appropriate gesture?

## B. REVEALING COMPETENCE (How much support is provided relative to what's needed?)

### 1. Ensures that AP understands (e.g. topic, questions)

### Verbal adaptations

Is talk adapted appropriately where necessary by use of:
Short and simple sentences? slow-normal rate? expressive voice? highlighting key words with voice? rephrasing?

Appendix 3.12

| Key | AP: | Aphasic Partner |
|-----|-----|-----------------|
|     | CP: | Conversation Partner |

## Non-verbal adaptations

GESTURE
Is the use of gesture (including body language and facial expression) appropriate? Is it meaningful? Is it clear, e.g. slightly exaggerated?

WRITING
Is the choice of key-words appropriate? Is the written material clear and visible to AP, e.g. use of marker, appropriate size, clear writing, orientation of paper, too much on the page/table? Are flashcards/bigger pieces of paper used appropriately e.g. flashcards for portability, larger pieces of paper for developing ideas? Is writing integrated with gesture?

DRAWING
Does CP use drawing where appropriate (for purpose of input and also to "equalize" the communication situation)? Are drawings clear, e.g. large enough, not too cluttered?
Are drawings as simple as possible? Is drawing integrated with gesture and writing where appropriate?

RESOURCES
Does CP use available resources when appropriate? Are the most appropriate resources chosen, e.g. globe, maps, pictographic material, photographs, real objects? Are resources clearly presented, e.g. not too much at a time, oriented so that AP can see them? Is the use of resources integrated with gesture/ writing/drawing where appropriate? When appropriate, has CP found/created resources if these are not readily available or are essential for to the depth of discussion?

## Response To Communicative Cues

Does CP make sure that he/she has AP's attention before talking? Is sufficient processing time allowed? Is CP sensitive to cues (e.g. facial expression) that AP is not understanding and appropriately modify input? Does CP appropriately maintain eye-contact while writing/drawing? Is CP sensitive to severity of aphasia (in terms of use/overuse of techniques)? Is CP sensitive to the conversational partnership in context to the type of conversation being engaged in? Is affect appropriate to context?

## 2. Ensures that AP has a means of responding

Verbal adaptations (e.g. use of Fixed Choice / Yes/No Questions)

Closed-ended questions (both YES/NO and fixed-choice questions?) Do YES/NO questions go from general to specific when necessary? Are inconsistent responses/conflicting responses (e.g. head nod while saying 'no') noted and dealt with in some way? Is AP given a means of responding to the question, e.g. something to point to?

Appendix 3.13

| Key | AP: | Aphasic Partner |
| --- | --- | --- |
| | CP: | Conversation Partner |

## Non-verbal adaptations

GESTURE
Is AP encouraged to gesture, e.g. 'Can you show me?' Are pointing responses to visual material modelled for AP? Are responses to YES/NO questions modelled for AP, e.g. gesture showing thumbs up/down?

WRITING
Are pencil and paper made accessible to AP with appropriate indications that he/she should use it? Are written choices or YES/NO provided for answering closed-ended questions? Is AP encouraged to write, e.g. 'Can you write something for me - word/first letter..? Are written materials from earlier discussions kept and used when appropriate so that AP has the opportunity to 'refer back' to a topic?

DRAWING
Does the CP encourage drawing, e.g. 'Can you draw something to help me understand? Does the CP use techniques to clarify drawings that are not clear, e.g. asking AP to indicate the most important part of the drawing, circling a part of the drawing and indicating the desired (bigger) size, interpreting AP's drawing with other drawings - 'Is this what you mean?' Is drawing integrated with gesture and writing where appropriate?

RESOURCES
Are resources used appropriately to facilitate output? Does CP model response modes for AP, e.g. pointing to different parts of a map? Is visual distraction reduced e.g. covering parts of a page if it contains too much information? Is the use of resources integrated with gesture/writing/drawing where appropriate? When appropriate, has CP found/created resources if these are not readily available?

General Note:  *Are the techniques appropriately used in terms of hierarchy, e.g. gesture is usually simpler than writing and interferes less with the feel and flow of conversation, so if it suffices, it should be used. The CP also has to know when it is appropriate to go straight for the less natural technique.*

## Response To Communicative Cues

Does CP allow AP enough response time?; Does CP project a 'listening attitude? Does CP respond appropriately to inconsistent responses (including inconsistent YES/NO responses)?

## 3.    Verification  (Accuracy of AP's response not automatically assumed)

If CP doesn't get appropriate/consistent responses from AP, does he/she verify that the message was comprehended e.g. When appropriate, does CP explicitly ask 'Do you understand'?

Are messages reflected back to AP? Are incomplete messages by AP expanded and verified by CP? Are complicated issues summarised and verified by CP, e.g. 'So you are saying that -, -, -, - have I got it right?

In some cases, it might be appropriate to include attempts by CP to verify best mode and consistency of YES/NO responses by AP as part of the scoring system. Difficult for volunteers, especially if inexperienced.

