Adaptation of the Capacity Evaluation Process to make Admission Decisions: Increasing Access for People with Aphasia and other Communication Barriers

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A thesis submitted in conformity with the requirements for the degree Doctor of Philosophy
Institute of Medical Science
University of Toronto

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Abstract

Background – Every competent person in Ontario has the right to decide whether or not he or she will be admitted to long-term care. If your capacity to make such a decision is in doubt, then it is evaluated. The current evaluation process is inaccessible to people with aphasia or other communication barriers, and social work evaluators report significant problems in communicating with this population. Competent individuals have been found lacking in capacity because of communication barriers.

Aims – To create a communicatively accessible capacity evaluation process with training in specialized communication techniques. Also, to test the validity and effectiveness of the Communication Aid to Capacity Evaluation (CACE) to reveal the inherent capacity of participants with aphasia using social work evaluators.

Methods – 32 social workers were partnered with 32 competent participants with aphasia. They were randomly divided into an experimental and control group. Both groups administered the current ‘Capacity to Make Admissions Decisions’ questionnaire to establish a baseline measurement of capacity. The social workers in the experimental group were introduced to CACE and received communication training. Following a two-
week interval they administered CACE and the control group re-administered the current capacity questionnaire. The 64 capacity evaluations were video recorded and 3 independent speech-language pathologists administered standardized assessment measures on the recordings. Finally, the participants completed surveys measuring confidence and communication abilities.

**Outcomes** - Using the current capacity questionnaire, one social worker found a competent participant lacking in capacity and one third of social workers were unable to determine capacity. Following the introduction of CACE with communication training, analyses of the standardized measures and survey results showed a statistically significant difference between the participants in the experimental group and the control group. The social workers in the experimental group had significantly better communication skills, (‘Revealing Competence’ $f(2, 29) = 12.03, p = 0.002$), the participants with aphasia’ abilities to ‘Transfer Information’ increased, ($f(2, 29) = 10.51, p < 0.003$), and the evaluators’ confidence in their determinations of capacity improved ($f(2, 29) = 13.511, p = .001$). The use of CACE with communication training resulted in accurate determinations of capacity in competent participants with aphasia.

**Conclusions** - CACE was an effective tool to evaluate the capacity to make a decision regarding admission to long-term care. It was communicatively accessible for this research population with aphasia, enhancing comprehension of the capacity process and enabling the person to communicate a response. Improved communication skills, transfer of information and confidence allowed the evaluators to accurately determine capacity.
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List of Abbreviations

ACE  Aid to Capacity Evaluation
ALS  Amyotrophic Lateral Sclerosis
ANCOVA  Analysis of covariance
ANOVA  Analysis of variance
CASLPO  College of Audiologists Speech Language Pathologists of Ontario
CAT  Capacity Assessment Tool
CCAC  Community Care Access Centres
CCTI  Capacity to Consent to Treatment Instrument
CMAD  Capacity to Make Admission Decisions questionnaire
ESL  English as a Second Language
I.S-LP  Independent Speech-Language Pathologists
MacCAT-T  MacArthur Competence Assessment Tool-Treatment
MPC  Measure of Participation in Conversation
MMSE  Mini Mental State Examination
MS  Multiple Sclerosis
MSC  Measure of Skill in Supported Conversation
PACE  Placement Aid to Capacity Evaluation
PD  Parkinson’s Disease.
PwA  Participant with Aphasia
SCAT™  Supported Conversation for Adults with Aphasia
S-LP  Speech-Language Pathologists
SSS  Scandinavian Stroke Scale
SW  Social worker
Chapter 1 Introduction

1.1 Thesis Introduction

Social workers were observed in a number of different environments to examine the obstacles they faced when providing services to individuals with communication barriers. The patient populations that were of particular interest were those with admitting diagnoses of stroke, head injury or progressive neurological diseases and those who spoke English as a second language or who had a hearing loss. The current capacity evaluation process to make a decision whether or not to go to long-term care was first introduced to this researcher when observing a social work case manager in a small general hospital. The social worker evaluated a patient’s capacity by asking ‘open-ended’ questions with no support in the form of written text or pictures. The patient verbally communicated the information required for the social worker to determine his capacity. This evaluation process brought into focus the barriers patients or clients with aphasia would have to overcome in order to reveal their capacity. The social worker reported that with such patients she sought the help of a speech-language pathologist; however, the speech-language pathologist was only in the hospital one day a week, and discharge would not wait for her visit. The implications of being found lacking in capacity are far reaching. The patient loses the right to make his or her own discharge decision; instead the healthcare team turns to the substitute decision maker. Having the right to decide where and how to live taken away because your capacity to make a decision is masked by a communication barrier masks is a grave ethical concern.

Bowman and Rowland\textsuperscript{1} in their article on capacity assessment and evaluation in Canada provided a case study to illustrate the potential dilemma of hidden capacity. The case study described a man who had recently arrived in Toronto from the West Indies. He had no immediate family in Ontario, but a strong network of friends in the city. Unfortunately, at the age of 63 he sustained a stroke that resulted in aphasia, a language disorder. As discharge from a rehabilitation hospital approached, his capacity was evaluated to determine if he could make a decision about where he would live. The symptoms of his aphasia, including echolalia and perseveration, combined with a strong
Caribbean accent masked his ability to show that he understood relevant information and appreciated the reasonably foreseeable consequences of a decision or lack of decision.

This gentleman was admitted to a long-term care facility although he made it clear to healthcare professionals that he did not agree with the decision of incapacity or his discharge plan. He was provided with the information on how to appeal the decision of incapacity but did not do so. The long-term care home was on the other side of the city to his neighbourhood and friends. He reported feeling isolated and extremely frustrated at the lack of opportunity to converse with his fellow residents due to their cognitive deficits and his aphasia.

Fortunately this gentleman had been referred to a community aphasia program, and at the initial interview he revealed his deep dissatisfaction with the changes that had occurred in his current living circumstances. An accurate exchange of information was achieved through the use of specialized conversation techniques, and the social worker at the community program arranged for re-evaluation of capacity by a geriatrician. The finding of incapacity was immediately overturned. This gentleman revoked his power of attorney, reclaimed control of his finances and with help, organized supportive housing in his original neighbourhood.

This case study raises a number of issues that are worthy of research. How many people are living with a communication barrier that places their legal rights in jeopardy? What is the law regarding the evaluation of capacity? What tools are available to evaluate capacity and what education do the evaluators receive regarding effective communication with this challenging and vulnerable population? This doctoral thesis will examine these issues and attempt to address the apparent disparity in capacity evaluation between those who can communicate freely and those who cannot.

1.2 Research Aims

1) To adapt the current capacity evaluation process so that it is accessible to people with aphasia and other communication barriers. To ensure that the content of the adapted
capacity evaluation reflects the content of the current evaluation questionnaire and the Health Care Consent Act, protecting a person’s right to decide on a proposed admission to long-term care. Every Ontarian has the right to understand why a capacity evaluation is taking place, to ask questions and to communicate their answers verbally or non-verbally. A communicatively accessible capacity evaluation process will address these rights and improve the evaluator’s skill in determining whether or not an individual has the ability to understand information relevant to making the decision, and to appreciate the reasonably foreseeable consequences of a decision.

2) To develop a training DVD for the capacity evaluators to remind them of what is required by law in the capacity evaluation process and introduce them to aphasia and different communication barriers that can mask competency. The training will outline the most effective way to administer the adapted capacity evaluation, maximizing the patient’s cognitive skills and psychosocial wellbeing. The DVD will also introduce the capacity evaluators to specific communication techniques that can enhance a person with aphasia’s ability to understand and communicate responses, and how to verify those responses.

3) To test the validity and effectiveness of the adapted capacity evaluation tool with communication training for social work evaluators and participants with aphasia.

1.3 Hypotheses

1) The use of a communicatively accessible capacity evaluation process, with training, will enhance the skills and confidence of a social worker to more accurately judge the capacity of people with aphasia to make an admission decision to long-term care.
2) The inherent capacity of a person with aphasia to make a decision regarding admission to a care facility will be revealed by the use of a communicatively accessible capacity evaluation process.

1.4 Rationale
The current capacity evaluation, the ‘Capacity to make Admission Decisions’ questionnaire is largely inaccessible to patients who have aphasia and other communication barriers such as English as a Second Language (ESL) or hearing loss. There is no visual support in the form of written text or pictures, the questions are lengthy and complex, and there is no vehicle to allow the person being assessed to communicate responses non-verbally. Capacity evaluators, typically social workers or nurse case managers, are not trained in the specialized communication skills needed to interact effectively with this population. Furthermore, some of the communication and counseling skills that they are taught at both an undergraduate or graduate level are counterproductive to interacting with people with aphasia and other language barriers. Overall, social workers report a lack of confidence in their evaluation of individuals with speech, language and hearing difficulties to make admissions decisions.

There are established and proven methods used in the areas of aphasia treatment, service and research to help a person with a language disorder or barrier to understand information and get his or her message across.³ The use of these communication techniques should help to ensure that the capacity evaluation process is fair and equitable resulting in a more accurate determination of capacity.

1.5 Research Questions
The following research questions arose from the hypotheses:

1) Does an accessible capacity evaluation process with communication training enhance the communication skills of the social worker to reveal capacity in a participant with aphasia?
2) Does an accessible capacity evaluation process with communication training increase the confidence of the social worker in his or her determination of capacity?

3) Does enhanced communication and confidence in social workers result in increased accuracy in the determination of capacity?

4) What are the perspectives of the participants with aphasia regarding the communication accessibility of capacity evaluation process?

1.6 Doctoral Thesis Chapter Outline

Chapter Two investigates the current literature to establish the need for an accessible capacity evaluation process through examination of the prevalence of communication barriers. It explores the legal requirements of capacity evaluation and the current capacity assessment process in Ontario, Canada and other jurisdictions. Evaluator education, both in the legal process governing capacity and in specialized communication skills is reviewed. In Chapter Three, the methodology and results regarding the development of the communicatively accessible capacity evaluation process are discussed. This chapter considers both quantitative and qualitative data. Chapter Four describes the methodology used to test the effectiveness of the Communication Aid to Capacity Evaluation with communication training, and Chapter Five reviews the results of the quantitative and qualitative analyses. Chapter Six discusses the results of the analyses that attempt to answer the research questions, focusing on legal, ethical, systemic and clinical implications. Proposed changes to the adapted tool and communication training are also considered. Finally, the limitations of the research study are reviewed. Chapter Seven addresses the future directions of the Communication Aid to Capacity Evaluation.
Chapter 2 Literature Review

2.1 Introduction and Chapter Overview
Informed consent for admission to long-term care concerns the law, medicine and ethics. Four key ethical principles govern patient consent; they are beneficence, non-malfience, justice and autonomy. All four principles are in jeopardy if a person living with a language or communication barrier cannot reveal his or her capacity because the evaluation process is communicatively inaccessible. To explore the issues of capacity evaluation with this population, this literature review will focus on the prevalence of communication barriers to establish the need for an accessible evaluation process. It will also examine the legal requirements of capacity evaluation, the current reality regarding evaluation and education, both in the legal process and in specialized communication skills.

2.2 Incidence and Prevalence of Communication Barriers
Successful communication relies on accurately hearing a message, understanding the content of the message, formulating a response, finding the desired words and putting them into the correct order, and speaking the words clearly so that the listener can understand the message. The vehicle of the message is language. Language is the innate ability of the human species to use symbols to represent, amongst others, objects, concepts, actions, people, and emotions for the purpose of communication. These arbitrary symbols are represented by speech, writing, gestures and other codes. The use of these symbols (language) is governed by rules shaped by the community in which people live. The rules and use of language are constantly changing, and a breakdown can occur at any stage of the communication continuum.

The literature review will establish the numbers of people who live their lives with one or more language disorders or communication barriers that have the potential to mask capacity. It will focus on adults living with aphasia, dysarthria, English as a second language and hearing loss, all of whom could benefit from an accessible system to help
reveal that they have the ability to understand and appreciate the consequences of moving to long-term care.

### 2.2.1 Definition of Aphasia and Aphasia Types

Aphasia is a good example of a communication barrier as it can disrupt a person’s abilities across the four language modalities: understanding language, verbal expression, reading and writing. However, a disruption in language is not related to general intellectual decline or sensory motor deficits.\(^6\) Aphasia does not affect your intelligence or experience.\(^7\) There are many types of aphasia that can result in different language deficits and abilities. The Connectionist Classification System is the most commonly used medical model to describe aphasia types. The classification system incorporates neuro-anatomical correlates with observable behaviours.\(^3\) The four most commonly occurring aphasias will be explored in this review. Broca’s aphasia, also known as ‘non fluent’ or ‘expressive’ aphasia, affects a person’s verbal output which becomes sparse, halting, with function words frequently omitted. Generally, with this aphasia, comprehension is relatively preserved in comparison to the person’s ability to verbally communicate. The brain lesion resulting in this aphasia type is in the Broca’s area (posterior, inferior frontal lobe of the left, or language dominant hemisphere).\(^3\) Wernike’s, ‘fluent’ or ‘receptive’ aphasia is caused by damage to the superior posterior regions of the left temporal lobe. This aphasia type gives rise to problems with understanding spoken and written language, finding specific words and the production of paraphasias. Global aphasia is caused by a large infarct in the perisylvanian area of the language dominant hemisphere resulting in both receptive and expressive language deficits. Finally, Anomia is an aphasia type where comprehension of language is largely preserved, but word retrieval is impaired.\(^6,3\)

The Copenhagen Study is one of the few stroke studies to examine the frequency of aphasia types. The study included 270 acute stroke patients with aphasia. Following diagnostic testing, the results showed the following rates of incidence: Global aphasia 32%, Anomic aphasia 25%, Wernicke’s 16% and Broca’s aphasia 12% (others 15%).\(^8\)
2.2.2 The Incidence and Prevalence of Aphasia

Incidence of Aphasia

The most common cause of aphasia is stroke (85%) followed by Traumatic Brain Injury (TBI), brain tumors and degenerative diseases. Most of the research findings arose from studies that explored the incidence of stroke and aphasia. Dickey et al. set out to determine the incidence of aphasia in Ontario, Canada resulting from stroke. The researchers focused on inpatient statistics gathered by the Ontario Stroke Audit, the information was augmented by data from the Registry of the Canadian Stroke Network. The results showed that 30% (965/3207) of people admitted to acute care services with a primary diagnosis of stroke presented with aphasia, and 35% (1131/3207) of those discharged from hospital had aphasia. The presence of aphasia at discharge gave an incidence rate of .06%, or 60 per 100,000 adult persons per year in Ontario. This data reflects the outcomes of the European BIOMED Study of Stroke. The study’s sample size was 4,499 patients across seven European countries hospitalized for first-in-a-lifetime stroke. One of the many variables the study examined was the presence of aphasia. The results showed that 32.6% of the participants had aphasia, 4% more in females than males.

Engelter et al. in the one-year prospective, population-based study to determine the incidence of stroke and aphasia in Basel city, Switzerland, found that 30% of persons admitted with a primary diagnosis of First Ever Ischemic Stroke (FEIS) presented with aphasia. The number of participants in their study totaled 269, eighty of whom were diagnosed with aphasia. The research team measured the type and severity of aphasia by using a bedside aphasia screen, the Minnesota Test for the Differential Diagnosis of Aphasia and the aphasia subscale of the Scandinavian Stroke Scale. The results regarding aphasia types are as follows: fluent or receptive aphasia 23 (29%) and non-fluent or expressive aphasia 48 (60%) (9, or 11%, of patients’ fluency ratings were unclassified or missing). With regard to severity, 35 (44%) patients had mild aphasia, 24 (30%) moderate, and 21 (26%) severe. There were no statistically significant differences between females and males with regard to aphasia severity ($P=0.31$) and fluency ($P=0.32$). The incidence of aphasia increased according to the age of the stroke patients,
tripling by the age of 85. Comparable results regarding age and aphasia were found by Dickey et al.’s study, ranging from 12 per 100,000 for the age band 20-64 years, to 360 per 100,000 for those between the ages of 75-84, and 685 per 100,000 for those over 85 years of age.\(^\text{10}\)

A similar investigation to the Basel study was carried out in the prefecture of Athens, Greece looking at first-ever acute stroke and the incidence of aphasia.\(^\text{13}\) The researchers lengthened the time of the prospective study to 10 years resulting in a total of 2,297 participants, 806 (35.1\%) of whom were diagnosed with aphasia. Again, aphasia severity was determined by using the Scandinavian Stroke Scale (SSS); 296 (36.7\%) were considered to have a mild aphasia, 145 (20.6\%) moderate and 365 (45.3\%) severe. Results showed that the aphasia was independently associated with age, severity of stroke on admission and presence of atrial fibrillation. Atrial fibrillation can cause thrombi from left atrium to embolise to the middle cerebral artery. Imaging studies in the majority of patients with severe aphasia showed that the site of lesion was in the Middle Cerebral Artery area.\(^\text{13}\) Although these results were interesting and confirmed the rate of incidence of aphasia, it must be pointed out that no diagnostic assessment of aphasia was reported in this study. Presence of absence and severity levels were garnered through the SSS which examined the following:

<table>
<thead>
<tr>
<th>Scandinavian Stroke Scale(^\text{14})</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Speech:</strong></td>
<td></td>
</tr>
<tr>
<td>No Aphasia</td>
<td>10</td>
</tr>
<tr>
<td>Limited vocabulary or incoherent speech</td>
<td>6</td>
</tr>
<tr>
<td>More than yes/no, but not longer sentences</td>
<td>3</td>
</tr>
<tr>
<td>Only yes/no or less</td>
<td>0</td>
</tr>
</tbody>
</table>

With regard to age and the incidence of stroke and aphasia an interesting study has come out of Dakar.\(^\text{15}\) From August 2003 to May 2005 the neurology department admitted 170 patients with a primary diagnosis of stroke. At one-month post stroke 55 patients were found to have aphasia giving rise to a frequency of 32.35\%. However, the mean age of the participants was 56.8 years (range 28 to 86 years), much younger than previous
A recent study from Scotland also found the incidence of stroke and aphasia occurring in younger people. The authors gathered data from three of the 14 health boards in Scotland. In the Borders region (the board with the largest population) 26% (15/58) of those participants who sustained a first-ever stroke with aphasia were under the age of 65.

### Aphasia Prevalence

The Heart and Stroke Foundation of Canada (2003) report that 300,000 Canadians are living with the effects of stroke. Even if the lower aphasia incidence statistic of 30% is used, that means 90,000 Canadians are living with this language barrier as a result of stroke. The American Speech and Hearing Association (ASHA) report that one million Americans have aphasia. The National Aphasia Association concurs with ASHA’s data, adding that in the United States, 1:250 people have aphasia. Moving to countries outside North America, the following data was gathered using an internet search. According to the National Health Service Direct (2006), approximately 250,000 people in England and Wales have aphasia. The Aphasia Forum in Italy reports that 150,000 Italians are living with aphasia with an annual increase of 10,000. In Australia, it is estimated that 26% of Australians who sustain a stroke will live with chronic aphasia.

The study from Dakar showed that, one year post diagnosis, 83.7% of the participants were still living with the effects of their language deficit, although 45% of the participants’ language skills had improved on re-testing. Different results were found in Naess’ study of young people with ischemic strokes (age 15-49). Some 195 patients were followed up five years after the FEIS. The Scandinavian Stroke Scale was administered and those with less than 10 points on speech subscale were diagnosed with aphasia. Twenty participants had persisting aphasia, a prevalence rate of 10.3%. However, as mentioned earlier, the SSS gives a very crude measure of aphasia emphasizing speech output.

### Aphasia and Traumatic Brain Injury
The Center for Disease Control and Prevention report that 235,000 Americans are hospitalized with Traumatic Brain Injuries every year, and the National Aphasia Association estimates that one third of patients with severe head injuries will have aphasia. Detailed Canadian data regarding Traumatic Brain Injury and aphasia was hard to find, however, according to the Brain Injury Association of Canada, each year over 6,000 Canadians become permanently disabled after a traumatic brain injury. In other words they sustain a ‘severe’ head injury. Using the data from the National Aphasia Association, it could be extrapolated that approximately 2,000 Canadians (1/3 of those with severe head injuries) are living with aphasia as a result of a traumatic brain injury.

Future Trends - Aphasia Incidence and Prevalence

Many jurisdictions are reporting that the general population is not only increasing in numbers but are also in age. Stroke incidence increases significantly with age, especially 65 years and above, and more people are reaching the stroke-prone age band. In Australia the National Stroke Foundation (2006) estimates that over 48,000 strokes occur in Australia every year, and that with the aging population this number will rise 74,000 by the year 2017. It is also estimated that by 2020 the number of people in United States living with aphasia will have risen to over 2,000,000.

Increased response times by Emergency Medical Services (EMS), medications such as the thrombolytic tissue plasminogen activator (tPA) and an organized stroke system have resulted in a 70% increased heart and stroke survival rate. However, increased survival rates could contribute to an increased incidence and prevalence of aphasia.

2.2.3 Bilingual Aphasia

Communication barriers can co-exist adding to the complexity of administering a capacity evaluation. Bilingual aphasia occurs when a person who speaks a different language than English or French acquires aphasia. According to the Heart and Stroke Foundation of Canada, 50,000 people succumb to stroke each year. By extrapolating the lower aphasia incidence rate of 30% of strokes (16,600) and demographic statistics of bilingualism (20% of Canadians) it could be said that, conservatively 3,300 people who
fall victim to stroke and aphasia each year are bilingual.

There has been a long history of observational bilingual aphasia case studies showing patients reverting to their first language post stroke. As these studies have become more refined, the research results have contributed to the development of cognitive models of bilingual language processing. Variables such as which language is acquired first, language dominance, age of acquisition of a second language, word frequency, imageability and cognitive status have an impact on language recovery. Six patterns of recovery have been observed:

1) Parallel recovery, both languages are similarly impaired and are restored at the same pace.
2) Differential recovery, languages recover at different rates relative to premorbid use.
3) Selective recovery, one language returns.
4) Antagonistic recovery, one language returns, but then regresses as the second language recovers.
5) Successive recovery, the first language recovers followed by the second language.
6) Mixed recovery with mutual interference.

However the patient recovers, the important issue to remember is that he or she is at a serious disadvantage when it comes to understanding the language surrounding the explanation of capacity evaluation and the evaluation itself.

2.2.4 Psychosocial Consequences of Aphasia

Communication barriers such as aphasia have a significant psychosocial impact on the patient or client. John Liechty, a young social worker, suffered a brain aneurysm leaving him with aphasia. He describes the feelings of loss:

“The frustration is ongoing. I become so tired of trying to say a phrase and having it come out different from what I meant. It is exhausting to keep up my morale. Sometimes it is so hard to communicate that I get really depressed from the continual frustration and struggle to express my view
about whatever I want. For a person with aphasia, language and communication are synonymous with depression and anger.”30 p.84

Laures-Gore et al. examined the stress-related consequences for people with aphasia, for example, the presence of anxiety, frustration, and depression leading to social isolation.31 The authors explore known coping resources that typically help people who are excessively stressed; they include good general health, energy, positive beliefs, problem-solving skills, social skills, social support and material resources.31 Following a stroke or head injury many of these coping skills are not available to patients or clients with aphasia. It is at this time that their capacity to make a decision regarding leaving home and moving to a long-term care home is evaluated, and currently, the evaluation process is dependent on verbal communication.

2.2.5 Aphasia Summary and Implications

Research shows that the incidence of aphasia resulting from stroke varies from between 30% to 35%. According to the Heart and Stroke Foundation of Canada, approximately 50,000 Canadians fall victim to stroke every year, and 6,000 Canadians sustain a severe head injury. That would give an approximate annual aphasia incidence rate of 17,000. However, it is important to note that many of the studies excluded participants who developed aphasia from a second or subsequent stroke and those who had hemorrhagic strokes.12 The numbers could be higher still. The prevalence rate of people living with aphasia is approximately 92,000. These figures represent different age groups and different levels of aphasia severity; nevertheless, the numbers are significant. Unequivocally studies are showing that age is an independent risk factor for stroke and aphasia, and that the aged population is rising.10,11,13 It is precisely these people for whom placement in long-term care is being considered, which exemplifies the need for a communicatively accessible capacity evaluation process. However, two studies showed that younger people are succumbing to stroke.15,16 For those individuals the discharge implications may be even more pronounced.

2.2.6 Definition of Dysarthria
Dysarthria is defined as impaired speech production, usually caused by pathology affecting the nerves controlling the muscles involved in speech, or by pathology affecting the speech muscles themselves. Dysarthria is also described as a motor speech disorder. The muscles of the mouth, face, larynx and respiratory system may become weak, move slowly, or not move at all after a stroke or other brain injury. The type and severity of dysarthria depend on which area of the nervous system is affected. People who communicate with dysarthria are frequently not understood or misunderstood due to the lack of clarity in their spoken utterances. This is a further example of a communication barrier.

This literature review will not explore congenital disorders such as cerebral palsy or Down’s syndrome that also give rise to dysarthria, or neurological diseases that affect cognition; for example, Huntington’s Chorea. Rather, it will focus on adult acquired dysarthria resulting from stroke and neurodegenerative disorders.

2.2.7 Incidence and Prevalence of Dysarthria

Dysarthria arising from Stroke

The European BIOMED Study of Ischemic Stroke in their examination of sex differences in stroke management in Europe included dysarthria as one of the variables studied. The researchers found that 33.7% participants presented with dysarthria, 36.2% male and 31.2% female. Brain stem strokes account for 10% of all strokes. An infarct in the brain stem can affect the cranial nerves which supply the muscles of the larynx, face, lips, tongue and soft palate, all of which are required for speech production. Data regarding the incidence and prevalence of Stroke in Canada shows that approximately 50,000 people succumb to stroke per year, 5,000 of those will have a brain stem stroke. Similarly, 300,000 Canadians are living with the effects of stroke giving a prevalence rate for brain stem stroke of 30,000. In a review of speech language therapy and dysarthria, analysis found from between 20 and 30% of people who sustain stroke will have dysarthria.
Dysarthria arising from Progressive Neurological Diseases

The three most common progressive neurological diseases that include dysarthria as part of their symptomology are Parkinson’s disease (PD), Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS). PD is a neurodegenerative disease affecting the substantia nigra in the brain stem. The primary symptoms include increased motor fore, resting tremor, bradykinesia and gait difficulty. The speech mechanism is frequently affected as volitional movements become slow and articulatory and respiratory muscles are rigid giving rise to short utterances separated by long pauses. The volume of the voice continues to weaken, so that sounds and syllables become less distinct. The rate of speech increases, and with repetition of syllables, words and phrases, the resulting utterances sound similar to stuttering.

Amyotrophic Lateral Sclerosis (ALS) is characterized by the degeneration of upper and lower motor neurons in the central nervous system. Motor neuronal cell death results in muscle weakness and wasting. Although the main clinical features are a combination of upper and lower neuron degeneration, a range of cognitive and behavioural changes occur in up to 30% of individuals with ALS related to frontal lobe dysfunction. With regard to speech production, the dysarthria associated with ALS is classified as ‘mixed’ with components of spasticity from upper motor neuron involvement and flaccidity due to bulbar deterioration. Utterances become increasingly difficult to understand due to imprecise consonants, hypernasality, monopitch and low volume of the voice.

Multiple sclerosis (MS) is an acquired, inflammatory, demyelinating disease of the central nervous system. Scattered plaques or lesions on neuronal axons produce varying combinations of motor, sensory, or cognitive impairments. It is also characterized by a series of relapses and remissions. It is difficult to define a typical pattern of speech problems in MS because of the variable site of the lesions and the broad spectrum of impairments that result. However, the most common dysarthria associated with MS is a ‘mixed’ type including spastic and ataxic components. The resulting speech can be imprecise and slurred, or the rate and rhythm can be affected resulting in erratic speech.
Episodes of dysarthria that last for up to a minute or so and recur several times a day, is particularly common in MS.\textsuperscript{32}

Research studies that have examined the incidence and prevalence rates for these progressive neurological diseases are summarized in the following Table:

\textit{Table 1 Incidence and Prevalence Rates for Parkinson’s disease, Amyotrophic Lateral Sclerosis and Multiple Sclerosis}

<table>
<thead>
<tr>
<th>Prog Neuro Disease</th>
<th>Study</th>
<th>Comment</th>
<th>Incidence Per 100,000 population</th>
<th>Prevalence Per 100,000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD</td>
<td>Laia et al (2003) The prevalence of Parkinson’s disease in British Columbia, Canada, estimated by using drug tracer methodology\textsuperscript{40}</td>
<td>Data from Drug tracer. Not all PD captured</td>
<td>125</td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>Parkinson’s Disease Foundation (Canada)\textsuperscript{41}</td>
<td>Estimate</td>
<td>235-294</td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>de Lau et.al (2004) Incidence of parkinsonism and Parkinson Disease in a general population The Rotterdam Study\textsuperscript{42}</td>
<td>Population cohort 55-85 years of age</td>
<td>188</td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>Mehta et al. (2007) Population prevalence and incidence of Parkinson’s disease in an Australian community\textsuperscript{35}</td>
<td>Population cohort 50 years of age and above</td>
<td>362</td>
<td></td>
</tr>
<tr>
<td>ALS</td>
<td>Abhinav et al. (2007) Amyotrophic Lateral Sclerosis in South-East England: A Population-Based Study\textsuperscript{43}</td>
<td>Resident population 15 years and older</td>
<td>1.06</td>
<td></td>
</tr>
<tr>
<td>ALS</td>
<td>Chio et al. (2001) Incidence of ALS in Italy Evidence for a uniform frequency in Western countries\textsuperscript{44}</td>
<td></td>
<td>2.50</td>
<td></td>
</tr>
<tr>
<td>ALS</td>
<td>Amyotrophic Lateral Sclerosis Association (ALSA) Facts and figures \textsuperscript{45}</td>
<td>Estimate</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>ALS</td>
<td>American Speech and Hearing Association, Dysarthria\textsuperscript{32}</td>
<td>Estimate</td>
<td>0.5-3</td>
<td></td>
</tr>
<tr>
<td>MS</td>
<td>Beck et al. (2005) Regional variation of multiple sclerosis prevalence in Canada\textsuperscript{46}</td>
<td>Data collected from Canadian Community Health Survey</td>
<td>240</td>
<td></td>
</tr>
<tr>
<td>MS</td>
<td>Warren et al. (2008) Contribution of incidence to increasing prevalence of multiple sclerosis in Alberta, Canada\textsuperscript{47}</td>
<td>Alberta</td>
<td>357.6</td>
<td></td>
</tr>
<tr>
<td>MS</td>
<td>Sloka et.al (2005) Incidence and prevalence of multiple sclerosis in Newfoundland and Labrador\textsuperscript{48}</td>
<td>Newfoundland and Labrador</td>
<td>94.4</td>
<td></td>
</tr>
</tbody>
</table>

Legend: Prog Neuro Disease = Progressive Neurological disease
Incidence of Dysarthria in Canada arising from Progressive Neurological Diseases

Ramig et al., in their meta-analyses of speech and voice disorders associated with PD, found that studies showed a wide variation in the numbers of people who go on to develop dysarthria. Between 50% to 90% of those with idiopathic Parkinson’s disease (IPD) will develop dysarthria in the course of their illness. Other studies report that approximately 90% of persons with PD will develop dysarthria during the course of the disease, however, this included mild dysarthria where patients themselves are unaware of the speech disturbances.

Yorkston, in her extensive review of degenerative dysarthria, states that approximately one third of individuals with ALS experience speech changes as an initial symptom of the disease. Approximately 80% of ALS patients will experience speech disturbances during the evolution of the disease, and approximately 75% of people with classic ALS will develop weakness and wasting of the bulbar muscles (muscles that control speech, swallowing, and chewing). Dysarthria is not universally seen in Multiple Sclerosis, but is estimated to occur in more than half of the population. Dysarthria correlates positively with MS severity and is seen more frequently in patients with a longer symptom duration. Rosen concurs with Yorkston, citing approximately 23–50% of patients with MS experience dysarthria during the course of the disease.

According to Statistics Canada, the population of Canada in April 2010 was 34,000,000. In order to arrive at an approximate overall prevalence rate for each disease, the Canadian prevalence rate per 100,000 (see table 1) will be multiplied by 340 (Canadian population). The product will then be divided by the lower dysarthria incidence rate (see above).

Table 2 Table to show the Calculations to Arrive at an Estimated Dysarthria Population for Progressive Neurological Diseases in Canada
The results of the extrapolated data in Table 2 show, conservatively, that over 60,000 Canadians are living with dysarthria, which interferes with speech production resulting in a communication barrier.

### 2.2.8 Psychosocial Consequences of Dysarthria

Dickson et al.’s study explored patients’ experiences living with post stroke dysarthria.\(^5^3\) Results of the study indicate that the effects of communication difficulties led to changes in self-identity, relationships, increased social and emotional disruptions, and feelings of stigmatization or perceived stigmatization.\(^5^3\) Similar results were found in Miller et al.’s research on life with communication changes in Parkinson’s disease.\(^5^4\) The authors report the resulting communication barrier of dysarthria led to feelings of frustration and depression at being neglected by others because of communication failure, and that these feelings resulted in social withdrawal. The importance of sustaining effective communication for patients with Amyotrophic Lateral Sclerosis (ALS) is essential, especially as the disease progresses.\(^5^5\) Communication allows the patient to remain in control and adapt psychosocially. The loss of immediate, spontaneous communication with the use of high or low-tech communication devices is frequently frustrating and dispiriting.\(^5^5\)

Communication barriers, in this case dysarthria, combined with psychosocial issues of dealing with chronic illness can negatively impact a person’s autonomy. This is an important factor for all evaluators to recognize as they assess a patient’s capacity to make treatment and discharge decisions.
“It is through autonomy, individuals develop a sense of their own power and control. These are known moderators against anxiety and depression.”

2.2.9 Dysarthria Summary and Implications
As with the epidemiological review of aphasia, the research studies show that the numbers of people with dysarthria are significant. When expressive communication becomes a barrier, people are at risk for being found incapable. Subsequent loss of autonomy has significant psychosocial ramifications. Currently there is no capacity evaluation process that helps people to communicate effectively showing that they have the ability to understand and appreciate information non-verbally. A person’s right to decide where and how he or she will live is compromised.

2.2.10 The Prevalence and Implications of Hearing Loss
Individuals who are hearing impaired do not present with expressive or receptive language problems; however, they frequently do not hear spoken messages accurately resulting in erroneous comprehension of the spoken message. The 1991 Participation and Activity Limitation Survey from Stats Canada (2002) define hearing loss as: “limited ability to hear what is being said in a conversation with one or more people, even when wearing a hearing aid.” An estimated 135,000 Ontarians between the ages of 16 and 65 are deaf, partially deaf or hard of hearing. Of this number 36% have difficulty hearing in a group setting, 39% demonstrate difficulty hearing one to one, and 25% are completely unable to hear. Reports indicate that more than 66% of patients over 75 years, rising to 80% of patients over 85 have difficulty hearing. In his study of individuals in Beaverdam, Wisconsin, Dalton found 46% of people aged 45-87 are living with a hearing loss.

The Canadian Hearing Society report that aging is the primary cause of hearing loss, consequently the incidence of hearing loss is poised to climb dramatically as the population ages. Currently one in four people over the age of 65 have a hearing loss. Statistics Canada report that 13.4% of the current population are over 65 years of age. One quarter of those would amount to 634,000, a significant number of people living
with hearing loss. According to Yueh, hearing loss is under diagnosed and under-treated, with only 25% of patients with aidable hearing loss receiving hearing aids.  

Common symptoms of hearing loss include confusion, communication impairment and social withdrawal. This symptomology can have a direct impact on capacity evaluation which relies on the evaluator’s spoken communication. If the patient or client did not accurately hear the message, an answer might be given that leads the evaluator to surmise that the patient did not understand. The Canadian Hearing Society, in their report to the standing committee for Accessibility for Ontarians with Disabilities Act 2004, stated that being able to communicate one’s symptoms or medical history and being able to understand what doctors and nurses are saying is the absolute cornerstone of health care. Without clear communication there can be no care.

2.2.11 The Prevalence and Implications of speaking English as a Second Language (ESL)

The demographic characteristics of the modern world have changed significantly in recent times. Bilingualism is becoming the norm rather than the exception, especially in countries that receive a large number of immigrants. Furthermore, in some countries, such as Canada and Belgium, bilingualism is a societal choice. Canada is proud of its cultural and linguistic diversity. Since 1901 the country has welcomed over 13 million immigrants. The Canadian Census Report (2006) shows that over 100 languages are spoken in Canada, and the number of allophones (those whose first language is not English or French) is over 6 million, or 20% of the population. In the Province of Ontario 16% of the people speak another language in the home. These statistics show that the numbers of people who do not speak English or French fluently, and are negotiating their way through the healthcare system at a time of great stress, are significant. Language skills affect literacy skills. According to the International Adult Literacy and Skills Survey as reported by Statistics Canada, 43% of immigrants whose mother tongue is different than the test language scored at the lowest level on the Prose Literacy Scale. The link between language and low literacy rates as identified by the Literacy Survey is cause for concern. This must be taken into consideration when
developing an accessible capacity evaluation process.

Language used in healthcare is complex and little understood by those who do not work in the system. Healthcare professionals have a tendency to use jargon. Jargon has been defined as ‘verbal shorthand’ and can be a useful tool when everyone has a common understanding of the terms used.\textsuperscript{28} Problems arise when jargon creeps into every day communications with patients or clients. For those who have difficulty processing English, medical and healthcare terminology can be intimidating;\textsuperscript{28} for example, in rehabilitation, therapists refer to the ‘upper extremity’ meaning the shoulder, arm, forearm, wrist, or hand. Those outside of rehabilitation and medicine have little idea what such terms mean. The responsibility to ensure that patient and healthcare professional understand one another rests with the professional.\textsuperscript{28}

\subsection*{2.2.12 Prevalence of Communication Barriers, Summary}

Prevalence rates as seen in Table 3 show that significant numbers of people are living with a communication barrier.