*(NOTE: Verification often involves checking in __another__ modality)*

Appendix 3.14

| Key | AP: | Aphasic Partner |
|-----|-----|-----------------|
|     | CP: | Conversation Partner |

# (M)SCA
## EXAMPLE OF RATING ANCHORS
## FOR CONVERSATION PARTNER
### (IN THE CONTEXT OF THE PAT ARATO APHASIA CENTRE)

|   | Acknowledge Competence | Reveal Competence |
|---|---|---|
| 0 | Competence of AP not acknowledged. Patronizing. Could cause harm. Should not be working with our members. | No use of techniques to reveal competence |
| 1 | Needs a lot of supervision/ or needs to volunteer with experienced co-leader. | Needs a lot of supervision/ or needs to volunteer with experienced co-leader. |
| 2 | Competence of AP acknowledged implicitly and explicitly as appropriate. Volunteer is ok. You do not have big concerns. Moderate level of supervision e.g. 1 x per month | Volunteer is able to get some information. You do not have big concerns re leaving them with this member. |
| 3 | Doesn't need much supervision e.g. 1 x per term (4 months) | Doesn't need much supervision e.g. 1 x per term (4 months) |
| 4 | Peer-trainer level. Interactionally outstanding. Just needs motivation and on-going opportunity to learn as opposed to supervision | Technically outstanding. May not always succeed but as good as any well-trained professional. |

Appendix 3.15

Key AP: Aphasic Partner
CP: Conversation Partner

## Appendix 4

## Informed Consent for Volunteers

Thank you for considering the possibility of participating in this research project.

<u>What is the project about?</u> Over the past 16 years, the Aphasia Centre-North York[1] has provided long-term service for aphasic adults. The program relies totally on the contributions of volunteers such as yourself. We have gained experience in how to train volunteers, but have never done any formal research on exactly what and how this should be done.

<u>Purpose of this research:</u> To examine what it is like for new volunteers and aphasic adults to try to talk and make conversation when they meet and chat for the first time. We are also interested to see whether or not things such as giving volunteers the opportunity to observe activities, just socialize with aphasic adults, or do some training, makes any difference.

<u>Who is doing the research?</u> The research is being conducted by Aura Kagan who is the program director at the Aphasia Centre and also a doctoral candidate at the University of Toronto.

<u>What will your participation involve?</u> You will meet twice with one or our aphasic members. The meetings will take place at the Aphasia Centre. Each meeting/session is approximately 15 minutes and involves getting to know each other and finding out some information. Your will be given an outline of exactly what to do in the session. The meetings will be videotaped.

<u>Possible risks:</u> There is no physical risk to participation in the study. However, in some cases, the session might be frustrating because of the aphasia. One of the staff at the Centre will be observing behind a one-way mirror so that she can interrupt if you need any help.

Your are free to withdraw from the study at any time for any reason.

<u>Confidentiality:</u> Only first names will be used in the videos which will be rated by a professional rater and one group of students. The videos will be kept at the Aphasia Centre and will not be used for any other purpose without your written permission.

<div align="right">Appendix 4.1</div>

---

[1] Name changed to the "Pat Arato Aphasia Centre" during the course of the research.

NAME: _____

I have read and understand the information presented on the previous page.

I agree to participate in the research project being conducted by Aura Kagan.

I have been given a copy of the consent form.

Signature  _____

Witness    _____

Date       _____

I understand that whether or not I choose to participate in the study or if I decide to withdraw from it at any time, this will not affect what I do at the Centre in any way.

## Instructions for Volunteer Conversation Partners

Date:_____          Video Code:_____

Name:_____

## TALKING TO YOUR PARTNER WITH APHASIA:  PART I[1]

Thank you for volunteering to participate in this research project.

Today you will be chatting to _____, a person with severe aphasia, who had a stroke in _____.  To help, we have given you an outline to follow.  It would really help our research project if you follow this outline exactly.  Try your best to cover each section.  PLEASE DON'T SKIP SECTIONS OR CHANGE THE ORDER.

We have given you suggestions for timing.  This does not have to be exact, but gives you a rough idea of how to divide up your time.

If your aphasic partner takes you off topic, gently let them know that you have to follow guidelines re the order of topics and approximate timing.

We know it can be difficult to have this type of conversation with an aphasic person, but we would like to keep things as natural as possible.  Just try your best to keep to the topic and the approximate timing.  We will let your know when the time is up.

Appendix 5.1

---

[1] Part II (for second interview) followed an identical format, but the volunteer was asked not to refer back to the previous interview

TOPICS


TOPIC 1.     Introduce yourself.

Feel free to tell your aphasic partner that you are a new volunteer.

**APPROXIMATE TIMING: 1 MINUTE**


TOPIC 2.     Some Social Chat.

To get things going and to make your partner feel more relaxed, chat socially about where both of you live, how far you both live from the Centre, how you both get to the Centre - how long it takes etc.

**APPROXIMATE TIMING: 3 MINUTES**

TOPIC 3.     (See attached sheet)

In order to help us with our planning, we really need more information from people who usually attend the program or who are thinking about attending the program in the future.  Use the attached form for your questions and **make notes of what your partner tells you**, so we can keep this information for planning purposes.


**\*\***     Please reassure your partner that you are just finding out how they feel.

Anything that is bolded and in quotation marks means that we are giving you the exact wording we want you to use. Please begin with this wording - it is very important.

**APPROXIMATE TIMING: See attached sheet**


TOPIC 4.     "I've been asking you a lot of questions . Now it's your turn.  Is there anything you want to know about me?"

**APPROXIMATE TIMING: 3 MINUTES**

TOPIC 3

MEMBER'S NAME: _____          DATE: _____

VOLUNTEERS NAME: _____

| | COMMENT WHERE APPROPRIATE |
|---|---|
| A. " I know that you had a stroke.<br>- When was it?<br>- What work did you do before the stroke?"<br><br><br>3 minutes | A.<br>EXAMPLES: _____<br>Occupation ? _____ _____<br>_____<br>_____<br>_____<br>Hobbies? (if there is enough time) |
| B. "When do you come to the Centre?"<br><br>3 minutes | B. Note information re days, time of day, how much time they spend per day etc.<br>_____<br>_____<br>_____<br>_____ |
| C. "What exactly do you do here at the Centre?"<br><br>"Tell me a bit about it?"<br><br>3 minutes | C.    ACTIVITIES AT THE CENTRE |

# Appendix 6

## Instructions to Research Assistants

<u>BEFORE THE VIDEO</u>

1. Ask volunteer if they have read and signed the consent form – (the form should have been given to them when they come in an are waiting at the reception area).

2. Take volunteer to desk where they can read through instructions for the video and browse through materials.

   Give them instructions (I or II, depending on whether pre- or post training). Tell them that they can take all the instructions in with them – this is not a test! Try to make them feel relaxed – remind them that they are helping us to evaluate what <u>we</u> do here – it's not a test of what <u>they</u> can do.

   **Read through the whole package with them** – all the main points have been emphasized in the instructions. Show them that the questions for TOPIC #3 can be detached so that they can keep the general instructions in front of them on the table. Mention that they shouldn't forget TOPIC #4
   at the bottom of the page.

   Tell them that they can take their time to read the instructions again. Mention casually that some people like to take stuff in with them (gesture to resources on the table) – others don't. Tell them that you will be checking in with them to see when they are ready. (Your first check-in time can be to return their copy of the consent form.) The maximum time allowed for preparation is half-an-hour, but you do not need to say this to the volunteer in the beginning – it makes them more anxious. Most do not use the full half-hour.

   NOTE THE TIME THAT YOU LEAVE THEM TO START PREPARING AS WELL AS THE TIME WHEN THEY SAY THAT THEY ARE READY TO BEGIN.

   Let the second research assistant bring the participant with aphasia to the video room. Check that the participant with aphasia is comfortably seated before you bring the volunteer in. The second research assistant will introduce the volunteer to the participant with aphasia and will start the videotape after saying – "see you in about 15 minutes". The research assistant will then leave the room.

## DURING THE VIDEO

1. Make sure that you have the questionnaire re competence of the aphasic partner with you so that you can go straight in after the video is completed.

2. Use your copy of the volunteer instructions to monitor the interview in terms of content and timing. If the volunteer strays from the topic or timing suggestions in a way that will interfere with the research, you may need to go in to the room and gently remind them to keep to the topic/order of topics/timing etc.

3. Although the consent form makes it clear that the interaction might be frustrating, watch for undue distress on the part of either the aphasic subject or the volunteer and end the interview early if necessary with appropriate follow-up for participants.

4. After the interview (shouldn't be more than 20 minutes maximum), end the video using the switch in the observation room. Go in to the video room, thank the participants – make some encouraging comments about the video. The participant with aphasia will leave **(tell them that you will be coming to chat to them in a few minutes)** and the volunteer will then be asked to fill out the form re competence of their aphasic partner. Read through the instructions with them. Come back after 5 minutes to get the form.

5. Go through the aphasic partner's evaluation of the volunteer.

## AFTER THE INTERVIEW

Note exactly what resource material was chosen by the volunteer. Collect interview forms, competence rating, and any written/drawn material produced during the video by the dyad. Make sure that this is filed in appropriate file.

# Appendix 7

## Pre-interview Chat with Members (Participants with Aphasia)

Aphasic subject_____

Date_____

Interviewed by_____

To:  Research assistants

For both pre- and post-interviews, please check in with the aphasic subject (and family member if they are here) WELL BEFORE the interview.  Note:  I am interested only in what is different from usual.

"Hello_____. - remember that you said you could help us with our research – talking to a new volunteer? They are in today.  I just want to see how you're doing – are you feeling ok?; is there anything you want me to know?" etc.  Use with full SCA techniques as necessary

_____

Complete the following after you have chatted with them:

Any indication of something wrong by member (health, emotional state etc.).      YES          NO

If YES, please indicate what it is in as much detail as you have.

Please indicate anything else that we should be made aware of ( - there may be things you can see that have not been reported by the aphasic person or their family member).

**Remind AP re details of procedure – use relevant pages of informed consent sheet showing videotaping of conversation etc.**

# HOW ARE YOU TODAY?

## ARE YOU HAVING A GOOD DAY?

# YES

# NO

~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

## IS THERE SOMETHING YOU WANT TO ASK/TELL ME?

# YES

# NO

## Guide to Speech-Language Pathologists for Hands-on Training

Volunteers assigned to you for hands-on training have completed the SCA™ training day. They have done a pre-training video and will be doing a post-training video following their hands-on experience.

### Goals for the hands-on training:
- develop a sense of comfort in their interactions with members
- practice some basic techniques in the context of natural talk e.g.
  - Use of close-ended questions making sure that members have response mode (YES/NO card; written/pictured choices etc.)
- Writing key words to indicate topic
- Starting again with different/additional techniques if get stuck
- Some verification
- Explicit acknowledgment of competence
- Make sure that the volunteer has an opportunity to do something challenging e.g. finding out about previous occupation, giving member an opportunity to initiate.

### Timing: 9:30 – 11:45. (They do not attend the morning meeting or the wrap up meeting for volunteers because I can't control what they will experience in these meetings.) On the days the Community Centre is open, timing is from 9:45 – 11:00 a.m.

- Go over the basic areas (use (M) SCA™-Basic Version)
- Give them an opportunity to use pictographic/other resources to prepare something on a complex topic:
  1. Previous occupation
  2. Facilitating Initiation of Questions

### Mode of Training: Observe – give quick suggestions on-line, "e.g. try YES/NO", without interrupting too much. Some demo and practice is fine. They should experience as much success as possible. Lots of practice.

- ◆ Initially, let trainees get to know the group. Encourage members to ask the volunteer questions. Use the newspaper.
- ● Look out for "overuse" of techniques.
- ● Opportunities to practice using less technique is as important as opportunities to practice more.
- ◆ Re: Initiation: As much practice as possible in creating key-words for members to point to. (cf. Just asking and answering the questions themselves)
- ◆ Practice in maintaining and expanding a topic.