<table>
<thead>
<tr>
<th>Communication Barrier</th>
<th>Crude Prevalence Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aphasia</td>
<td>93,400</td>
</tr>
<tr>
<td>Bilingual Aphasia</td>
<td>18,400</td>
</tr>
<tr>
<td>Dysarthria From PD, ALS and MS</td>
<td>60,000</td>
</tr>
<tr>
<td>Hearing Loss (over 65 yrs)</td>
<td>634,000</td>
</tr>
<tr>
<td>ESL</td>
<td>6,800,000</td>
</tr>
</tbody>
</table>

The need for an accessible version of capacity evaluation is an ethical obligation and only makes sense. Also, it is important to note that a patient or client can present with more than one communication barrier at any given time. O’Halloran et al. found in their study of patients in acute stroke units that 27\% of the participants had two or more communication impairments of moderate or greater severity.\textsuperscript{66} The incidence of stroke
induced aphasia, Parkinson’s disease, and hearing loss significantly increases with age, and can coexist. Admittance to Long-Term Care also increases with age.

This group of individuals with communication barriers not only needs communicatively accessible medical processes, but also healthcare professionals to provide treatment and advocate on their behalf. Speech Language pathologists are the logical choice. However, studies show that only 3% to 4% of individuals with Parkinson’s disease receive speech therapy\textsuperscript{36} and in Ontario 35% of patients diagnosed with aphasia do not receive the services of speech pathology.\textsuperscript{10} This has implications for conducting capacity evaluations as social work case managers cannot rely on recommendations from speech-language pathology regarding communication strategies if they are not involved.

2.3 Capacity Evaluation and the Law
A review of the law will serve to define the content of an adapted capacity evaluation and will help to situate Ontario’s capacity evaluation process in comparison to other legal jurisdictions. The Health Care Consent Act (1996) (HCCA) lays out the legal requirements for capacity evaluation. It provides rules that aim to give consistency in interpretation. The goal is to ensure that a person’s right to consent to admission to a care facility will follow the same rules and criteria in any setting throughout the Province of Ontario. The ‘Purposes’ (section 1 (a) – (f)) of the Act are to enhance the autonomy of persons for whom treatment or admission to a care facility is proposed. The most relevant ‘purpose’ for the patient population in question is:

“to promote communication and understanding between health practitioners and their patients and clients.” (Part 1, d)

Capacity Evaluators
It would appear that, in practice, there is some confusion about who can administer the capacity evaluation for admission to long-term care\textsuperscript{67}. There are three types of capacity
assessment or evaluation which commonly occur in the health care system, and different health practitioners are responsible for each kind:

1) When obtaining consent to treatment, it is the responsibility of the *treating* health practitioners to judge whether the patient has the capacity to consent to the health practitioners’ treatment. In the section on ‘Interpretation’ (section 2) “health practitioners” is defined as a member of one of the Colleges legislated under the Regulated Health Professions Act (1991).

2) If a patient’s mental capacity to make decisions regarding his or her property (including finances) or personal care is in question, then a capacity assessment is conducted by a trained assessor, who must follow specific guidelines laid out in the Substitute Decisions Act (1996). In order to qualify as a capacity assessor, a person must be a member of one of the following colleges:
   - (a) The College of Physicians and Surgeons of Ontario
   - (b) The College of Psychologists of Ontario
   - (c) College of Nurses of Ontario (as a Registered Nurse)
   - (d) Ontario College of Social Workers and Social Service Workers (and registered as a Social Worker)
   - (e) College of Occupational Therapists of Ontario

   The practitioner must also successfully complete a training course approved by the office of the Attorney General. 68

3) Health practitioners who can evaluate the capacity to make a decision for admission to long-term care are defined as a member of one the following regulated colleges:
   - (a) College of Audiologists and Speech-Language Pathologists of Ontario
   - (b) College of Nurses of Ontario
   - (c) College of Occupational Therapists of Ontario
   - (d) College of Physicians and Surgeons of Ontario
   - (e) College of Physiotherapists of Ontario
   - (f) College of Psychologists of Ontario
   - (g) Ontario College of Social workers and Social Service Workers
The original thought behind including members of these colleges is that they are the healthcare professionals that most frequently provide service to the elderly, the population most likely admitted to long-term care. It would also seem common sense to make sure that the appropriate healthcare team members educate the patient before the capacity evaluation. However, in contrast to capacity ‘assessors’ who must receive education, ‘evaluators’ are not required to receive special training. They are considered qualified solely based on their membership in a designated college. Regrettably, many college members, other than social workers and nurse case managers, are unaware that they can perform this role.

Definition of Capacity
The HCCA defines what is meant by ‘capacity’:

If the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. (Sch. A., para 4 (1))

The key word is ‘able’ to understand and appreciate. A patient may not understand the body’s chemistry regarding electrolytes, but is able to understand that they need to be in balance. In *Starson v. Swayze*, [2004] the presiding member pointed out:

“… the Act (*Health Care Consent Act*) requires a patient to have the ability to appreciate the consequences of a decision. It does not require actual appreciation of those consequences. The distinction is subtle but important. . . . The patient's lack of appreciation may derive from causes that do not undermine his ability to appreciate consequences. A lack of appreciation may reflect the attending physician's failure to adequately inform the patient of the decision's consequences.”

In order to provide clarity, the Capacity Assessment Office, Ministry of the Attorney General of Ontario, has provided definitions of the key constructs in capacity evaluation:
As a construct, to ‘understand’ refers to a person’s cognitive abilities to factually grasp and retain information. To the extent that a person must demonstrate understanding through communication, the ability to express oneself (verbally or through symbols or gestures) is also implied.

The ‘appreciate’ standard attempts to capture the evaluative nature of capable decision making, and reflects the attachment of personal meaning to the facts of a given situation. The act goes on to inform health practitioners that a person may have the capacity to make one decision, but be incapable of making another decision, consequently the evaluator must always presume that a person has the capacity to make the decision in question: it is up to the practitioners to find to the contrary. Finally, a person can refuse to give consent, and if does so the capacity evaluation cannot proceed.

An Individual’s Consent to Capacity Evaluation

According to the HCCA, before the capacity evaluation is administered, the patient must be informed that his or her capacity to make a decision regarding admission to long-term care is going to be evaluated. The health practitioners must then ask the patient whether he or she consents to the capacity evaluation. The rules in the HCCA differ with regard to informing the patient about a finding of incapacity. For treatment decisions the health practitioner must explain the consequences of a finding of incapacity and the right to challenge the finding. The health practitioner is not required to explain findings of incapacity when making admission decisions. Nevertheless, in Saunders v. Bridgepoint Hospital, [2005] Spies wrote:

“I am however, of the view, that as a matter of procedural fairness, a patient must be informed of the fact that a capacity assessment, for the purpose of admission to a care facility, is going to be undertaken, the purpose of the assessment and the significance and effect of a finding of capacity or incapacity. Given what is at stake for the patient, this seems to be a minimal requirement for procedural fairness. Furthermore, this will ensure that the information collected from the patient, which forms the basis of the assessment, is reliable.”
Also, in *H.P. v. Lakeridge Health* [2007] the Consent and Capacity Board Presiding Member stated:

“Providing “rights advice” to persons found incapable of making an admission decision is standard practice across this province.”

The expectation is that the evaluator will give the patient or client ‘rights advice’. That is an explanation of the potential consequences of a finding of incapacity, namely that the patient’s substitute decision maker will be approached to make the decision on behalf of the patient. The patient should also be informed that he or she can appeal a finding of incapacity, and that either the evaluator or another health professional will help with the appeal process. Finally, the patient should be asked if the or she has any questions and whether or not he or she agrees to participate in the capacity evaluation. Wahl (2006) sites Re: Koch case, where Mr. Justice Quinn stated that the evaluators should:

“... inform the person being evaluated of the purpose and consequences of the evaluation and should not evaluate if the person refuses.”

The Presiding Member in *H.P. v. Lakeridge Health* went so far as to overturn a finding of incapacity by a neuropsychologist evaluator because the process was not fully explained:

“Section 4(2) of the HCCA sets out a presumption that a person is capable of making his or her own health care decisions. A health practitioner who makes a finding that rebuts this presumption bears the onus of proving the lack of capacity. In my view, that onus extends also to proving that the assessment was procedurally fair. Because of the delay in providing rights advice and because of the fragmented method by which Drs. X and X assessed H.P.’s capacity, I concluded on a balance of probabilities that they did not meet this onus. I was therefore obliged to conclude that Mrs. H.P. was capable, at the time of this Hearing, of making her own decision about admission to a care facility.”

**Current Capacity Evaluation**

The HCCA does not provide a formal capacity evaluation tool to determine whether an individual has the capacity to make an admission decision to long-term care. Instead the
Ministry of Health and Long Term Care developed a questionnaire to assist the evaluators. The expectation is that the evaluators approach the evaluation in the same way as trained designated capacity assessors. The questionnaire, entitled “The Capacity to Make Admissions Decisions” (CMAD), contains 5 questions, which are as follows:

1) What problems are you having right now?
2) How do you think admission to a nursing home or home for the aged could help you with your condition /problem?
3) Can you think of other ways of looking after your condition/problem?
4) What could happen to you if you choose not to live in a nursing home or home for the aged?
5) What could happen to you if you choose to live in a nursing home or home for the aged?

Questions 1) and 3) examine whether the patient or client has the ability to understand, and questions 2), 4), and 5) look at the ability to appreciate the consequences of a decision. This questionnaire has come under a great deal of criticism for its simplified use. It was not designed to be a pass or fail test, rather, a framework to guide the evaluator and provide a reference point for subsequent questions that help establish whether the patient has the ability to understand and appreciate a decision regarding admission to long-term care. To that end, all of the questions use the grammatical construct of an open-ended question. This encourages an individual to verbalize sufficient information allowing the evaluator to determine capacity. Open-ended questions are difficult for people with aphasia and other language barriers to answer. They frequently know what they want to say, but have difficulty in finding the right words and putting them into meaningful sentences. The current CMAD questionnaire does not provide visual material to help the individual to understand the capacity questions and communicate a response non-verbally. It is the evaluator’s responsibility to ensure that the patient knows about his or her health limitations, understands the nature of long-term care and how this type of accommodation would help him or her.
The Placement Aid to Capacity Evaluation (PACE) *(see appendix 2)* was developed by Paul Rivers and Sincere Wong, two social workers dissatisfied with the ambiguity of the CMAD questionnaire as an evaluation tool. The purpose of PACE is to help clinicians systematically evaluate capacity and document findings. The tool provides a comprehensive list of questions or prompts to augment each capacity domain; for example in the domain “Understand Care Needs” (question 1 in the CMAD questionnaire) the evaluator may draw from a bank of 29 questions. The PACE tool has good face validity insomuch as many social workers use the tool as an aid for determining capacity, but it has not undergone any form of investigation to determine its effectiveness.

**Presumption of an Individual’s Capacity**

It is important to explore the legal tenet of ‘presumption of capacity’ further. An individual may not have the ability to understand the complexities of his or her investment portfolio, but has the ability to understand and decide where to live. Consequently, the individual should be presumed competent for every new decision. The Capacity Assessment Office of the Ontario Ministry of the Attorney General states that there should be reasonable grounds to prompt an evaluation of capacity. They go on to say:

“Routine screening of whole classes of individuals cannot and should not be endorsed, as this prejudges an individual’s capacity based on class membership. For example, it is incorrect to assume that all intellectually disabled persons must be incapable by virtue of their disability.”*68 p.6*

This should be applied to people who have aphasia following a stroke or head injury. Just because he or she cannot easily understand verbal information or give a full verbal response does not necessarily mean that they do not have decision-making capacity.

**Decisional Capacity and Risk**

Capacity evaluation is a complex process that frequently puts health practitioners at odds with the patient. Rehabilitation professionals and case managers consider a patient’s safety a high priority, especially regarding mobility and activities of daily living (ADLs).
When a competent patient makes a decision that puts him or her at risk, it is difficult for the healthcare team to accept that decision. However, as the Ministry of the Attorney General (2005) states:

“The issue for the assessor is not whether the person's actions or choices appear reasonable or will put them at increased risk, but whether the individual is able to understand critical information and appreciate the reasonably foreseeable consequences of his or her decisions or lack of them. Unless there is clear and compelling evidence of impaired “ability to understand and appreciate”, the assessor can not use a finding of incapacity as a means to manage risk.”

The Finding of Incapacity

If the evaluator finds that a patient does not have the capacity to make this specific decision, the evaluator provides the patient with information on his or her rights. The current “Rights Information” is as follows:

An evaluator has decided that you are not capable of making a decision about admission to a nursing home or home for the aged. This means that another person must make a decision about admission for you.

If you do not agree with the evaluator’s finding, you have the right to ask for a review of this decision from the Consent and Capacity Board. To apply for a review call: (phone number)

You may ask this same Board (Consent and Capacity Board) to appoint someone to make admission decisions for you. As well, a person who would like to be appointed as your representative may apply to the Consent and Capacity Board to be granted this authority.

If you have a guardian or Power of Attorney for Personal Care, this is the person who would make the admission decisions for you.

If you would like further information about your rights, please call your Community Care Access Centre, or your coordinator.
The Right’s Advice information does not clearly state that the evaluator will help the patient to contact the Consent and Capacity Board should the patient wish to appeal the finding of incapacity. However, the standards of practice for members of the College of Social Workers and Social Service Workers require that social workers help the individual to exercise ‘options’ when finding that individual incapable with respect to their admission to a care facility. Options include applying to the Consent and Capacity Board for review of the finding of incapacity. In reference to the health practitioner’s obligations the presiding member in his finding for K, Resident of Trilogy Long-Term Care (2009) wrote the following:

“Part of the process of evaluation also involved determination of what was required of an evaluator should an individual’s right(s) to make their own decision be removed by the evaluator’s finding of incapacity. Plainly put, there was an obligation on the social worker evaluator to provide assistance with the application process (to the CCB). She did not. Surely nothing less should have been expected of the occupational therapist, the second evaluator.”

2.3.1 Consent and Capacity in Other Jurisdictions - Canada

Having explored Ontario’s legislation regarding consent and capacity to make decisions, this review will also consider legislation and practice in other provinces in Canada to determine whether content should be considered in the adaptation of the current capacity evaluation to a communicatively accessible format.

In Canada, only two Provinces, Ontario and British Columbia (BC), include admission to a care facility in their legislation regarding healthcare consent. In BC the act is entitled the Health Care (Consent) and Care Facility (Admission) Act [RSBC 1996]. However, very little specific information is forthcoming regarding admission to long-term care, with the following exception:

**Presumption of capability**

3 (1) Until the contrary is demonstrated, every adult is presumed to be capable of

(a) giving, refusing or revoking consent to health care, and
(b) deciding to apply for admission to a care facility, to accept a facility, care proposal, or to move out of a care facility.

It is interesting to note that BC’s legislation also includes the right to leave a care facility.

Quebec’s Act respecting Health Services and Social Services (1991, amended 2002) uses language such as ‘care’ rather than ‘treatment’ which has a medical connotation, and expands its remit to include social services and welfare:

1) Before giving his consent to care concerning him, every user of health services and social services is entitled to be informed of his state of health and welfare and to be acquainted with the various options open to him and the risks and consequences generally associated with each option. 991, c. 42, s. 3; 2002, c. 71, s. 2.

Alberta, Prince Edward Island, and New Brunswick approach consent through Mental Health legislation. Manitoba and Saskatchewan tackle consent and capacity through legislation on Health Care Directives and Substitution Decision Makers, while Nova Scotia includes capacity in their Medical Consent Act 1989. All use a standard definition of capacity, that is, the ability to understand and appreciate.

British Columbia’s legislation pays particular attention to the individual’s communication abilities regarding capacity evaluation. The Health Care (Consent) and Care Facility (Admission) Act’s section on Presumption of Capacity includes the following:

(2) An adult's way of communicating with others is not, by itself, grounds for deciding that he or she is incapable of understanding anything referred to in subsection (1).

This legal tenet, although pertaining to BC, is important to emphasize in the training of evaluators who assess people with aphasia or other communication barriers. BC’s legislation includes the following on garnering consent:
Duty to communicate in appropriate manner

8) When seeking an adult's consent to health care or deciding whether an adult is incapable of giving, refusing or revoking consent, a health care provider

(a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and
(b) may allow the adult's spouse, or any relatives or friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.

Although Alberta does not include admission to long-term care in their legislation concerning consent and capacity, the government has developed a Continuing Care Strategy. The goal is to give seniors greater autonomy over where they live and provide sufficient supports in the home allowing those who might have been admitted to long-term care to remain at home: “(Seniors) prefer choices that permit them to preserve their independence, quality of life and personal dignity.”

2.3.2 Consent and Capacity in Other Jurisdictions – Overseas

Interestingly, both the United Kingdom and the United States include other constructs than ‘understand’ and ‘appreciate’ when evaluating capacity. According to the Mental Capacity Act 2005 governing England and Wales the definition of capacity includes the ability to understand information, the ability to retain information relevant to the decision and the ability to use or weigh that information while making a decision. The final construct is the ability of the patient to communicate decisions. The United States also includes four constructs to be measured in the assessment of capacity. These are outlined in United States’ Case Law; 1) expressing choice, the ability to communicate a choice, 2) understanding, the ability to comprehend the meaning of information, 3) appreciation, the ability to recognise how information applies to a person and 4) reasoning, the ability to compare options and infer consequences of choices. Western Australia have recently followed the expanded definition of capacity established by United States and the United

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Kingdom in their Consent to Treatment Policy (2009); they include the capacity to understand and retain relevant information, the ability to manipulate the relevant information rationally, the ability to reflect and make a judgement based on personal values and the situation and finally the capacity to freely communicate a decision.

It is noteworthy that these legislations include the *ability to communicate* a decision, a construct that is missing from Ontario’s Health Care Consent Act. However, this can be viewed both positively and negatively; it is satisfying to see that those who developed the respective legislations considered ‘communication’ in the assessment of capacity. For those with aphasia or English as a Second Language who are competent, their capacity may be masked by an inability to communicate, and therefore are at risk of being judged incapable to make a decision. New Zealand makes an effort to overcome this issue in their Code of Health and Disability Services Consumers' Rights Regulation (1996). The code includes the ‘Right to Effective Communication’:

1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.

2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

Again, these rights are worthy of inclusion in the training of capacity evaluators, especially the right to “effective communication in a form, language, and manner that enables the consumer to understand the information provided”. Although it cannot be backed by legislation here in Ontario, it is a sound principle.

In Ontario there is no distinction between ‘capacity’ and ‘competency’. However, in other jurisdictions the words convey different meanings. Competency’ is described as a legal judgement, whereas designated healthcare professionals can evaluate whether
someone has the capacity to make a decision. The outcomes are the same: if someone is judged to be competent or have the capacity, he or she can choose for themselves.\textsuperscript{76}

### 2.3.3 Common Misapprehensions in Capacity Evaluation

Returning to the Ontario legislation, although the Health Care Consent Act clearly lays out the procedure for capacity evaluation, there appear to be some common misunderstandings either with the evaluation itself or with the interpretation of the results.\textsuperscript{1}

1) **Global Incapacity**

Many healthcare workers continue to believe in the concept of global incapacity, that is a patient or client either has or does not have capacity to make decisions. This thinking is apparent when there has been a finding of incapacity for one decision documented in the patient’s medical record.\textsuperscript{1} In the case brought before the Consent and Capacity Board, \textit{K, Resident of Trilogy Long-Term Care (2009)},\textsuperscript{73} \(K\) had been found lacking in capacity to make a decision for admission to long-term care. At the time of evaluation he was in a sub acute rehabilitation hospital. The medical-staff at the long-term care facility to which he was transferred made the assumption that because \(K\) was found incapable to make the admission decision, he must be incapable of making decisions regarding his treatment. As a consequence, the staff went to \(K\)’s substitute decision maker for treatment decisions including medications. This was immediately overturned at the Consent and Capacity Board hearing.

2) **Autonomy versus Beneficence**

The issue of autonomy versus beneficence remains controversial. A case was brought before the Consent and Capacity Board in Ontario\textsuperscript{77} where the case manager found a patient lacking in capacity because she thought an admission to long-term care was in the patient’s best interests. The case manager believed that consent was based on whether the patient agreed with her care plan which was based on her perceived view of ‘best interests’. Meadus emphasizes the danger of this approach; Ontarians’ trust in the health
system must be maintained in this era of escalating healthcare costs, overcrowded hospitals and the constant need for beds.

‘Respect for a person’s legal rights and adherence to one’s own legal obligations in professional relationships is a minimum ethical standard for any healthcare professional’. 77 p.6

What is considered to be an unreasonable choice is no longer accepted as a standard for incompetence. 78

3) Cognitive Testing of Capacity
Health care professionals who are not familiar with the legal requirements of capacity evaluation frequently resort to formal tests that measure cognition and memory. Their logic is understandable insomuch that the tests reveal the patient’s cognitive abilities, which are tied to executive functioning and activities of daily living. However, these tools test the wrong issue and are not sufficient to make a determination of capacity. 77 This will be explored further in the literature review.

2.3.4. Capacity Evaluation and the Law - Summary
Ontario’s Health Care Consent Act combined with findings from the Consent and Capacity Board clearly lay out the process of evaluating a person’s capacity to make a decision regarding admission to long-term care, and the consequences of a finding of incapacity. Other jurisdictions, notably B.C. and New Zealand, have considered the diverse ways in which people communicate in their legislation, and these principles should be included in the capacity evaluation training process. Capacity assessments are ultimately human judgments occurring in a social context, combined with the patient’s situation and values. 75 The ‘situation’ of the population under consideration in this research are those living with communication barriers.

My aphasia relates very closely to my perceived levels of control and confidence with regard to my various life events. 79 p.38
Capacity evaluation must be a fair process for all people. Consent should be informed, the patient or client should be able to understand the reasons why an admission to long-term care is being considered. This includes patients with communication barriers. If the process of capacity evaluation is not carried out conscientiously then that person’s rights have been violated and a subsequent admission to a care facility is illegal, in other words it is unlawful confinement.

2.4 Current Approaches to Capacity Assessment and Evaluation

Capacity is a dichotomous judgement as to whether an individual is capable of understanding relevant information and appreciating the reasonably foreseeable consequences of a decision, or not. Although this doctoral thesis focuses on the capacity to make a decision to be admitted to a long-term care facility, the majority of the research studies found in this literature review concerned ‘consent to treatment’. In Ontario the standards and requirements for assessing capacity remain the same for both scenarios, so the research is considered relevant and has been included. The testing of capacity in children is not included in this review.

Vellinga et al. carried out an extensive review of the instruments that are currently used to assess decision-making capacity. They fall into two main categories, realistic and hypothetical assessments.

Realistic Capacity Assessments

The capacity assessment that is best known in this field is the MacArthur Competence Assessment Tool-Treatment (MacCAT-T). The instrument assesses patients' competence to make treatment decisions by examining their capacities in four areas: understanding information relevant to their condition and the recommended treatment, reasoning about the potential risks and benefits of their choices, appreciating the nature of their situation and the consequences of their choices, and expressing a choice. Before the assessment the clinician selects relevant information regarding the patient’s diagnosis, symptoms and treatment needs. This information is read aloud to the patient at the
beginning of the assessment. The MacCAT-T guides the clinician and the patient through the process that assesses the patient’s capacity for decision-making. One of the drawbacks of this assessment is the scoring. Although there is a score for each of the four areas of capacity (understanding, reasoning, appreciation and choice) there is no overall score or cutoff scores for each of the areas. It is important to note that the MacCAT-T is not designed to determine global capacity, rather is intended to identify areas of specific capacity or incapacity and should be interpreted in the context of other relevant clinical information.

According to Ontario’s Health Care Consent Act, the healthcare professionals involved in the patient’s care are responsible for determining the capacity of a patient to consent to treatment. Clinicians often form general impressions from an interview and previous knowledge of the patient. This method can be biased, and does not necessarily agree with the opinion of expert capacity assessors, especially in the grey area of ‘probably capable/incapable’. The Aid to Capacity Evaluation (ACE) was developed in Ontario by Etchells et al. The authors wanted to create a capacity assessment focusing on medical patients rather than psychiatric patients making decisions about medical treatment. ACE is a semi-structured evaluation of a participant’s ability to understand relevant information and appreciate the reasonably foreseeable consequences regarding a decision about a specific medical treatment. The results of the effectiveness study of ACE highlighted one area of particular interest. The medical students involved in the study were given one hour’s training on both capacity and the administration of ACE. Their subsequent capacity judgments closely agreed with both the residents and the capacity “experts” across a broad range of medical decisions. However, there was less agreement between the staff physicians and the capacity experts. The staff physicians gave a general impression of capacity from their knowledge of the patient. A comparative drawback to ACE is its design. ACE can only be used in Ontario as it was designed to comply with the Health Care Consent Act, which defines capacity as the ability to understand and appreciate. Both the United States and the United Kingdom include other constructs in their capacity definition and therefore ACE cannot be used in those jurisdictions.
Other researchers have developed instruments for specific populations or circumstances. The Capacity Assessment Tool (CAT) is a relatively short capacity measure designed for use in primary care settings.\textsuperscript{83} The CAT is administered to patients who are facing a specific medical decision. It covers the four major areas of capacity of the United States, and gives an overall score of the patient’s capacity for the specific decision. The advantages of the CAT are its focus on capacity for specific health care decisions (not global determinations of competency) and its potential use with many different groups of patients.\textsuperscript{84} CAT fairs well in comparison to the MacCAT-T, as it is considered to have more structure, clearer scoring procedures, and thresholds that can be used to determine competence.\textsuperscript{84}

**Hypothetical Capacity Assessments**

These capacity assessments centre on hypothetical decisions that are also known as “vignettes”. Capacity to Consent to Treatment Instrument (CCTI) is one such assessment.\textsuperscript{85} The CCTI was developed primarily to test the capacity in patients with Alzheimer’s disease and other cognitive disorders. A hypothetical description of a disease, treatment situation, and treatment recommendations with accompanying risks and benefits is read out to the patient. The patient makes a decision regarding treatment and provides a rationale, thus revealing whether he or she has the capacity to make a decision. However, deciding about a real personal medical situation is different from a hypothetical one,\textsuperscript{85} and requires the patient to have a good grasp of the abstract.\textsuperscript{86} Furthermore, to be of value, the vignettes should be close to the patient’s actual social, environmental and medical issues.\textsuperscript{86}

**2.4.1 Limitations of Standardized Measures**

1) Psychometric Testing of Capacity Assessment Tools

The most prominent limitation of the current capacity assessments lies in the lack of validity and reliability testing. Many of the instruments have been tested only once, despite showing promise as a useful measure.\textsuperscript{81} Thus far, the most common way of establishing validity has been to compare assessment findings with expert psychiatric
opinion, which is understandable given the absence of a gold standard measure. The psychiatrists’ assessments may be idiosyncratic posing a problem in the measurement of reliability. Assessment tools that measure understanding have been compared to the MacCAT-T, and have performed well with regard to concurrent validity, but only in the area of understanding, not appreciation.

Sturman, in his review of standardized capacity assessment tools also highlighted the problem of small sample sizes used to test capacity instruments. He goes on to state that they are adequate for pilot studies, but are insufficient to evaluate a tool psychometrically. Etchells acknowledges a further weaknesses in the development of ACE, that being the participants, the majority of whom were of North American or European descent:

“Capacity assessments may be less reliable if cultural or linguistic barriers are present, or if the therapeutic relationship is problematic.”

2) Administration of Capacity Assessment - Information Disclosure
Although standardized capacity assessments have helped educate healthcare professionals in the legal aspects of capacity and have improved procedural equity, issues remain regarding the consistency of the evaluation process. For example, the amount of information revealed about the patient’s real or hypothesized event. An individual’s understanding of a medical situation and treatment options is dependent on the amount and type of information the assessor provides. Too much information with numerous details can overwhelm a patient, affecting his or her ability to process and lay down significant information in the memory. On the other hand, too little information may be insufficient for the patient to make an informed choice. Discrepancies can occur in information disclosure to different groups of patients. One study showed that psychiatric patients generally received less information than medical inpatients, and both groups performed better when the information was disclosed in several units or segments, with the designated question following each unit. Finally, whether or not the patient received sufficient education on their medical condition and recommended treatment made a difference in the capacity assessment results. This illustrates the point that
understanding not only depends on the patient’s inherent ability, but also on the amount, quality and timing of the information.\textsuperscript{78,88}

3) Training in Capacity Assessment

The receipt of formal training on capacity assessment remains a challenge for new clinicians.\textsuperscript{1} Consistency of training and proficient assessment skills remains an important quality measure in healthcare today.\textsuperscript{89} Capacity assessment training should be part of clinical training for all health care professionals.\textsuperscript{75}

2.4.2 Capacity Evaluation - Decisions to move to Long-Term Care

The balance between taking away a patient’s right to decide to go home, and being negligent by supporting an excessively risky discharge is difficult for physicians and healthcare professionals to achieve.\textsuperscript{90} The answer lies in assessing the capacity of the patient to make a decision regarding discharge. If the patient is capable, he or she has the right to make a ‘risky’ decision.\textsuperscript{1} All acute medical disorders, both functional and organic should be treated before capacity to make a decision concerning discharge is assessed.\textsuperscript{90} The results of a finding of incapacity are far-reaching, a person may lose the right to decide where and how he or she will live due to the acute effects of their admitting diagnosis. The implications of placing a person in a long-term care home should not be underestimated. Many patients who are found to have the capacity to make discharge decisions remain vulnerable to healthcare teams, friends and families who, with the best intentions, do not agree with the discharge decision.\textsuperscript{90} One solution to a risky discharge home could be an increase in the use of trial discharges. This would promote more accurate measurements of management and insight in the patient’s own environment.\textsuperscript{90}

Effective capacity evaluation regarding discharge decisions also depends on the quality and quantity of information that the physician or evaluator can gather about the patient’s previous level of functioning at home and in the community. This information acts as the cornerstone for evaluating insight and appreciating the issues and risks of returning home.\textsuperscript{91}
2.4.3 Cognitive Assessments of Capacity

The Mini Mental State Examination (MMSE) is a screening tool developed to assess cognitive deficits. It is a well-known and frequently used tool in Canadian healthcare and in other English speaking countries, it has also been translated into many other languages. The literature review reveals that the MMSE is commonly used as an assessment tool to determine a patient’s capacity to make treatment or admission decisions. The MMSE is divided into 5 sections; Orientation, Registration (immediate recall), Attention and Calculation, Recall (delayed) and Language and Praxis. The maximum score is 30, and the authors’ state that a score of 25-30 falls within normal limits. A number of studies examining seniors and their ability to consent to participate in research trials show the MMSE scores have a strong association with capacity. Meadus on the other hand, argues that cognitive assessments by themselves are not sufficient to determine capacity. Assessments of memory or cognition are precisely that, in other words, they are not assessments of decisional capacity.

Kim and Caine examined the usefulness of using the MMSE as a capacity instrument for agreeing to participate in research. Their specificity and sensitivity results are particularly interesting. Within a certain range of scores, the MMSE was, at best, a modest discriminator of decisional capacity in this study group. No MMSE cutoff score produced both high sensitivity and high specificity. A cutoff score of 26/30 had a sensitivity of 91–100% showing that the participants were indeed capable. When identifying incompetent patients, the cutoff score of 19/30 had a specificity of 85–94%. In other words, the MMSE scores at the extreme ends of the continuum correlated with capacity or incapacity. The scores between 19 and 26 proved to be a grey area with regard to the determination of capacity. The authors concluded that the MMSE was not a good predictor of incompetence. Even Whelan admits that, although they advocate the use of the MMSE in research trials, it should not be used in lieu of a ‘clinico-legal’ assessment.

Other studies support the notion that healthcare professionals rely too heavily on the assumption that cognitive abilities are the sole determiner of capacity. There is the
chance that a psychiatric patient could score highly on the MMSE, but due to a psychosis might not have the capacity to consent to treatment.¹ Karlawish found in his study of capacity assessment that the construct of ‘insight’ was more predictive of capacity.⁷⁶ Some participants scored higher on cognitive tasks including the MMSE, but had impairments in insight. These patients were found not to have the capacity to make a decision. In other words, preserved awareness of one’s medical condition and prognosis is closely associated with the capacity to make decisions regarding care needs.⁷⁶ Also, the MMSE does not assess a patient’s decision-making abilities.⁷⁶,⁸²

The administration of the MMSE is highly dependent on expressive language skills. The person being assessed has to name objects, recall words and complete complex linguistic tasks such as spelling ‘world’ backwards. Therefore, the interpretation of results is difficult with individuals with aphasia and other language barriers. Pashek cites Golper’s research:

“Mental status tests were invalid for individuals with focal cortical damage, citing a concern that health care professionals inexperienced with language-impaired adults may misinterpret the low scores of individuals with aphasia.”¹³⁹

In summary, cognitive tests such as MMSE have an uncertain value for assessing capacity to consent to treatment,⁷⁶ especially for anyone living with a language barrier, and by extension would be inappropriate for the evaluation of capacity to make an admission decision to Long-Term Care.

2.4.4 Barriers to Capacity Assessments

1) Environmental Issues and Performance Variation

Numerous factors can affect performance in capacity assessments, for example, lack of motivation, inattention, mistrust, or a misunderstanding of expectations.⁸¹ Different environmental issues can affect decision-making abilities, such as medications that cause drowsiness, and physical, visual and auditory distractions in hospital settings affecting attention and performance.⁹⁵ These issues influence the patient’s ability to attend and respond appropriately, and ultimately can affect the determination of capacity.⁸¹
2) Cultural Variations and Capacity Assessments
The roles of culture and religion play an important part in capacity assessments. Patients frequently live in a cultural context that is different from the evaluator. Diverse social and cultural norms, especially around the issues of health and care-giving, could affect the results of an assessment calling into question the validity of the determination of capacity. Consequently, the questions contained in the CMAD questionnaire must be modified for each patient and his or her unique circumstances.

3) Activities of Daily Living and Capacity Assessment
If a medical condition such as stroke causes a loss of independence in mobility, Activities of Daily Living and Instrumental Activities of Daily Living (ADL), the patient becomes vulnerable with regard to decisional capacity and autonomy. Some professionals and family members equate a loss of independence with a loss of the ability to make decisions regarding medical treatment and discharge destination. If capacity is determined on a ‘best interests’ basis rather than an evaluation, then the patient’s rights have been violated and a subsequent admission to a care facility is illegal.

4) Decision Making Process and Capacity
The process of making a decision is frequently complex and can be approached in a variety of different ways. There is, for example, an observed difference between age groups and medical decision-making. Older patients rely more on the physician and his or her advice about what to do. They also tend to ask fewer questions; even if they need clarification. This behaviour could adversely affect the results of a capacity assessment. One study evaluated people with Mild Cognitive Impairment (MCI) where executive functioning and information processing were strongly correlated to understanding. If participants were given more time to process the information they performed better in the decision-making. Also, it is important for the evaluator to examine the process of how a patient arrives at a decision.

5) Stress and Cognition, the Effects on Capacity
Attention, especially selective attention, plays an important role in memory processing.\(^9^8\) How we encode and remember information is dependent on the degree of attention that is paid to the activity. Stressful situations, such as a capacity evaluation with its life altering consequences, can affect attention, memory and recall abilities. The stress response induces the secretion of glucocorticoids. This hormone can adversely affect hippocampal function and consequently attention and short-term memory.\(^9^8\) These two cognitive processes are essential to complete a capacity evaluation. Elevated corticosteroid levels can also produce detrimental effects on declarative memory retrieval.\(^9^9\) Chronic exposure to the negative effects of stress can exert changes in mood and increase anxiety\(^9^9\) which in turn can affect understanding and information retrieval. With capacity evaluation effective recall of information is so important to show that you understand relevant information and appreciate the consequences of a decision and thereby has capacity.

### 2.4.5 Capacity Assessments and People with Communication Barriers

Communication barriers arise from one or more of the following problems: being able to accurately hear the message, deficits in language comprehension and processing, difficulty selecting the appropriate words and putting words into a meaningful utterance, or producing utterances clearly enough to be intelligible to the listener. There are numerous elements of capacity assessment or evaluation that are challenging to those living with one or more communication barriers. ACE requires the administrator to ask open-ended questions to elicit a response that confirms the information has been understood.\(^8^2\) Using this question format is difficult for people with aphasia and ESL.\(^4\) These individuals frequently know what they want to say, but are less able to retrieve the words or construct a sentence to get their message across.\(^6^7\) Adding stress to the mix exacerbates the problem for people living with aphasia and ESL, since stressful situations interferes with word recall.\(^9^8\)

The ability to show that a person appreciates the consequences of a decision can be difficult to establish.\(^7^6\) ‘Appreciation’ is not only related to insight, but also to the cognitive concepts of verbal fluency, attention and conceptualization.\(^7^5\) Aphasia, dysarthria and ESL can affect verbal fluency and the ability to express concepts. The
speed of information processing needs to be considered, and more time given to people to respond.\textsuperscript{97} This is important for those with a hearing loss as they have to piece the message together from what they have heard. Jefferson et al. discuss the benefits of interventional strategies such as corrective feedback and repetition of information; however, these strategies have yet to be studied.\textsuperscript{97}

Tunzi, in his paper on physicians administering capacity assessments, points out that those patients with significant cultural and language barriers and with low literacy are at an increased risk for impaired decision making. He goes on to point out that a lack of ability in these areas (language) does not necessarily preclude the ability to understand and make a decision.\textsuperscript{100}

The use of professional interpreters is the ‘gold standard’ in the evaluation of capacity for individuals who do not speak the prevailing language.\textsuperscript{101} They are usually impartial, have knowledge of the patient’s culture and customs, and follow policies regarding patient confidentiality. In reality, the use of ad hoc interpreters is a common practice in healthcare.\textsuperscript{101} Frequent use of family members not only compromises family dynamics and patient confidentiality but also can interfere with the accuracy of information.

“The most important ethical principle of patient information is the autonomy of the patient consisting of free will, the ability to communicate, speak and make decisions, as a precondition for informed consent”.\textsuperscript{101} p207

A similar situation exists for people with aphasia.\textsuperscript{102} Not only do skilled conversational partners (capacity evaluators) enhance communication success and increase the opportunity of an accurate assessment, but conversely, unskilled conversational partners can compromise effective and meaningful communication with individuals with aphasia.\textsuperscript{102} As stated earlier, the evaluator is obligated to modify the capacity evaluation questions to meet the patient’s unique circumstances.

“The CCB has consistently held that asking the 5 questions in the “Consent to Make Admission Decisions” is not sufficient for the finding of incapacity”.\textsuperscript{77} p.8
In a meta-analysis study of the incidence of stroke and depression, two-thirds of patients with aphasia met DSM-III-R criteria for depression in the first year after stroke. This was significantly greater than for those without aphasia.\textsuperscript{103} Both depression and anxiety are common mood disorders that accompany stroke. The identification and treatment of these disorders is essential as both can interfere with rehabilitation and recovery as the patient can become amotivational, excessively fatigued and can begin to lose hope.\textsuperscript{103} Just as depression and anxiety can adversely affect rehabilitation and recovery, they can also affect performance in capacity evaluations.

2.4.6. Capacity Assessment and Evaluation - Summary

Capacity and consent should be viewed within the framework of established medical ethical principles including autonomy, respect for autonomy, beneficence, non-malfience and justice.\textsuperscript{2} To seek informed consent for medical treatment, to participate in research or for a discharge destination is both a legal and ethical obligation.\textsuperscript{2} Capacity assessment is a complex process involving medical knowledge, clinical assessments, ethics and the law. Assessments should be interactive, and change depending on the patient’s context; consequently a test score alone cannot substitute a professional clinical judgment.\textsuperscript{75} Capacity assessment tools do not by themselves constitute a determination of competency. They should be considered as one part of the assessment. Specifically, the different instruments attempt to quantify functional abilities that are relevant to competence.\textsuperscript{81} As Rosin and van Dijk point out:

\textit{“Competence is not a unitary concept: there are multiple competencies, and the assessment must be fitted to the particular area in which competence is required” .}\textsuperscript{96} p.17

Capacity assessments are ultimately human judgments occurring in a specific context, combined with the patient’s situation, culture and values. Professional clinical judgments should be considered as important as test scores:

\textit{“The effects of multiple interacting medical conditions on decision making abilities vary across individuals, affecting some aspects of}
Returning to the ethical principles of justice and autonomy, it is essential that the capacity evaluation process be opened up to people living with communication barriers. A communicatively accessible process will better ensure that such individuals have the opportunity to demonstrate that they have the ability to understand and appreciate the reasonably foreseeable consequences of a decision regarding where and how they will live. The need for this is made more compelling when considering the prevalence of communication barriers in healthcare and multi-ethnic societies as discussed earlier in the chapter.

2.5 Capacity Evaluator Education

2.5.1 Role of a Social Worker

Social workers are currently the health care professionals who most frequently administer capacity evaluations in the Ontario hospital system. According to the Canadian and Ontario Associations of Social Work Code of Ethics, social workers believe in the following:

In the value and worth of all people. That all members of society regardless of age, race, place of origin, language, religion, gender, sexual orientation or abilities deserve the same basic rights, protections, opportunities, obligations and social benefits.

This would include those living with communication barriers being accorded the same rights regarding the fair evaluation of the capacity to make admission decisions.

In Ontario a large part of the hospital social worker’s role is case management, also known as discharge planning. The Canadian Association of Discharge Planning and Continuity of Care: Guidelines and Standards for Discharge Planning Coordinators states that social workers, in their role of case managers, should assess and identify potential discharge issues from the moment a patient is admitted to hospital or a specialized facility such as a rehabilitation unit. If a timely and successful discharge is to occur, collaboration
with the healthcare team, which includes the patient and family, is essential. A significant component of case management concerns the decision to be discharged home or to another living environment such as a long-term care home.

### 2.5.2 Training in Capacity Evaluations

As reported earlier in this literature review, the Ministry of Health and Long-Term Care does not require formal training for capacity evaluation. However, the findings from the Consent and Capacity Board appeals outlined in the previous section, ‘Capacity Evaluation and the Law’, clearly show that ongoing education for healthcare practitioners in the legal requirements of capacity evaluation is warranted.

The Community Care Access Centres (CCAC) in Ontario are the gatekeepers of the long-term care admission process, every admission has to go through them. CCAC needs evidence from the hospital or community case manager/discharge planner that the patient is either capable to make an admission decision, or that the decision has been made by a substitute decision maker. A search of the CCAC website revealed that different areas in the province are developing their own evaluation training and approaches based on different philosophies. One area has used the expertise and research of a geriatrician specializing in dementias, while another area has focused on garnering knowledge and input from lawyers specializing in Elder Law. The latter training manual includes information on potential communication barriers, but does not provide education or information on how to overcome those barriers. Both approaches are meritorious, but could result in a lack of continuity in capacity evaluation Province wide.

### 2.5.3 Social Work Education in Specialized Communication Skills

A search was conducted to establish what communication skills are taught to social work students in order to interact with specific populations, for example, individuals living with aphasia or who speak ESL. The data bases used were: Medline, Psych Info, Sociological Abstracts, ERIC and Scholar’s Portal. The terms selected for the search comprised: social work, education, communication, aphasia, English as a Second Language (ESL) and communication disorders. There was a dearth of studies or research
on social work and communication disorders; and what there was primarily related to the service of children with special needs such as autism.

Trevithick’s extensive review of the literature on the learning and teaching of communication skills in social work education emphasized the need for more research in this area. The Social Care Institute for Excellence commissioned the review in collaboration with the Social Work and Social Policy Learning and Teaching Support Network. This initiative was carried out in the United Kingdom, however much of the literature included was from North America. The review found the greatest educational need to be in the area of learning specific communication strategies in order to interact with people with communication disorders. Different forms of social work intervention necessitate more relevant communication skills training. But for this to be successful, research has to first take place into the communicative needs and experiences of patients, families and social workers themselves. Providing counseling and case management to patients with aphasia is an example of a population that requires specialized communication training.

Dinham also reviewed the teaching and learning of communication skills for social workers. The distinction between core, specific and technical communication skills is discussed in his review. Examples of ‘specific’ skills training would include working with interpreters for patients who do not speak the language of the social worker, or working with sign language interpreters for deaf patients and clients. Dinham stresses that there is a need to learn ‘technical’ communication skills so as to promote communication with groups with particular needs. The author goes on to highlight the current debate in social work education; that is what constitutes core, specific or technical communication skills; and at what level should more specific skills be taught; for example, at the university level or when working with specific populations post qualification.

2.5.4 Bi-lingual Social Work Education

Healthcare and social service organizations are trying to reduce cultural and communication barriers and to increase cultural competency and cross-cultural
education. The study of the experiences of bi-lingual social work students in their clinical placements was carried out by Engstrom. The results of a survey administered to bi-lingual social work students after completion of their clinical practicum showed the following: almost all bilingual MSW students reported having clients who spoke little English in their caseloads. These proved to be more complicated cases, took more time, and required more work than English-speaking clients. Also, the bi-lingual students reported that they received little to no training in how to work with such clients and how best to communicate professional language to them.

The bi-lingual students used a non-English language in everyday situations. However, it is an entirely different skill set to ensure that clients comprehend the meaning of health and social services terminology. An unspoken assumption appeared to be that bi-lingual students would intuitively know how to translate professional terminology into another language and then be able to use colloquial terms to ensure that their clients understood the issue at hand. One qualitative comment summed up the dilemma:

"The most difficult aspect of working with LEP clients was finding the correct terminology for therapeutic terms in the second language." 

The authors concluded that more research was needed in the field of bi-lingual social work service to provide the students with the skills and language to communicate effectively with patients and clients ensuring that their needs are fully met in their language of choice.

2.5.5 Current Social Work Communication Education

Given the lack of published research in the area of communication training for social workers, Rowland and McDonald carried out a web search of university social work programmes to examine whether acquired communication disorders and strategies to overcome the barriers were being addressed as part of the curriculum. The search was conducted on 17 university social work programmes in Canada and three programmes in the United Kingdom, examining both the undergraduate and graduate syllabi. Seven departments were contacted directly to explore the issues of providing service to this
particular population. The results are as follows:

- No programmes dealt with communication disorders *per se*. Some of the challenges were discussed in courses such as bio-psychosocial understanding of behaviour and functioning, (dis)ability, aging, research seminars or as concerns arising in practicum seminars.
- Issues faced by those for whom English is a second language were covered in courses on cross cultural issues, research seminars, diversity and oppression. Different cultural communication styles, including the importance non-verbal communication, were not covered.
- Hearing loss and the deaf culture were addressed by a minority of universities within courses focusing on (dis)ability and critical disabilities.
- Communication disorders arising from stroke and progressive neurological disorders such as multiple sclerosis, Parkinson’s disease and amyotrophic lateral sclerosis were covered in presentations, but only if the faculty member had a particular interest or expertise in that area.\(^4\)

The Social Work departments contacted directly agreed that providing social work students with the skills to interact with patients or clients living with communication barriers was important. However, there were barriers to the inclusion of a specific course:

- Competing requests for new courses, sometimes determined by government departments as the changing needs of the population need to be met.
- Specialization versus generalization. Faculties are striving to include the core subjects. Some faculty members contacted believed a course in communication barriers and specific conversation skills was too specialized.
- Financial. The expense of designing and teaching a new course.\(^4\)

Some possible solutions to teaching social work students specialized communication skills were generated by the university faculty interviewed; for example, creating an elective course that is offered to a number of different departments, such as social work, psychology, nursing and the recently developing field of disability. Also, practical training seminars could be developed, focusing on communication skills for interacting
with individuals with communication barriers. These seminars could be included in ‘practicum’ preparation courses and courses on disability. Finally, over half of the universities surveyed had continuing education programmes that are open to current students and to graduates, it was suggested that this would be an appropriate venue to teach such a course.\(^4\) The bottom line is that social workers are regularly interacting with, and evaluating the capacity of individuals with complex communication barriers largely without the support of specialized communication training.

### 2.5.6 Social Work Counseling Communication Education

It must be stated that many of the counseling communication skills that are currently taught in social work programmes are beneficial to patients with communication barriers.\(^4\) The strengths approach as described by Benard is one such example. By its very nature it acknowledges the person’s strengths.\(^1\) Social workers provide patients or clients with opportunities for real participation that includes problem solving and making decisions. Through this method individuals develop a sense of their own control and self-determination, which are known agents against anxiety and depression.\(^56,112\) This approach can easily be transferred to interacting with and advocating for people with communication barriers. The positive effects of acknowledging competence, of recognizing that an individual with a communication barrier knows more than he or she can say has been well documented.\(^116\)

Empathic communication is the ability to perceive the inner feelings of patients and reflect the feelings of the patient’s inner experience with accuracy and sensitivity.\(^113\) Social workers are taught to look at the whole person, reading body language as well as listening to the message. Paying close attention to a patient’s non-verbal communication, especially when he or she cannot articulate precisely what he or she wants to say, and reflecting back those feelings, is an immensely positive counseling technique made all the more powerful because of communicative success.\(^4\)

Adapting language and speaking in terms that patients and clients understand is another communication skill that is beneficial to those for whom language is a challenge. One of
the functions of social work education is to teach students the ability to understand various professional terms and then be able to communicate the meaning of those terms in everyday language. However, these skills have to be developed further when communicating with people with aphasia or ESL.

**Counter-productive Social Work Communication Skills**

Rowland and McDonald in their evaluation of Social Work communication skills revealed that some of the communication and counseling skills specifically taught to students are counter productive to interacting with patients and clients living with communication barriers. These include asking open-ended questions to draw out more relevant information, paraphrasing when not sure of the message, using complex vocabulary to reflect the degree of emotion felt by the patient or client, and not making assumptions. When communicating with this challenging population it is important to be direct, concrete, ask closed-questions at times and to verbalize assumptions made through close observation of person.

**2.5.7 Speech-Language Pathology Training – Capacity Evaluations**

Speech-language pathologists (S-LP) are the healthcare professionals that would appear to be the most appropriate healthcare professionals to evaluate capacity in this challenging population. The S-LP is educated in working with different communication disorders, and has the advantage of multiple visits in the course of the participant’s rehabilitation. Such a relationship allows for better understanding of the patient as a person and whether capacity responses are consistent with what is known of the patient. A patient should not be excluded from the decision-making process based on the diagnosis of a communication disorder. Sometimes all that is required is repetition, time to process information or the use of supported conversation techniques such as writing words or using pictures.

Ontario’s Health Care Consent Act allows for registered members of the College of Audiologists and Speech-Language Pathologists (CASLPO) to evaluate the capacity of a patient or client making a decision regarding discharge destination. Regrettably this is not
widely known either within the profession or outside. Following ethics approval, this researcher conducted an on-line survey with S-LPs who provide service to adults across the continuum of healthcare. Two questions were asked:

1) Did you know that according to the Health Care Consent Act Speech Language Pathologists can evaluate a patient’s capacity to make admission decisions?

2) Have you ever completed a ‘Capacity to make Admission Decisions’ evaluation either on your own or with another professional?

A total of 75 S-LPs providing service to adults with acquired communication deficits from different regions in Ontario responded. The results showed that 61 (81%) respondents did not know that as registered members of CASLPO they are able to evaluate capacity. Of the 14 (19%) of respondents who were aware of their role as an evaluator, only 5 had administered a capacity evaluation independently and 8 (11%) had carried out an evaluation with a social worker. Finally, only 6 (8%) speech-language pathologists had received formal training in the capacity evaluation process from a bioethicist.

2.5.8 Capacity Evaluation Education - Summary

The overriding message from the literature review is that more research is needed in the area of teaching social workers specific communication skills to meet the psycho-social needs of people living with communication barriers. With regard to providing service to patients for whom English is a second language, researchers advocate for university social work programmes to prepare social workers to deliver a culturally competent service. By examining the curriculum and clinical placement needs of bilingual students, schools will be better able to educate culturally and linguistically competent social workers. The principles of consent and capacity are rarely taught in many healthcare training programmes. It is assumed that these skills will be learned during externships or in the work environment. Unfortunately, it would seem from the survey of speech-language pathologists that this is not the case. A significant amount of education needs to take place regarding the law, how to administer a capacity evaluation
to people with communication barriers, and who is eligible to carry out these evaluations.\textsuperscript{67}

\section*{2.6 Literature Review Summary}

The issues that arose from the Case Study in the introduction led this researcher to explore the prevalence of individuals living with communication barriers, and the current law, practice and education regarding capacity evaluation in Ontario. The results of this review show that there is no specific capacity evaluation tool that takes into account the communication needs of people living with language, speech and hearing barriers. The ability to reveal their competence to make a decision whether or not to go to long-term care is frequently compromised. This omission in the field of consent and capacity strongly supports the need to develop a communicatively accessible capacity evaluation process for the surprisingly large numbers of people who live life with a communication barrier. The second factor that emerged is the inconsistent approach to capacity evaluation training in the Province, and the lack of education for evaluators in how to communicate effectively with this specific group of people. A communicatively accessible evaluation system combined with training that includes the legal obligations of the evaluator as well as specific communication techniques will better protect the rights to autonomy in this vulnerable population.
Chapter 3 Development of the Communication Aid to Capacity Evaluation – Methods and Results

3.1 Chapter Overview
The results of the literature review revealed a compelling need for a communicatively accessible capacity evaluation process with an accompanying training in specialized communication techniques. This chapter focuses on the following: a critical appraisal of the current evaluation process, the methodology of developing an accessible capacity evaluation process with training, procedures to ensure the tool’s validity including a face and content validity study and external expert review, and finally, the introduction of the adapted evaluation tool with the accompanying DVD training.

3.2. Critical Appraisal of the Current Capacity Evaluation Process

3.2.1 Limitations of Current Capacity Evaluation Tools
In Ontario, the Ministry of Health and Long Term Care requires all individuals for whom long-term care is an option to be evaluated using the Capacity to Make Admission Decisions (CMAD) questionnaire (see appendix 1). The questionnaire should trigger questions that explore the patient’s context and environment. The Placement Aid to Capacity Evaluation (PACE) (see appendix 2) goes into more depth by providing the evaluator with an extensive list of questions and prompts. Both CMAD and PACE rely on the individual having sufficient language and conversational skills to reveal capacity. Neither tool provides communication support in the form of written text or pictures to augment understanding and expressive communication. Also, the majority of the evaluators come from social work and nursing and do not routinely have the specialized skills needed to communicate with people with aphasia or dysarthria. Finally, neither tool has been subjected to psychometric evaluation or effectiveness studies, rendering their reliability and validity unknown.

3.2.2 Requirements of the Health Care Consent Act
The Health Care Consent Act clearly lays out the process for evaluating capacity to make an admission decision to a care facility. The following legal tenets must be part of every evaluation process:

1) Explanation of why the capacity evaluation is being administered
2) Explanation of the capacity evaluation process
3) Presumption of capacity
4) Consent to be evaluated
5) Explanation of a finding of incapacity
6) Rights advice to appeal a finding of incapacity
7) Information on the Substitute Decision Maker, Consent and Capacity Board and the Office of the Public Guardian and Trustee.

The current evaluation process does not help the evaluator to explain these complex legal tenets, and there is no format to elicit vital information non-verbally such as the consent to evaluate. These omissions have the potential to render subsequent determinations of capacity invalid and illegal.

3.2.3 Evaluator Focus Groups to Review the Current Capacity Evaluation Process

Focus groups are an efficient way to explore people’s knowledge and experience regarding a research topic. The communicative interactions between group members generates a rich corpus of data and the interactive nature allows for examination of how and why people think in a certain way. The first stage in this approach is to develop questions that guide the research but are not too confining. The goal is to elicit detailed, objective material that can be analyzed through a process of steps. After reading and re-reading the transcripts, common themes and patterns are identified and tentative linkages are developed between the theoretical concepts and the data. The data is then reduced to form key categories, and put into a matrix or table. The researcher then draws conclusions and considers their implications. The final stage equates to ‘validity’ in quantitative research methods. The conclusions are tested to see if they are credible, defensible and warranted, and able to withstand alternative explanations.
Two focus groups were formed (following Research Ethic’s approval) to examine the issues surrounding the current capacity evaluation process from the evaluator’s perspective. The goal was to identify specific barriers and elements that worked when administering the CMAD questionnaire to individuals with communication barriers. It was hoped that the results would help determine the key areas that needed to be changed in the adaptation of the current questionnaire. The data generated was analysed using a qualitative research methodology.

Focus group selection was purposive in order to recruit social workers with the insight and interest in discussing the following open-ended research questions: What barriers do you face when administering the ‘Capacity to Make Admission Decisions’ to people with aphasia? How do you ensure that people with communication barriers understand information and appreciate the reasonably foreseeable consequences of a decision? What parts of the capacity evaluation work well? What would you change to help evaluate capacity with people with communication barriers?

The two groups comprised social workers providing service to a 1206 bed teaching hospital in a large metropolitan area and a Complex Continuing Care - Rehabilitation hospital in a medium sized urban area. There were four members in each group. The sessions were digitally recorded and later transcribed. The data was read, re-read and coded according to subject theme, such as, patient’s comprehension, insufficient time, and lack of communication education. Themes were linked to form three coherent categories that brought meaning to the data.

The first category was ‘Communication Difficulties’. This included the social worker’s lack of knowledge as to whether the patient understood the process, problems with communicating and using communicative supports:

“They (S-LPs) often have wonderfully creative ideas of getting information from those patients or resources like picture cards, but I never really know how to use it properly” \textit{focus group member}.
The social workers reported that they did not have the specific skills to communicate effectively and verify whether or not the person with aphasia understood the evaluation process or questions. The evaluator was in a quandary; did the patient not understand because of the aphasia, or because of a lack of capacity? The focus group members stated that they needed both the communication tools and training in how to use them in order to decipher the cause of an apparent lack of understanding.

The second category was ‘Confidence’. The focus group members expressed a lack of confidence in the evaluation process and in their abilities to determine capacity: “I went back four times I was so unsure about my decision.” “I always feel nervous, self-doubting and under pressure.” focus group members. The lack of confidence could be related to a lack of knowledge in how to communicate effectively with the patient with aphasia. A common fear of health care professionals working with this population is that they will not be able to understand the message communicated by the patient with aphasia or dysarthria (unclear speech). Many professional speech-language pathology organizations (Canadian Association of Speech-Language Pathologists and Audiologists CASLPA and ASHA,) exhort healthcare professionals not to pretend to understand, or abandon a conversation. They encourage healthcare professionals to be honest and admit when they have not understood the patient or client, and help the individual to get his or her message across by another means. Confidence in the determination of capacity is essential. The evaluator must be sure of his or her decision to preserve or take away the patient’s rights to decide where to live.

‘Procedural Dissatisfaction’ or frustration with the current capacity tool itself was the final category. Reported problems included the wording, repetitive nature of the questions, and questions not asked, “the way the questions are worded, um, the language at times isn’t user friendly and I struggle with it.” focus group member. The group discussed solutions such as the addition of pictures, but stressed that they needed education on how to use the pictures effectively: “What I would be looking for is more specific tools related to just the capacity assessment with questions that are more focused that they could answer appropriately.” focus group member.
In summary, the analysis of data arising from the focus groups showed that, according to the social workers, the current capacity evaluation process was not working with this population. The inaccessible nature of the capacity evaluation tool itself and the lack of education in how to understand and communicate with individuals with aphasia resulted in a lack of confidence in the determination of capacity. The conclusion drawn was that a communicatively accessible tool to evaluate capacity needed to be developed. The tool should be simple to use, and include a training module to teach techniques on how to communicate more effectively with individuals with aphasia and other communication barriers. The use of an accessible tool with communication training would hopefully increase the evaluator’s confidence in the determination of capacity.

3.3 Development of an Accessible Capacity Evaluation Tool - Methodology
This researcher set out to adapt the current Capacity to Make Admission Decisions (CMAD) questionnaire making it communicatively accessible. Legislation from the Health Care Consent Act was integrated, as were the key themes resulting from the focus groups. Many of the questions and prompts from PACE were also included.

3.3.1 Strategies to Increase Communication Accessibility
The following methods to promote communication accessibility are well established in the literature,\textsuperscript{119,120} and were used to develop the first draft of the tool:
- Reduced complexity of the language
- Enlarged size of font
- Sentences changed to the present tense
- The use of active rather than passive voice
- Reduced length of sentences
- Concrete, frequently occurring vocabulary that was easy to understand
- No contractions permitted
- Key words selected that carry meaning and were highlighted in bold font
- Pictographs chosen to illustrate different concepts
- Gender neutral pictographs that were culturally representative and age balanced
3.3.2 Working Groups to develop an Accessible Capacity Evaluation Tool

An attempt was made to recruit the most appropriate stakeholders who could review drafts of the capacity evaluation tool and make recommendations for change. Following Research Ethics approval, three working groups were formed comprised of social workers, speech-language pathologists and members of a community aphasia program. Each group brought their professional training and life experience to the process. All members signed informed consent documentation. The consent information for the working group of people with aphasia was in a communicatively accessible format. The initial draft of the adapted version was given to the three working groups who reviewed the contents and suggested amendments.

Speech-Language Pathology Working Group

This group included five Speech-Language Pathologists (S-LPs) who worked with adults with acquired speech, language and communication deficits across the healthcare continuum. Three members had been trained in Supported Conversation for Adults with Aphasia (SCA™), and one member had given evidence to the Consent and Capacity Board. The group reviewed and changed the first draft focusing on the above-mentioned methods to increase communication accessibility.

It was immediately apparent that comprehensive instructions on how best to administer the evaluation were needed. The group also agreed with the recommendations arising from the literature review and the focus groups that evaluators needed training on how to communicate effectively with this population. The working group met on five occasions, twice on an individual basis and three times with the social work group.

Social Work Working Group

This group comprised four social workers who provided service at different stages across the healthcare continuum. Three were familiar with the CMAD questionnaire. The fourth member worked exclusively with individuals with aphasia who attended a community
programme at the Aphasia Institute in Toronto. One of the members was a co-author of PACE, and another was the co-author of a capacity evaluation training program. The purpose of this group was to critically evaluate the initial drafts of capacity evaluation tool. They focused on ease of administration and determination of capacity, and ensured that given choices were not leading. As with all the groups, there was an ongoing role of evaluation and incorporation of recommendations made by the other working groups. The group met on five occasions, twice on an individual basis and three times with the speech-language pathology group.

**Individuals with Aphasia Working Group**

Four individuals with different types and severities of aphasia and dysarthria agreed to participate in this working group. These members, who attended a community aphasia group in Niagara, were the true experts in living with aphasia. They were asked to evaluate the capacity evaluation tool focusing on the following questions: Did you understand the introduction to the capacity evaluation process? Did you understand the questions? If you were answering the questionnaire could you express your thoughts/choices? Was the text understandable? Was there too much or too little text? Were the pictures clear? Would they help you to understand? Did they help you to communicate your answer if you had to do so non-verbally? Were there too many pictures per page? What would you change? The group met on two occasions.

**3.3.3 Working Group Results**

The working groups produced a version of the capacity evaluation tool with instructions for administration. Areas of development went smoothly, but others proved to be a struggle. The adaptation of legal terms into a communicatively accessible format was lengthy and complex. The speech-language pathologists wanted to breakdown elements of the capacity process and keep the explanations short and concrete, for example, “Capacity means you understand you medical condition.” However, the social workers pointed out that to comply with the Health Care Consent Act the sentence had to be changed to “Capacity means you have **the ability** to understand your medical condition” a subtly different construct to evaluate and more information for the person with aphasia to
process. The construct ‘appreciate’ demanded much deliberation and was the subsection that changed most frequently, for example:

Draft1) Capacity also means you understand what will happen when you make a decision or don’t make a decision
Draft 3) Capacity also means that you are able to understand and appreciate the outcome when you make a decision or don’t make a decision
Draft 6) Capacity also means you are able to appreciate or realize what will happen when you make a decision or don’t make a decision.
Draft 9) Also, capacity means you understand what will happen. You appreciate the consequences when you make a decision or don’t make a decision.
Draft 12) Also, capacity means you understand what might happen. You have the ability to appreciate the consequences when you make a decision or do not make a decision.

The social work group was concerned with the concept of ‘making assumptions’. Social workers are strongly encouraged in their training not to make assumptions when interacting with their patients or clients. The groups’ preference was to use open ended questions for example, “How do you feel about living at home?” The speech-language pathologists advocated for a closed question and, after much deliberation, the social workers settled for “Do you feel safe at home?” The social workers’ point was well taken and strategies to make CACE more conversational rather than responsive were added to the Instructions for Administration.

The social workers were also concerned that the pictographic choices in CACE could be leading the patient, and that cultural and religious variations needed be acknowledged. The S-LPs again advocated for a simple and straightforward presentation because too many pictures or choices could confuse the patient. The solution lay in the inclusion of the phrase “or something else” as a potential choice. This overcame the concern that choices were leading and allowed for the expression of an alternate perspective reflecting the patient’s cultural or religious mores and customs. This solution necessitated the
evaluator to be trained in communication techniques in order to help the patient to communicate a unique choice.

The working group of people with aphasia examined the clarity and flow of the evaluation. They found choices moving from left to right easier to understand than moving from up to down. This group was insightful and raised issues that the other groups missed. When considering the question “Do you need to go to a Long Term Care Home?” a group member communicated that she did not need to go now, but might have to some time in the future. She advocated strongly that the word ‘now’ be added to the question.

3.4 Measures to Test the Validity of the Adapted Capacity Evaluation Tool
Following extensive revisions to drafts of the capacity evaluation tool, the working groups were sufficiently satisfied with the product to submit it to external review.

3.4.1 Panel of Experts Measurement of Face and Content Validity of the Adapted Capacity Evaluation Tool
The face and content validity of the adapted capacity evaluation tool needed to be assessed to ensure that it reflected the content of the CMAD questionnaire and complied with legal tenets of the Health Care Consent Act (1996). Face validity refers to conceptual validity, which means does a measure (the adapted capacity evaluation tool) appear to make sense? Content validity is a matter of expert judgement regarding the accurate representation of an entity, in other words, does the adapted tool represent the content of the original tool? Following Research Ethics approval, and with advice from this researcher’s doctoral team, a list of potential members for a panel of experts was generated.

Panel of Experts - Membership
Representation was sought from academics in the areas of communication, social work, psychology, medicine, ethics and law (see table 4). Representation was also garnered from healthcare professionals who administered capacity evaluations and worked with
people with communication barriers. Finally, efforts were made to ensure that a variety of regions within the province of Ontario were represented.

Table 4: Membership of Panel of Experts to Measure Content and Face Validity of the Adapted Capacity Evaluation Tool

<table>
<thead>
<tr>
<th>Member</th>
<th>Profession</th>
<th>Area of Expertise</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Professor of Neurology, Dept of Clinical Neurological Sciences, University of Western Ontario.</td>
<td>Aphasiologist. Director of Cognitive Neurology and Alzheimer’s Research Centre at St. Joseph's Health Care London</td>
<td>St. Joseph's Health Care London The University of Western Ontario</td>
</tr>
<tr>
<td>2</td>
<td>Philosophy Academic</td>
<td>Personal autonomy, Decision-Making Capacity and Mental Competence</td>
<td>Ryerson University Toronto</td>
</tr>
<tr>
<td>3</td>
<td>S-LP Academic. Chair of School Communication Sciences and Disorders</td>
<td>Adult and older adult neurogenic-based language, communication, and cognitive-communication disorders including dementia, aphasia, right brain injury, and traumatic brain injury</td>
<td>The University of Western Ontario</td>
</tr>
<tr>
<td>4</td>
<td>Social work Academic. Dean Faculty of Social Work</td>
<td>Recovery from trauma Workplace and secondary trauma Law and mental health Legal aspects of practice Practice competency</td>
<td>University of Toronto</td>
</tr>
<tr>
<td>5</td>
<td>Neuropsychological Academic.</td>
<td>Memory, attention, inhibitory control, and error monitoring. Aging and frontal lobe function. The relationship between physiological reactivity, cognitive function, and socially adaptive behaviour</td>
<td>Brock University</td>
</tr>
<tr>
<td>6</td>
<td>Speech-Language Pathology Academic</td>
<td>Discourse comprehension and production by adults with and without neurologically-based communication disorders.</td>
<td>Brock University</td>
</tr>
<tr>
<td>7</td>
<td>Social work Academic</td>
<td>Gerontology and clinical practice, survivors of genocide and clinical issues of post-traumatic stress disorder</td>
<td>University of Toronto</td>
</tr>
<tr>
<td>8</td>
<td>Barrister &amp; Solicitor</td>
<td>Institutional Advocate. Representation of clients in long-term care facilities, hospitals, psychiatric facilities and care homes (retirement homes) with respect to related legal issues.</td>
<td>Advocacy Centre for the Elderly., Toronto</td>
</tr>
<tr>
<td>9</td>
<td>Speech-Language Pathologist</td>
<td>Adult acquired communication disorders. In the hospital setting melding traditional therapeutic approaches with the social model of</td>
<td>Brantford General hospital. Brantford Seniors Centre</td>
</tr>
</tbody>
</table>
Panel of Experts Study Procedure

The panel was asked to review the CMAD questionnaire, the adapted capacity evaluation tool, sections of the HCCA and to complete a survey. Space was included after each survey question should a panel member have a specific comment.

Panel of Experts Survey

The survey asked whether or not the adapted tool reflected the content of the current capacity questionnaire, if it complied with points in the Health Care Consent Act and if the consent process explanation was adequate (see appendix 5). After each statement the panel members were asked to complete a five point Likert Scale indicating whether he or she: Strongly agreed, Agreed, Neither Agreed nor disagreed, Disagreed or Strongly disagreed. The following legal definitions were provided to the panel members:

CAPACITY - A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. (Health Care Consent Act 1996, c. 2, Schd. A, s. 4 (1).)
As a construct, to "understand" refers to a person's cognitive abilities to factually grasp and retain information. To the extent that a person must demonstrate understanding through communication, the ability to express oneself (verbally or through symbols or gestures) is also implied. (Capacity Assessment Office, Ministry of the Attorney General 2005)

The "appreciate" standard attempts to capture the evaluative nature of capable decision-making, and reflects the attachment of personal meaning to the facts of a given situation. (Capacity Assessment Office, Ministry of the Attorney General 2005)

Members were thanked for their participation.

Panel of Experts' Survey Results

*Table 5: Panel of Experts Face and Content Validity Survey Results*

<table>
<thead>
<tr>
<th></th>
<th>Adapted reflects original</th>
<th>Patient understands</th>
<th>Patient appreciates</th>
<th>Enhance autonomy</th>
<th>Promote communication</th>
<th>Presumed Capable</th>
<th>Understands process</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4.85</td>
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<td></td>
<td></td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4.57</td>
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<tr>
<td></td>
<td></td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4.87</td>
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<tr>
<td></td>
<td></td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>3.28</td>
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<td>3</td>
<td>5</td>
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<td>5</td>
<td>1</td>
<td>4</td>
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<td>3.57</td>
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<td>3</td>
<td>3</td>
<td>4</td>
<td>3.8</td>
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<td></td>
<td></td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Total Mean</td>
<td></td>
<td>52</td>
<td>48</td>
<td>40</td>
<td>50</td>
<td>52</td>
<td>46</td>
<td>45</td>
</tr>
</tbody>
</table>

As Table 5 shows, the statements that resulted in the highest face and content validity scoring 4.7 (5 = strongly agree) were:

- *The adapted version reflects the content of the original ‘Capacity to make Admission Decisions’*
“to promote communication and understanding between health practitioners and their patients or clients”
followed closely by;
- “to enhance the autonomy of persons for whom admission to a care facility is proposed”
scoring 4.5. The high validity ratings of these constructs were important because they confirmed that the adapted capacity evaluation tool reflected the content of the CMAD questionnaire and the Health Care Consent Act. All of the other constructs scored closer to ‘agree’ with one exception:
- The adapted version allows the evaluator to assess whether a patient appreciates the reasonably foreseeable consequences of his or her decision or lack of decision.

This construct received a score of 3.63, midway between ‘neither agree or disagree’ and ‘agree’.

Qualitative Analysis
The experience and diversity of the panel of experts provided an excellent opportunity to ask for narrative comments to augment the quantitative results of the validity survey, and broaden the review of the adapted capacity tool. The majority of panel members volunteered comments regarding the current and adapted capacity evaluations. Their perspectives represented medical, ethical, legal, cognitive, communication and psychosocial approaches to patient consent and capacity. The comments were collated and read a number of times to elicit themes and connections between themes. The resulting data served to confirm the results of the validity survey and generated recommendations for change. The following themes included:

1) CACE Format
It was noted that some of the issues highlighted by the panel of experts were also important to the working groups, for example, detailed instructions for administration:
“I think that your “chart review and team consultation” page is excellent and will cue evaluators to gather appropriate information in a way they probably haven’t thought of before. In addition, your “how to administer” instructions should facilitate communication.” panel member

One member reported: “I liked that you included “Don’t know” to most questions, as that is a common response.” This option should help the evaluator to establish whether the individual being evaluated truly understands a question, rather than the communication barrier masking comprehension. Two panel members brought up the issue of the pictographs, questioning whether there were too many on some pages. One member suggested, “I’d like to see them ‘road tested’” which had in fact occurred with the working group of people with aphasia. As a result of the comment, the communication technique of covering some of the pictures to enhance visual and language processing was explicitly explained in the Instructions for Administration and in the training DVD. Another panel member urged consistent lay out and wording. The adapted tool was re-examined and changes were made to ensure consistency.

2) Need for Unique Probing in Capacity Evaluation Tools

The need to take each individual’s unique circumstances and context into consideration was one of the themes:

“In my view no form can guarantee a correct judgment about decisional capacity simply because the holistic nature of human thought may require follow-up questions which cannot be fully anticipated (neither version of the forms gives guidance about this).” panel member

This point corroborated the need for training in specialized communication techniques to allow both the evaluator and the individual with aphasia to elaborate on unique information. The evaluator needs to be encouraged not to use CACE prescriptively, but to depart from it to gather extra information when required to determine capacity.

3) Need for Training in Specialized Communication Techniques

In their comments, two panel members focused on the communication-training component contained in the Instructions for Administration, but from different
perspectives. One member felt that this was an opportunity to educate evaluators on the inherent competence of people with aphasia: “Exposure to training on and use of the tool will help to educate evaluators that many people “know more than they can say” and that ability to speak does not reflect intelligence.” panel member. This is an important area of education as many healthcare professionals are under the assumption that aphasia equates to a cognitive disorder affecting intelligence. The second comment concerned the specific need to learn communication strategies:

“My only hesitation here is that evaluators with less training and experience working with people who have aphasia may still not recognize the importance of using adequate supports for comprehension, especially with fluent or severe aphasia.” panel member

This comment confirmed the data arising from the focus groups and the working groups regarding the need for communication training to accompany the accessible tool to ensure a thorough evaluation of capacity.