## *Appendix 9a*

## Instructions to Experimental Rater (JW)

### (Rating Volunteer Participants)

Each video has a numeric label. Please rate videos in the order specified. The order has been randomly assigned.

Rate the video after watching it once. (Rate Volunteer first). Read through relevant behaviours before assigning rating. Watch a second time and adjust scores if necessary. You can watch up to a **MAXIMUM OF THREE TIMES**. Make sure that your rating reflects your agreement with the suggested rating anchors.

Make scoring decision taking into account the conversation as a whole.

Avoid contamination between categories.

e.g. Technical skill in using a technique such as verification should be scored under 'Revealing Competence'. Overuse of verification is patronising and should therefore be taken into account under 'Acknowledging Competence'.

**Make sure that your rating takes into account whether the overall goal of the particular category was achieved, rather than rating a specific behaviour or activity.**

## Instructions to Experimental Rater (JW)

### (Rating Participants with Aphasia)

Each video has a numeric label. Please rate videos in the order specified. The order has been randomly assigned.

Rate the video after watching it once. (Rate Volunteer first). Read through relevant behaviours <u>before</u> assigning rating. Watch a second time and adjust scores if necessary. You can watch up to a **MAXIMUM OF THREE TIMES**. Make sure that your rating reflects your agreement with the suggested list of rating anchors.

AP cannot get highest rating without initiating. If fully participatory but no initiation – give 3 or 3.5 depending on level of participation.

Note: For interest, distinguish between the initiation of a non-verbal strategy and the initiation of a conversational topic. Comment if necessary.

**Make sure that your rating takes into account whether the overall goal of the particular category was achieved, rather than rating a specific behaviour or activity.**

# Appendix 10

# SCA™ framework for use by speech-language pathologists working in diverse settings

As suggested in Chapter Six, the SCA™ framework can be used by speech-language pathologists in various settings. The following three ways in which this might happen are described in detail in this Appendix and in Table 1 at the end of the appendix:

1. The speech-language pathologist can serve as a conversation partner for an individual/s with aphasia

2. The speech-language pathologist can train other partners to converse with a particular aphasic person or group

3. The speech-language pathologist can work on creating a generic infrastructure of communication ramps that can potentially benefit many individuals with aphasia in an agency, in the community, and/or in society at large.

## 1. The speech-language pathologist as conversation partner

Isn't this what speech-language pathologists do anyway? According to Parr & Byng (1998) 'what at first sight looks familiar, is, in fact, significantly different'. Taking on the role of conversation partner means being open to a broader scope of practice, for example, seeing opportunity for conversation as a valid part of professional work, rather than something that occurs in intermissions before and after the 'real' work. As Holland (1998) states, this is a role for which we are often "ill-prepared and consequently uneasy".

Clearly, the needs of those affected by aphasia differ in the acute or sub-acute as compared to the rehabilitation stages of recovery. However, whatever the stage of recovery, it is always important to acknowledge the competence of the person with aphasia. Immediately post-injury, this may just involve thinking about what is communicated and how it is communicated. The person with aphasia might not be able to respond, but a pattern of

interaction is already being established. In descriptions of their early experiences, individuals with aphasia complain bitterly about being treated in a patronizing manner. The following excerpts from interviews conducted with individuals with aphasia (Parr, Byng, Gilpin, & Ireland, 1997) are poignant illustrations of this situation. Fred, for example, felt 'talked over':

> *'If they could help me by speaking to me it would help me. Yes. Even the doctor would come in and ask my wife questions, not me. He would come in and ask the wife: "How are you today? How is he today?" I was sat along, silent – I kept trying to tell him: "Ask me. Ask me." But er that time they...they say to her: "And has he been cantankerous today?" '*

Cath described how some staff made her feel like a child when they insisted that she try and ask for the things she needed:

> *'Well why should I?'*

Alf found his first experience with a speech-language pathologist infuriating. Instead of the information he wanted, he was subjected to what seemed to him to be bizarre and pointless activities and started to suspect that:

> *'they was trying to put me into an asylum.' 'What is actually was was I thought somebody was trying to make me look a dim dim. What they call that word? Illit....?...When you can't read and write - ..'*

Lionel's encounter with a sensitive professional highlights the fact that being treated as competent stands out for the person with aphasia. Unfortunately, this contrasts markedly with the far more frequently reported experiences of being treated in a patronizing manner.

Appendix 10.3

*'Well actually doctor, actually I'm surprised actually because the doctor actually*

*talked to me – in hospital and talking down and I...something about I was trying to*

*say um? No I don't remember exactly when but...er...um...the doctor answered me*

*and I thought: "Yes, good. Yeah. Yeah." '*

As soon as the person with aphasia is able to participate in conversation, even minimally, the speech-language pathologist can provide an opportunity to talk and ask about what has happened. Within this type of conversation, ways of transacting and interacting are modeled naturally. Availability of appropriate resources makes it possible to provide depth and breadth not normally available to those with severe-moderate aphasia. For example, by using written key words and pictographs depicting choices within the flow of natural-sounding talk, the person with aphasia can be given the opportunity to select topics and ask questions that would otherwise be difficult or impossible to communicate. These topics might include what has happened and what might happen, the nature of conversational partnerships, choices about treatment, or questions about the future (see Table 10.1 at the end of this appendix for other examples).