4) Recommendations for the Use of an Adapted Capacity Evaluation Tool
One panel member raised a thought provoking point regarding the inappropriate use of the adapted tool with different patient populations:

“I think this tool will enhance the autonomy of many people. My only concern was with respect to the instructions – whether the tool should be limited- and not used where there would be other better modes of communication - just because it was easier.” panel member

During the development process, the social work group commented that an adapted tool would be beneficial for those with mild cognitive deficits. This opinion was at odds with the panel member. This issue was out of this researcher’s realm of practice. The effectiveness of the adapted tool would be tested with people with communication barriers. If, after testing, it proved to be effective, and used as a capacity evaluation tool, healthcare professionals should realize that its effectiveness had not been tested on any other populations.
Panel of Experts – Discussion of Results

The Panel of Expert’s survey results demonstrated one area of concern, the construct regarding the ability to appreciate the consequences of a decision or lack of decision. It reflected the literature concerning the dilemma of how to measure the ability “to appreciate consequences”.\textsuperscript{76,97} Karlawish found participants in his study scored lower when explicitly measuring ‘appreciation’ in comparison to ‘understanding information’. He discussed what was required to measure ‘appreciate’; the participant must understand and accept facts, and relate them to his or her own situation.\textsuperscript{76} The individual being evaluated also needed to provide some plausible explanation of why a decision would or would not benefit him or her. Karlawish’s research found that this required the cognitive construct of ‘insight’.\textsuperscript{76} Three scenarios were included in the adapted evaluation tool that specifically examined ‘insight’:

- What would you do if you fell in the bathroom?
- What would you do if there were a fire in your house?
- What would you do if you became ill?

To improve the measurement of ‘appreciate’ in the adapted capacity version, the wording was changed to require the individual to reflect on their present situation while answering the three questions.

In summary, the panel of experts agreed that adapted capacity evaluation tool reflected the content of the current capacity evaluation questionnaire and encompassed the legal requirements contained in the HCCA. The panel’s comments highlighted some important issues that needed to be addressed, for example the unique circumstances of an individual. This would require the evaluator to be trained in specific communication techniques that would allow for novel conversations to take place.

3.4.2 Results of External Reviews of the Adapted Capacity Evaluation Tool

The three working groups reviewed the recommendations from the Panel of Experts, and the majority of the suggestions were incorporated into the evaluation tool, either in the instructions for administration, the training DVD or in the capacity evaluation itself. The
doctoral committee reviewed the subsequent draft of the adapted capacity evaluation tool. It was then presented to the Advocacy Centre for the Elderly who specialize in elder law issues including capacity evaluation, and to the Consent and Capacity Board of Ontario (CCB). These reviewers focused on the legal aspects of the evaluation tool. The most significant changes made by the CCB concerned the law regarding Substitute Decision Makers (SDM) and the Public Guardian and Trustee (see appendix 4). Changes included the wording surrounding the existence of a SDM. By law, every citizen has a SDM, even if it has to be a public guardian. Following the final reviews the adapted tool entitled the Communication Aid to Capacity Evaluation (CACE) was ready to be tested to determine if it was an effective capacity evaluation tool when used with people with aphasia and other communication barriers.

3.5 Results - Communication Aid to Capacity Evaluation (CACE)

CACE includes the following sections (see appendix 3):

1. Instructions for administration of CACE
2. Information on specialized communication techniques
3. Response cards and addendums explaining legal concepts
4. Explanation of the capacity evaluation process
5. Consent to evaluate capacity
6. Orientation of person, place and time
7. CACE capacity evaluation questions
8. Scoring form and instructions

1) Instructions for Administration of CACE

Wahl advocates for a fair capacity evaluation process by considering each patient’s context and knowledge of medical issues, treatment and the system. To that end, the first recommendation in CACE is a thorough chart review and consultation with the healthcare team. The focus is on gathering information about different communication barriers, and medical, psychosocial and emotional issues which could interfere with a fair evaluation. Evaluators are prompted to consider both the best time of day for the patient
or client, and for themselves. People with aphasia and other communication barriers need time to process language, and their barrier precludes them from giving quick responses. CACE, as well as any thorough capacity evaluation, requires time to administer.

Patients or clients with stroke or traumatic brain injuries frequently have difficulties with attention. If the patient is visually, auditorily or physically distracted he or she will not be able to process given information and formulate a response effectively. Consequently, the evaluation environment needs to be taken into consideration. Strategies to adapt the process to the patient’s context are included in the subsection ‘How to Administer CACE’. CACE provides the evaluator opportunities to personalize the evaluation and offers different levels of communication support according to the patient’s needs. Tips are provided to maximize communication and focus such as: close observation of the patient’s non-verbal behaviours, allowing extra response time, covering some pictures on the page, and adapting language to promote comprehension. Finally, commonsense reminders are provided such as making sure the patient is wearing the correct glasses and a working hearing aid, paper and markers are available and that there is practice time before the evaluation for using a communication device.

2) Information on Specialized Communication Techniques
Supported Conversation for Adults with Aphasia (SCATM)116 is a series of techniques proven to be effective when communicating with people with aphasia and other communication barriers. An abbreviated version has been included in CACE. The SCATM techniques focus on interaction, that is developing and maintaining a relationship and trust between the evaluator and the patient, and transaction, getting information in, allowing the patient to get information out, and verifying information. The training DVD focuses on these skills and uses examples of an evaluator interacting with a person with aphasia to illustrate each technique. Effective communication can help reveal competency116 by ensuring that the person being evaluated understands the relevant information and has a method of showing that he or she appreciates the consequences of a decision.
3) Response Cards for the Person with Aphasia, and CACE Legal Addendums
CACE includes cards for the patients’ and evaluators’ use. They include “YES/NO/DO NOT KNOW” and “STOP, I HAVE A QUESTION/COMMENT” cards (see appendix 3). The addendums contain more in-depth information on three legal entities should the patient with aphasia request further clarification; the Substitute Decision Maker, the Consent and Capacity Board and the Office of the Public Guardian and Trustee (see appendix 4).

4) Explanation of the Capacity Evaluation Process
The Health Care Consent Act outlines requirements for a legal capacity evaluation. These include an explanation of why the capacity evaluation is taking place, the presumption of capacity, what is meant by capacity, the consequences of being found lacking capacity, and the process of appeal. The explanation of the evaluation process makes up one third of CACE.

5) Consent to Evaluate Capacity
The patient is informed that he or she has the right to refuse to answer any questions during the capacity evaluation process. The patient is also given the opportunity to ask questions before consent to evaluate is sought. Consent to evaluate is as follows; “Can I ask you the questions now? Tell me or show me”. Two pictures accompany the question with the words ‘Yes’ and ‘No’ under the respective pictures (see appendix 3 page 10).

6) Orientation to Person, Place and Time
Orientation to person, place and time is a common test used by many healthcare professionals to screen for neurological disturbances. The causes of disorientation are varied, such as medical and neurological complications, adverse drug reactions, surgery, fever, hydrocephalus, subdural hematoma, seizures, dehydration, confusion, and the onset of delirium, all of which could affect capacity evaluation. The section on orientation is optional, but could be beneficial in some evaluation situations. Pictures, choices and text support all three spheres of orientation.
7) The Communication Aid to Capacity Evaluation - Questions

The five questions contained in the Capacity to Make Admissions Decisions were adapted as follows:

**CMAD: 1) What problems are you having right now? (Does the person understand her/his problem?)**

**CACE: Do you have any health problems?** Do you have any of these health problems? Stroke, Head injury, Heart, Diabetes, Cancer, Breathing? Depression or anxiety or emotional problems? Do you have any of these: Parkinson’s disease, Lou Gehrig’s disease – ALS, Multiple Sclerosis, Huntington’s disease, Laryngectomy, something else? **At home do you need help with. . . ?** Getting in and out of bed, Walking or getting around, Getting dressed, Going to the bathroom, Having a shower or bath, Cleaning the house, Preparing meals, Shopping, Taking medication, Managing money, Something else? Are you forgetful? Do you get confused? Would you feel safe living at home? **Who helps you at home?** Partner/Spouse, Children, Friends, Family, brother or sister, Nurse or care-giver, Neighbour? **How often do they help you?** Everyday, 1,2,3,4,5,6,7 times a week? **Who lives in a Long-Term Care Home?** People who can look after themselves? People who cannot manage by themselves, who do not get enough help at home?

**CMAD: 2) How do you think admission to a nursing home or home for the aged could help you with your condition/problem?**

**CACE: Which one is a Long-Term Care Home?** Hotel, House, Apartment Hospital, Nursing home, Retirement home, Something else, Do not know? **Do you need to live in a Long-Term Care Home now?** __________ think/s that you should live in a Long-Term Care Home now. Do you agree? Yes, No, Do not know.

**CMAD: 3) Can you think of other ways of looking after your condition or problem?**

**CACE: What would you do if you fell in the bathroom?** Do nothing, Call out for help, Phone 911, Have a bath, Wait for help, I will not fall, Press Lifeline. **What would you do if there was a fire in your home?** Phone 911, Wait for
help, Leave the home, Call out for help, Put the fire out yourself, Press Lifeline, There will not be a fire, Do nothing. **What would you do if you were sick?** Take medication, Go shopping, Call out for help, Press Lifeline, Do nothing, I will not get sick, Phone someone.

**CMAD:** 4) **What could happen to you if you choose not to live in a nursing home or home for the aged?**

**CACE:** If you do not go to a Long-Term Care Home where will you live?
Home, Hospital, Hotel, Friend’s house, With family, Retirement home, Do not know. **If you live at home who will help you on a daily basis?** Partner/spouse, Children, Friends, Family, Brother or sister, Caregiver or nurse, Neighbour, I do not know, Someone else, I do not need help. **If you cannot look after yourself and do not have enough help at home what will you do?** Pay someone to help me, I have money, I have Private Insurance, I do not know, Move to Long-Term Care Home, Something else.

**CMAD:** 5) **What could happen to you if you choose to live in a nursing home or home for the aged?**

**CACE:** **What would a Long-Term Care Home help you with?** Getting in and out of bed, Walking or getting around, Getting dressed, Going to the bathroom, Having a shower or bath, Taking medication, Preparing and eating meals, Nothing, I do not need help. **So do you think you should move to a Long-Term Care Home now?**

8) Scoring Form and Instructions for Completion

CACE recommends that evaluators record verbatim the patient’s verbal and non-verbal responses. A list of non-verbal responses has been provided to guide the evaluator. The list includes: writing or drawing, pointing to a picture or object, sounds with positive or negative intonation, head nodding for ‘yes’ or agreement, head shaking for ‘no’ or disagreement, shrugging shoulders for ‘unsure’ or ‘don’t know’, gestures and facial expressions, purposeful eye gaze and other symbols of intent or acknowledgment. A scoring sheet is included in CACE (see appendix 3 page 34). For ease of administration, the five questions are broken down into subsections, for example, question 1) addresses
the patient’s ability to understand his or her care needs. This section is subdivided into health needs, care needs, who helps the patient, frequency of help and cognitive and emotional needs.

The evaluator determines capacity for each subsection by selecting YES, NO or UNSURE. The rationale of including UNSURE is to encourage the evaluator to explore a specific area further, either during the evaluation or at another time, and possibly with another healthcare professional. The inclusion of UNSURE also guides the evaluator to gather more information regarding a particular issue from the family or healthcare team. Finally, it could prompt the evaluator to educate the patient in a specific area. If there is some doubt as to whether the patient understands his or her health needs, the physician or nurse can be asked to explain the medical condition and proposed treatment again. Although the option of UNSURE has been provided for each subsection, the evaluator has to eventually determine capacity or incapacity. If the patient is found lacking in capacity the patient’s rights must be explained and an appeal of incapacity noted.

### 3.6 Development of the Training DVD

To ensure that the training of evaluators was consistent and comprehensive, and to incorporate the recommendations made by the focus groups, working groups and panel of experts, a training DVD was developed to accompany CACE. The training DVD was divided into five sections; an introduction, legal requirements of capacity evaluation, communication barriers that mask capacity, effective administration of CACE and strategies to communicate with people with aphasia and other communication barriers.

#### Legal Requirements of Capacity Evaluation

Lawyers from the Advocacy Centre for the Elderly and the legal counsel from the Consent and Capacity Board reviewed CACE and requested basic information regarding capacity evaluation and the law be included in the training DVD. This included the definition of capacity, constructs of ‘understand’ and ‘appreciate’, who can evaluate capacity, the presumption of capacity, and consent to be evaluated.
Communication Barriers that Mask Capacity
The following communication barriers are discussed in the training DVD; aphasia, dysarthria, English as a Second Language (ESL) and hearing loss. Definitions are provided as well as information on how each barrier might mask potential capacity to make a decision regarding admission to long-term care.

Instructions for Administration
The working groups recommended that explicit written instructions be included on how to administer CACE. These were used as a basis for this section of the training DVD (see appendix 3 Pg 1-2).

Strategies to communicate with people with aphasia and other barriers
Following approval from the University of Toronto Research Ethics Board, an individual with Broca’s aphasia of moderate to severe severity attending a community aphasia conversation group in Niagara and a speech language pathologist trained in SCA ™ were approached to be in the training DVD. The two participants consented to be filmed administering the CMAD questionnaire without communication support, and then to carry out CACE with support. They also agreed to have a conversation illustrating different supported communication techniques. The DVD was viewed by the working groups and by this researcher’s doctoral committee who suggested recommendations. Changes that could be completed without re-shooting were made accordingly (see appendix 6).

3.7 Development of the Communication Aid to Capacity Evaluation
Summary
The Communication Aid to Capacity Evaluation (CACE) was developed in conjunction with three working groups who were key stakeholders in the capacity evaluation process. The face and content validity of CACE was found to be high by a panel of experts, and recommendations from the panel and external agencies were incorporated into the final
version with its training DVD. It was this version of CACE that was tested with social work evaluators and participants with aphasia. The methodology of how the testing was designed and carried out will be discussed in the next chapter.
Chapter 4 Methods

4.1 Introduction and Chapter Overview

This chapter describes the methodology used to provide evidence for the effectiveness of the Communication Aid to Capacity Evaluation (CACE), with communication training as a capacity evaluation tool for people with aphasia. The chapter will be divided into four sections. The first section describes the data collection tools to be used, including inter-rater reliability and survey development. The second section outlines the selection of participants and the third describes the methodological procedure. The final section explains the qualitative methods used in the study.

At this stage it is beneficial to review the hypotheses that the methodology will be testing:

1) The use of a communicatively accessible capacity evaluation process, with training, will enhance the skills and confidence of a social worker to more accurately judge the capacity of people with aphasia to make an admission decision to long-term care.

2) The inherent capacity of a person with aphasia to make a decision regarding admission to a care facility will be revealed by the use of a communicatively accessible capacity evaluation process.

Four research questions were generated in order to test the null hypotheses: 1) Does CACE with communication training enhance a social worker’s communication skills to reveal capacity in a person with aphasia? 2) Does CACE with communication training increase a social worker’s confidence to determine capacity? 3) Does enhanced communication and confidence in social workers result in increased accuracy in the determination of capacity? Finally, what are the perspectives of the participants with aphasia on the communication accessibility of capacity evaluation process?

Experimental Design
A Randomized Controlled Trial with repeated measures was chosen to test the effectiveness of CACE with communication training as an evaluation tool to determine the capacity of individuals with aphasia to make an admission decision. A Randomized Controlled Trial tests the effectiveness of an intervention. It typically uses participants that have been randomly allocated to two groups, an experimental group that receives an intervention, and a control group that does not. Tests are administered to determine whether or not the intervention makes a difference. By combining a repeated measures design, a baseline measurement was achieved by administering the current Capacity to Make and Admissions Decision (CMAD) questionnaire. The effectiveness of the intervention (CACE with training) was then tested by comparing results from the experimental group with the results of the control group. This was considered to be the most reliable method to test the effectiveness of CACE with communication training. If a repeated measures design was used exclusively, that is, every social work (SW) participant acted as their own control, then the variables of repetition and familiarity between the social worker and participant could have confounded the results.

4.2 Selection, Development and Reliability of Data Collection Tools

4.2.1 Measure of Skill in Supported Conversation (MSC) and Measure of Participation in Conversation (MPC)

The MSC and MPC (see appendices 8 and 9) are two standardized measures that were created to objectively measure communication skills between people with aphasia and their conversational partners using a conversation format. The MSC examines the communication partner’s (evaluator) ability to acknowledge and reveal communication competence in the person with aphasia; both constructs are measured using a 9 point Likert scale. With ‘Acknowledging Competence’ an Independent Speech-Language Pathologist (S-LP) rates the SW participant’s use of pragmatics, that is, appropriate language and tone of voice. Also rated, is the SW’s acknowledgement of the Participant with Aphasia’s (PwA) attempts at communication and levels of frustration. ‘Revealing Competence’ involves assessment of the SW participant’s behaviours to ensure that the
PwA understands information and has a means of response, and that the given information is verified.\textsuperscript{102}

The MPC examines the interactional and transactional elements of conversation from the PwA’s perspective, and is again measured on a 9-point Likert scale. The construct of ‘Interaction’ concerns both verbal and non-verbal social and emotional connections between the PwA and the conversational partner (evaluator). The measurement of ‘Transaction’ looks at the exchange of verbal and non-verbal information within the dyad, but focusing on the PwA. The MSC and MPC give a score from between 0 and 4 with 0.5 intervals on the 9-point Likert scale.\textsuperscript{102}

**Inter-rater reliability process in scoring MSC MPC**

Three Independent S-LPs who were experienced in providing therapeutic service to adults with acquired speech and language disorders, and who were trained in Supported Conversation for Adults with Aphasia (SCA™) techniques met with this researcher. The scoring of the MSC and MPC was discussed in detail to ensure consistency and reliability. Agreement was achieved as to what behaviours and the frequency of the behaviour constituted a particular score. Following the training, four film clips were viewed showing conversational partners interacting with individuals with aphasia. Two of the clips showed an individual having a conversation with a person with aphasia, the first clip without any conversational support and the second clip with support. The next two clips showed a healthcare professional administering a capacity evaluation with a person with aphasia without support, followed by a clip using CACE with conversation support. The Independent S-LPs scored the behaviours viewed in the film clips using the MSC and MPC. This was done independently with no contact between the S-LPs. The resulting data was analyzed using an Intraclass correlation coefficient to measure the homogeneity between the Independent S-LPs’ MSC and MPC scores. A score of 0-3 = weak correlation coefficient, 4-6 = moderate correlation coefficient and 7-10 = high correlation coefficient.

**Independent Speech-Language Pathologist Inter-rater Reliability Results**
As Table 6 shows, the Intraclass correlation coefficient between the three Independent S-LPs’ MSC and MPC scores are between moderate to high (.69) and high (.93) when examining single measures. ‘Acknowledging Competence,’ the construct that scored in the moderate to high range, examined the evaluator’s sensitivity to the PwA by using appropriate language and tone of voice. There was some discussion regarding the difference of being a caring person versus overtly acknowledging the competence of an individual by using collaborative talk and striving for equal roles in the conversation. The intraclass correlations for the three other constructs in MSC and MPC were high, showing homogeneity between the Independent S-LPs in their scoring behaviour.

Table 6. MSC and MPC Inter-rater Reliability between Independent S-LPs using Intraclass Correlation Analysis – Results

<table>
<thead>
<tr>
<th>MSC MPC Constructs</th>
<th>Intraclass Correlation Single Measures</th>
<th>F Test with True value 0</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Value</td>
</tr>
<tr>
<td>Acknowledging</td>
<td>.69</td>
<td>6.125</td>
</tr>
<tr>
<td>Competence</td>
<td>.90</td>
<td>29.058</td>
</tr>
<tr>
<td>Revealing</td>
<td>.90</td>
<td>41.368</td>
</tr>
<tr>
<td>Competence</td>
<td>.93</td>
<td>42.654</td>
</tr>
</tbody>
</table>

Legend: Intraclass Correlation Coefficient. 7-10 = High Correlation

4.2.2 Independent Speech-Language Pathologist Clinical Observations

The Independent S-LPs were asked to review the DVD of the capacity evaluations for a second time and determine, through observation, whether the PwA understood each of the capacity questions and fully communicated his or her answer.

Speech-language pathologists are trained to use clinical observational skills to determine whether or not an individual both understands and successfully communicates his or her message. The verbal and non-verbal behaviours studied include: eye contact, facial expressions, gestures, body language, pointing, intonation of utterances, choice of vocabulary and expressions of emotion, both positive and negative.

4.2.3 Participant Survey Development
A literature search for a standardized questionnaire/survey regarding confidence levels in
decision-making proved unsuccessful. Three articles were worthy of consideration but
the questionnaires required extensive adaptation and did not meet the needs of this
research protocol. However, an article was found addressing the same dilemma.

"Since no instrument on transition from curative treatment to palliative care
was found in the literature, a four-page questionnaire was developed. To
improve the face validity, the questionnaire was discussed in doctoral
seminars and judged by experts in the field, and 10 healthcare personnel (not
included in the sample) answered and commented on preliminary versions of
the questionnaire."

Content Validity for Social Work Surveys - Procedure

Two surveys were developed to examine confidence in communication skills and in the
determination of capacity. The third survey evaluated the PwA’s comprehension and
expressive language skills. A panel of eight social work experts comprising academics,
iclinical educators in capacity evaluation and front line workers were asked to evaluate the
surveys. The SW participants from the research study were not included in the panel. Six
panel members agreed to participate. They read the research methodology summary, the
three surveys, and then completed the content validity questionnaire. After reading four
statements the panel members were asked to indicate on a scale of 1-5 whether they
strongly agreed (5), agreed, neither agreed nor disagreed, disagreed, or strongly disagreed
(1).

Content Validity for Social Work Surveys - Results

Table 7: Social Work Panel of Experts - Results of Face and Content Validity Survey

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
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<td>3</td>
<td>5</td>
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<td>5</td>
<td>5</td>
<td>5</td>
<td>1- 5</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>
Table 4 shows that panel member 5 originally scored 1 for the Post Capacity Evaluation, but his comments led this author to conclude that he had misunderstood the question. He was contacted and he confirmed the misunderstanding and voluntarily amended his score. Panel members gave suggestions to improve the survey, for example underlining words and using a bold font to draw focus to key concepts.

Social Work Participant Surveys

1) Survey to measure confidence in the SW participants’ own communication abilities to ensure that the PwA understood the capacity process, and communicated answers leading to a determination of capacity (see appendix 10). The survey, comprising three questions, used a 9-point Likert scale to measure the response. The goal was to measure the potential differences in communication confidence levels as a result of using CACE with communication training.

2) Survey to measure the SW’s confidence in his or her determination of capacity (see appendix 11). Again, a 9-point Likert scale was used to measure the response. The goal was to measure any differences in the confidence of capacity determination by using the CACE with training.

3) Survey to measure the SW participants’ observations of how much the PwA both understood and communicated (see appendix 12). The results were compared with the PwA’s own perceptions of comprehension and expressive language. The goal was to determine whether or not the SWs had accurate observational skills and whether the administration of CACE with training increased the accuracy of those observations. The responses were measures using a 9-point Likert scale.

Participant with Aphasia Survey
The survey measured whether the PwA understood the capacity process and questions and was able to answer questions to his or her satisfaction. The final survey question examined the PwA’s frustration with the level of communication support (see appendix 13). The responses to all of the questions were measured using a 9-point Likert scale. The S-LP working group helped to design the survey in a communicatively accessible format. The goal of the survey was two fold: to measure the potential differences in the survey results using CACE with training, and to determine whether or not the survey results correlated with the SW participant’s observations of comprehension and expressive language.

Capacity Evaluation Preference Surveys
Members of the experimental group (SW and PwA) completed a survey measuring their preference between the two capacity evaluation processes: the CMAD questionnaire and CACE. The survey for PwA was communicatively accessible.

4.2.4 Summary of Data Collection Tools used to Measure Research Questions

Table 8 Summary of Tools Selected to Answer each Research Question.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Data Collection Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Question 1)</strong> Does CACE with communication training enhance a social worker’s communication skills to reveal capacity in a person with aphasia?</td>
<td>• MSC, MPC</td>
</tr>
<tr>
<td></td>
<td>• Independent S-LP’s clinical observation</td>
</tr>
<tr>
<td></td>
<td>• Survey to measure SW observational skills</td>
</tr>
<tr>
<td><strong>Question 2)</strong> Does CACE with communication training increase a SW’s confidence to determine capacity?</td>
<td>• 2 SW participant surveys measuring confidence</td>
</tr>
<tr>
<td><strong>Question 3)</strong> Does enhanced communication and confidence in SWs result in increased accuracy in the determination of capacity?</td>
<td>• Capacity Evaluations</td>
</tr>
</tbody>
</table>
Question 4)
What are the perspectives of the participants with aphasia on the communication accessibility of the capacity evaluation process?

- PwA survey measuring ability to understand, communicate and level of frustration

4.3 Participants: Rationale, Sample Size Calculation, Inclusion Criteria and Recruitment

4.3.1 Rationale for Selection of Participants
As outlined in the literature review, the Health Care Consent Act clearly lays out which Regulated College members are allowed to evaluate capacity. For the purposes of this research study, social workers were considered to be the ideal evaluator participants for a number of reasons. Social workers are the healthcare professionals who most frequently administer capacity evaluations in the hospital setting, so they have familiarity with, and experience of the evaluation process. In their undergraduate and graduate training they are taught not to make assumptions or to judge individuals, and to view a patient as a whole person rather than a diagnosis. Also, social workers must possess knowledge of the consent and capacity legalities regarding all health and welfare decisions. Finally, one of the most significant roles a social worker plays is that of advocate. People with communication barriers are in need of advocates who will speak on their behalf. These attributes were considered to be beneficial when interacting with a person whose inherent capacity is masked by a communication barrier.

People living with aphasia were chosen to be the participants with a communication barrier who would undergo the evaluation. Aphasia is not a well-understood diagnosis. Some, or all of the language modalities can be affected, that is, speaking, understanding language, reading and writing. Intellectual and decision-making abilities can remain intact, but the aphasia symptomology acts as an obstacle to revealing these abilities. Because aphasia has the potential to affect all language modalities it can be used as a paradigm to represent key elements of the other communication barriers
described in the literature review. For those with hearing impairments, seeing the text and pictographs in CACE will help to provide context, allowing a person to predict, or fill in missing information not heard. People for whom English is a second and unfamiliar language will benefit from the pictographs and highlighted words to help them understand and process language. If they are struggling to find a specific word in English they can point to a picture, or the phrase “something else” to communicate their response. Finally, for people with dysarthric speech who cannot be clearly understood, pointing to the picture and words will give context to the evaluator who can then try and determine what they are trying to say. The development of CACE and the communication training took the four language modalities into account.

4.3.2 Social Work Participants

Social workers were recruited from the following healthcare settings: Sunnybrook Health Sciences Centre, London Health Sciences Centre, Providence Healthcare, Toronto, North York General Hospital, and the Ottawa Hospital.

The Inclusion criterion was as follows:

The SW regularly administered the ‘Capacity to make Admission Decisions’ questionnaire to patients for whom placement in long-term care was being considered.

4.3.3 Participants with Aphasia (PwA)

Participants with aphasia were recruited from the following sites: the Aphasia Institute, Toronto, the University of Western Ontario Aphasia Program, Providence Healthcare Outpatient Clinic, York Durham Aphasia Centre and the Aphasia Centre of Ottawa.

The Inclusion criteria were as follows:

- The participant had aphasia evidenced by a physician’s diagnosis and confirmed by a Speech-Language Pathologist
- The participant was medically stable and at least six months post-stroke to counter the variable of spontaneous recovery
- The participant was able to tolerate a one-hour evaluation session
- The participant presented with a moderate to severe expressive aphasia as determined by the current site S-LP through clinical expertise and knowledge of
the participant. Standardized testing to determine severity level was not used (see below for rationale)

- The participant had sufficient receptive language skills to ensure that he or she understood that the capacity evaluation did not apply to him or her. The current site S-LP determined the severity level through clinical expertise and knowledge of the participant
- The participant was judged to be competent to make a decision regarding admission to a care facility. The participant had the ability to understand relevant information and to appreciate the reasonably foreseeable consequences of a decision
- The participant was living at home or in a retirement home

Rationale for not using Standardized Aphasia Testing

Standardized assessments to diagnose aphasia, type and severity focus on error. Ethically, it was felt that the PwA’s consent to have his or her capacity evaluated was sufficiently stressful without adding a formal assessment focusing on communication deficits. Also, experienced S-LPs working in the social model of aphasia reported potential discrepancies between standardized assessment results and communication abilities. Some individuals with a severe expressive aphasia were excellent communicators and naturally used techniques to ensure the successful transmission of their messages. Other individuals, who were comparatively verbal, found a mild disruption in communication a challenge. The goal of CACE was to enhance the PwA’s ability to understand and communicate answers to questions, not to improve verbalizations.

Participant Deception

The SW participants were blinded to the fact that the PwA had been judged to be capable to make an admission decision to long-term care by the site S-LP. The rationale was twofold: the PwA needed to understand that the capacity evaluation administered as part of the research protocol did not apply to them. Second, in order to test the effectiveness of
CACE, the SW participants needed to be blinded to the actual competency of the PwA. Deception de-briefing will be discussed later in this chapter.

4.3.4 Speech-Language Pathologists

1) Three Independent Speech-Language Pathologists (Independent S-LP)

_The Inclusion criteria were as follows:_

The Independent S-LPs were experienced in providing therapeutic service to adults with acquired speech and language disorders. They were trained in Supported Conversation for Adults with Aphasia (SCA™) techniques, and were familiar with the Measure of Skill in Supported Conversation (MSC) and the Measure of Participation in Conversation (MPC).

2) Site Speech-Language Pathologists

_The Inclusion criteria were as follows:_

The S-LP worked at the clinical trial site and could identify potential participants with aphasia ensuring that all inclusion criteria were met. The S-LP was available to administer a post evaluation survey to the participants with aphasia.

4.3.5 Participant Recruitment (SW and PwA)

Following approval from the University of Toronto and the data collection sites’ Research Ethics Boards, information sessions were held at the hospital sites and community aphasia groups. The sessions provided the rationale for, and development of CACE, and outlined participant requirements. The aphasia group presentation used a communicatively accessible format. Time was allocated to address any questions. Informed consent documents were left at each site for the participants to consider and sign. The informed consent document for the participants with aphasia was created using a communicatively accessible format (see appendix 7). The site speech-language pathologist (S-LP) provided communication support, if needed, to the PwA to complete the Informed Consent.

4.3.6 Sample Size Calculation

Calculation of Effect Size has two purposes in research methodology; it measures the
The strength of the relationship between two variables and helps to calculate the sample size required for statistical tests of significance.\textsuperscript{122} Cohen’s $d$ is one type of Effect Size. The greater the Effect Size, the greater the difference between the experimental and control group which increases the practical or clinical significance.\textsuperscript{122} The smaller the difference between two groups necessitates a larger sample size.

Cohen’s $d$ was calculated by finding the difference between the pre and post intervention MSC and MPC mean scores for the experimental group from the first eleven participants. The difference between the two mean scores was divided by the combined standard deviation. The sample size required was then determined by consulting statistical Tables.\textsuperscript{123}

| Table 9 Cohen’s d Effect Size and Sample Size Calculation |
|--------------------------------------|-------|-------|---------|-----------|
|                                      | Exp grp 1 | Exp grp 2 | Cohen’s $d$ | Sample size |
|                                      | M      | SD    | M      | SD       |           |
| MSC Acknowledge                      | 3.1    | .37   | 3.6    | .49      | 1.1       | 23        |
| MSC Reveal                           | 2.9    | .47   | 3.6    | .39      | 1.7       | 11        |
| MPC Interaction                      | 3.3    | .40   | 3.7    | .40      | 1.0       | 28        |
| MPC Transaction                      | 2.7    | .55   | 3.6    | .37      | 1.6       | 12        |
| **Mean Sample Size**                 |        |       |        |          | **18**    |

Legend: Alpha = 0.5 – type 1 error, Beta = 0.5 – type 11 error

The sample sizes for the different constructs of the MSC and MPC varied considerably (see Table 9). The mean sample size was calculated at 18 for each experimental and control group. Consequently, the sample size required for this methodology was 36 SW participants and 36 participants with aphasia.

**4.4 Capacity Evaluation and Data Collection - Settings**

The research settings included four community aphasia centres where participants with aphasia and other communication barriers attended conversational groups and one sub acute rehabilitation and complex continuing care hospital.
4.5 Procedure - Randomized Controlled Trial

4.5.1 Pretest stage

Controlling for Biases

A bias is defined as anything that produces a systematic error in research findings. The following measures were undertaken to reduce biases in the research design. An individual with no personal connection to this researcher used computer software to randomize 36 participant numbers into two groups, the experimental group and the control group. The results of the randomization process were blinded to the site S-LPs, participants with aphasia and social work participants until after the initial evaluation appointments had been set up at each site. This was done to counter any bias in the recruitment process. Each participant couple (SW and PwA) was allocated a participant number in sequence according to the evaluation appointment, the first appointment at the first site was allocated number one.

Three Independent S-LPs were recruited to act as independent assessors to ensure that there was no bias in the administration of MSC and MPC. Following the same theme, the site SLPs helped the PwA complete the post evaluation survey to ensure that the results were not biased. A script was provided to the site S-LPs to ensure that each PwA heard the same information regarding the completion of the survey (see appendix 14).

A diagram of the room set up was created so that the test environment was as similar as possible for each participant couple (see appendix 15). Blank paper and a marker were left on the Table, but no instructions were given as to their use.

Instructions were read aloud to the SW participant and PwA from a script, thus ensuring that each participant heard the same information (See appendices 16 and 17).

SW Participant and PwA Demographic Information

Typical demographic information such as gender, age, education, occupation, years of SW practice, date of stroke, head injury was gathered from both the SW and the PwA. This
information was subsequently analyzed and enabled the completion of an information sheet regarding the PwA (see figure 1). The information sheet was given to the SW to make the capacity evaluation as authentic as possible and to determine the accuracy of information given by the PwA. Care was taken not to include any information that might reveal the PwA’s competency. The information sheet was also sent to the Independent S-LPs to help them confirm whether the given information was accurate. All the participants were asked whether they would like to use their own name, or change it for the interview. None of the participants chose to change their name.

*Figure 1 Background Information on Participant with Aphasia (Given to SW participant and Independent S-LP)*

<table>
<thead>
<tr>
<th>Name</th>
<th>Joe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>69</td>
</tr>
<tr>
<td>Aphasia/Apraxia/Dysarthria cause</td>
<td>Stroke X  Head Injury □  Other ____________</td>
</tr>
<tr>
<td>Date:</td>
<td>____________</td>
</tr>
<tr>
<td>Medical History</td>
<td>multiple strokes □  hypertension □  heart attack □</td>
</tr>
<tr>
<td></td>
<td>diabetes X  cancer □  seizures □  recent surgery □</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>Loss - Yes □  NoX  Hearing Aid - Yes □  NoX</td>
</tr>
<tr>
<td>English as a second Language</td>
<td>□  1st language: Portuguese</td>
</tr>
<tr>
<td>Lang spoken at home</td>
<td>English</td>
</tr>
<tr>
<td>Living situation</td>
<td>Home</td>
</tr>
<tr>
<td>People living with participant</td>
<td>Wife and adult son</td>
</tr>
<tr>
<td>Ambulation</td>
<td>Independent with cane</td>
</tr>
</tbody>
</table>

**Measure of SW Communication Confidence**
The participant pairs were introduced and asked to engage in a general conversation for five minutes. The conversation was video recorded. The SW left the room and
completed a survey to measure the level of confidence in his or her own communication skills regarding the capacity evaluation (see appendix 10). The following questions were asked in the survey:

1) How confident are you in your communication skills that you can enable the person with aphasia to understand the capacity evaluation process?
2) How confident are you in your communication skills that you can enable the person with aphasia to communicate his or her answers?
3) How confident are you that you would be able to evaluate the capacity of the person with aphasia to make admission decisions?

The SW participant returned to the room.

Capacity Evaluation - Filmed

Every SW participant, to generate a base line measurement of capacity in the PwA, administered the CMAD questionnaire. The SW participants were told to complete the questionnaire as they would with any patient or client, and write down given information in the space provided.

CMAD Questionnaire (see appendix 1):

1) What problems are you having right now?
2) How do you think admission to a nursing home or home for the aged could help you with your condition/problem?
3) Can you think of any other ways of looking after your condition/problem?
4) What could happen to you if you choose not to live in a nursing home or home for the aged?
5) What could happen to you if you choose to live in a nursing home or home for the aged?

Following the administration of the CMAD questionnaire the SW participant left the room to complete the capacity evaluation form and two surveys (see appendices 11 and 12). Questions in the survey to measure the SW’s observations of the PwA included the following:
1) Did the person with aphasia understand the capacity evaluation process?
2) Did the person with aphasia understand the questions?
3) Did the person with aphasia communicate their answers?

The survey measuring confidence in capacity determination asked the following:

1) How did you evaluate your participant?
   Has Capacity □ Does NOT have capacity □ ** Unable to determine capacity at this time □
   ** Please use this option as a last resort

2) How confident are you in your evaluation of capacity?