Taking on the role of conversation partner in the early stages of intervention does not mean that the speech-language pathologist ignores language deficits or functional communication. Indeed, work on impairments is desirable as people with aphasia should be as well equipped as possible to deal with the wide variety of skill levels they are bound to encounter in others (Parr & Byng,1998). This work should incorporate the social dimension of conversation where possible (e.g. Conversational coaching, Holland,1991; and Conversational prompting, Cochrane and Milton,1984). There does however need to be a shift away from the idea that intervention *necessarily* follows a linear progression over time, from impairment level work to

Appendix 10.4

the psychosocial and social domain. First, the social domain should be incorporated from the start, and second, people with chronic aphasia can still benefit from impairment level work at a later stage than when it is traditionally available (Holland, Fromm, DeRuyter, & Stein, 1996).

The case-conference scenario illustrates the potential role of the speech-language pathologist as conversation partner. Preparatory conversations might include giving concrete information about this event, such as the people who will attend and topics that will be discussed. The speech-language pathologist might also find out what the person with aphasia wants to know or share with others, and the nature of his/her concerns. Pictographic resource material can be used to support the conversation (see Figure 1 in this appendix for examples from the case-conference section of the PCR). At times, the speech-language pathologist might switch roles from conversation partner to coach or therapist by, for example, introducing role-plays of situations likely to occur at the case-conference. These role-plays can be used to give the person with aphasia practice in initiating questions and thus increase his/her confidence about participation.

At the same time as providing conversational opportunity for the person with aphasia, the speech-language pathologist can be providing training to other potential partners, including families. This is discussed in more detail below.

Appendix 10.5

WHAT will be discussed?

hospital → home

leaving the hospital

house    apartment

independent seniors' residence
or nursing home

where you will live

**Figure 1 (Appendix 10)**

**Excerpts from the case-conference section of the Pictographic Communication Resource Manual**

WHAT do YOU want to talk about at the meeting?

| family issues | your progress | your progress |
| speech-language therapy | occupational therapy | physiotherapy |
| your job | driving/ transportation | medication |

Appendix 10.6

## 2. The speech-language pathologist as a trainer of other conversation partners for a particular aphasic individual

Training of conversation partners for adults with aphasia is analogous to therapy in the field of vocational rehabilitation where it would be inconceivable to work only with the affected individual and not the work environment. By assuming the role of conversation partner as described in the previous section, the speech-language pathologist has already had the opportunity to be role-model for family members and other health professionals. In addition SCA™ can be used to formally train other conversation partners for a particular aphasic person or group, making adaptations for individual needs and situations as suggested by Simmons-Mackie (1998). SCA™ encourages the training of a broad array of partners, including family, friends, health professionals, employers and relevant people in the community. Methods for identifying social networks for intervention are described by Simmons-Mackie and Damico (1996b). Information on existing social networks is gathered through interviews with the person who has aphasia and others. Data is collected on whom the individual interacts with on a daily, weekly or monthly basis, the nature of the relationship, and potential for expanding interactional opportunities.

Recent developments of SCA™ include resources for partner training that allow for a focus on both partners simultaneously (Kagan, Cohen-Schneider, Hain-Cohen, & Podolsky, 1999, see Appendix 11). In addition to providing a framework related to the content of conversation (transaction), this resource material encourages individuals with aphasia and their conversation partner to think in terms of satisfying social interaction with the other person. Both partners practice giving support or help that facilitates social and information exchange, and, in addition, the partner with aphasia practices using the support provided by his/her conversation partner.

Techniques such as these can be used for increasing communicative access to conversational partnerships within the health care system and outside of it. Outside of the health care system, for example, the potential for someone with aphasia to get back into the workforce is increased when employers and co-workers know how to acknowledge and reveal the competence of the person with aphasia. Getting back to work is notoriously difficult for those with aphasia (Garcia, Barrette, & LaRoche, 1998). Providing SCA™ training that is adapted to individual needs and situations would be a concrete step in alleviating this situation, but this would need to go hand-in-hand with infrastructure change discussed in the following section.

Communicative access can also be increased *within* the health care system. For example, because the brain-injury causing aphasia most likely impacts other areas of functioning besides language, the person with aphasia needs access to physical and occupational therapy. Traditionally, professionals in these areas work on increasing mobility and independence in activities of daily living, in parallel with the speech-language pathologist's work on language. When working directly to increase life participation opportunities for those affected by aphasia, all professionals involved should be skilled conversation partners and work as a team, problem-solving different challenges together with the aphasic person and his/her family. The speech-language pathologist can play a key role in facilitating these partnerships by providing SCA™ training. Training on its own however, is not sufficient. In order to maximize the benefits of SCA™, the speech-language pathologist should also work on ensuring that conversational opportunities with these partners actually do ensue.

Similarly, the involvement of social work in partnership with speech-language pathology is particularly important in providing appropriate service to those affected by aphasia. As mentioned above, this joint service needs to be integrated rather than delivered in parallel. Specific social work skills that complement those of speech-language pathology include knowledge of community resources (relevant in terms of integration), counseling (experience with issues such as loss, changes in relationships and living arrangements) and group skills

Appendix 10.8

(essential in providing meaningful support to aphasic adults and their families). Social work / speech-language pathology partnerships in providing service to those affected by aphasia have been described by Stiell & Gailey (1995) and Bindman et. al. (1995).

The case-conference scenario further illustrates the potential role for the speech-language pathologist as the trainer of other conversation partners. For example, if all participants at the case-conference, including the person with aphasia, are going to engage in a mutually satisfying conversation on relevant issues, the speech-language pathologist might consider a training session for at least one or two key professionals attending the case-conference e.g. nurses, social workers and physicians, as well as family members, so that they know how to support the person with aphasia.