If you were unable to determine the participant’s capacity please indicate why:
   1) Unable to communicate with the participant
   2) Unable to get sufficient information to determine capacity
   3) Unable to understand participant’s responses
   4) Need another session to determine capacity
   5) Need to determine capacity with other professional.
   6) Other (please describe)

The site SLP met privately with the PwA immediately after the evaluation to administer the survey. The initial part of the script read to the participant reassured the PwA that the capacity evaluation that had just been administered did not apply to him or her. Also, that the SW participant would not see the results of this survey. This was to encourage the PwA to measure exactly how they felt without fear of offending the SW participant. The survey examined whether the participant understood the process, the questions, and had the opportunity to express their decisions. (see appendix 13)

Information Verification
The completed capacity evaluation form was given to the researcher. The content of the capacity evaluation form was checked with a family member or the site S-LP to ensure its accuracy.
MSC MPC/Clinical Observation

The three independent S-LPs were randomly assigned an equal number of participants. Each Independent S-LP was given the PwA information form, results of the information verification and a DVD recording of the evaluation. After watching the recorded capacity evaluation they administered the MSC and MPC. Following the scoring of the two measures, the Independent S-LPs watched the DVD again to determine whether or nor the PwA understood each capacity question and was able to answer to the best of his or her ability.

4.5.2 Intervention

The SW participants in the experimental group met with this researcher one-week post the initial capacity evaluation. They were given a copy of CACE and were taken through each of the sections before they watched the training DVD. They were given the same information at each site to maintain consistency (see appendix 18), and time was allocated for questions. The group was informed that they could contact this researcher via e-mail or telephone should they have any further questions. The social work manager/professional practice leader kept a copy of the training DVD for review, however, no SW participant asked to review the training DVD.

The control group SW participants were e-mailed the following information on aphasia.

Aphasia – Frequently Asked Questions

Question 1: "How do I recognize if a person has aphasia?"
Aphasia affects people in different ways. They may have little or no speech. They may be unable to come up with the right words. Or they may mix up their words or utter nonsense words. They may find it hard to understand what others are saying, resulting in misunderstandings. Reading and writing may be difficult or impossible. The person with aphasia may also be frustrated, angry or depressed because they cannot communicate.

Question 2: "What type of brain injury causes aphasia?"
Aphasia results from injury to the speech and language centres of the brain. These centres primarily reside in the left frontal part of the brain. You may hear aphasia described in terms such as Broca's aphasia or Wernicke's aphasia. These descriptions
relate to specific brain centres that have been damaged (Broca’s area or Wernicke’s area are the most common).

**Question 3:** "Does aphasia affect intelligence?"
Aphasia does not affect intelligence or social manners. People with aphasia still have their intelligence and creativity intact. They know what they want to say.

**Question 4:** "How long does it take to recover speech?"
Each situation is different. No one can predict how much speech will be recovered. Speech recovery depends on the location and size of the brain injury, age, therapy, motivation. Some people do not recover speech, likely due to the size and location of their injury. Others continue to improve slowly for many years.

**Question 5:** "What can I do to help someone with aphasia?"
You can use communication strategies to help the person with aphasia to have a meaningful conversation. It is important to reinforce and encourage all means of expression: gestures, pointing, facial expressions, drawing, communication book/board, speech, writing… whatever works to communicate!

*Information retrieved from York Durham Aphasia Centre Web site (04/12/09)*
http://www.ydac.on.ca/faqs.html

**4.5.3 Post-Test Stage**
A minimum of two-weeks between the initial capacity evaluation and the final capacity evaluation was established to guard against the variable of learning in the control group; that is, the possibility that the PwA might remember the questions and his or her previous responses.

**Measure of SW Confidence**
The SW participants from both groups completed the survey to measure their confidence in communication skills regarding the capacity evaluation. On this occasion the SWs rated their level of confidence based on the previous capacity assessment and the intervention.

**Capacity Evaluation - Filmed**
The SW participants in the experimental group administered CACE, while the control group participants re-administered the CMAD questionnaire. Following the evaluation the SW participant left the room.

Social Work Participant Post-Evaluation Surveys
The SW participants from both groups completed the two post-capacity evaluation surveys.

Participant with Aphasia Post Capacity Evaluation Survey
The site SLP met with the PwA immediately after the evaluation and administered the survey that examined whether the participant understood the process, the questions, and had the opportunity to express decisions.

Capacity Evaluation Preference Survey
Each SW participant and the PwA in the experimental group who experienced both capacity evaluations were asked to complete a short survey asking which one they preferred, the CMAD questionnaire or CACE.

Information Verification
The completed capacity evaluation form was given to the researcher. The content of the capacity evaluation form was checked for accuracy.

MSC MPC/Clinical Observation
The Independent S-LPs received the PwA information form, the results of the information verification and the DVD recording of the capacity evaluation. After watching the DVD they administered the MSC and MPC. They then determined whether the PwA understood and answered each capacity question.

Social Work De-briefing Session
Deception Explanation
This took place at the research site following the second administration of capacity evaluation and completion of surveys. The following statement was read aloud to the SW participants:

“The goal of the research project was to assess the effectiveness of the Communication Aid to Capacity Evaluation (CACE). This could only be achieved by asking you as expert evaluators to participate in the research. Does CACE with communication training enable you to reveal a person’s capacity to make decisions?

As social work participants you were blinded to the fact that the participants with aphasia were all judged to have the capacity to make an admission decision. This was achieved by careful selection of participants by speech-language pathologists. They were informed about the legal tenets of capacity, that is, the ability to understand relevant information and the ability to appreciate the reasonably foreseeable consequences of a decision.

This is an extremely challenging population to evaluate because aphasia can be a significant barrier to conversation and the consequent revelation of capacity. It is hoped that if you did find a participant to be lacking in capacity that you would realize that it is not to do with your skills as an evaluator, rather the inaccessibility of an evaluation process. You have played a major role in the development of a tool that makes the process fair and accessible to those with communication barriers. Please remember that the results of the capacity evaluations were not shared with the participants you evaluated; also, that the data is completely anonymous, and will remain so.

The participants all had a diagnosis of severe expressive aphasia and moderate to mild receptive aphasia. They were all over six months post stroke either living at home or in a retirement home. One of the most important reasons for the deception was that the participants with aphasia
had to have the level of comprehension to know that the evaluation did not apply to them or their living circumstances; otherwise the research design would have been distressing and would not have conformed to ethical standards. Further rationale for the deception was that the participants with aphasia have had the opportunity to learn and use supported conversation techniques. The use of these skills is dependent on the conversational partner (you). If a conversational partner does not use communicatively accessible materials (CACE) or supported conversational skills (contained in the DVD training) the person with aphasia is stuck and unable to communicate his or her capacity.

It was hypothesized that CACE with communication training would allow evaluators to reveal the competence of a person living with a communication barrier, but you had to prove this. By comparing the results of the first administration with the second administration following the intervention, it was hoped that CACE with training was effective in revealing capacity and increasing your confidence in the determination of capacity.

If at this time you would like to withdraw from the study please contact your manager of social work services. She has the master list of names attached to participant numbers. She will contact this researcher and your corresponding data will be removed. There will be no adverse consequences from withdrawing from this study.

Again, I would like to thank you so very much for participating in this research project and I would be very happy to respond to any questions.”

4.6 Qualitative Methodology
Statistical tests determine whether an intervention, in this study the introduction of CACE with specific communication training, makes a significant difference, or if the difference
is a product of chance. In other words, is a conclusion drawn from data correct? Tests of statistical significance do not tell the researchers why the intervention makes a difference, the nature of the intervention’s strengths or the areas that will benefit from change. Qualitative research methods seek to create theories that answer these questions.

Grounded theory is a qualitative research approach created by Glaser and Strauss in 1967 and further developed by Strauss and Corbin. It consists of a set of steps whose careful execution produces a theory grounded in data as the outcome. Grounded theory involves the collection of different types of narrative data that are transcribed and read a number of times. The data goes through a reduction process, that is selecting, simplifying and transforming comments or non-verbal behaviours to illustrate the issues being addressed. Pre-set categories or questions can help the researcher to look for specific information in the transcription, for example, what did you like about CACE and what would you change? The ability to perceive variables and relationships is termed "theoretical sensitivity." Sensitivity is augmented by developing specific research questions, establishing pre-set categories and conducting a literature review of the research subject. Careful analysis of the data can generate ‘emergent’ themes that are unexpected. The data is coded to help organize themes into coherent categories. Patterns and connections within and between categories appear, and gradually the importance of certain themes becomes evident and a theory is developed.

Content analysis is another research method utilized to determine the presence of meaningful concepts within texts. This field of research was developed in the 1930’s. The core analytical questions were developed in the 1950s by Harold Laswell, an American political scientist: "Who says what, to whom, why, to what extent and with what effect?" Stemler (2001) cites Holst (1969) who developed a broad definition of content analysis as, "any technique for making inferences by objectively and systematically identifying specified characteristics of messages" (p. 14). Although a branch content analysis relies heavily on quantitative analysis of messages, the field of social sciences uses this analysis as a qualitative methodology. There are similarities between Grounded Theory and content analysis insomuch as the data is broken down into manageable categories or
units, for example, words, phrases or sentences; concepts are established and relationships explored. \(^{140}\) Also, the researchers in both approaches promote the use of constant re-examination of emerging themes and concepts. Triangulation is a common method used in social science research. Data triangulation involves gathering data from more than one source over different time periods. Methodological triangulation refers to different methods of data collection for example’ survey comments and key informant interviews. The inferences and theories drawn from multi-method research are more credible and reliable.

It would appear that the biggest difference between the two methodologies is the initial approach. With Grounded theory research questions are formulated and then as a result of the analytical process a theory is developed which addresses the questions. With content analysis, researchers establish the presence of predetermined concepts that reflect their research question. Lists are formed based on frequently occurring words within a semantic category. Meaningful relationships are then identified between the concepts, this is known as relational or semantic analysis. Relationships can be represented as logical, inferential, causal or sequential. The results can help to form inferences and identify the intention or the psychological or emotional state of an individual of group. \(^{140}\)

To determine why CACE with communication training was effective, a qualitative approach was used including Content Analysis and in one instance a Grounded Theory methodology (see chapter five). The goal was to generate meaningful theories and inferences regarding why CACE was effective, what elements worked well, what was missing, and what needed to be changed. What also needed to be determined were the elements of the communication training DVD that were effective and brought about change in the evaluators’ communicative behaviours. The results of the Grounded Theory process and Content Analysis would help to answer the research questions and generate recommendations for changing and improving sections of CACE and the communication-training module. A variety of data collection methods were undertaken, from written survey responses to Key Informant Interviews.
4.6.1 Data collection Social Work Participants
Following the capacity evaluation, if the SW participant was unable to determine capacity he or she was asked to provide a written narrative as to why he or she selected this option. Also, after administering CACE, the SW participants in the experimental group were asked to complete a survey to determine which evaluation process they preferred, the CMAD questionnaire or CACE, and to provide a written narrative explaining their preference.

4.6.2 Independent Speech-Language Pathologists
Participants in Key Informant Interviews typically have unique skills or insights related to the research issues or intervention being analyzed and have knowledge regarding the project participants. Key Informant Interviews took place by telephone with the Independent S-LPs on an individual basis. The Independent S-LPs watched a total of 64 evaluations between them, so were considered to have a unique and knowledgeable perspective. Their opinions were considered to be objective because they were not involved in the development of CACE or the research methodology. The initial question was open ended to encourage detailed comments.

Question: “I want to hear your thoughts and opinions on the capacity evaluations you reviewed. Think about the participants, the evaluation process and anything else you might want to say. How did it go?” Subsequent questions in the interview were posed to elicit more information; for example, “What do you mean by that?” “Could you give an example” “Please could you expand on that?” Their responses were written verbatim.

4.6.3 External Social Worker Evaluation
A Key informant Interview took place with an external social worker who was a capacity trainer for Community Care Access Centres, and part of the social work working group. Although he had an interest in CACE, his knowledge of capacity issues and training rendered him an informative reviewer. He was shown DVD clips from three randomly selected DVD recordings, and one purposely-selected recording of the SW participant
who found a PwA to be lacking in capacity. The external SW was asked to give his opinion during and after the viewing of the DVD. His responses were written verbatim.

4.7 Data Analyses
Descriptive statistical and inferential statistical analyses included:

- Analysis of Covariance (ANCOVA) to determine inter-group variations and whether a statistically significant change occurred from the pre-test to post-test results of the Measure of participation in Conversation (MPC) and Measure of Skill in Supported conversation (MSC) in the experimental and control groups. ANCOVA controls for extraneous variables or covariates such as the wide differences in the PwA’s expressive language skills. An Alpha level of 0.5 will show if the intervention is statistically significant and that the null hypothesis can be rejected.

- McNemar’s Chi Squared Test to measure change in the pre-test to post-test results of the Independent S-LP’s determination of whether the PwA understood each of the 5 capacity questions and answered to the best of their abilities. McNemar measures dichotomous dependent variables in a pre-test-post-test or matched-pair design to evaluate change as a result of the effectiveness of an intervention. Alpha level = 0.5

- Paired Samples t-test to measure the difference in the PwA experimental group means between pre-test and post-test survey results. Alpha = 0.5

- Repeated Measures Analysis of Variance (ANOVA) to determine whether a statistically significant change occurred between the experimental group and control group in the pre-test and post-test results of the surveys which measure the SW participants’ confidence in the determination of capacity. Alpha level = 0.5

- Intra-class Correlations to measure the homogeneity between SW participants and PwA perceptions regarding comprehension of the capacity evaluation and questions as well as the degree to which answers were effectively communicated.

0-3 = weak correlation coefficient
4-6 = moderate correlation coefficient
7-10 = high correlation coefficient
• Grounded Theory analysis of qualitative data to elicit significant themes and draw conclusions, which are then verified.

4.8 Significance
The results are expected to have important and far-reaching consequences for people living with aphasia and other communication barriers in the Province of Ontario. If proven to be effective, the use of CACE with training in communication will ensure that the capacity evaluation process is fair and just for all Ontarians. Depending on the results of the Randomized Controlled Trial, meetings will take place with key players to disseminate the findings and introduce CACE with the training DVD. The organizations contacted will include the Ontario Association of Community Care Access Centres, the Consent and Capacity Board, the Ontario Case Managers Association and the Ontario Association of Social Workers.

4.9 Summary
The methodology was designed to examine the effectiveness of CACE as a capacity evaluation tool for individuals with aphasia and other communication barriers. Although the design included some elements that were contrived; for example, the participant had a specific type of aphasia, it was not considered to be an efficacy study. Efforts were made to make the capacity evaluations as authentic as possible. The SW participants were asked to carry out each evaluation as they would in a real-life situation. The SW inclusion criteria was very broad allowing for greater ‘within group’ differences. Although the PwA inclusion criteria was more narrow, no participant was considered ineligible based on age, education, literacy, ESL, hearing loss or concomitant diagnoses of dysarthria or apraxia. This allowed for greater ‘within group’ differences. It is hoped that the results, as discussed in the next chapter, show CACE to be an effective capacity evaluation tool to be used in the real world.
Addendum
Following the data collection, the research sites were revisited and CACE with communication training was introduced to the SW members of the control group.
Chapter 5 - Results

5.1 Chapter Overview
As discussed in the previous chapter, the quantitative and qualitative methodologies were designed to measure the effectiveness of CACE with communication training as a capacity evaluation tool for people with aphasia. Does the use of CACE increase the communication skills and confidence of the evaluator resulting in more accurate determinations of capacity? What are the perspectives of the participants with aphasia? This chapter will include a description and analysis of the participant demographic information. This will be followed by the results of statistical analyses that attempt to answer the four research questions that test the null hypotheses. Subsequent statistical analyses arising from the results themselves will also be reported, and finally, data from qualitative analyses will be discussed. Data entry was checked at the time of input and rechecked following statistical analyses to ensure accuracy. Statistical analyses were conducted using SPSS-18 (student version).

5.2 Participants
5.2.1 Participants who completed the Data Collection
The sample size was calculated at 36 participant pairs. Five hospital sites and four aphasia centres agreed to participate in the study. The goal was to recruit 72 participants, 36 social workers (SW) and 36 participants with aphasia (PwA). Following information presentations, 68 participants consented to take part in the study, 34 SWs and 34 PwA. One PwA moved to a long-term care facility so was no longer eligible, and one SW participant from a different site withdrew for personal reasons. Thirty-two pairs completed two capacity evaluations and surveys. The randomization of participants into the control group and experimental group took place before the two withdrawals; consequently there were 17 participant pairs in the experimental group and 15 in the control group.
5.2.2 Social Work Participant Demographic Information

All the SW participants were women with a Master’s degree in social work providing service in a city location. Their ages ranged from 27 to 66 years, with the mean age of 42 years. The mean years of practice of 13.3 years showed that they were an experienced group. This figure decreased to 7.4 years for administering capacity evaluations. Six participants (19%) had between 1 and 3 years experience in both social work practice and capacity evaluation. Although all of the SW participants worked in a hospital environment, a wide range of different units and services were represented.

Table 10 Social Work Participants Demographic Information

<table>
<thead>
<tr>
<th>Social Work Participants</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>42</td>
<td>10.8</td>
<td>27 – 66</td>
</tr>
<tr>
<td>Years of practice</td>
<td>13.3</td>
<td>9.6</td>
<td>1 – 30</td>
</tr>
<tr>
<td>Years of capacity evaluation</td>
<td>7.4</td>
<td>6.1</td>
<td>1 - 25</td>
</tr>
</tbody>
</table>

**Work Environment**

- Acute Medicine: 12
- Emergency: 2
- Stroke Unit: 4
- Psychiatry: 2
- Management: 1
- Rehab: 3
- Neurology: 3
- CCC: 2
- Oncology: 3

Two of the SW participants had formal training in communicating with individuals with aphasia. Nine participants (28%) had received informal training from the speech-language pathology staff at the respective hospital sites, although the type of training was not specified. All of the social workers indicated that they would benefit from formal training in communicating with patients or clients with aphasia.

5.2.3 Statistical Analysis arising from SW Participant Demographic Information
This researcher wanted to determine whether training and experience made a difference in the levels of confidence felt by the SW participants in their own communication skills. Ten SW participants received some education in communication strategies, either from the site S-LPs or by attending an aphasia communication-training program. There was a wide range of professional experience within this group (see Table 10). Finally, the participants represented diverse clinical areas. A Multiple Regression Analysis was carried out to learn more about the relationship between several independent or predictor variables on the dependent variable. The SW survey results measuring confidence in communication skills was the dependent variable. The independent or predictor variables were previous communication education, professional experience (0-3 years, 4-10 years and >10 years experience), and service units (acute, rehab/stroke units and others).

The results showed that the independent variables did not have a statistically significant effect on the survey results (ensured the PwA understood $p = .18$, ensured the PwA communicated $p = .83$, was able to determine capacity $p = .88$). The Multiple Regression Analysis also gave a Pearson’s Correlation Coefficient; the results of the survey question ‘ensured the PwA understood’ showed a weak correlation with ‘years of experience’ (.29, $p = .05$). Consequently, an ANOVA was completed using the survey question as the dependent variable, and ‘years of experience’ as the factor. The Turkey post hoc test showed that although there was a difference between the mean scores; 0-3 years mean = 2.2, 4-10 years mean = 2.8 and > 10 years mean = 2.9, the difference was not significant ($f(2, 29) = 1.69, p = .20$).

5.2.4 Participants with Aphasia Demographic Information
With regard to the PwA, 18 were male and 14 were female (please refer to Table 11). Their ages ranged from 42 to 77 years with a mean of 61.9 years. There was a negligible difference in the mean ages between male and female participants. Ten of the participants spoke English as a Second Language (ESL) and were currently bi-lingual. None of the participants required translation services. Five of the participants spoke a language other than English at home. Only two participants’ reported a hearing loss and both were unilaterally aided.
All of the participants completed a minimum of Grade 10 education and over half of the participants completed college or university education. There was a wide range of occupations ranging from a Provincial Government Minister to a roofer. Among the female participants there were five registered nurses. Other occupations included an economist, beautician, professional golfer, photographer, financial advisor, audiology professor, flooring contractor, engineer, mechanic, teacher, volunteer, secretaries, sales manager and two computer programmers. Finally, the majority of the participants lived at home (88%). Three of these participants lived on their own, while the others lived with spouses, partners or family members. One participant lived in a boarding house, but was looking for alternative living arrangements with the help of his outpatient S-LP. The three participants who lived in retirement homes were active and participated in a number of community activities.

Table 11 - Participants with Aphasia Demographic Information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total Participants (N = 32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Men – 18</td>
</tr>
<tr>
<td>Age</td>
<td>Mean 61.9</td>
</tr>
<tr>
<td>ESL/Bilingual</td>
<td>10 (31%)</td>
</tr>
<tr>
<td>Hearing Aid</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Education</td>
<td>Grades10-12 - 5</td>
</tr>
<tr>
<td>Living Environment</td>
<td>Home – 28</td>
</tr>
</tbody>
</table>

*legend:*  
SD = Standard Deviation, Grades 10-12 = High school grades completed  
Col Uni = College or University, Retirement = Retirement home.

Participants with Aphasia - Information on Stroke and Aphasia

The information gathered on stroke and aphasia (see Table 12) shows that all but one participant had a diagnosis of stroke. The remaining participant had a subdural hematoma. Information on the site of lesion was found in the participant’s chart at the
relevant aphasia centre or outpatient facility. The quality and detail of the information was dependent on the healthcare professional that completed the referral. Some of the information was very general. All of the participants showed infarcts in the left hemisphere. Twenty-two of the participants’ sites of lesion were documented as left hemisphere Middle Cerebral Artery (MCA). This artery supplies the major language areas in the brain (Wernicke’s area, Broca’s area) and the arcuate fasciculus connecting these two brain regions that mediate language. The remaining lesions were documented as occurring in the frontal, parietal or temporal regions of the cortex, and one in the basal ganglia. The range of years post-stroke was 4 months to 16 years; the mean was 5.1 years and the median was 7.5 years. The most recent stroke occurred in January 2010; this participant was evaluated in May, so was 4 months post stroke, but was determined to be sufficiently stable by the site S-LP.

Table 12 also shows that the majority of the participants presented with expressive aphasia, and half of those had a concomitant diagnosis of verbal apraxia. Apraxia affects the planning and sequencing of volitional articulatory movements needed for speech production⁶ giving rise to further expressive difficulties. The remaining four participants had transcortical motor, mixed and Wernicke’s aphasias. The respective site S-LPs determined that these 4 participants had sufficient comprehension to understand that they were participating in research, and that the capacity evaluation did not apply to them.

All of the PwA conformed to the admission criteria regarding levels of comprehension; 87% were classified as having mild or mild to moderate comprehension deficits. Four of the PwA were judged to have moderately impaired receptive language skills, however, each participant was de-briefed by a familiar S-LP and understood that the capacity evaluation did not apply to them. Fewer than 10% of the participants had better expressive skills than desired, two in the experimental group and one in the control group. The remaining participants presented with moderate, moderate to severe or severe expressive language deficits (see Table 12).
Even though the majority of the participants were at least one year post-stroke, 31% had been in an aphasia program for less than one year. This was beneficial to the study design, as these participants remained highly dependent on the conversational partner’s communication skills, which was more representative of an actual capacity evaluation situation.

Table 12 - Participants with Aphasia – Stroke and Aphasia Information

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Years Post-stroke</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVA – Sub Dural Hematoma</td>
<td>0-1</td>
<td>5.1 years</td>
<td>.5 – 16 years</td>
</tr>
<tr>
<td></td>
<td>1-3</td>
<td>4 (12%)</td>
<td>10 (31%)</td>
</tr>
<tr>
<td></td>
<td>3-5</td>
<td>7 (22%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5-10</td>
<td>6 (19%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; 10 years</td>
<td>5 (16%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site of Lesion</th>
<th>Aphasia Type</th>
<th>Severity Comprehension</th>
<th>Length of time in Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>L MCA Area</td>
<td>Broca’s Aphasia</td>
<td>Mild</td>
<td>0-1</td>
</tr>
<tr>
<td></td>
<td>Broca’s with Apraxia</td>
<td>Mild-Moderate</td>
<td>1-3</td>
</tr>
<tr>
<td></td>
<td>Transcortical Motor</td>
<td>Moderate</td>
<td>3-5</td>
</tr>
<tr>
<td></td>
<td>Wernicke’s Aphasia</td>
<td>Moderate-severe</td>
<td>5-10</td>
</tr>
<tr>
<td></td>
<td>Mixed Aphasia</td>
<td>Severe</td>
<td>&gt;10</td>
</tr>
<tr>
<td>L Frontal Temporal</td>
<td></td>
<td>14 (44%)</td>
<td>10 (31%)</td>
</tr>
<tr>
<td>L Frontal Parietal</td>
<td></td>
<td>14 (44%)</td>
<td>12 (38%)</td>
</tr>
<tr>
<td>L Temporal</td>
<td></td>
<td>4 (12%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>L Parietal</td>
<td></td>
<td>1 (3%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>L Temporal parietal</td>
<td></td>
<td>3 (9%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>L Basal Ganglia</td>
<td></td>
<td>12 (38%)</td>
<td></td>
</tr>
</tbody>
</table>

5.2.5 Statistical Analysis Arising from PwA Demographic Information

The PwAs’ demographics showed that one third of the group spoke English as a Second Language. The question arose whether or not ESL was a further language barrier. A McNemar’s Chi Squared Test was conducted to analyze the difference between the English as a First Language and the ESL scores from the Independent S-LPs’ clinical observations of comprehension. The results showed that there was no significant
difference in understanding the capacity evaluation questions between these groups ($p = 1.0$).

### 5.3 Research Question 1 - Results of Analyses

**Question1)** Does CACE with communication training enhance a social worker’s communication skills to reveal capacity in a person with aphasia?

#### 5.3.1 Data Collection Tool - MSC and MPC

The Independent S-LPs administered the Measure of Skill in Supported Conversation (MSC), which specifically looked at the communication skills of the SW participants by examining their ability to ‘Acknowledge Competence’ and ‘Reveal competence’. Did the SW participant enable the PwA to understand and express a response and was the response verified? The Measure of Participation in Conversation (MPC) evaluated the PwA’s ability to maintain social and emotional connections (‘Interaction’) and ‘Transfer Information’ through communication. The rationale for including the MPC in the analyses was that an improvement in the SW participants’ communication skills through training and the use of CACE should have had a direct effect on the PwA’s ability to interact and transfer information. The difference in MSC and MPC scores between the experimental and control groups, pre and post-intervention, was analyzed by using an Analysis of Covariance (ANCOVA). The MSC and MPC pre-test results were the covariate because the SW participants had different skill levels and the PwA different levels of expressive and receptive abilities. The post-test scores were the dependent variable, and the two groups were the factor. The results, as seen in Table 13, showed that with all four constructs in the MSC and MPC, there was a statistically significant difference between the experimental and control groups over two administrations as a result of the intervention. CACE with communication training significantly improved the participants’ abilities to acknowledge and reveal competence (MSC), and interact and transfer information (MPC). The greater the $f$ ratio indicated more variance between the two groups and, as with this analysis, the null hypothesis was rejected. The Partial Eta
Squared examined how much of the variance in the dependent variable (MSC MPC score) could be explained by the independent variables (the two groups).

Table 13 Differences in MSC MPC Scores between Experimental and Control Groups, Pre and Post-Intervention using ANCOVA

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Mean</th>
<th>Std. Error</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Con</td>
<td>Exp</td>
<td>Con</td>
<td>Exp</td>
<td></td>
</tr>
<tr>
<td>MSC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acknowledging</td>
<td>3.244</td>
<td>3.660</td>
<td>.118</td>
<td>.111</td>
<td>6.504</td>
</tr>
<tr>
<td>Revealing</td>
<td>3.125</td>
<td>3.709</td>
<td>.112</td>
<td>.115</td>
<td>12.038</td>
</tr>
<tr>
<td>Interaction</td>
<td>3.306</td>
<td>3.642</td>
<td>.111</td>
<td>.105</td>
<td>4.836</td>
</tr>
<tr>
<td>MPC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transaction</td>
<td>3.062</td>
<td>3.607</td>
<td>.122</td>
<td>.114</td>
<td>10.517</td>
</tr>
</tbody>
</table>

Legend: Covariates appearing in the model are evaluated at the following values: Time 1-Acknowledge = 3.13, Reveal Competence = 3.0284 Interaction = 3.2578, Transaction = 2.9297

R squared: Acknowledge = .558, Reveal competence = .514, Interaction = .366, Transaction = .597

The graphs in figure 2 give a visual representation of the experimental group’s increase in mean scores across all four constructs post intervention

Figure 2 Graphs showing group and time differences in MSC and MPC scores between Groups over Time
5.3.2 Independent S-LP Clinical Observations

The Independent S-LPs used their clinical skills to observe whether or not the PwA understood the evaluation questions, and answered each question to the best of his or her ability. A McNemar’s chi Squared Test was used to measure the change in the pre-test and post-test results of the experimental group as a result of the intervention.

*Table 14 Differences in Understanding the Capacity Process and Questions Pre and Post-Intervention in the Experimental Group*

<table>
<thead>
<tr>
<th>Hypothesis Test Summary</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Null Hypothesis</td>
<td>Test</td>
</tr>
<tr>
<td>1 The distributions of different values across Understood and Understood_2 are equally likely.</td>
<td>Related-Samples McNemar Test</td>
</tr>
</tbody>
</table>

Asymptotic significances are displayed. The significance level is .05.

\(^1\) Exact significance is displayed for this test.

*Table 15 Differences in Communicating Answers Pre and Post-Intervention in the Experimental Group*
The results, seen in Tables 14 and 15, showed that the intervention, the use of CACE with communication training, produced a statistically significant difference in the comprehension \( (p = .000) \) and expressive communication \( (p = .000) \) scores, pre and post-intervention in the experimental group. In other words, the PwA understood more and communicated more effectively. A McNemar’s Chi Squared Test was also used to measure the change in the pre-test and post-test results of the control group to determine if repetition of the capacity evaluation improved comprehension and expressive communication. The results showed that this was not the case \( (\text{understanding } p = 0.10, \text{expressive communication } p = 0.10) \).

### 5.3.3 Social Work Participants’ Observational Skills of the Participants with Aphasia’s Communicative Abilities

Good clinical observational skills are especially important when communicating with people with aphasia. The SW participant should have been constantly observing whether or not the PwA understood the information and had something further to say. Following the capacity evaluation, the SW participants completed surveys measuring their observations of the PwA’s comprehension and expressive communication. The PwA completed the same survey, reflecting on his or her own communication skills during the evaluation. The question to be answered was did the survey scores agree or correlate? The data was analyzed through Intra-class correlation coefficient (ICC) a measure to test the reliability of survey ratings. The analysis provides two indices: 1) individual measures, an index for the reliability of the ratings for a typical, single rater, and 2) average measures, an index for the reliability of different raters averaged together. The reliability ratings show whether the rating behaviours...
from each group correlate (ICC).

When using the current CMAD questionnaire the results of the analysis showed that the scores did not correlate (see Table 16, Time 1). Perceptions of communicative success were disparate. However, the results of the Intra-class correlations in the experimental group on the second administration using CACE showed a moderate correlation between the SW participants and the PwA in understanding questions (ICC average measures .7, $p = .004$) and a moderate/weak correlation with communicating answers (ICC average measures .57, $p = 0.57$) (see Table 16 Time 2).

Table 16 Intraclass Correlations between Experimental Group’s SW Participants’ and PwA’s Perceptions of Understanding and Communication Success

<table>
<thead>
<tr>
<th>Survey Results</th>
<th>Time 1 – Both groups</th>
<th>Time 2 – Experimental group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ICC Single measures</td>
<td>ICC average measures</td>
</tr>
<tr>
<td>Understand process</td>
<td>.04</td>
<td>.077</td>
</tr>
<tr>
<td>Understand Questions</td>
<td>.06</td>
<td>.118</td>
</tr>
<tr>
<td>Communicated Answers</td>
<td>-.107</td>
<td>-.239</td>
</tr>
</tbody>
</table>

Examination of the raw data showed that one SW participant in the experimental group gave conflicting results. Following the administration of CACE, she found the PwA to have had capacity, and on completion of the survey, was moderately confident in her determination (3/4). The Independent S-LP assessed the SW’s skills highly on the MSC (4/4), and the PwA scored equally as well on the MPC (4/4). The independent S-LP judged that the PwA had understood the process and all of the questions except one, and had communicated effectively. However, when completing the Observation Survey, the SW scored the PwA’s understanding of the process and questions very low: 1.5 and 2 respectively (lower than the first administration when she was unable to determine capacity). She also scored the PwA’s communicative success low (2). The PwA judged
his own comprehension to be 4/4 and 3.5/4 and communicative abilities 4/4. If this participant pair’s scores were removed from the analysis, the results became highly significant (see Table 17, Time 2).

Table 17 Intraclass Correlations between Experimental Group’s SW Participants’ and PwA’s Perceptions of Understanding and Communication Success, Minus Participant pair 3.

<table>
<thead>
<tr>
<th>Survey Results</th>
<th>Time 1 – Both groups</th>
<th>Time 2 – Experimental group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ICC Single measures</td>
<td>ICC Average measures</td>
</tr>
<tr>
<td>Understand process</td>
<td>.04</td>
<td>.077</td>
</tr>
<tr>
<td>Understand Questions</td>
<td>.06</td>
<td>.118</td>
</tr>
<tr>
<td>Communicated Answers</td>
<td>-107</td>
<td>-.239</td>
</tr>
</tbody>
</table>

5.4 Research Question 2 - Results of Analyses

Question 2) Does CACE with communication training increase a SW’s confidence to determine capacity?

5.4.1 Data Collection Tools – Social Work Surveys to Measure Confidence

Social Work Survey to Measure Confidence in Capacity Determination

All SW participants, pre and post-intervention, completed a survey to measure their level of confidence in their determination of capacity (see appendix 11). Those SW participants who were unable to determine capacity scored zero on the confidence scale. A Repeated Measures ANOVA was used to calculate whether or not a statistically significant change occurred in the SW participants’ confidence as a result of the intervention (CACE with communication training).

Table 18 Differences in Confidence in Capacity Determination between Experimental and Control Groups Pre and Post-Intervention using Repeated Measures ANOVA
The Group*Time result which compared the two groups (experimental vs. control) across two administrations showed that the difference in confidence to determine capacity using CACE as compared to CMAD was highly significant ($f(1, 31) = 13.511, p = .001$). The Partial Eta Squared showed that 18.9% of the variance was due to the intervention. In summary, CACE with training increased the SW participants’ confidence in determining capacity.

**Social Work Survey to Measure Communication Confidence**

The SW participants also completed a survey measuring their communication confidence. This was administered after the conversation with the PwA, but before the capacity evaluations. Before the second capacity evaluation, after the intervention, the SW participants completed the confidence survey again, without reviewing their pre-test communication confidence survey scores. A Paired Samples $t$-test was used to examine whether or not the intervention made a difference with the SW participants’ evaluation of confidence in the experimental group.
The results from Table 19 showed a statistically significant difference pre and post intervention with survey question ‘Confidence in the ability to ensure the PwA communicated’ ($p = .008$), and question 3), ‘Confidence in the communication skills needed to determine capacity’ ($p = .007$), but not with question 1) ‘Confidence in the ability to ensure the PwA understood’ ($p = .111$). This was interesting because the SW participants’ scores in the experimental group improved significantly following the intervention for ‘Revealing Competence’, which included enabling the PwA to understand. This might suggest that confidence played a role in how the SW participants perceived their communication abilities.

### 5.5 Research Question 3 - Results of Analyses

Question 3) **Does enhanced communication and confidence in Social Work participants result in increased accuracy in the determination of capacity?**

#### 5.5.1 Data Collection Tools – Capacity Evaluation

The major component of the methodology was the capacity evaluation itself. Following the administration of the original CMAD questionnaire and CACE, the SW participants determined whether or not the PwA had capacity to make an admission decision to long-term care. For the purposes of this research study, the SW participants could select
‘unable to determine capacity’, but were asked to do so as a last resort. If this latter option was chosen, the social workers were asked to select from a given list to explain their reasons (see appendix 11).

Table 20 Determination of PwA’s Capacity by SW Participants

| Time | Control Group | | | Experimental Group | | |
|------|---------------|----------------|
| | Capacity | Unable | No capacity | Capacity | Unable | No capacity |
| One | 13 (86%) | 1 (7%) | 1 (7%) | 9 (53%) | 8 (47%) | 0 |
| Two | 12 (80%) | 3 (20%) | 0 | 17 (100%) | 0 | 0 |

Legend: Unable = unable to determine capacity, Time one = first administration, time two = second administration

The data in Table 20 showed that one SW participant in the control group found a competent PwA lacking in capacity on the first administration using the CMAD questionnaire. Eight of the SW participants (47%) in the experimental group were unable to determine capacity when initially administering the CMAD questionnaire. However, when they administered CACE, 100% of the SW participants in the experimental group were able to determine capacity and reveal that the PwA was competent to make a decision whether or not to go to a Long-Term Care home. Fewer members of the control group were initially unable to determine capacity. On the second administration of the CMAD questionnaire one SW participant reported that she still could not determine capacity. Two SW participants changed their decisions from the first administration to the second, one from having capacity to ‘unable to determine’, and the other from not having capacity to ‘unable to determine’.

5.6 Research Question 4 - Results of Analyses

Question 4) What are the perspectives of the participants with aphasia on the communication accessibility of the capacity evaluation process?
5.6.1 Data Collection Tools – Participant with Aphasia Survey Measuring the Ability to Understand and Communicate, and the Level of Frustration

The final research question concerning the effectiveness of CACE examined the results of the survey completed by the PwA measuring two constructs: their ability to communicate and their levels of frustration with the SW participants’ communication support.

Survey to Measure PwA’s Perception of their Communication Skills

A Paired Samples $t$-test was used to analyze the mean scores of the experimental group’s pre and post-intervention survey results measuring comprehension of the capacity evaluation and the ability to communicate. The data found in Table 21 showed that CACE with training resulted in improved understanding of the capacity process (approaching significance $p = .056$), and a highly significant change in communicating his or her answers ($p = .001$).

Table 21 Participants with Aphasia from the Experimental Group’s Perception of Comprehension and Communication Pre and Post-Intervention using a Paired Samples $t$-test

<table>
<thead>
<tr>
<th>Paired Samples Test</th>
<th>Paired Differences</th>
<th>95% Confidence Interval of the Difference</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std. Deviation</td>
<td>Std. Error Mean</td>
<td>Lower</td>
<td>Upper</td>
<td>t</td>
</tr>
<tr>
<td>Understanding Process</td>
<td>-.23529</td>
<td>.47162</td>
<td>.11438</td>
<td>-.47778</td>
<td>.00719</td>
<td>-2.057</td>
</tr>
<tr>
<td>Understanding Questions</td>
<td>-.13235</td>
<td>.39645</td>
<td>.09615</td>
<td>-.33619</td>
<td>.07148</td>
<td>-1.376</td>
</tr>
<tr>
<td>Communicating Answers</td>
<td>-.95588</td>
<td>.73013</td>
<td>.17708</td>
<td>-1.33128</td>
<td>-.58048</td>
<td>-5.398</td>
</tr>
</tbody>
</table>

The difference in scores between the PwA in the experimental group using CACE, and the control group using CMAD were also analyzed using a Paired Samples $t$-test. A statistically significant difference was seen between the two groups in the survey question regarding ‘Communicating Answers’ ($t = 3.322, p = .006$). In their opinion, PwA from the experimental group were able to communicate answers more effectively through the use of CACE.
Survey to Measure PwA’s Frustration with Communicative Support

The final question in the PwA survey addressed the level of frustration that the PwA felt regarding the communication support they received from the SW evaluator. A Paired Samples t-test was carried out on the results of this last question in the experimental group to determine whether or not there was a difference in the levels of frustration pre and post-test as a result of the intervention.

Table 22 Differences in the levels of Frustration felt by PwA in the Experimental Group, Pre and Post-Intervention using a Paired Samples t-test

<table>
<thead>
<tr>
<th>Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>17</td>
<td>2.8</td>
<td>1.17</td>
<td>-3.598</td>
<td>.002</td>
</tr>
<tr>
<td>Post</td>
<td>17</td>
<td>3.8</td>
<td>.281</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There was a statistically significant difference in the levels of frustration felt by the PwA regarding communicative support pre and post-test (see Table 20). The SW participants’ improved communication skills, combined with the administration of CACE, was less frustrating for the PwA.

5.7 Statistical Analyses Arising from the Research Questions

Question 3) Does enhanced communication and confidence in Social Work participants result in increased accuracy in the determination of capacity?

On twelve occasions SW participants were unable to determine whether or not the PwA had capacity, even though the participants were guided to use this option as a last resort. This required further analysis. What, if any, were the factors that caused the SW participants to conclude that they were unable to determine capacity? The SW Participants’ comments in the survey measuring capacity determination confidence led this researcher to hypothesize that the PwA’s communication deficits were a causal factor. The following variables were therefore chosen to be analyzed:
- Severity level of PwA’s expressive skills
- Severity level of PwA’s receptive skills
- SW Participant’s experience

Different severity levels were assigned a number: 1 = mild, 2 = mild to moderate, 3 = moderate, 4 = moderate to severe, and 5 = severe.

The dependent variable selected was the ‘ability to determine capacity’ from the first administration where both groups used the CMAD questionnaire, plus the three findings of ‘unable to determine capacity’ from the control group post-test, who also used the CMAD questionnaire. The data from the experimental group post intervention was not included in the analyses. A Logistical Regression Analysis was chosen to analyze the data because the dependent variable was dichotomous (able or unable to determine capacity). This type of analysis is commonly used to predict whether or not a factor affected the dependent variable. Did the severity level of the PwA’s expressive skills cause the SW participant to be unable to determine capacity? The results in Table 23 showed that none of the independent variables were significant predictors of the SW participants’ ability to determine capacity.

*Table 23 Measurement of Independent Variables on SW Participants’ Ability to Determine Capacity using a Logistical Regression Analysis*

<table>
<thead>
<tr>
<th>Variables in the Equation</th>
<th>B</th>
<th>S.E.</th>
<th>Wald</th>
<th>df</th>
<th>Sig.</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exp_Aphasia_Severity</td>
<td>.168</td>
<td>.361</td>
<td>.215</td>
<td>1</td>
<td>.643</td>
<td>1.182</td>
</tr>
<tr>
<td>Rec_Aphasia_Severity</td>
<td>.736</td>
<td>.574</td>
<td>1.645</td>
<td>1</td>
<td>.200</td>
<td>2.087</td>
</tr>
<tr>
<td>SW_Experience</td>
<td>-.254</td>
<td>.501</td>
<td>.258</td>
<td>1</td>
<td>.612</td>
<td>.776</td>
</tr>
<tr>
<td>Constant</td>
<td>-2.011</td>
<td>1.951</td>
<td>1.062</td>
<td>1</td>
<td>.303</td>
<td>.134</td>
</tr>
</tbody>
</table>

a. Variable(s) entered on step 1: Exp_Aphasia_Severity.

The final variables to be considered were the SW participants’ communication skills as measured by the MSC construct ‘Revealing Competence’ and their confidence as measured by the surveys. Did a lack of ability and confidence in communication skills contribute to the SW participants inability to determine capacity? An Analysis of
Variance (ANOVA) was conducted to compare the means of the two groups, those who could and those who could not determine capacity. The MSC ‘Revealing Competence’ scores were the dependent variable and the ability to determine capacity was the factor. The results showed that there was a significant difference between the two groups in their communication skills. Those who could determine capacity scored higher on the MSC.

Table 24 Difference in MSC ‘Revealing Competence’ Scores between those Social Workers who could determine Capacity and those who could not, using ANOVA

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>df</th>
<th>f</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to determine capacity</td>
<td>21</td>
<td>3.24</td>
<td>.49</td>
<td>29</td>
<td>6.17</td>
<td>.019</td>
</tr>
<tr>
<td>Unable to determine capacity</td>
<td>12</td>
<td>2.73</td>
<td>.61</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

An ANOVA was also used to measure the variance between the two groups in the results of the survey measuring the SW participants’ communicative confidence.

Table 25 Means and Standard Deviations for Communication Confidence Survey Scores between SW participants who determined Capacity and those who did not

<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Unable to determine Capacity</th>
<th>Able to determine Capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
</tr>
<tr>
<td>1)</td>
<td>12</td>
<td>2.3</td>
</tr>
<tr>
<td>2)</td>
<td>12</td>
<td>2.1</td>
</tr>
<tr>
<td>3)</td>
<td>12</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Table 26 Differences in Communication Confidence Survey Scores between SW participants who determined Capacity and those who did not using an ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confid_Svy_Q1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2.520</td>
<td>1</td>
<td>2.520</td>
<td>3.867</td>
<td>.058</td>
</tr>
<tr>
<td>Within Groups</td>
<td>20.200</td>
<td>31</td>
<td>.652</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>22.720</td>
<td>32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confid_Svy_Q2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2.192</td>
<td>1</td>
<td>2.192</td>
<td>3.508</td>
<td>.071</td>
</tr>
<tr>
<td>Within Groups</td>
<td>19.369</td>
<td>31</td>
<td>.625</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>21.561</td>
<td>32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confid_Svy_Q3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between Groups</td>
<td>2.652</td>
<td>1</td>
<td>2.652</td>
<td>3.975</td>
<td>.055</td>
</tr>
</tbody>
</table>

125
The results in Table 26 were worth reporting because the difference in communication confidence between the two groups was approaching significance, especially with questions 1 and 3 (p = .058 and .055 respectively).

1) How confident are you in your communication skills that you can enable the person with aphasia to understand the capacity evaluation process?

3) How confident are you that you would be able to evaluate the capacity of the person with aphasia to make admission decisions?

A lack of confidence in communication skills in conjunction with lower MSC ‘Revealing Capacity’ scores appeared to be contributing factors to the inability of some social workers to determine capacity.

### 5.8 Statistical Power and Effect Size

The purpose of calculating the statistical power of a test and the effect size is to help assess the clinical or practical importance of the results of tests of statistical significance. The calculation of power detects relationships and rejects a false null hypothesis. The power of a test is calculated by subtracting the probability of a Type II error from 1.0. The maximum power is 1.0 and 0.8 is considered an acceptable level. The effect size measures the strength of the relationship between two variables, that is, is the difference real or due to a change in factors? The greater the effect size, the greater the practical or clinical significance. Cohen suggested that effect sizes of .20 are small, .50 are medium, and .80 are large, enabling researchers to compare an experiment’s effect-size results to known benchmarks. It is important to remember that you can have a Cohen’s $d$ greater than 1.0. Cohen’s $d$ was calculated by finding the difference between the pre
and post intervention MSC and MPC mean scores for the experimental group. The difference between the two mean scores was divided by the combined standard deviation.

Table 27 Cohen’s d Effect Size and Statistical Power Calculations using MSC and MPC Results Pre and Post-Intervention in the Experimental Group

<table>
<thead>
<tr>
<th></th>
<th>Exp grp pre</th>
<th>Exp grp post</th>
<th>Cohen’s d</th>
<th>Statistical Power</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>MSC Acknowledge</td>
<td>3.05</td>
<td>.68</td>
<td>3.61</td>
<td>.56</td>
</tr>
<tr>
<td>MSC Reveal</td>
<td>2.97</td>
<td>.60</td>
<td>3.67</td>
<td>.66</td>
</tr>
<tr>
<td>MPC Interaction</td>
<td>3.26</td>
<td>.68</td>
<td>3.64</td>
<td>.58</td>
</tr>
<tr>
<td>MPC Transaction</td>
<td>2.8</td>
<td>.83</td>
<td>3.5</td>
<td>.54</td>
</tr>
</tbody>
</table>

Legend Exp grp pre = Experimental Group Pre-Intervention. post = post-intervention

Three of the four constructs in the MSC and MPC showed strong power with a large effect size confirming the clinical or practical significance of the results. The construct of ‘Interaction’ showed a moderate effect size.

5.9 Qualitative Methods – Results

The overall results of the qualitative methods were mixed. Sufficient data was gathered to pursue a grounded theory approach to answer one research question. Content analysis was completed to draw inferences regarding perceived differences between the use of CACE and the CMAD questionnaire. Regrettably insufficient data was gathered in order to thoroughly conduct either content analysis or grounded theory in order to elicit inferences or develop theories in other areas. Results of priori concepts and emerging themes have still be included as they provide insight and could be the basis for further research.

5.9.1 Social Work Participants' Inability to Determine Capacity

The results from Research Question 3, does increased communication skill and confidence result in more accurate determinations of capacity, revealed that on twelve
occasions the SW participants were unable to determine whether or not the PwA had the capacity to make a decision regarding admission to long-term care. To briefly review the methods procedure, following the capacity evaluation of the PwA, the SW participants left the room and made their determination of capacity. They were asked to make every effort to decide if the PwA had capacity or was lacking in capacity. For the purposes of this research and only as a last resort, the SW participants were allowed to select “Unable to determine”. If this option was chosen, they were asked to write explanatory comments. The aim of allowing this option was two-fold. First, to generate qualitative data that could identify the potential barriers to capacity evaluation in this population and second, to determine whether the use of CACE with communication training could overcome the barriers, or if changes in the tool and the communication training were required.

The research question generated by the dilemma faced by those SW participants regarding capacity determination was as follows: “What factors caused SW participants to be unable to determine capacity?” The explanatory comments were analyzed using Grounded Theory. All twelve social workers wrote comments to justify their selection of ‘unable to determine’. The number of identifiable themes each SW wrote varied from one to ten. The data was grouped into themes, coded and reduced. Three themes predominated; the most prominent of which was the social workers’ inability to understand and communicate with the PwA: “….other times I was not sure if he understood my questions and his answers were repetitive” SW participant. One SW participant acknowledged how hard the PwA was working to try and get his message across “… but I was unable to understand his responses” SW participant. The second theme concerned the issue of communicative confidence. Many of the SW participants reported the need for another evaluation session, preferably with a S-LP who could help with communication. This suggests that the SWs did not have the confidence in their own communication skills to determine capacity, preferring instead to rely on the S-LP. The final theme was the need to verify information externally, either with a family member or with the healthcare team. “He stated that he was independent with all his ADLs but it was too difficult to determine if this is accurate.” SW Participant. The PwA was successful in transferring the required information regarding ADLs, but the SW appeared to need
verification. The specific skill of verifying given information is part of SCA™ and is illustrated in the CACE DVD communication training.

The second corpus of data came from the Independent S-LPs who administered the MSC, MPC and completed forms determining whether or not the PwA understood each question. The hard copy forms were re-examined, and written comments by the Independent S-LPs were gathered. The comments concerning the SW participants who were unable to determine capacity were used in the data analysis. On twelve occasions the S-LPs had written comments regarding the evaluation process and six concerned the twelve SW participants. Descriptive comments were grouped into themes, coded and reduced. Two themes emerged, ‘time’ and ‘communicative support’. The Independent S-LPs identified that the SW participants did not always provide the PA sufficient time to process information and generate an answer: “SW often did not provide participant with enough time to communicate everything he wanted to.” Independent S-LP. With five of the six evaluations the Independent S-LPs commented on the lack of communication support provided to the PwA “The person had a lot more to say given the right support.” Independent S-LP.

The combined data underwent a process of axial coding, an example of which is contained in Table 28. Axial coding provides a framework to further analyze the identified themes or phenomenon taking into consideration the context and events that lead to the occurrence of the phenomenon.

Table 28 Axial coding of the phenomenon of “Expressive Language”

<table>
<thead>
<tr>
<th>Element</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phenomenon “Expressive Language”</td>
<td>SW participants and Independent S-LPs reported that PwA had problems with verbally expressing the required information.</td>
</tr>
<tr>
<td>Causal conditions</td>
<td>Complexity of the task. The need to express detailed, specific concrete and abstract information.</td>
</tr>
<tr>
<td>Context</td>
<td>Current capacity evaluation process.</td>
</tr>
<tr>
<td>Intervening conditions</td>
<td>Varying communication abilities of SW participants. Varying skill levels and knowledge in providing the PwA with the communication supports needed to express themselves.</td>
</tr>
</tbody>
</table>
### Action strategies

<table>
<thead>
<tr>
<th>Action strategies</th>
<th>Communication training of SW participants with accessible capacity evaluation tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequences</td>
<td>All SWs who received training and used accessible tool able to determine capacity accurately</td>
</tr>
</tbody>
</table>

The context, causal conditions and intervening conditions were remarkably similar across the different themes.

To return to the research question, it asked what factors caused the SW participants to be unable to determine capacity. Five themes or properties emerged from two sets of data: language barrier (comprehension and expression), verification of information, communicative confidence, lack of processing time and lack of communicative support. These themes linked together to form a coherent category of ‘Evaluator Communication Barriers’. Those social workers who demonstrated problems with understanding, communicating with and verifying information given by the PwA were unable to gather and verify sufficient information to make a determination of capacity. The Independent S-LPs also identified that a lack of communication support, including the provision of time, contributed to communication breakdown and an inability to determine capacity.

The resulting theory was as follows:

> In order for social work evaluators to confidently evaluate the capacity to make admission decisions in people with aphasia that they must be trained in specific communication skills.

This theory supported the results of the quantitative analysis comparing the mean scores of the MSC ‘Revealing Competence’ of those SWs who could and could not determine capacity. Those SWs who could not determine capacity had lower ‘Revealing Competence’ scores. The results of the analysis strongly confirmed the need for evaluator communication training and highlighted the importance of verifying information.

### 5.9.2 Social Work Participant Evaluation of CACE

After administering CACE, the SW participants in the experimental group were asked to complete a survey to determine which evaluation process they preferred and to provide a
written narrative for their preference. Seventeen SW participants provided written comments. Again, a second body of data was used to help verify the inferences drawn, this time from the Independent S-LP Key Informant Interviews. The subsequent data was analyzed through content analysis and the following concepts and emerged:

1) **Confidence - Increase in Capacity Evaluation Confidence using CACE**

Evaluators’ lack of confidence in communicating with and evaluating people with aphasia’s capacity was established in the social work focus groups (Chapter Three). Identifying changes in confidence levels with the administration of CACE following communication training was reflected in the second research question. Conceptual analysis established the frequency of the following predetermined concepts ‘confidence’, ‘understand’, ‘communicate’ and ‘CACE’. Synonyms and Key Words In Context (KWIC) were examined, for example, “more sure” as a synonym for ‘confident’, and confirmation that a word, such as ‘communicate’ truly reflected the concept and did not refer to something else. Through relational analysis a meaningful relationship between ‘confidence’ and ‘understand’, and ‘confidence’ and ‘communicate’ was established. Furthermore, there was a meaningful relationship between those concepts and ‘CACE’.

Many of the SW participants reported that the use of CACE with communication training increased their confidence because they felt that they now had the skills to get their message across and to understand the PwA’s responses (concepts are underlined): “CACE increases assessor’s confidence that info is conveyed in a meaningful way. Provides clarification options for person being evaluated.” and “I preferred using CACE because it enabled me to be more sure that the client understood me and that I understood him.” SW participants. The results of the content analysis confirmed the findings of the statistical analysis conducted to answer the second research question, that is, CACE with communication training increased a SW’s confidence to determine capacity. Confidence in carrying out capacity evaluations was important to the SW participants themselves, as one of the participants pointed out: “It is such an important task and the outcome could potentially deprive someone of their right to make decisions about where they will be living. This is really big and I always feel the burden of this task.” SW participant.
2) Decreased Stress - using CACE

At the best of times, capacity evaluation is a stressful process to go through. If it is carried out conscientiously, the individual is told that his or her ability to make a decision to remain at home or move to a care home is being assessed, and that the consequences of a finding of incapacity is a loss of autonomy. A communication barrier such as aphasia adds to both the evaluator and individual’s levels of anxiety.

“I always feel nervous, self doubting and under pressure. It is hard enough to assess someone who does not have communication barriers but even harder when a communication barrier exists.” *SW participant.*

The concepts searched for were ‘stress’, ‘anxiety’ ‘frustration’ and ‘CACE’. Review of the SW participants’ narratives regarding the administration of CACE not only demonstrated that CACE reduced the evaluator’s stress, but also that it helped to alleviate the PwA’s stress during the evaluation process: “The tool is very helpful in communication. The tool decreases stress for participant when dialoguing about capacity.” *SW participant.* Antonyms were also included in this analysis as they illustrated a positive correlation between the use of CACE and the reduction of stress “Both the SW and the person with aphasia seemed much more comfortable and at ease.” *Independent S-LP.* Stress and anxiety have a negative effect on the cognitive processes needed to successfully reveal capacity. If these effects could be reduced by an accessible system then an individual with aphasia would be able to use his or her language skills more effectively to reveal capacity.

3) Organization of CACE

An organized and logical evaluation process helped to mitigate the effects of stress for this population. Comprehension was augmented by the questions following a logical sequence. “It provides a standardized structure for asking the questions which is helpful for use with any client.” and “Good flow. Easy to Administer/follow.” *SW participants.* Supported Conversation for Adults with Aphasia (SCA™) recommended giving information clearly, in manageable sections or units, and to offer logical choices to the
These SCA™ techniques were used in the design of CACE and were included in the communication training DVD. It would appear from the SWs’ comments that the organization of CACE was a positive attribute.

5.9.3 Key Informant Interviews Independent Speech-Language Pathologists

The Independent S-LPs were the clinical experts in the field of communication. Their experience with working with individuals with aphasia across a number of healthcare settings, and following a variety of approaches provided credibility to the testing process. Their comments following the data collection (64 evaluations in total) were objective, informative and echoed some of the themes resulting from the SW participant analysis.

1) Stress – Stress of the PwA During the Capacity Evaluation

Even though the PwA were well prepared for the research trial with information regarding the research protocol and the testing of CACE, both the Independent S-LPs and the SW participants commented on the participants’ levels of stress. One Independent S-LP reflected on the contrived nature of the capacity evaluations. The PwA knew that the questions were not real, but had to answer them as if they were. Consequently, a minority of the PwA were visibly distressed by the evaluations. The Independent S-LPs went on to state that even though the PwA understood that the evaluation did not apply to them personally, they were focusing on very real concerns that may, one day, necessitate a decision about the most appropriate place to live.

2) Response to Stress - the SW Participants’ Response to the PwA’s Stress

According to the Independent S-LPs, the way in which the SWs responded to the PwA who were distressed varied. When using CACE, one SW said that the PwA’s wife was concerned about the PwA living at home and actually wrote down the wife’s name. Suddenly the situation was too personal. The SW participant did not pick up on the PwA’s distress and kept on repeating the information: “I wanted to climb into the evaluation to reassure the PwA.” Independent S-LP 1. Another Independent S-LPs reported similar findings, especially with the use of the CMAD questionnaire. She observed that the questions were too challenging: “The questions didn’t always make sense to me, let
alone the person with aphasia.” Independent S-LP 2. Combined with a lack of communication support from the SW participants, it was not surprising that the PwA did not understand and was, at times, distressed by his or her own confusion. Other SW participants picked up on the PwA’s anxiety immediately, and reassured them by reminding them that they were participating in a research project.

3) Communicative Confidence - Differences in SW Participant’s Communicative Confidence

With regard to the SW participants, the Independent S-LPs reported a variety of unique styles used when relating to, and communicating with PwA. By and large, the SWs appeared more relaxed at the beginning of the session during the conversation and at the end, but were tense during the evaluation. The difference between SW participants’ confidence and comfort while evaluating capacity was also noticeable. Some SWs were relaxed, conversed and took no notes during the evaluation, while others appeared strained, almost ‘stuck’ and a few wrote copiously, “With one SW at the expense of the relationship.” Independent S-LP 1.

4) Enhanced Communication Skills - with CACE and Training

Two Independent S-LPs commented that the training in SCA™ combined with the pictographs in CACE helped the SW participants to verify information more effectively, so that they were more confident in the accuracy of the response: “They (SW participant) verified more information, especially with getting the patient to understand.” Independent S-LP 1. Verification of information was one of the themes arising from the data of the SW participants who were unable to determine capacity. When the consequences of an evaluation are so life altering, verification of information was an essential tool for the evaluator.

5) Clear Explanations - Explanation of Capacity Evaluation Process

The Independent S-LPs observed that with the CMAD questionnaire, the explanation of capacity evaluation process was scattered and on occasion omitted completely. They went on to comment that one of the strengths of CACE was the systematic way in which
the PwA was taken though the introduction to the capacity evaluation. This resulted in a greater understanding on the part of the PwA of the evaluation’s rationale and consequences, and the subsequent questions. Although, as mentioned by both the SW participants and the Independent S-LPs, capacity evaluation was an inherently stressful procedure, not fully understanding what was happening was much more anxiety provoking.

6) Organization of CACE
One Independent S-LP stated that the difference between the two assessments (CMAD and CACE) was “night and day.” Independent S-LP 2. When asked to expand, she reported that the support from the pictographs and text made a considerable difference, and that CACE had a logical flow: “The questions had been “fleshed out and made more sense.” Independent S-LP 2. The organization and flow was one of the themes emerging from the SW participant’s data as well. When communicating with the PwA, clarity, organization and logic were observable assets.

7) Recommendations - Recommendations for Changes to CACE
It was reported that the PwA’s understanding of the term ‘long-term care home’ proved to be a problem area in CACE. The current focus in healthcare, both in the community and in hospital discharge management is on changing the name from ‘nursing home,’ which has a negative connotation, to ‘long-term care home’. Many of the PwA struggled to understand what was meant by long-term care. One possible solution generated in the interview was to define the term ‘long-term care’ in the CACE introduction.

5.9.4 Key Informant Interview, External Social Work
The original intent was to interview an external social worker from the working group who trains evaluators in capacity evaluation in order to elicit additional feedback and perspective regarding the effectiveness of CACE. The external social worker agreed to view some of the evaluation recordings. However, his comments largely focused on the philosophy of capacity evaluation rather than specific remarks regarding the usefulness of CACE. Nevertheless, his comments were considered to be of value and have been
included. The following themes emerged from the data, however they do not arise from rigorous qualitative methods, as there was insufficient data so to do.

1) Role of Capacity Evaluator
The external SW’s first comment was particularly thought provoking. He stated that the SWs or nurse case managers in the community should be themselves and not take on the persona or ‘role’ of an evaluator. The SW participants should apply the principles of evaluation in a conversational manner while maintaining their own personality: “You are you, you are not an ‘evaluator’.” External social worker. The Independent S-LPs also observed a difference in the SWs’ communicative behaviours between conversing with the PwA and formally evaluating the participant.

2) Evaluate what you see
Another comment from the external social worker concerned Wahl’s recommendation to “probe and verify”.

The External SW was watching a SW participant using CMAD. The first question asked was “How are you doing at home?” The PwA communicated that she was managing well at home. However, she was sitting in a wheelchair. The external SW wanted the SW participant to follow up with questions regarding mobility and ADLs. “Evaluate what you see.” The wheelchair should have been a trigger for further questioning. Overall, from his observations, he commented that many of the questions used in the CMAD were too general. The Independent S-LP who found the CMAD questions both too general and confusing also observed this.

3) Don’t take the Process for Granted
While watching an evaluation using CACE, the external SW remarked that nothing should be taken for granted in the explanation of the capacity process. He was referring to the Substitute Decision Maker (SDM). The SW participant was conscientiously explaining the process of approaching the Substitute Decision Maker while pointing to the pictographs in CACE. The SW said, “That’s your husband right?” Even if the husband’s name as SDM is in the medical record, this should have been verified at the time of the capacity evaluation. The SDM has to be willing, capable and available, and
every individual has the right to reject a SDM at any time. According to the External social worker, the SW’s role is to advocate on the participant’s behalf, and if necessary approach the Consent and Capacity Board to change the SDM. Although this is a procedural issue that applies to every capacity evaluation, a reminder to confirm the SDM with the person being evaluated will be added to the Instructions for Administration.

4) Evaluation Principle of Communication

Finally, the external SW brought up ‘evaluation principles’, one of which was communication. In his training he talked about ‘meaningful communication’ that is based on trust. There are three considerations to meaningful communication: the first is the right to be evaluated in your own language, if at all possible. This would entail finding a capacity evaluator who spoke the same language or using an official interpreter. The second consideration described was the ‘physical ability to speak’, which included barriers such as aphasia and dysarthria. Finally, the patient or client’s pre morbid education and comprehension should be taken into consideration and explanations altered accordingly. With regard to building and maintaining trust, one Independent S-LP commented that at times it appeared that the SW did not believe the message communicated by the PwA. This could be construed as a lack of trust. The DVD communication training gave some information on the nature of aphasia and hidden capacity, however, whether or not it was sufficient will be discussed in the next chapter. Verification of information given by an individual, and belief in the information, would hopefully lead to the effective building and maintenance of trust, an essential ingredient in capacity evaluation.

5.9.5 Qualitative Research Results Summary

The rationale for including qualitative research in the methodological design was to elicit theories and inferences that would explain why CACE with training was effective and identify areas that would benefit from change. The results were mixed in large part due to the limited amount of data collected. It was not possible to triangulate the content of the key informant interviews, although the content of the interviews was used to triangulate data from survey comments completed by the SW participants. There was sufficient
narrative data however, to produce one grounded theory regarding the need to be an effective communicator with this population in order to confidently evaluate capacity. The theory confirmed the findings from the tests of statistical significance. Results of content analyses highlighted specific concepts demonstrating that CACE with communication training worked effectively; for example, the increase in evaluator confidence and reduction of stress. Also, areas that would benefit from change were identified such as adding an explanation of long-term care, and checking on the choice of Substitute Decision Maker. This valuable important information could not have been elicited from quantitative analyses alone.

5.10 Results Summary
Overall, the results of both the quantitative and qualitative data analyses showed promise in demonstrating that CACE with communication training was an effective capacity evaluation tool for people with aphasia. The results addressed the four research questions and helped to reject the null hypotheses. CACE with communication training enhanced the evaluators’ skills and confidence resulting in accurate determinations of capacity in this research population. The PwA were able to transfer information more effectively and were less frustrated by the level of communicative support from the trained social workers. An additional result of importance was the preference for CACE over CMAD. One hundred percent of the participants in the experimental group (both SW and PwA) reported that they preferred CACE, even those PwA who presented with very mild receptive and expressive aphasia. The implications and recommendations arising from the results will be discussed in the next chapter.
Chapter 6 Discussion

6.1 Chapter Overview
At the outset of this thesis, problems with the current capacity evaluation process were illustrated by the case history of the gentleman from the Caribbean. His aphasia acted as a barrier to revealing his capacity to make a decision about where he would live. This scenario was a major motivation for this research study. The aim of this doctoral thesis was to take a complex legal process, simplify and organize the legal components, and develop an accessible capacity evaluation tool for people living with communication barriers. The tool was then tested to determine if it was effective with participants with aphasia (PwA). The results, as described in the previous chapter, showed that the Communication Aid to Capacity Evaluation (CACE) with training in communication techniques showed promise as an accessible evaluation process for participants with expressive aphasia. The results also confirmed findings in the literature regarding the inadequacy of the current capacity evaluation process.¹

As a result of using the current Capacity to Make Admission Decisions (CMAD) questionnaire in this study, a competent PwA was found to be lacking in capacity. On twelve other occasions SW participants concluded that they were unable to determine capacity. This chapter will discuss the implications of the results for the application of capacity evaluation, the evaluators, people with aphasia, the healthcare system and communication training. Each research question will be explored and the results will be compared to similar research studies. Finally, the limitations of the study will be examined.

6.2 Research Question 1
Does CACE with communication training enhance a social worker’s communication skills to reveal capacity in a person with aphasia?

6.2.1 The Effectiveness of the Communication Aid to Capacity Evaluation
The analyses of quantitative and qualitative data showed that CACE, with communication training enhanced the communication skills of the evaluator and helped the PwA to reveal their capacity. The participants and external reviewers reported that the key to CACE was its accessibility and communication support. A complex legal process, as described in chapter 3, was simplified and supported through the use of clear language, pictographs and highlighted text. The evaluators read the text aloud while pointing to the words and the pictographs. The structure and support of CACE helped the PwA to understand the purpose of the capacity evaluation as well as specific information and questions. The pictorial and written choices in CACE allowed the PwA to communicate information, which then could be verified by the SW participant. Similar results were found in Rose et al.’s study on the effectiveness of aphasia-friendly printed health education materials for people with aphasia following stroke. Their analysis showed a significant increase in the participants with aphasia’s comprehension of information on four different medical topics when presented in an accessible format. Participants in the trial were more confident in answering questions about the medical information in comparison to those who read the non-adapted materials. The researchers used simple words and short sentences, large and standard font, white space, and relevant pictures in their printed education materials. The same techniques were used in the development of CACE.

The SW participants had to have the communication skills to depart from CACE when necessary to pursue novel information given by the PwA. A prerequisite of a thorough capacity evaluation is the ability of the evaluator to “probe and verify” to elicit specific, relevant information about the patient’s context. Every individual participating in the capacity evaluations was different, living in a unique set of circumstances. This necessitated the SW participants in the experimental group being trained in specific communication skills to interact with the PwA. Kagan et al.’s research also examined the effectiveness of communication training through the teaching of Supported Conversation to Adults with Aphasia (SCA™) to volunteers who regularly interacted with people with aphasia at a community Aphasia Centre. Kagan et al.’s two-day program included information on aphasia as well as interactive training and practice in SCA™ skills. Kagan
et al. developed the MSC and MPC to measure the conversational behaviours that changed as a result of the training. Their results conclusively showed that communication training made a difference across the 4 constructs that comprise the MSC and MPC.\textsuperscript{102} The communication training that accompanied CACE was not interactive and did not offer the depth of training that Kagan used in her study.\textsuperscript{102} Instead, a DVD format that included key components of SCA™ illustrated by a S-LP and an individual with aphasia was used. This allowed for multiple viewings of different training techniques that comprise SCA™. If CACE is to be accepted as a capacity evaluation tool, all capacity evaluators in the Province will require communication training. The DVD format was thought to be the most practical solution considering the number of potential evaluators. Although this research study used a different training method, analyses of the communication training through the administration of the MSC and MPC showed similar results to Kagan et al.’s study across the four constructs. Communication training combined with CACE improved the SW participants’ communication skills. The PwA had the vehicle to reveal his or her inherent capacity to make a decision regarding admission to a care facility.

6.2.2 Implications of Results and the Law

Capacity Evaluation to make an admissions decision is a legal process and every individual in Ontario has the right to a fair and just evaluation of capacity. The legal tenets within the Health Care Consent Act that guide the evaluation of capacity were discussed in the literature review and in the chapter concerning the development of CACE. In summary, they included an explanation of why the evaluation is taking place, the consequences of a finding of incapacity, presumption of capacity, and consent to evaluate. The participants with aphasia had the right to understand these tenets, ask questions, understand the answers, and express their consent. The results of the analyses showed, that with the use of the CMAD questionnaire, the PwA did not always understand the legalities of the evaluation process, and were unable to communicate their responses, including consent to be evaluated, as effectively as they would have liked. Their rights to a fair and just evaluation were compromised. Through the use of the CMAD questionnaire, a competent person with aphasia was found to be incapable. In the
real world her rights to decide where and how she would live would be taken away, and her Substitute Decision Maker would make the discharge decisions on her behalf. The PwA’s age made this situation more of an issue; she was only 42 years old. A comparatively young vulnerable person because of her stroke and aphasia would be placed in an even more vulnerable situation as her autonomy was eroded.

The ability of an evaluator to communicate effectively is reflected in one of the ‘purposes’ of the Health Care Consent Act. The purpose of the Act, as discussed in the literature review, was “to promote communication and understanding between health practitioners and their patients and clients.” This was one of the driving principles behind the development of CACE. The results of the research study clearly showed that the use of CACE with communication training gave the SW participants the skills to promote understanding and communication with the PwA. Conversely, the current CMAD questionnaire negated the SW participant’s ability to interact effectively with this population for the purposes of capacity evaluation. The current questionnaire worked against the purpose of the HCCA by denying the PwA’s right to understand information that a reasonable person would need to appreciate the issues at hand to make an informed decision.

All capacity evaluation tools seek to determine the same finding; is the individual capable of making a decision. Many times through the course of this thesis capacity has been defined as the ability to understand relevant information and the ability to appreciate the reasonably foreseeable consequences of a decision. It is worth revisiting what is meant by ‘understand’. The Ministry of the Attorney General defines it as:

“A person’s cognitive abilities to grasp and retain information. To the extent that a person must demonstrate understanding through communication, the ability to express oneself (verbally or through symbols or gestures) is also implied.”

The person with a communication barrier requires support to ‘demonstrate understanding through communication’ and to ‘express oneself (verbally or through symbols or
gestures). If a legal process such as the administration of the CMAD questionnaire is inaccessible, then erroneous judgments of capacity are possible, as evidenced by the PwA in this study and the gentleman in the introduction.

According to the Independent S-LPs who observed a total of 64 evaluations, the SW participants, when administering the CMAD questionnaire, did not consistently explain every legal construct concerning capacity evaluation. Constructs, such as the right of appeal, are complicated to describe at the best of times, but if the person being evaluated has a language barrier, the difficulties are magnified. Nevertheless, in a real life situation the evaluator is placing an individual’s rights at risk if the legal requirements are not followed. The literature review gave examples of the capacity evaluation process not being adhered to according to the law. On appeal, the Consent and Capacity Board overturned all of the findings of incapacity. CACE with communication training gives the evaluator the structure and tools needed to ensure that every legal tenet is clearly explained. It also provides a vehicle for the PwA to ensure that consent to be evaluated is informed and freely given.

In summary, CACE with communication training helped to preserve the legal rights of the participants whose capacity to make an admission decision was being evaluated. The results also showed that the use of the current CMAD questionnaire and a lack of evaluator training in specific communication skills put the participants’ legal rights to a fair evaluation at risk. The use of the current capacity evaluation system for this population needs to change.

6.2.3 Implications of Results and Social Work Ethics

Social work practice, including capacity evaluation, is driven by clear principles contained in the Canadian Association of Social Work’s Code of Ethics. Ethics is defined as “the application of moral values and responsibilities in the areas of medical practice”.

The Core Social Work Values and Principles contained in the Code of Ethics
include the “Respect for the Inherent Dignity and Worth of Persons”. Social work is founded on a long-standing commitment to respect the inherent dignity and individual worth of all persons and to uphold the human rights of those persons. These principles relate directly to capacity evaluation. Human rights include “each person’s right to self-determination, consistent with that person’s capacity and with the rights of others” and “respect for the client’s right to make choices based on voluntary, informed consent”. If a communication barrier cannot be overcome because of an inaccessible evaluation process and a lack of knowledge regarding how to communicate effectively, then a person’s human rights are under threat.

Hassan discusses the four key ethical principles that govern patient consent, they include: beneficence, non-malfience, justice and autonomy. All individuals have the right to give or withhold consent to having their capacity evaluated. Healthcare professionals who are eligible to conduct capacity evaluations should bear in mind the ethical principles when eliciting patient consent to partake in a capacity evaluation. The four ethical principles are compromised if a person living with aphasia is not given an opportunity to express his or her consent to be evaluated.

The majority of the SW participants verbalized concern about the ethics of carrying out capacity evaluations with people with aphasia. They supported the development of CACE with training in communication skills as a method of evaluating capacity in an ethical, conscientious manner. Comments from the qualitative data brought their concerns into focus:

“It is such an important task and the outcome could potentially deprive someone of their right to make decisions about where they will be living. This is really big and I always feel the burden of this task. It is hard enough to assess someone who does not have communication barriers but even harder when a communication barrier exists.” SW Participant

The concern was palpable, but it appeared that CACE with communication training helped to ensure that the SW participants had the tools and communication skills to ‘lessen the burden of the task.’ Revealing the individual’s capacity helped to protect his
or her right to make choices based on voluntary, informed consent. The adapted process helped to ensure that SW participants abided by their professional code of ethics.