### 3. The speech-language pathologist's role in creating an infrastructure for all those affected by aphasia within an agency, or wider community


Conversation partner training adapted to the needs of a particular individual or group of people with aphasia, differs from that suggested in this section where the speech-language pathologist might provide generic training for conversation partners. This type of activity can be described as making the environment more 'aphasia-friendly'. There are at least two potential situations for speech-language pathologists to consider when creating an infrastructure to support communication: 1) Increasing communicative access and reducing communicative barriers to life participation in contexts where the needs of people with aphasia are not usually taken into consideration, and 2) creating groups or communities where aphasia is the common denominator, barriers to participation are minimized, and the right to communicative access is taken for granted.

*Increasing access in situations where needs of those with aphasia is not usually taken into consideration*

Efforts in this area can be directed to making a particular agency or unit within an agency 'aphasia-friendly' and/or doing the same in the outside community. For example, innovative research by Garcia (1998) highlights the potential for education and partnerships with employers. Focus groups that participated in this research identified many potential barriers related to communication and other areas. Although work at the level of infrastructure cannot replace work done at the individual level, the use of SCA™ methods and resources to increase awareness and provide generic training for employers and co-workers could be used to address some of these concerns.

Providing information in an accessible format to people with aphasia so that they can make informed choices, is another example of activity in this area. Activities can range from giving information about fee structure within an agency, to providing information about financial rights and available services. Some British speech-language pathologists have taken a leading role in this area (e.g. Byng, Pound, & Parr, In Press; Parr, Pound, Byng, & Long, 1999; Pound, 1998b). By providing generic SCA™ training, inservices, and practice opportunities for health, recreation, and social work professionals, speech-language pathologists can play a significant role in increasing access to generic services for those affected by aphasia. Efforts to train students in these fields is seen as particularly worthwhile.

*Increasing access in situations where aphasia is the common denominator*

Re-integration into the community is often touted as the goal of rehabilitation. 'The community' however is an abstract concept. In reality, participation in the community usually occurs within the context of smaller 'communities'. We are all members of many such

communities which may include our immediate and extended family, work colleagues, special interest groups, religious or spiritual communities, or small subgroups within a larger community center framework. The onset of aphasia often interferes with membership in these communities. Ironically, many stroke clubs are not much more aphasia-friendly than other communities.

Intervention can directly target re-engagement in prior and/or new communities and might include work on increasing generic communicative access and reducing barriers to participation. Thus, for example, the speech-language pathologist might work on making a particular stroke club more accessible to people with aphasia by providing training for speaking members, as well as providing communicatively accessible resources. There are also however opportunities to provide for community membership in a context where communicative access already exists.

In this context, the speech-language pathologist might ensure the availability of on-going conversation groups and/or communities where aphasia is taken for granted, and opportunities for adult conversation are guaranteed (Bernstein-Ellis & Elman, 1999; Byng et al., In Press; Holland & Ross, 1999; Kagan & Cohen-Schneider, 1999; Patterson, Paul, Wells, Hoen, & Thelander, 1994; Pound, 1998b). While participation in such activities often results in improved communication (Elman & Bernstein-Ellis, 1999), it is Ferguson's (1994) idea of 'membership' rather than improved communication that is the goal of intervention. The availability of environments such as this should not lessen professional incentive to work on increasing access to the wider community. However, it does provide a place where it is possible to *forget about aphasia*, and where there does not need to be a continual and conscious effort to reveal individuality and competence.

The two situations described above are not necessarily mutually exclusive. For example, Walker-Batson, Curtis, Smith & Ford (1999) describe a program that provides a community for adults with aphasia at the same time as providing a training ground for speech-language

Appendix 10.11

pathology, occupational and physical therapy students to collaborate as partners on projects chosen by participants with aphasia.

The case-conference scenario was used above to illustrate the potential role of the speech-language pathologist as conversation partner and as the trainer of other conversation partners. These roles can be concurrent with each other and with work at the level of creating infrastructure change. Thus, for example, the speech-language pathologist might create written material or conduct in-services that address issues such the rights of those with aphasia, even when severe, to participate in a case-conference where decisions are made about their lives, and the right to appropriate support in the form of skilled conversation partners and appropriate resource material in the case-conference context. Achieving this understanding is likely to involve a long-term process of education and advocacy that will require creative thinking, for example, presenting videotaped interactions in a case-conference setting before and after professionals/family members have received training.

SCA™ can be used to effect change within the system. However, energy can also be directed toward advocating for a change in system as described in Chapter Six.

Appendix 10.12

**Table 1 (Appendix 10): Roles, supports, and activities of speech-language pathologists (SLP's) using 'Supported Conversation for Adults with Aphasia' (SCA™) (adapted with permission from Kagan, 1998[1])**

| Role and context in reducing barriers to conversation | Nature of support | Examples of activities |
|---|---|---|
| 1. SLP as conversation partner | Acknowledge inherent competence and help to reveal it | Begin with conversation using as much support as necessary rather than beginning with testing that removes support and reveals deficits. Can always come back to testing later with explanations of why it is necessary.<br><br>Emphasis on communicating needs and frustrations rather than on assessing skill. |
| | Demonstrate that slp is genuinely interested in a conversational partnership and not only focused on the language impairment | Prepare/create on-line resource material for a conversation about aphasia, e.g. what has happened?, opportunity to express feelings and ask questions relating to prognosis, treatment etc. |
| | Provide opportunity for autonomous choice | Prepare resource material for conversation about treatment options, questions about treatment, contract re mutual responsibilities.<br><br>Partner with person who has aphasia in the case-conference situation to ensure opportunity to exercise choice. |
| | Provide opportunity for 'conversation about conversation' and difficulties resulting from aphasia | Prepare resource material for conversations in the following areas:<br><br>• helping person with aphasia understand and acknowledge the frustration of their conversation partner e.g. spouse<br><br>• importance of being as effective a communicator as possible - especially when their partner does not have skill<br><br>• learning to maximize opportunities with skilled partners. |