6.2.4 Implications of Results and the need for Communication Training

The research question under discussion (does CACE and training improve social work communication skills?) examined both the effectiveness of CACE as an evaluation tool and the communication training. When considering the implications of the results, one important question arose: were they interdependent? If a social worker was well trained in specialized communication skills, did they need CACE in order to reveal the capacity of a person with aphasia? The results of the analysis showed that the answer was yes. Demographic data showed that two SW participants had attended a two-day training in SCA™ and that eight other participants had received varying amounts of communication education from the site S-LPs. The results of the MSC ‘Revealing Competence’, which specifically examined the SWs’ communication skills, showed that there was no significant difference in the skill set between those who received education and those who did not. Examination of the raw data showed that some of the SW participants who were unable to determine capacity had received some form of communication training. It would appear that the SW participants still needed CACE to effectively evaluate capacity.

The reverse question was, can social workers evaluate capacity using CACE but without communication training? It would be very difficult to determine an answer using this methodological design. A further study in which training was given to half of the SW participants would have to be carried out. However, results of the qualitative data shed some light on this question. Comments made by the Panel of Experts and Independent S-LPs in the Key Informant Interviews confirmed the need for evaluator education in communication strategies rather than depending on CACE alone:

“My only hesitation here is that evaluators with less training and experience working with people who have aphasia may still not recognize the importance of using adequate supports for comprehension, especially with fluent or severe aphasia.” panel member
The panel member astutely pointed out that CACE was designed to be used with people who presented with a variety of different types and severities of aphasias. With an individual with a severe comprehension deficit, evaluators would have to rely more on their communication skills to try and establish a level of capacity. One Independent S-LP noted that overall, the SW participants were more comfortable when asking questions using CACE rather than CMAD, but that the comfort levels improved further if the social workers had good communication skills. The SW participants themselves identified the need for further training in specific communication skills to successfully interact with, and evaluate the capacity of people with aphasia. In the demographic information the SW participant was asked if he or she would be interested in pursuing further training. All of the SW participants indicated that they would benefit from further communication training.

Finally, capacity examines the ability to understand relevant information, that is, relevant to the person’s own circumstances. There are an infinite number of differences between people, their knowledge, values, beliefs, circumstances and situations. No one tool can encompass all possible scenarios. The evaluator has to “probe and verify” in order to thoroughly determine whether or not an individual understands relevant information. This requires training in specific communication skills.

### 6.3 Research Question 2

**Does CACE with communication training increase a social worker’s confidence to determine capacity?**

Concerns regarding communication confidence expressed in the focus groups were the impetus for including the measurement of social work confidence in the research methodology. One focus group member reported returning to a patient with aphasia four times because she was so unsure of her decision regarding capacity. Another SW participant stated: “I usually dread it if the person isn't clearly capable or incapable. I get very nervous because I do not take the task lightly.” *SW participant.* Part of the motivation
for developing CACE with an accompanying communication training DVD was to provide tools that would increase the evaluator's communicative confidence.

Social worker confidence was measured twice during the methodological process, once following a five-minute conversation with the PwA, and after the evaluation of capacity. The results showed, that with this research population, CACE, combined with training in specific communication techniques, significantly increased the levels of confidence felt by the SW participants in the experimental group. An increase in confidence was not observed in the control group with the second capacity evaluation, despite receiving written information about aphasia and being familiar with the PwA.

6.3.1. The Emotional Toll of Capacity Evaluation on Social Workers

In the Methods chapter, Social workers were described as the ideal participants for this study. They were chosen for their evaluation experience, knowledge of the law regulating consent and capacity, and because of their role as patient or client advocates. This decision was vindicated by the comparatively high scores seen with all the SW participants in the MSC construct ‘Acknowledging Capacity’, that is, appropriate use of language and sensitivity to the PwA’s attempts to communicate. The social workers in this study scored significantly higher than the volunteer participants in Kagan et al.’s study (3.6 vs. 2.6)\(^{102}\). If social workers, with their exceptional skills, were struggling with the current capacity evaluation process, then the need for a communicatively accessible capacity evaluation process was paramount.

All of the social workers involved in this research study from the focus groups, the working groups and those who participated in the research trial took the responsibility of evaluating capacity very seriously. Many of them reported feelings of anxiety and self-doubt, of being overwhelmed and under pressure when administering the CMAD questionnaire. The depth of some of their feelings and lack of confidence showed how seriously they took this process:

“I feel anxious when evaluating capacity because of the responsibility- I don't want to make an error as I believe fundamentally in individuals right
Their commitment to carrying out the process conscientiously should be acknowledged. They were all aware of the consequences of taking away a person’s right to decide where he or she would live. Nevertheless, from some of their comments it would appear that there was an emotional cost to being an evaluator. It is hoped that the use of CACE with communication training will go far in increasing evaluator confidence and ameliorate some of the negative emotions surrounding capacity evaluation.

6.3.2. The Inter-related Effects of Confidence and Communication Skills

The SW participants needed to be confident in the tool itself, and in their communication skills to use the tool. From both the quantitative results from research question two and the Content Analysis, it would appear that the use of CACE increased their confidence. The SW participants had to have the confidence as well as the communication skills to leave the comparative safety and structure of CACE to ask or answer novel questions. In that way the SW participant was able to gather enough information to be confident in their determination of the capacity. Those SW participants who were unable to determine capacity (all of whom used the CMAD questionnaire) had lower survey scores in their communication confidence and in their communication skills as measured by the MSC ‘Revealing Competence’ construct. This might suggest a link between confidence and the ability to communicate. The more confident the SW participant felt in their abilities the more effective they were as communicators:

“I was able to properly administer the capacity evaluation this time using CACE and now felt confident in my decision of capacity. It allowed me to feel confident in my finding compared to last week when I was unsure of his capacity.” SW participant

6.3.3 Misconceptions of Social Work Participants’ Experience

Surprisingly, the years and type of experience the SW participants brought to the research study did not have a significant effect regarding confidence to evaluate capacity with this population. The SW participants, as a group, had many similarities such as being female, possessing post-graduate degrees in social work and working within a hospital system.
The two areas in which they differed were the diverse healthcare departments they serviced, and years of experience. The majority of the SW participants worked in acute care services where case management, discharge planning and bed utilization was central to their role. From participant report this group carried out capacity evaluations most frequently and were therefore more experienced with the consent and capacity process. The SW participants who reported familiarity with working with individuals with aphasia were those providing service to Stroke Units and Rehabilitation Units. Finally, the length of professional experience could suggest increased confidence when interacting with different patients and clients. It was worthwhile examining whether or not capacity evaluation experience, increased exposure to patients with aphasia, and increased length of service resulted in enhanced levels of confidence.

The results of two sets of statistical analyses showed that the SW participants in question were not more confident in their communication skills or findings of capacity than other social workers. Experience in regularly carrying out capacity evaluations, or working in a stroke unit did not result in increased levels of confidence to effectively interact with a person with aphasia and thereby determine capacity. An accessible evaluation tool with the specialized training was still required.

### 6.3.4 Communication Confidence Summary

In the real world, evaluators have the benefit of consulting with the healthcare team and the individual’s family. However, these professionals are the final arbiters of the evaluation process. Unless appealed, their finding of capacity is final. It is hoped that the use of CACE with communication training increases the evaluator’s confidence in their determination of whether or not a patient or client has the capacity to decide where and how he or she will live.

### 6.4 Research Question 3

**Does enhanced communication and confidence in social workers result in increased accuracy in the determination of capacity?**
SW members in the experimental group who used CACE found every competent PwA to be capable of making a decision regarding where they should live. The intervention increased the SW participants’ communication skills and confidence resulting in increased accuracy in capacity evaluation. On the other hand, as a result of using the current CMAD questionnaire in this study, a competent PwA was found to be lacking in capacity. In the real world her rights to autonomy regarding admission to long-term care would be taken away and her Substitute Decision Maker would decide where and how she would live. On twelve other occasions SW participants concluded that they were unable to determine capacity. These numbers are significant. This study used participants with one type of aphasia, Broca’s or expressive aphasia. The literature review revealed that over 90,000 people are living with aphasia, and the Copenhagen Study found that 12% of their participants had Broca’s aphasia. In Canada that would conservatively equate to 11,000 individuals with Broca’s aphasia. How many of these people are at risk for erroneously being found lacking in capacity because of their communication barrier?

### 6.4.1 Systemic Implications of Capacity Evaluation

From the outset of this doctoral research, the premise has been that it is the patient or client who lives with, or owns the communication barrier. This is evident in the speech-language pathology literature. The results of this study demonstrate that a shift in healthcare thinking needs to take place regarding ownership of the ‘barrier’. This change in focus has systemic implications.

In real-life, the social work evaluator must come to a decision regarding the patient’s capacity to make an admission decision. The rationale for allowing the selection of “unable to determine capacity at this time” was to explore further the barriers to capacity evaluation with this population. The results of the capacity evaluations led this researcher to explore the predictive variables that might account for the larger than expected numbers of social workers who were unable to determine capacity. Two of the three variables were the PwA’s communication barriers themselves broken down to expressive and receptive deficits. They were found not to be significant. The severity level of the
communication barrier did not account for the SW participants’ inability to determine capacity. The only factor that was significant was the SW participants’ own communication skills and confidence. This conclusion calls into question the perception of where the barrier exists.

The results of the literature review examining the current reality surrounding capacity evaluation, combined with the results of this study show that the barrier is multifactorial. There is a lack of accessible healthcare literature\textsuperscript{119,120,131,132} and assessment tools, and a lack of knowledge surrounding the legalities of capacity evaluation\textsuperscript{77} and how to communicate with people with aphasia. Unfortunately, there is also lack of money to fund the development of accessible materials and to provide evaluation and specialized communication training. The external pressures to move patients through the system are intense, sometimes resulting in evaluations being administered too early in a less than conducive environment.

“Often we have elderly patients come to ED (Emergency Department) because of a psychosocial crisis or a fall or other medical issue……. We assess their capacity to make long term care decisions when they are out of their usual environment (home) and they may be disoriented just on that basis alone. As well, they probably slept on an uncomfortable stretcher within a noisy emergency department, may not have eaten and may also be fearful or anxious, and are not agreeable to nursing home placement. All these elements, I'm sure, could seriously impact their cognition in a very negative way.” \textit{SW Participant}

The SW participant highlights multiple barriers to the fair evaluation of capacity such as distraction, disorientation, fear and a lack of sleep. The idea that the communication barrier belongs to individual needs rethinking. The system has to change if the barriers are to be overcome and the legal tenets contained in the Health Care Consent Act adhered to. This will require a commitment on the part of the Ministry of Health and Long-Term Care. A financial investment and extensive education is required to ensure that the human and legal rights of all individuals, including those with language and communication barriers, are respected and preserved.
6.4.2 Beneficence versus Autonomy

Returning to the twelve occasions when, following the capacity evaluations, the SW participants selected ‘unable to determine’, it is impossible to determine whether these would have transferred to a finding of capacity, or incapacity. The literature review brought into focus the contentious issue of beneficence versus autonomy, or safety versus risk. Healthcare professionals have to constantly balance a patient’s right to decide where he or she will live against being negligent by supporting an excessively risky discharge. Some rehabilitation and medical professionals erroneously believe that they know better than the patient when it comes to safety versus risk. There is also the notion that aphasia equates to cognitive deficits and cognitive deficits equates to incapacity. This is not the case. Nevertheless, taking into consideration current thinking and the pressure to move people through the system, it would not seem unreasonable to assume that some of the twelve SW participants, if pushed into making a decision, would opt for the safe alternative and find the person with aphasia lacking in capacity. However, as the Office of the Attorney General point out:

“Unless there is clear and compelling evidence of “impaired ability to understand and appreciate”, the assessor cannot use a finding of incapacity as a means of to manage risk.”

The pressure, even on patients who have been found to be capable, can be intense. The individual remains vulnerable to the family and the team who disagree with the individual’s discharge decision. What is considered to be a risky and unreasonable choice is no longer accepted as a standard for incompetence.

6.4.3 Capacity Evaluation Results and the Impact on Participants with Aphasia

One of the most compelling features of the demographic information from the PwA group was their mean age of just under 62 years. This is young. The majority of stroke and aphasia studies cited in the literature review reported higher mean ages: 73 years, 71.8 years and 75.8 years. Only the Dakar Study identified participants with a younger
mean age of 56 years.\textsuperscript{15} Twenty (63\%) of the PwA from the study were under the age of 65, the established age of retirement in Canada. The implications of finding the participants in the research study lacking in capacity are all the more compelling because of their comparatively young age. In Dickey et al.’s research on the incidence of aphasia in Ontario, the data gave information on hospital discharge destination. Twice as many patients with stroke and aphasia were discharged to long-term care than those who presented with stroke alone.\textsuperscript{10} Only 33\% of patients with aphasia returned to their home, whereas 54\% of stroke patients who did not have aphasia were discharged home.\textsuperscript{10} The individual in the introduction’s case study was in his early 60s when he was admitted against his wishes to a long-term care facility. Long-term care, by its very nature, is designed to care for the elderly or for those who truly cannot care for themselves, not for someone under the age of retirement with full mobility and hidden capacity. The competent individual found lacking in capacity in this research study was only 42 years old, the implications of this happening in the real world are ethically alarming.

Individuals who live with the consequences of stroke and aphasia have to face many losses in their lives. An admission to long-term care compounds those losses. You lose the right to live in your own home and live life how you choose. People’s right to privacy is protected in the Long-Term Care Patient’s Bill of Rights, but many do not have the resources to pay for private accommodation and have to share a room with up to three other people. The loss of your own environment and space can be hard to bear.

Using quotes from people with aphasia from other publications, the effects of losses are described, from the loss of communication:

“\textit{Oh my God. I want to die – when I could not speak – because I know I could not live that way}”.\textsuperscript{114} p.16

to the loss of a job or profession (nearly two thirds of the PwA are currently under retirement age):

“\textit{Got no job at all now. That hurts. Hurts a lot you know – angry really. Why me? Good job and all}”.\textsuperscript{114} p.29
the loss of identity:

“We make a choice of multiple identities acted out through languages”. ¹⁰⁴ p.17

The loss of autonomy to decide where and how you will live is traumatic enough. For someone who, up until the day of their stroke, was working as a Provincial Minister, mechanic, or Registered Nurse, and who can no longer communicate as they once did, can have devastating psychosocial and emotional effects. If the determination of capacity is wrong because of the aphasia, the effects can be magnified.

6.5 Research Question 4
What are the perspectives of the participants with aphasia on the communication accessibility of capacity evaluation process?

For CACE to be a truly credible tool it was essential that the PwA had the opportunity to express their opinions regarding their comprehension, ease of communication, levels of frustration and their preference of evaluation tools. None of the articles found in the literature review regarding the development of capacity assessment tools included feedback from the recipients of evaluation.⁸¹,⁸² Following Integrated Knowledge Translation principles, there should be mutual learning between the researcher and the ‘knowledge users’. This principle necessitates the ‘knowledge users’ (PwA) not only being part of the development stage, but also contributing to the analysis stage.¹²⁸

The PwA survey results measuring their communication skills showed a statistically significant difference in the experimental group following the intervention. CACE helped to increase the PwA’s understanding of the capacity evaluation process and to communicate answers to the capacity questions more fully. There was not, however, a statistical difference pre and post intervention measuring the survey question, “Did you understand the questions in the capacity evaluation?” It should be remembered that all of the PwA had sufficient comprehension to understand that they were participating in
research and that the capacity evaluation did not apply to them. In other words, they were competent. Looking at the raw data, the PwA reported that they understood the questions in both evaluation tools. The most significant difference in the data was in their ability to communicate their answers. The communication supports in CACE, combined with improved evaluator communication skills helped the PwA overcome his or her language barrier and express answers to questions revealing capacity.

6.5.1 Frustration with the Capacity Evaluation Process and Clinical Implications

One of the goals in the development of CACE was to make a complex and emotive legal process sufficiently accessible for people with aphasia, thereby reducing the frustration of communication failure. The desire to communicate answers to questions showing that we are competent is profound in all of us, but especially with those for whom communication is an obstacle. Le Dorze and Brassard described the consequences of aphasia on participants with aphasia in their research study. The stigma and embarrassment their participants with aphasia felt when communicating was considerable. We reveal so much of who we are through conversation, and we all want to reveal that we are competent. It is therefore not surprising that PwA reported frustration with their own communication and with the support they received from the SW evaluators when using the CMAD questionnaire.

Qualitative data from the Key Informant Interviews with the Independent S-LPs corroborated the survey results. They reported visible signs of frustration in the PwA at their inability to communicate because of an inaccessible process and lack of support. The external SW who viewed the taped evaluations discussed the need to build trust through meaningful communication, this is difficult to achieve when both participants cannot overcome a communication barrier. One SW participant reported that she ended the evaluation early because of the PwA’s obvious frustration. Extreme frustration can result in communication withdrawal on the part of the individual with aphasia, which in itself becomes an added barrier:
“It is difficult to build rapport and establish trust when the patient is not ‘free’ to express himself and is having to work so hard for the SW to understand.” SW Participant

Communicative success does much to dissipate the negative effects of frustration. Those participants in the experimental group who were evaluated with CACE, reported a significant decrease in ‘frustration.’ The successful transfer of information on the part of the PwA through an accessible format decreased levels frustration and confirmed that communicative success is an essential component for a fair and just capacity evaluation.

6.6 Research Questions Summary
The use of CACE with communication training increased the skills and confidence in the SW participants resulting in accurate evaluations of capacity and communicative success on the part of the participant with aphasia. Legal, ethical, systemic and clinical implications regarding capacity evaluations have been discussed. The need for communication training to accompany CACE has been well established. The next section will discuss elements that are missing from the current training and the rationale for their inclusion.

6.7 Communication Training
6.7.1 Education on the Nature of Aphasia
Despite the experience of many of the SW participants, many of them showed a lack of knowledge regarding the symptomology of aphasia:

“The participant was able to clearly communicate some answers (ie about where he lives and his daughters). Other times I was not sure if he understood my questions and his answers were repetitive or not appropriate (i.e. lots of counting).” SW Participant

This statement says much about the nature of aphasia. It is not a static condition; there are moments when a word or sentence is expressed with comparative ease, while at other times the name of a wife or husband is difficult to retrieve. Repetition of utterances could be verbal perseveration, a frequent symptom of aphasia. Perseveration is the repetition of
a previously given response when it is no longer appropriate. When a person with aphasia is trying unsuccessfully to retrieve a word, stereotypical utterances frequently replace the target words. Counting is one common stereotype. It is an ‘over-learned’ language activity of childhood and can be one of the first verbalizations that returns post stroke.

Perseveration, stereotypes and other forms of communication breakdown require acknowledgement from the conversational partner. Acknowledging conversational competence was one of the constructs measured in the MSC. By showing respect, being sensitive to the PwA’s communication attempts, and acknowledging that the PwA knows what he or she wants to say helps to increase confidence and motivation to continue with the conversation. The SW participants were, by and large, effective at acknowledging competence, but if they learned more about common aphasia symptomology they would be more understanding about communicative attempts. These skills require training, and one of the core elements of SCA™ is learning how to acknowledge communicative competence in people with aphasia.

It was also evident to the Independent S-LPs that the SW participants needed more information about aphasia and competence. One Independent S-LP questioned whether some of the SW participants believed whether the PwA were competent. The Site S-LPs were asked about the PwA who were not found to have capacity. Over half of the PwA in question led independent and active lives, despite their aphasia. One participant made his own wine, traveled extensively and booked all of his vacations on-line, another drove the car and did the weekly family shopping, and a third lived on her own and attended a number of community programs. Was there an assumption that if you have aphasia you are somewhat cognitively impaired and therefore could not be fully participating in life? For many health care professionals, aphasia is a hard concept to understand.

“Aphasia damages the lines of communication going in and out, not the thought, intelligence or experience of the person. This is hard to grasp, especially in a society that places value on the ability to communicate through speech and writing and considers these skills to be signs of intelligence.”

7 p. 5
Education in the common symptomology of aphasia and other communication barriers needs to be added to CACE. This would help the evaluators to understand the nature of communication disorders and not misinterpret observable behaviours. One SW participant commented that she had already learned much about aphasia from being in the experimental group:

“I asked him what month it was and he said ‘October’ but pointed to May (in CACE). I said do you mean May and he said ‘yes’. Before I would have just accepted October and thought that he didn’t know.” SW participant

6.7.2 Supported Conversation for Adults with Aphasia (SCA™)

The training included in the DVD is based on Supported Conversation for Adults with Aphasia (SCA™) developed by Kagan et al.,116 and described in Chapter 3, the development of CACE. Speech-Language Pathologists who work with individuals with aphasia and other speech and language disorders become very skilled communicators, especially if they have been trained in SCA™ or other methods to communicate. The difference in skill level between the S-LP and the SW when interacting with people with aphasia was to be expected; but, at times, the difficulties the SW participants’ faced were surprising. This researcher met with a PwA to gather demographic information. He presented with severe expressive aphasia and apraxia and was essentially non-verbal. The PwA had attended an Aphasia Centre for many years, and through the use of SCA™ techniques proved to be an excellent communicator. He communicated that he was an economist, had worked as a Vice President for a large Investment firm and (on hearing my English accent) had spent a year at the London School of Economics (LSE). We talked about Mick Jagger from the Rolling Stones who also attended the LSE. The reason for highlighting this conversation is because it illustrates how training in SCA™ can enable the person with aphasia to transfer information successfully and build a rapport between the conversational partners. In SCA™ this is described as ‘Interaction’. The PwA was animated, amusing and obviously proud of his achievements. The SW participant who was randomly assigned to this gentleman reported the following post evaluation:
(The participant) “is having to work so hard for the SW to understand, but I was unable to understand his responses.” *SW participant*

Unfortunately the communication barrier was such that the SW participant was unable to determine whether the PwA had capacity or not. When examining the survey scores that measure whether, in her opinion, the participant understood the capacity evaluation process and questions she scored 2/4 and 2.5/4 respectively. The site S-LP asked the PwA the same questions, that is, did you understand the evaluation process and questions. The PwA scored 3.5/4 for his comprehension of the process and questions. This gentleman’s competence was not in doubt, he read the Globe and Mail newspaper and kept up to date with political developments. His intellect and ability to understand and appreciate a decision were masked by aphasia. Fortunately this participant pair was in the experimental group. The SW participant was introduced to CACE and watched the DVD illustrating different SCA™ techniques. The SW participant subsequently found him to be competent, scoring 3/4 in her confidence with her decision.

Watching the pre and post intervention DVD recordings of the evaluation highlighted a number of important points. In the first capacity evaluation the SW participant appeared to be “stuck”. She did not know how to reveal the participant’s competence or repair a communication breakdown. There were periods of silence while she tried to think of what she could do next. Following the training in basic SCA™, the SW participant became “unstuck”. She approached the evaluation with more confidence, used the pictures in CACE effectively, and wrote down key words to augment understanding and to verify the content of the PwA’s message. When asked which capacity evaluation tool she preferred she selected CACE and added:

> “The aid made it much easier to communicate purpose and administer the assessment. It is not possible to evaluate this individual’s capacity without it.” *SW participant*

A 45-minute training via a DVD may not be sufficient for interacting with individuals with severe communication barriers. It is strongly suggested to the evaluators that they seek out more in-depth training in SCA™ in order to improve their communication skills
to ensure a fair evaluation of capacity for people with severe aphasia or multiple communication barriers.

### 6.7.3 Research Studies Examining Effectiveness of Communication Training and Accessibility

Kagan et al.’s study showing the effectiveness of training conversational partners in SCA™\(^{116}\) set the scene for the development of other programs. Partner and family training has been found to be effective,\(^{134,135}\) but less research has been undertaken to study programs designed for healthcare professionals. The Communicate Access Improvement Project (CAIP) is one study that included communication training for healthcare professionals. The project’s goal was to improve access to information and decision making for people with aphasia at the three levels of healthcare: acute care services, rehabilitation and long-term care.\(^{130}\) The participants included clinical nurse specialists, nurses, physiotherapists, occupational therapists, rehab assistants, social workers, health care aids, recreation therapists and speech-language pathologists. The participants in the study underwent a two-day training program in SCA™. The educational component was one of the successful elements across the three levels of healthcare. At follow-up sessions the participants reported an increased knowledge of supported communication methods, a change of attitudes regarding the competency of people with aphasia, and improved interactions with patients or residents with aphasia or similar communication barriers.\(^{130}\)

The carryover to systemic change was most successful in the long-term care facility followed by the rehabilitation site. Unfortunately such change was not evident in the acute care setting where many obstacles prevented the establishment of communicative supports in daily work. One quote from an acute team member was forthcoming from the study:

> “Like the decision about where you are going to go. That is a major decision but it is not really up to the patient—like they can’t say I want to go here”.\(^{130}\)

The comment made by a healthcare professional in an acute care setting in a major city
demonstrates the need for on-going training in the competency of people with aphasia. It would appear that attitudes need to change, and education in the legal requirements of the Health Care Consent Act to evaluate capacity needs to take place. It could be argued that the best way to preserve people’s legal rights is if the health care system commits to systemic change, as discussed earlier in this chapter.

Simmons-Mackie in the CAIP project identified on-going support as an issue, suggesting that the assigned S-LP intervene and provide communication support when necessary. This doctoral study also found that for communication training to be effective it should be on-going. Those SW participants who had previously received communication training either formally or informally through site S-LPs did not feel at an advantage with regard to confidence in communicative abilities or capacity determination. There are pros and cons in using a DVD format to deliver communication training. It is available for review providing repetition of the SCA™ strategies, but the benefits of in depth face-to-face training cannot be undervalued.

The problems of communicative access for people with aphasia and other communication barriers in healthcare have been a point of discussion for many years. Studies have shown the effectiveness of making health information and the informed consent process accessible to people with aphasia. Regrettably, change has been slow as evidenced by Rose et al.’s recent study on people with aphasia receiving information on stroke and aphasia. The results of their study showed that only one third of the participants with aphasia received written information on aphasia and stroke, and that the information was unnecessarily complex. Also, the participants interviewed did not receive the information when needed, that is, in the acute phase of their recovery. More work needs to take place in persuading health care systems to make information about their services consistently accessible.

6.7.4 Education - Social Work Communication Strengths
Although the SW participants found communication to be a challenge they came to this research study with many strengths. The first construct to be examined in MSC is
‘Acknowledging Capacity’. The skills that are being evaluated include establishing equal roles in a conversation, talking collaboratively, using an appropriate emotional tone, demonstrating active listening and being sensitive to the PwA’s communicative attempts. These are skills described as ‘empathic communication’ in the Social Work literature. Empathic communication is the ability to perceive accurately and sensitively the inner feelings of patients, and to reflect back the feelings of the patient’s inner experience. As reported earlier, the participants in this study scored significantly higher than the volunteer participants in Kagan et al’s study (3.6 vs. 2.6). Another area in which many of the SW participants excelled was giving time to the participants to process information and formulate a response. The Independent S-LPs did identify a few SW participants who were lacking in confidence and tended to rush the PwA, but they were in the minority and did not receive CACE communication training. Allowing for a longer response time is part of the SCA™ methodology. It was these skills that could have accounted for the higher scores in the MPC’s construct, ‘Interaction’. Although the MPC focused on the PwA rather than the SW participant, if the PwA felt comfortable, respected and acknowledged, he or she was better able to establish and maintain a relationship. Many of the PwAs were frustrated with their communicative attempts in the evaluation, but the majority expressed how much they had enjoyed meeting the social workers. The higher than expected scores in ‘Interaction’, pre and post-intervention in both groups, could account for the moderate Effect Size with this construct.

6.8 Applications of CACE
6.8.1 Multiple Communication Barriers
The rationale for selecting people with aphasia to represent the participants with Communication Barriers was discussed in the Methodology Chapter. An interesting factor resulting from the demographic information was the numbers of PwA with concomitant communication issues. This helped to make the research sample more representative and increased the likelihood that CACE with training could be an effective evaluation tool to use with people with dysarthria, ESL or hearing loss.
The type and severity of communication barriers was explored in depth with the members of the experimental group. These were the participants who experienced both evaluation systems. Of the 17 members of this group, 15 had expressive aphasia, one was diagnosed with Transcortical Motor, and one with ‘mixed’ aphasia. Eleven PwA had a concomitant diagnosis of articulatory apraxia (a speech motor planning deficit). All four of the participants with moderate comprehension difficulties were in the experimental group. This was considered to be beneficial for the purposes of the study because if these participants could understand the capacity evaluation process and questions, then CACE should be an effective tool with people with others with moderate comprehension deficits. Seven participants were judged to have severe expressive aphasia and three moderate to severe expressive difficulties. Finally, four PwA spoke English as a second language and one person had an aided hearing loss. This group presented with complex language and communication barriers, yet were able to communicate their capacity with the use of CACE.

A further barrier to the capacity evaluation process concerned the effects of stress and frustration. Two Independent S-LPs reported that for some of the PwA, the conversation about the possibility of moving to long-term care was stressful and emotional. The effects of these emotions can adversely affect cognitive communication skills.98,99

One surprising finding regarding the PwA was that speaking English as a Second Language did not prove to be an added communication barrier. By re-visiting the demographic data it was noted that all but one of the PwA who spoke ESL had been living with their stroke and aphasia from between 2 and 7 years. Also, English had become their dominant or proficient language pre-stroke. Problems with bilingual aphasia, including code mixing or loss of one language, tend to occur early in stroke recovery.93 It is therefore hypothesized that bilingual aphasia would present as a more significant communication barrier for those early in post stroke recovery, or for those who have recently learned English. With the current drive to reduce patient length of stay in the hospital system,36 capacity evaluations to make admission decisions are
occurring sooner than later. Bilingual aphasia will likely prove to be a further complication in the real-world environment.

6.8.2 CACE Format and Compliance with the Health Care Consent Act

An unexpected advantage to CACE was its format and legal compliance. As mentioned earlier, the Independent S-LPs were asked to determine through clinical observation whether the PwA understood the capacity evaluation process. After reviewing a number of evaluations, the Independent S-LPs reported that with the CMAD questionnaire the SWs gave different amounts of information regarding the capacity evaluation process. Five SW participants did not explain the process at all. It should be pointed out that this was a research trial and possibly those SW participants would have given a more thorough explanation with their own patients or clients. However, the SW participants were instructed to carry out the capacity evaluation in the same manner as they would with their own patients. The first 10 pages of CACE explain the capacity evaluation process and the consequences of being found lacking in capacity. Consent to evaluate is then sought. This structure compels the evaluator to abide by the legislation contained in the Health Care Consent Act.

6.8.3 The Use of CACE in Different Health Care Environments

CACE was designed to be used in specific evaluation environments such as acute care, rehabilitation, and specialized units that typically admit patients with stroke or progressive neurological diseases. CACE was also designed to be used in the community when people face the decision whether or not to leave home for a more supportive living environment. Social workers from other areas of healthcare volunteered to participate in the research study and expressed an interest in using CACE with the patients and clients they served. Ontario and other regions of Canada are facing the dilemma of providing hospital services to patients with fewer beds. Social workers from Emergency Departments reported that there was pressure not to admit patients if they can be cared for elsewhere. It is not uncommon for social workers to administer a capacity evaluation in the Emergency Unit to determine whether the patient can decide to move to long-term care where some of their non-acute medical needs can be met:
“Often we have elderly patients come to ED (Emergency Department) because of a psychosocial crisis or a fall or other medical issue and they are medically cleared for discharge but clearly they have been at risk to remain living independently and we tend to proceed, too quickly in my opinion, to place them urgently on a "crisis" basis as they do not qualify for an acute care admission to hospital.” *SW Participant*

Although these might not be ideal circumstances to administer a capacity evaluation, CACE provides considerably more support than the CMAD questionnaire.

Psychiatry brings a different set of issues to capacity evaluation. Patients with psychiatric disorders can have intact cognitive skills but lack insight into environmental factors. These SW participants found CACE particularly useful because specific questions such as taking medication compels the patient or client to consider issues such as who will help and how often. This also addresses the construct of insight. It was interesting to note that three SW participants from oncology elected to join the study. They reported two scenarios where CACE would be beneficial: following surgical procedures such as laryngectomies and glossectomies resulting in dysarthria and voice disorders, and with advanced care planning. This can include the evaluation of a patient’s capacity to decide on a future discharge destination.

Many of the SW participants from the experimental group and the SW working group expressed an interest in using CACE with patients who present with minimal cognitive impairments, who are capable of making some decisions but not others. The SWs reported that this patient population would benefit from the communicative supports and the logical flow and clarity of the questions in CACE. It was pointed out that CACE has not been trialed with people with cognitive impairments so its effectiveness with this population is unknown.

**6.9 Proposed Changes to the Communication Aid to Capacity Evaluation**

The Analysis of the qualitative data generated ideas for changes to be made in CACE. The SW participants in the experimental group were asked to comment on CACE and
recommend changes. One recommendation was forthcoming:

“However, the depth of questions and answers is not as great (ie a lot of Yes and No)” SW participant

This was a valid point and spoke to the original intent of capacity evaluation. The questions contained in the CMAD questionnaire were designed to be a framework to stimulate a conversation, allowing the person being evaluated to communicate whether or not he or she had capacity to make an admission decision. It was never designed to be a pass/fail questionnaire. The capacity assessments described in the literature review largely concerned consent to treatment, which can vary from a life threatening surgical procedure to participating in a walking program. As a consequence the assessments did not use fixed questions. Wahl, in her paper on Capacity and Capacity Assessment in Ontario exhorts evaluators to constantly “probe and verify” information by asking questions that reflect the individual’s context.

At first glance CACE appears to be a prescriptive evaluation tool as it asks fixed questions such as “Who helps you at home?” “How often do they help you?” However, in the instructions for administration, the issue of expanding on a question or answer is discussed. Cards are included for the patient with a communication barrier that say; “Stop, I have a question” and “Stop, I want to add a comment”. The SCA™ training, both in the DVD and in the Instructions for Administration, shows the evaluator how to ask questions outside of those in CACE. It also gives information on how to encourage patients or clients to use different communication strategies to get a unique message across, and then how to verify the message.

In the development of CACE, the SW working group was concerned about the questions and choices of answers being leading. One of the solutions was to include “Or something else” to allow for unique responses. It must also be emphasized that CACE is a tool. The word tool was chosen carefully referring to the definition “A device that aids in accomplishing a task”. CACE should stimulate a conversation and the communication supports should be used as little or as much as the patient with a communication barrier
needs. The evaluator should continue to “probe and verify”\textsuperscript{69} until enough information is communicated to show capacity or otherwise. The flexible use of CACE needs to be clarified further in the Instructions for Administration.

Information contained in the Instructions for Administration and in the training DVD regarding the nature of aphasia and a person’s right to effective communication needs to be enhanced. A language problem does not equate to a lack of capacity. An individual with speech, language or hearing difficulties has the right to hear and understand information. Returning to legislation discussed in the Literature review, one of the purposes set out in the Health Care Consent Act is as follows:

“To promote communication and understanding between health practitioners and their patients and clients.” (Part 1, d).

New Zealand takes Patients’ or consumers’ rights one step further with their ‘Right to Effective Communication’:

Every consumer has the right to effective communication in a form, language or manner that enables the consumer to understand the information provided.

These rights would benefit from further emphasis in CACE.

The Independent S-LPs observed that the term ‘long-term care home’ was a problem area for many PwA’s. Some participants did not appear to understand what it meant. In health and community care the term ‘nursing home’ has been changed to ‘long-term care home’, but such changes need time to enter the common vernacular. With Ontario’s large immigrant population, the concept of ‘care home’ might also be alien. Following Wahl’s recommendation of educating the individual being evaluated in the key concepts involved in capacity evaluation,\textsuperscript{69} one possible solution is to define what is meant by the term ‘long-term care’ in the ‘Capacity Explanation’ section of CACE.
6.10 Limitations of the Research Study

Participant selection was one of the limitations in this research study. For the purposes of the methodological design, the participants with a communication barrier were predominantly people with an expressive aphasia. Testing such a sensitive area as a person’s capacity to make a decision about where he or she should live necessitated the participants to understand that they were taking part in a research study. The narrow inclusion criteria were a limitation of the research. It would have been informative to determine whether CACE was as effective with participants with different types aphasias and severity levels. A case was made in the methodology for using participants with aphasia as a paradigm for other communication barriers. However, the effectiveness of CACE and the communication training with the hard of hearing or deaf community, people with a limited grasp of the English Language and those with severe dysarthria would have been beneficial to establish. Also, all of the SW participants worked in a hospital environment. Recruiting representation from community case managers who bring different experiences to the process would have contributed to the results.

In a randomized controlled trial it is preferable if research participants are chosen through a process of random selection. That is, a pool of appropriate participants is recruited greater than the number of participants required for the study. Participants are then randomly selected from the pool. Random selection or sampling ensures that a representative sample of the population under study is chosen, increasing the probability that the study’s results can be generalized. Regrettably, despite best efforts, this researcher was not able to recruit enough participants to generate a sufficiently large pool from which to randomly select. This was a further limitation.

With regard to the qualitative methodology, more narrative data needed to be collected in order to generate theories and inferences as to why CACE was effective and what needed to be changed both in the tool and in the communication training. Asking the Independent S-LPs to write brief comments regarding their perceptions of the evaluation process after viewing each DVD recording and interviewing the PwA would have generated rich data to analyze. The results of the analyses would have contributed to the conclusions drawn
regarding the effectiveness of CACE as a capacity evaluation tool.