[1] Kagan. A. (1998). Philosophical, practical and evaluative issues associated with 'Supported Conversation for Adults with Aphasia': A reply. Aphasiology. 12(9), 851-864.

| Role and context in reducing barriers to conversation | Nature of support | Examples of activities |
|---|---|---|
| 2.SLP as trainer of other conversation partners | Provide role-model for others to ackowledge and reveal competence of person with aphasia | Give family members, health professionals and others in contact with the aphasic person opportunities to observe SLP as conversation partner. Reveal competence of aphasic person by engaging them in conversation on contextually relevant topics with others present. Help others see that: <br><br> • The language problem might be masking inherent competence, and <br><br> • Conversation about complex topics is possible. |
| | Facilitate communicative access to others - family, friends, service providers,colleagues with shared interests: | Provide training and clear explanations of key concepts of SCA™ in relation to the specific aphasic person/s as appropriate to the context (e.g. use the SCA™ video as a starting point). <br> Provide others with appropriate resource materials. |
| | • Family | As above. <br> Explain that providing supported conversation is tiring and that family members should not expect themselves to do this all the time. |
| | • Services e.g. family doctor or lawyer, social worker, case-conference team | As above (modified in relation to context) e.g. for case-conference, accompany person and prepare resources to help him or her participate in conversation re placement or other treatment options; work with social worker in group work or counseling situations. <br> Offer to act as mediator/translator once or twice. |
| | • People who have no obligation to the aphasic person e.g. volunteers | As above. |
| | • Communities of friends, colleagues or those with shared interests | As above. <br> Create or re-create these communities by working with people selected by the aphasic person who agree to participate. |

Appendix 10.14

| Role and context in reducing barriers to conversation | Nature of support | Examples of activities |
| --- | --- | --- |
| 3. SLP creates infrastructure to reduce barriers | Increase public awareness and advocate for people with aphasia e.g.within hospitals, long-term care institutions for the elderly, government services, places of worship, financial institutions | Use principles of SCA™ and the social model of aphasia in public talks and written material e.g. illustrate barriers that impede communicative access to participation in life for those with aphasia; present concept of masked competence; move from picture of aphasic people as victims to more positive image of human rights issues. |
| | Increase generic communicative access to services | Conduct in-services for relevant groups such as:<br><br>• health professionals e.g.nurses, physicians, social workers, physical and occupational therapists<br><br>• other groups e.g. staff at community centers. |
| | Expand pool of trained professional conversation partners | Train trainers. |
| | Make environments more 'aphasia-friendly | Create resources for administrative staff to have conversations re fee schedules and payment conditions; ensure that relevant written information is accessible. |
| | Advertise SLP role as 'mediator' or 'translator' | Let medical staff know that they can call on SLP because of expertise in SCA™ e.g. to ensure that an aphasic person is given an opportunity to give informed consent to a medical procedure or to participate in a program or research. |
| | Create barrier-free environments for people with aphasia | Initiate programs where aphasic individuals have the opportunity to participate in conversation and activities of interest and 'forget about the aphasia' e.g. conversation groups. |

Appendix 10.15

*Appendix 11*


# Partner Training Material


based on "Supported Conversation for Adults with Aphasia"

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Judy Hain-Cohen
Lorraine Podolsky

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# IMPROVING COMMUNICATION FOR PEOPLE WITH APHASIA, FAMILIES, FRIENDS AND CAREGIVERS

## (Learning how to help each other and become better partners)

- Before the stroke, you probably took communication for granted.
  But now, **APHASIA** forces us to **THINK ABOUT HOW WE COMMUNICATE**

- We are going to work together so that **communication gets better for all of us:**

  PERSON WITH APHASIA

  FAMILY MEMBER/FRIEND/CAREGIVER

  STAFF/VOLUNTEERS

  your FRIENDS

## THREE IMPORTANT POINTS FOR: PEOPLE WITH APHASIA

1. Working on UNDERSTANDING BETTER

2. Working on EXPRESSING YOURSELF BETTER

3. MAKING YOUR PARTNER FEEL GOOD

## THREE IMPORTANT POINTS FOR: FAMILY/FRIENDS/CAREGIVERS

1. Helping your partner with aphasia TO UNDERSTAND YOU BETTER (getting your message IN)

2. Helping your partner with aphasia to EXPRESS WHAT THEY WANT TO SAY (getting their message OUT)

3. MAKING YOUR PARTNER FEEL GOOD

**PERSON WITH APHASIA**

# HOW TO IMPROVE YOUR UNDERSTANDING

| Environment | Be in control of your environment whenever your can |
|---|---|
| Glasses <br><br> Hearing Aid <br><br> Too noisy e.g. too many people <br><br> Distractions e.g. T.V. | |

| Help your partner | Tell them when you don't understand e.g. say/gesture/point to: <br><br> I DON'T UNDERSTAND <br><br> Tell them **what helps you** to understand better: <br><br> SLOWER PLEASE <br><br> PLEASE SAY IT AGAIN <br><br> PLEASE WRITE THE MAIN WORD IN BIG LETTERS |

Appendix 11.3

FAMILY/ FRIENDS/ CAREGIVERS

# HELPING YOUR PARTNER WITH APHASIA TO UNDERSTAND WHAT YOU ARE SAYING (Getting your message IN)

| | |
|---|---|
| **Environment**<br><br>Glasses<br><br>Hearing aid<br><br>Noise level e.g. too many people<br><br>Distractions e.g. T.V. | **Ask or remind your partner about these things if appropriate**<br><br>**Do any of these affect you as well?** |
| **Help your partner to understand you better** | **Slow/normal rate**<br><br>**Lots of expression in your voice and on your face**<br><br>**Use gestures**<br><br>**Draw something in a simple way**<br><br>**Use pictures or objects in the room**<br><br>**Say things in more than one way** |
| **Check-up to see if your partner is understanding** | **Look to see if they have a puzzled expression**<br><br>**Respond if they have given you an answer that doesn't make sense e.g. say:**<br><br>    **"Did I explain that ok?"**<br><br>**"You look puzzled – let me try again.."**<br><br>**MAKE SURE THE PERSON WITH APHASIA KNOWS THAT YOU ARE HAVING TROUBLE EXPLAINING THINGS CLEARLY** (you don't want them to think that you are questioning their competence) |

Appendix 11.4

**PERSON WITH APHASIA**

# HOW TO EXPRESS YOURSELF BETTER

| Help your partner | Ask for what you need e.g. say/point to: |
|---|---|
| | PLEASE WRITE 'YES/NO'  YES 👍 <br><br> NO 👎 <br><br> PAPER AND PENCIL PLEASE |
| **Give clues** | **Point** to words/pictures that your partner shows you <br><br> **Gesture with your hands** <br><br> **Use expression on your face** <br><br> **Use your communication book or other device** |
| **Be patient** | **Don't give up too quickly** <br><br> KEEP GOING! |
| **Ask for help** | **Say/point to:** <br><br> I NEED MORE TIME TO ANSWER <br><br> PLEASE CAN YOU HELP WITH THE WORD? |
| **Check in (does your partner understand what you mean?)** | **Look to see if your partner is puzzled** <br><br> **Say/point to:** <br><br> WRONG TRACK! |

Appendix 11.5

**Name:** _____

# HELPING YOUR PARTNER WITH APHASIA TO EXPRESS THEMSELVES
## (or get their message 'out' so that they can reveal their competence)

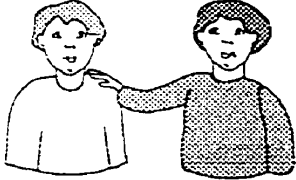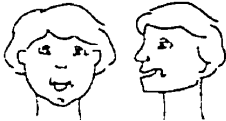| | |
|---|---|
| **Help your partner** | **Ask questions in a way that the person can answer e.g. by pointing to yes/no or a picture**<br><br>**Is there a way for the person with aphasia to indicate YES/NO or is there something for them to point to?**<br><br>**Do you both have pencil and paper?**<br><br>**Ask or get to know what helps your partner to express him/herself e.g.**<br><br>**More time to respond?** |
| **Ask for clues** | **Say/ask things such as:**<br><br>**"Can you give me a clue?"**<br><br>**"Can you show me?**<br>**In the room?**<br>**On yourself?"**<br><br>**"Can you write something – maybe the first letter?"**<br><br>**"Can you draw something?"** |
| **Be patient** | **Try to continue with topics rather than shifting constantly e.g. try these ways of keeping conversation going:**<br><br>**"Oh – that's interesting – I also..."**<br><br>**"Really – so what do you think about..."** |
| **Check up** | **Did YOU get what your partner is trying to tell you e.g.**<br><br>**"So – let's see if I got this right.... You're saying that...."**<br><br>**Support what you say with writing key words** |

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Appendix 11.6

**PERSON WITH APHASIA**

## HOW TO MAKE YOUR PARTNER FEEL GOOD ABOUT TALKING TO YOU

| | |
|---|---|
| **Be sensitive to your partner** | **Let your partner know that you REALLY WANT to talk to them, e.g.**<br><br>keep good eye-contact<br>show that you are interested by the way you sit and use your body<br><br>**Ask yourself:**<br><br>Too many sounds!<br>Am I talking too much?  TOO MUCH |
| **Acknowledge frustration** | **Say/point to e.g.**<br><br>IT'S HARD FOR YOU TOO |
| **Be a good listener** | **Sit forward**<br><br>**Eye-contact**<br><br>**Look interested**<br><br>**Use sounds to show that you are interested** |
| **Do something when it is taking a <u>long time</u>** | **Say/gesture/point to:**<br><br>I'M SORRY —IT'S VERY IMPORTANT<br><br>IT'S OK – IT CAN WAIT |
| **Keep your sense of humour** | **Laugh together when things go wrong** |

Appendix 11.7

**FAMILY/ FRIENDS/ CAREGIVERS**

# MAKE YOUR PARTNER WITH APHASIA FEEL GOOD ABOUT THEMSELVES (acknowledge their competence)

| | |
|---|---|
| **Be sensitive to your partner** | **Make sure you that you indicate that YOU KNOW your partner is a competent person e.g.**<br><br>**Talk as naturally as possible  (Don't patronize)**<br><br>**Say things like "I know you know"**<br><br>**Ask your partner what you can do to help e.g.**<br><br>**Do they usually like you to guess or to wait until they get it themselves?** |
| **Acknowledge frustration** | **Say things like:**<br><br>**"I can see that it's so frustrating – I know you know what you want to say"** |
| **Be a good listener** | **Sit forward**<br><br>**Eye-contact**<br><br>**Look interested**<br><br>**Use comments e.g  "mm"; "oh"; " that's great"** |
| **Do something when your partner is taking a long time** | **Does your partner look upset? If 'yes', let them know if it is ok with you to continue, or let them know that you don't have time right now e.g.**<br><br>**"Just take your time – that's ok"**<br><br>**" I know you have something to tell me, but I can't do this right now. Can it wait until later?"** |
| **Keep your sense of humour** | **Laugh together when things go wrong** |