CACE, with training, needs to be evaluated in real time in an authentic situation. The methodological design was somewhat contrived because the trial necessitated repeated measures. In real time spontaneous recovery and therapeutic intervention would have been confounding variables. The contrived nature of the methodology brought its own set of problems, such as a lack of information on the PwA for the SW participants. There was also some distress for the PwA who were successively living in the community but had to focus on an alternative. Finally, CACE needs to undergo reliability testing, both test-retest and inter-rater reliability.

6.11 Discussion Summary
CACE with training proved to be an effective capacity evaluation measure for this research population. The advantages of using CACE for people living with aphasia and the evaluators themselves was explored, and the serious legal and ethical implications for the continued use of the current system discussed. The next chapter will focus on the conclusions of the research study and the future directions of CACE with communication training.
Chapter 7 Conclusions and Future Directions

Following the discussion of the results arising from the data collection in the randomized controlled trail, this chapter will provide a conclusion to the doctoral thesis and discuss the future directions for both the Communication Aid to Capacity Evaluation (CACE) and for communication training.

7.1 Conclusions

The first two aims of this doctoral research study were realized. The current Capacity to Make Admissions Decisions questionnaire and legal tenets from the Health Care Consent Act were adapted and a communicatively accessible capacity evaluation tool for individuals with hearing, language and speech barriers was created. Also, a training DVD was developed that introduced CACE, and demonstrated to the evaluators the best ways to administer the tool and communicate with this population. CACE underwent extensive review and a panel of experts found the adapted tool to have high face and content validity.

The final research aim was to test the effectiveness of CACE with the training DVD as a capacity evaluation tool administered by experienced evaluators to participants with aphasia. The results of the tests of statistical significance from the randomized controlled trial, and the qualitative data analyses showed that CACE was an effective capacity evaluation tool for the research population.

The SW participants’ communication skills were enhanced through the training, which, combined with an accessible tool, raised their level of confidence. The increase in skills and confidence resulted in accurate determinations of capacity to make a decision regarding admission to long-term care: “It is not possible to evaluate this individual’s capacity without it (CACE).” *SW participant.* The results supported the initial hypothesis that the use of a communicatively accessible capacity evaluation process, with training, would enhance the skills and confidence of a social worker to more accurately judge the capacity of people with aphasia to make an admission decision to long-term care.
The second hypothesis focused on participants with aphasia and whether the use of CACE combined with evaluator communication training would reveal their inherent capacity to make a discharge decision. The design of CACE was communicatively accessible resulting in enhanced understanding of the capacity evaluation’s purpose and questions. There were sufficient supports to allow for responses to be communicated more effectively by the PwA. By reducing the barriers through the use of an accessible system, which included evaluator communication training, the levels of frustration felt by the PwA significantly decreased, and they were able to reveal their inherent capacity.

It is worthwhile recalling the numbers of people who live with a communication barrier: approximately one third of those who sustain a stroke and severe head injury, people living with a progressive neurological disease, one fifth of Ontarians who speak another language than English or French in the home, and one quarter of people over 65 years who live a hearing loss. This adds up to a significant number of people who are vulnerable to erroneous judgments of capacity because of their communication barriers and an inaccessible capacity evaluation system. The legal and ethical implications regarding the continued use of the current process with such high numbers of people are concerning. In this research study the administration of the CMAD questionnaire gave rise to inconsistent explanations of the legal tenets surrounding capacity evaluation putting at risk the participant’s rights to informed consent and a fair evaluation. One third of the social work participants were unable to determine capacity, and a young, competent participant with aphasia was found to be lacking in capacity. This is undoubtedly a human rights issue.

During the recruitment process the story of the 63-year-old gentleman from the Caribbean who was found to be incapable because of his communication barriers was related to the potential participants with aphasia. The story resonated with the group. One man, who was eager to participate, slammed his fist on the table and said “never, never” meaning that this should never happen again. The potential of finding someone lacking in capacity to make a decision about where and how he or she will live because of
a communication barrier is a grave ethical concern. With the use of a practical and accessible evaluation tool combined with specialized training, the chances of this happening again are reduced.

7.2 Future Directions

7.2.1 Future Directions for the Communication Aid to Capacity Evaluation

Following this doctoral thesis, meetings will be arranged with the working groups and the Independent S-LPs to discuss the proposed changes in CACE and Instructions for Administration as a result of the randomized controlled trial. Amendments and additions to the training DVD that do not require re-shooting will also be considered. The final version of CACE will be taken to the Niagara Aphasia Centre for the working group with aphasia’s input and final approval.

For CACE to be accepted in the healthcare system it needs to be administered in real time with patients and clients with communication barriers. To this end, following research ethics approval, one of the research sites, Sunnybrook Health Sciences Centre has been approached to use the tool and provide feedback in the form of a survey. So far, the feedback has been extremely positive. To increase the data collection, another of the research sites will be approached to participate in the trial. The survey data will be analyzed, written up and will be added to the results arising from this study.

Meetings will then be arranged with the Ministry of Health and Long-Term Care (MOHLTC) and the Consent and Capacity Board to present the research findings and introduce them to CACE with the training DVD. The goal is for them to accept CACE as a capacity evaluation tool for use with individuals living with communication barriers. The legal dilemma regarding the continued use of the CMAD questionnaire by capacity evaluators who are not trained in specific communication skills with individuals with aphasia and other communication barriers will be raised. If the MOHLTC and the CCB
accept CACE, meetings with the Ontario Association of Community Care Access Centres (CCAC), the gatekeepers for admission to long-term care, will take place.

CACE will eventually be published. The format of publication, however, will need consideration. The results of this study unequivocally showed that the communication training is an integral part of CACE. If possible, CACE will be published on the ‘web’ and each individual will watch the training before they can access to the tool. It is not entirely realistic to expect every evaluator to be trained once the tool is in circulation. However, the recommendation to view the training with the website address will be added to CACE.

7.2.2 Future directions for Capacity Evaluation and Communication Training

The research results showed that Speech-Language Pathologists who provide service to adults with speech and language disorders would benefit from training in the legislation governing the Capacity Evaluation process. They also need to be inspired to advocate for this population, volunteering to evaluate, or be part of the evaluation process for people with aphasia and other barriers. S-LPs are the health care profession who knows the most about communication and the potential for hidden capacity. The profession’s responsibility does not end there. There are many decisions patients and clients have to make in the course of an illness or hospitalization. Health care professionals need to be trained in specialized communication techniques by hospital or community S-LPs so that difficult conversations can take place directly with the individual with aphasia. Due to time and resource constraints, and a lack of ability and confidence in communication, busy healthcare professionals frequently turn to the family, partner or friend to help make a decision. The Aphasia Institute and other aphasia centres in Ontario offer direct communication training for healthcare professionals, or ‘train the trainer’ sessions for S-LPs and other. Finally, a meeting with the College of Audiologists and Speech-language Pathologists will be requested to try and promote training for the membership in the legalities of capacity evaluation to make admission decisions and the use of CACE.
The legislation regarding admission to Long-Term Care is changing, and CCAC community case managers will be administering more capacity evaluations. This group would benefit from education regarding the hidden capacity of people with language barriers and training in the use of CACE and how to communicate more effectively.

People’s rights to a fair evaluation of capacity are not always being met. It is hoped that the results of this doctoral thesis will initiate a systemic change in healthcare that includes the adoption of CACE and training in communication skills and in the legal tenets that govern the process, thus preserving every competent individual’s human rights to decide where and how they will live.
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Appendix 1
Capacity to Make Admission Decisions
Section 2 – Determination of Capability
(Please complete with as much detail as possible)

1. What problems are you having right now? (Does the person understand her/his condition or problem?)

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2. How do you think admission to a nursing home or home for the aged could help you with your condition/problem? (Does the person appreciate the foreseeable consequences of admission or not?)

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3. Can you think of any other ways of looking after your condition/problem? (Does the person understand the condition/problem?)

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4. What could happen to you if you choose not to live in a nursing home or home for the aged? (Does the person appreciate the foreseeable consequences of admission or not?)

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5. What could happen to you if you choose to live in a nursing home or home for the aged? (Does the person appreciate the foreseeable consequences of admission or not?)

_________________________________________________________________
Appendix 2

PACE: Placement Aid to Capacity Evaluation

Instructions for Administration

Capacity is defined as the ability to understand information relevant to a decision and the ability to appreciate the reasonably foreseeable consequences of a decision (or lack of a decision)*. The purpose of the PACE tool is to help clinicians systematically evaluate capacity and to document findings when a person is facing a decision regarding admission to a long term care facility. It is intended to be most useful when a clinician is not able to presume a person is capable and capacity is uncertain. The following are some guidelines to consider before and during any capacity evaluation:

1. A qualified evaluator is a member of one of the following: (a) the College of Audiologists and Speech-Language Pathologists of Ontario, (b) the College of Nurses of Ontario, (c) the College of Occupational Therapists of Ontario, (d) the College of Physicians and Surgeons of Ontario, (e) the College of Physiotherapists of Ontario, (f) the College of Psychologists of Ontario, and (g) the College of Social Workers and Social Service Workers.

2. Before evaluating capacity, identify and address any barriers to communication (i.e., hearing impairment, visual impairment, language barrier). People other than family/friends/POA may help the person communicate (i.e., by translating). These other people should not attempt to answer questions for the person being evaluated and, if available, should be trained professionals. If a communication barrier is due to dysphasia or dysarthria, it is recommended that a speech-language pathologist be consulted.

3. Before and while evaluating capacity, the evaluator must:
   a) Explain the purpose and consequences of the evaluation, obtain informed consent from the person being evaluated, and whenever possible, provide information that a reasonable person would require in the same circumstance in order to make an admission decision.
   b) Respond to any questions or requests for other information the person being evaluated may have.

4. Before evaluating capacity, obtain and document any information (i.e., assessments/reports from health care professionals, EMS staff, police, formal/informal community supports, family/significant others, etc.) related to the ability of the person to safely cope at home and/or the capacity of the person to make decisions regarding admission to a long term care facility.
5. Before evaluating capacity, consultation with a physician is recommended to ensure that the person is medically stable and that any acute and reversible medical conditions that may cause confusion (i.e., delerium secondary to pneumonia, infection, drug toxicity) have been ruled out or appropriately treated.

6. While evaluating capacity, be aware of the cognitive signs of depression (i.e., hopelessness, worthlessness, guilt, and punishment) as this may affect decision-making (i.e., “Just let me die...there’s no point in sending me to a nursing home”). Also, if the person is suffering from a mental health illness, decision-making may be affected by delusion/psychosis (i.e., “I don’t want to go to a nursing home because the vampires there will kill me”). Further, the person may suffer from a chronic/progressive cognitive impairment (i.e., dementia). In such cases, it is recommended that a referral be made to a physician, psychiatrist or psychogeriatrician for an independent assessment and appropriate treatment. It may be necessary to evaluate the person’s capacity over time or to wait until the person is declared stable.

7. The process of disclosure may continue throughout the capacity evaluation. For example, if the person does not appreciate that they may be unsafe to live at home and may require more supervision and assistance with ADLs than can be provided at home, then redisclose this information and reevaluate appreciation/understanding.

8. Use the person’s own words whenever possible (i.e., “old folk’s home,” “nursing home,” “old age home”).

9. Do not evaluate whether you agree or disagree with the person’s decision. Evaluate the person’s ability to understand and appreciate their decision.

*This is the definition of capacity from the Health Care and Consent Act, 1996 legislation in Ontario, Canada. Although similar definitions exist across North America, we suggest that users check existing legislation, case law and professional policy statements in their own province or state.

Top of Page
PACE: Placement Aid to Capacity Evaluation

SECTION I: IDENTIFICATION

Last Name: ___________________________  First Name: ___________________________

Date Of Birth: Day ___ Month ___ Year ___  Health Card #:__________________________

APPLE  PRESUMED CAPABLE  (Evaluation not indicated, proceed to Section IV)

If in doubt and not able to presume person is capable, proceed with Sections II, III and IV. Indicate your score for each domain with a checkmark. Record observations that support your score in each domain, including exact responses of the person being evaluated. Refer to attached sample questions as a guide.

SECTION II: EVALUATION OF CAPACITY

APPLE  Person expressed consent to capacity evaluation or did not express refusal after being informed regarding implications of evaluation results and right to refuse capacity evaluation.

1. ABLE TO UNDERSTAND CARE NEEDS
Observations: ________________________________________________________________

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4. ABLE TO APPRECIATE REASONABLY FORESEEABLE CONSEQUENCES OF ACCEPTING PROPOSED LONG TERM CARE PLACEMENT

Observations: ____________________________________________

________________________________________________________

 unfold

5. ABLE TO APPRECIATE REASONABLY FORESEEABLE CONSEQUENCES OF REFUSING PROPOSED LONG TERM CARE PLACEMENT

Observations: ____________________________________________

________________________________________________________

6. ABLE TO UNDERSTAND ALTERNATIVE TO PROPOSED LONG TERM CARE PLACEMENT (if any)

Observations: ____________________________________________

________________________________________________________

PACE: Placement Aid to Capacity Evaluation

SECTION II (CONT’D): EVALUATION OF CAPACITY

OVERALL IMPRESSION

<table>
<thead>
<tr>
<th>CAPABLE</th>
<th></th>
<th>INCAPABLE</th>
<th></th>
<th>UNSURE</th>
<th></th>
</tr>
</thead>
</table>

COMMENTS/RECOMMENDATIONS:

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If the overall impression is UNSURE, then take further steps to clarify. It may be necessary to reevaluate over time. Further disclosure and discussion with the
person which specifically focuses on domains evaluated as *UNSURE* is recommended. Similarly, it may be necessary to have further discussion with family/significant others. It may also be appropriate to consult with cultural/religious figure(s) and/or other health care team members (i.e., Physician, Psychiatrist, Psychogeriatrician, Social Worker, Occupational Therapist, Physiotherapist, Speech-Language Pathologist, etc.).

**SECTION III: RIGHTS INFORMATION (FOR PERSON EVALUATED AS INCAPABLE ONLY)**

If the person is evaluated as incapable, the person must be informed of the findings and informed of his/her rights (i.e., given the CCAC “Rights Information Sheet—Admission to a Long-Term Care Facility”). If the person wants to appeal the finding of incapacity and make application to the Consent and Capacity Board for review, he/she can apply directly or with the assistance of the evaluator.

- Informed of finding of incapacity
- Given rights information
- Intention to appeal finding of incapacity not indicated
- Intention to appeal finding of incapacity indicated

**SECTION IV: EVALUATOR IDENTIFICATION**

Evaluator’s Name: ________________________________

(include credentials/title)

Evaluator’s Signature: ________________________________

Evaluator’s Telephone #: ________________________________

Date: Day: _____ Month: _____ Year: _____ Hour: _____

Time taken to administer PACE: _______ minutes
PACE: Placement Aid to Capacity Evaluation

Sample Questions

The list of sample questions below is not exhaustive. The questions are meant as a guide only and it is not necessary to ask all questions for each evaluation. The questions do not need to be asked word for word but should be communicated in an informal and natural manner that is culturally sensitive. It is important that communication be at a level of expression compatible with that of the person being evaluated. It may be necessary to repeat questions and to rephrase questions in a way that is relevant to the individual person being evaluated. It is important to document the specific responses either verbatim or paraphrased. The responses/comments should be recorded in the corresponding sections of the PACE. A copy of the PACE can be used for documentation purposes (i.e., for CCB review hearings, for hospital chart) and should be forwarded with the application to long-term care.

Sample Preamble
Hello, my name is ________, I am a (state profession). I have been talking with the doctors/health care team/your family and there are concerns about your ability to live at home. It has been suggested that you need to move to a long term care facility/nursing home. I need to ask you some questions to decide if you are able to make a decision about where you should live. If you are able to decide for yourself, I need you to tell me where you want to live and what help you will need. If I think you are unable to make a decision for yourself, I will talk with (legally authorized substitute decision maker) to help decide where you should live. You have the right to refuse a capacity evaluation. Also, if you are found to be incapable, you have the right to appeal this decision by applying to the Consent and Capacity Board for a review (provide rights info sheet). If you do not understand or do not want to answer any questions and refuse to be evaluated, please let me know. (Proceed if person expresses consent or does not object/indicate refusal).

ORIENTATION/MEMORY
Before using the PACE tool, it is recommended to assess and document a general impression of the person's orientation/memory. Sample questions would include the following:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your name?</td>
<td></td>
</tr>
<tr>
<td>How old are you?</td>
<td></td>
</tr>
<tr>
<td>What is your date of birth/birthday?</td>
<td></td>
</tr>
<tr>
<td>Where do you live/what is your home address?</td>
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</tr>
<tr>
<td>What is your home tel. #?</td>
<td></td>
</tr>
<tr>
<td>Who is your family doctor?</td>
<td></td>
</tr>
<tr>
<td>Who is your family/emergency contact?</td>
<td></td>
</tr>
</tbody>
</table>
Where are you right now?  
What is the date/month/year/season?

If the person presents as confused, disoriented and/or forgetful, consultation with a physician or psychiatrist is recommended and more formal cognitive assessment/testing (i.e., MMSE) may be indicated.

**DEPRESSION/DELUSION/PSYCHOSIS (Optional)**

After using the PACE tool, below are suggested questions if there are concerns that the person’s ability to make a decision is affected by depression or delusion/psychosis. Always refer to a physician, psychiatrist, and/or psychogeriatrician for further assessment and treatment as appropriate.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you help me understand why you’ve decided to accept/refuse placement?</td>
<td></td>
</tr>
<tr>
<td>Do you feel that you are being punished?</td>
<td></td>
</tr>
<tr>
<td>Do you think you are a bad person?</td>
<td></td>
</tr>
<tr>
<td>Do you have any hope for the future?</td>
<td></td>
</tr>
<tr>
<td>Do you deserve to be taken care of?</td>
<td></td>
</tr>
<tr>
<td>Do you think anyone is trying to hurt/harm you?</td>
<td></td>
</tr>
<tr>
<td>Do you trust your doctor/nurse?</td>
<td></td>
</tr>
</tbody>
</table>

**PACE: SAMPLE QUESTIONS (Cont’d)**

1. **ABLE TO UNDERSTAND CARE NEEDS**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>What happened that brought you here (i.e., for person in hospital)?</td>
<td></td>
</tr>
<tr>
<td>What health problems are you having right now?</td>
<td></td>
</tr>
<tr>
<td>What has the doctor told you?</td>
<td></td>
</tr>
<tr>
<td>What problems are you having at home?</td>
<td></td>
</tr>
<tr>
<td>What do you need help with on a daily basis?</td>
<td></td>
</tr>
<tr>
<td>What help do you receive at home on a daily basis?</td>
<td></td>
</tr>
<tr>
<td>Who provides you with help at home and how often?</td>
<td></td>
</tr>
<tr>
<td>What do you need more help with on a daily basis?</td>
<td></td>
</tr>
<tr>
<td>What problems are you having when you walk?</td>
<td></td>
</tr>
<tr>
<td>What do you use to help you walk (i.e., cane/walker/person)?</td>
<td></td>
</tr>
<tr>
<td>Have you had any falls?</td>
<td></td>
</tr>
<tr>
<td>How often do you fall?</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response/Comments</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>What happened the last time you fell?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when getting in and out of bed?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when going to the bathroom?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when having a bath/shower?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when getting dressed?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when you eat?</td>
<td></td>
</tr>
<tr>
<td>What help do you need when preparing meals?</td>
<td></td>
</tr>
<tr>
<td>What help do you need with cleaning/doing laundry?</td>
<td></td>
</tr>
<tr>
<td>What help do you need with shopping/buying groceries?</td>
<td></td>
</tr>
<tr>
<td>What help do you need with transportation (i.e., to doctor’s appointment, to go home today)?</td>
<td></td>
</tr>
<tr>
<td>What help do you need with getting/taking medications?</td>
<td></td>
</tr>
<tr>
<td>What problems do you have with your memory?</td>
<td></td>
</tr>
<tr>
<td>When/how often do you feel confused?</td>
<td></td>
</tr>
<tr>
<td>When/how often do you feel forgetful?</td>
<td></td>
</tr>
<tr>
<td>What concerns do you have if you are alone at home?</td>
<td></td>
</tr>
<tr>
<td>What concerns do you have about your safety at home?</td>
<td></td>
</tr>
<tr>
<td>What concerns do you have about your ability to manage at home (i.e., if discharged from hospital today)?</td>
<td></td>
</tr>
</tbody>
</table>

### 2. ABLE TO UNDERSTAND PROPOSED LONG TERM CARE PLACEMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you know about any LTC facility/nursing home/home for the aged?</td>
<td></td>
</tr>
<tr>
<td>What kind of help/care is available at a LTC</td>
<td></td>
</tr>
</tbody>
</table>
Who needs to live at a LTC facility and why?

### PACE: SAMPLE QUESTIONS (Cont’d)

#### 3. ABLE TO UNDERSTAND OPTION OF REFUSING PROPOSED LONG TERM CARE PLACEMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I/the healthcare team/your family think you need to move to a nursing home. Please tell me if you agree or disagree.</td>
<td></td>
</tr>
</tbody>
</table>

#### 4. ABLE TO APPRECIATE REASONABLY FORESEEABLE CONSEQUENCES OF ACCEPTING PROPOSED LONG TERM CARE PLACEMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>What will happen if you move to a nursing home?</td>
<td></td>
</tr>
<tr>
<td>What kind of help could you receive if you live in a nursing home?</td>
<td></td>
</tr>
</tbody>
</table>

#### 5. ABLE TO APPRECIATE REASONABLY FORESEEABLE CONSEQUENCES OF REFUSING PROPOSED LONG TERM CARE PLACEMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>What will happen if you refuse to move to a LTC facility?</td>
<td></td>
</tr>
<tr>
<td>If you felt sick or unsafe, what would you do?</td>
<td></td>
</tr>
<tr>
<td>If you had a fall, what would you do?</td>
<td></td>
</tr>
<tr>
<td>What could happen if you smoke in bed or leave the stove on?</td>
<td></td>
</tr>
<tr>
<td>If there was a fire, what would you do?</td>
<td></td>
</tr>
<tr>
<td>What could happen if you do not take your medication?</td>
<td></td>
</tr>
<tr>
<td>What could happen if you do not have 24 hour care and supervision?</td>
<td></td>
</tr>
</tbody>
</table>

#### 6. ABLE TO UNDERSTAND ALTERNATIVE TO PROPOSED LONG TERM CARE PLACEMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Response/Feedback</th>
</tr>
</thead>
</table>

If you do not move to a nursing home, where will you live (i.e., when you leave the hospital)?

Who will help take care of you on a daily basis (i.e., be specific re: care needs/concerns identified by health care team assessment or by family or by other informants such as CCAC staff, EMS staff, police, etc.)?

Where/how can you get the help you need? (Note: identify and confront conflicts if expectations do not meet reality of what formal/informal supports are able/willing to provide)

Where/how can you get the help you need that your family/friends/CCAC can not provide (i.e., insurance benefits, privately hired help to supplement family/CCAC)?

PACE: Placement Aid to Capacity Evaluation

Instructions for Scoring

1. Domains 1 - 3 evaluate whether the person understands and appreciates his/her current care needs, the proposed option of long term care placement, and the consequences of a decision to accept the proposed placement. Domains 4 - 6 evaluate whether the person understands and appreciates the option to refuse the proposed placement, the consequences of a refusal, and other realistic options if any exist (i.e., hiring private help, living with family) (see sample questions above).
2. If the person responds appropriately to open-ended questions, score YES. If they need repeated prompting by closed-ended questions, score UNSURE. If they cannot respond appropriately despite repeated prompting, score NO.
3. Record observations that support your score in each domain, including exact responses of the patient.
4. Remember that people are presumed to be capable. If you are uncertain regarding your overall impression, then do not err on the side of calling a person incapable. Reevaluate at another time and consult with other professionals (i.e., OT, PT, Psychiatrist) to request additional evaluation and assessment.
The developers of the PACE (i) assume no liability for any reliance by any person on the information contained herein; (ii) make no representations regarding the quality, accuracy or lawfulness related to the use of the PACE, and (iii) recommend that PACE users attend a PACE training session.

The PACE may be copied by any person for non-commercial use.

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For an additional resource on capacity, please see Dr. Etchells' paper, "Bioethics for Clinicians: 3. Capacity" (Canadian Medical Association Journal 1996; 155: 657-61)  
Updated 10 April 1997
Communication Aid to Capacity Evaluation - CACE

Alexandra Carling-Rowland M.Sc. SLP-C
Doctoral Candidate
Institute of Medical Science
University of Toronto
The Communication Aid to Capacity Evaluation CACE
Instructions for Administration

Introduction
The Communication Aid to Capacity Evaluation (CACE) was developed to be used with patients/clients who have a communication barrier or disorder. Please follow all of the instructions to maximize your ability to evaluate whether your patient/client has the ability to understand information that is relevant to making a decision about admission to a long term care home, and has the ability to appreciate the reasonably foreseeable consequences of his or her decision or lack of decision.

We strongly recommend that you view the training DVD before you administer CACE.

1) Chart Review and Team Consultation
To ensure that your capacity evaluation is fair you must gather background information about the patient/client. Conduct a thorough chart review and consult with members of the healthcare team. Note the existence of anything that might affect the capacity evaluation, for example, mental health issues such as depression, delusions, anxiety and aggressive behaviours. Other conditions can affect capacity evaluation such as sleeping problems, pain, fever and cognitive deficits. You also need to make careful note of the following:

<table>
<thead>
<tr>
<th>Communication</th>
<th>Present</th>
<th>Not noted</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disorders, e.g. Aphasia, Dysarthria, Apraxia, Anomia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most effective form of communication. Consult with SLP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English/French as a second language. Interpreter available</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing impairment Hearing aid</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual impairments Visual field deficits, neglect, cataracts etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Name of Substitute Decision Maker: ___________________________ Unknown: □
(Power of Attorney for Personal Care)

2) **When to administer CACE**
   - Evaluate capacity at the best time of day for the patient/client, when she/he is most responsive.
   - Evaluate capacity when **you** have sufficient **time**.
   - Be prepared to complete CACE over a number of sessions if needed.

   - **Where to administer**
     - Evaluate capacity in a quiet place, free of distractions.
     - Sit the patient/client opposite you with the light on **your** face. If the patient/client can see you clearly it helps attention and focuses communication.
     - Ensure that the patient/client is as comfortable as possible to avoid physical distraction of pain.
     - Preserve privacy.

4) **How to administer**
   - You will see lines throughout CACE, e.g. “______ is worried about you living at home”. These are designed to make the tool personal to the patient/client and his or her circumstances.
   - Relate the pictograms to the patient/client’s context, e.g., if he or she lives in an apartment building point to that picture when talking about ‘home’.
   - The Orientation section is optional.
   - Further cards and addendums have been provided for your use. They include;
     1) Yes/No/Don’t know  2) Stop I have a Question/Comment  3) Substitute Decision Maker  4) Consent and Capacity Board  5) Office of the Public Guardian and Trustee.

**Patient/client**
   - If you are administering CACE with a colleague, introduce him or her to the patient/client.
   - Observe the patient/client carefully, look for non-verbal communication and acknowledge.
   - Make sure that the patient/client can clearly see the pages of CACE. If needed, cover parts of a page to focus attention.
   - Give the patient/client adequate time to respond.
   - Adapt your language so the patient/client understands you; for example, use “nursing home” if the patient/client does not understand “Long Term Care Home”.

**Items to Remember**
   - Does the patient have a **communication book** or **system**? Familiarize yourself with how it works.
- Check that the patient/client has **glasses** and/or a **hearing aid** and check that they are working.
- Have paper and markers close to hand.

**Stop administration of CACE when:**
- The patient/client becomes **excessively** frustrated, agitated, emotional or fatigued.
- The patient/client is unable to understand the questions.
- The patient/client is non-responsive or responses are unclear, for example, if the patient/client does not look at the picture choices he/she selects, or makes non-specific gestures as a response.

5) **Scoring CACE**
- Circle choices and record the patient/client’s verbal responses verbatim. We recommend doing this in the body of CACE. It helps to verify and refer back to choices.
- Record the patient/client’s non-verbal responses. These could include:
  - Writing or drawing
  - Pointing to a picture or items (body part, objects, elsewhere)
  - Sounds with positive or negative intonation
  - Head nodding for YES or AGREEMENT
  - Head shaking for NO or DISAGREEMENT
  - Shrugging shoulders for ‘unsure’ or ‘don’t know’
  - Gestures and facial expressions
  - Purposeful eye gaze
  - Other symbols of intent or acknowledgement
- A separate scoring sheet is provided. Its use is optional. The scoring sheet can be placed in the patient/client’s health record.
- Record whether the patient/client has the capacity, or not, to make an admission decision, or whether he or she refuses to be evaluated.

**Supported Conversation for Adults with Aphasia (SCA™) Techniques**

Supported Conversation for Adults with Aphasia (SCA™) is a variety of communication techniques that have proved to be beneficial when interacting with people with aphasia and other communication barriers (Kagan 1998). By using these techniques with CACE it is hoped that the patient/client’s capacity to understand and appreciate information will be revealed.

**Observe the patient/client carefully to see how much support is needed**

**Getting the Information In (understanding):**
- Speak at a slower rate, but keep your natural speaking voice.
o  Group information into manageable units to help your patient/client understand and process:

   “My name is Sarah, I am a social worker” pause “I would like to talk to you about your discharge” pause “We could go to my office where it is quieter.”

o  Write down key words to help get your message across,

   “My name is SARAH pause I am a SOCIAL WORKER pause I would like to TALK to you about your DISCHARGE.”

o  Point to the words and pictographs in CACE while you are talking to help understanding.

o  Use natural gestures, facial expression, pointing and drawing to support your message.

Getting the Information Out (communication):

o  Give the patient/client time to communicate. Encourage verbal responses if possible.

o  Ask an open ended question, it helps to set the context of the question. However, if the patient/client is unable to answer, use the pictographs provided to help him or her respond.

o  During the evaluation give the patient/client opportunities to add information or ask questions (see enclosed card for your use). We suggest you do this at the end of each section.

o  If the patient/client needs help to ask a question use the pictographs to help you, for example, at the end of section 3,

   “Is your question about the bathroom, fire or feeling sick?” (Patient/client points to the bathroom)
   “Is your question about one of these pictures?” (Patient/client points to Lifeline)
   “Do you want to know more about Lifeline?” (Patient/client indicates ‘yes’)
   “We can talk about Lifeline afterwards; I’ll help you with it”

o  If his or her question is about something else, provide logical, contextual choices. Always include “something else” to let the patient/client communicate that you are on the wrong track.

   “Is it about this EVALUATION or SOMETHING ELSE?”

o  Encourage the patient/client to use gesture, drawing, writing or pointing to previous pictures.

   “Can you show me? Can you draw or write something to help me? Is it about one of these pictures?”
Verify the Information:
Verify frequently, it will keep both of you on track, save time and help you to confirm whether the patient/client both understands and has been understood.

“So, you showed me that you do not need help at home” *(Point to the picture showing no help).*

“I want to make sure that I've got it right”.

“Do you need help at home?” *(Write words HELP and HOME)*

“YES” or “NO” *(Use Yes/No/Don’t know card)*
Communication Aid to Capacity Evaluation (CACE)

Introduction and explanation

Hello my NAME is ____________________

I am a __________________________

We are here today to TALK about where YOU should LIVE.

WHERE?

or
is worried about YOU
living at HOME,

so I am going to ASK you some QUESTIONS. I want
to hear, or see YOUR IDEAS about where you should
live.

It is a DIFFICULT decision.
There is a lot to THINK about.

I THINK you CAN make the DECISION
but I HAVE to CHECK.
I am going to use these **PICTURES** to **HELP** you.

I understand that you have **DIFFICULTY COMMUNICATING** because of _________________

The questions will help us to **EVALUATE** your **“CAPACITY to make ADMISSION DECISIONS”**.

That is, can **YOU** decide where **YOU** **LIVE**?
What does **CAPACITY** MEAN?
What are we talking about?

**CAPACITY** means that you have the ability to UNDERSTAND

your **MEDICAL** condition

what YOU can do **YOURSELF**

and how it affects **WHERE** you **LIVE**.

your **HEALTH**

when you need **HELP**
Also, **CAPACITY** means you **UNDERSTAND** what **MIGHT HAPPEN**.

You have the ability to **APPRECIATE** the consequences when. . .

you **MAKE** a decision

**OR**

**DO NOT MAKE** a decision.
AFTER the evaluation:
If you are NOT CAPABLE to make a decision about where to live

Because:

you do NOT have the ability to UNDERSTAND

or

you do not know, or APPRECIATE what will HAPPEN when you MAKE a decision or DON’T make a decision.
We will talk to your SUBSTITUTE DECISION MAKER

____________________

____________________ will DECIDE where YOU should LIVE.

or

or

or
If you do not **KNOW** who is your **SUBSTITUTE DECISION MAKER**

I will contact the **PUBLIC GUARDIAN AND TRUSTEE**

and **THEY** will decide where you will live.

or

or
If you **DO NOT AGREE** with **MY** decision,

___________ will **HELP** you to **CONTACT** the **CONSENT AND CAPACITY BOARD**.

They will **REVIEW** my **DECISION**.
You have the right to REFUSE to ANSWER my questions.

Do you have any QUESTIONS?

?? ??

Can I ask YOU the QUESTIONS now? Tell me, or show me.

YES ☑️  NO ✗
**Orientation (these questions are optional)**

1) Tell me your **FULL NAME**?
   
   ________________________

1b) Is your NAME _______________ or ____________?

2) **WHERE** are you right **NOW**?

   - HOME
   - HOSPITAL
   - LONG TERM CARE HOME
   - RETIREMENT
   - SOMEWHERE ELSE __________
   - Do not know
3) What **DAY** is it today? __________________

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday</td>
<td>Saturday</td>
<td>Sunday</td>
<td></td>
</tr>
</tbody>
</table>

4) What **MONTH** is it now? __________________

<table>
<thead>
<tr>
<th>January</th>
<th>May</th>
<th>September</th>
</tr>
</thead>
<tbody>
<tr>
<td>February</td>
<td>June</td>
<td>October</td>
</tr>
<tr>
<td>March</td>
<td>July</td>
<td>November</td>
</tr>
<tr>
<td>April</td>
<td>August</td>
<td>December</td>
</tr>
</tbody>
</table>

5) What **SEASON** is it now? __________________

<table>
<thead>
<tr>
<th>Spring</th>
<th>Summer</th>
<th>Fall</th>
<th>Winter</th>
</tr>
</thead>
</table>

6)) What **YEAR** is it? __________________

|------------|------------|------|------|------|------|
1. Able to understand care needs

Do you have any HEALTH problems?

Do you have any of these HEALTH problems?

- STROKE
- INJURY
- HEAD
- HEART
- DIABETES
- CANCER
- BREATHING
I have NO PROBLEMS.

Do you have any of these?

- Parkinson’s Disease
- Lou Gehrig’s – ALS
- Multiple Sclerosis
- Huntington’s Disease
- Laryngectomy
- Something else

DEPRESSION or ANXIETY
or
EMOTIONAL PROBLEMS.
At home, do you need **HELP** with . . . ?

Getting **IN** and **OUT** of **BED**

**WALKING** or getting around **DRESSED**

**Going to the BATHROOM**

**Having a shower**
At home, do you need HELP with . . . ?

CLEANING the house

Preparing

SHOPPING

Taking MEDICATION

Managing MONEY

I DO NOT HELP.

Something else?
**WHO helps you at home?**

- Partner/spouse
- Children
- Friends or sister
- Family, brother
- Nurse or care giver
- Neighbour

**How OFTEN do they help you?**

- **EVERYDAY**
- OR _____ times a week.

[Calendar image showing days of the week]
Are you **FORGETFUL**?

Where is it?

Do you get **CONFUSED**?

Would you feel **SAFE** living at home?
2. Able to understand proposed care placement

Which one is a **LONG TERM CARE HOME**?

a) HOTEL  

![Hotel Image]

b) HOUSE  

![House Image]

c) APARTMENT  

![Apartment Image]

d) HOSPITAL HOME  

![Hospital Image]

e) NURSING  

![Nursing Home Image]

f) RETIREMENT HOME  

![Retirement Home Image]

g) SOMETHING ELSE  

![Something Else Image]

h) Do not know
WHO lives in a LONG TERM CARE HOME?

People who CAN look after themselves?

OR

People who CANNOT manage by themselves, who DO NOT have enough HELP at HOME?
2. Able to appreciate proposed care placement

Do YOU NEED to LIVE in a Long Term Care Home NOW?

____________________

think/s that you

SHOULD live in a Long Term Care Home NOW.

Do you AGREE?

YES  ✓  NO  X

Do not know ?
3. Able to understand present condition

What would you **DO:**
If you **FELL** in the **BATHROOM**?

<table>
<thead>
<tr>
<th>Do <strong>NOTHING</strong></th>
<th><strong>CALL OUT</strong> for help</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td><img src="image2.png" alt="Image" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>PHONE 911</strong></th>
<th><strong>Have a BATH</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td><img src="image4.png" alt="Image" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>WAIT</strong> for help</th>
<th><strong>Press LIFELINE</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image5.png" alt="Image" /></td>
<td><img src="image6.png" alt="Image" /></td>
</tr>
</tbody>
</table>

I **WILL NOT** fall.
What would you **DO:**
If there was a **FIRE** at your **HOME**?

**PHONE 911** your home

**WAIT** for help

**LEAVE**

**CALL OUT** for help

Put out the fire

Press **LIFELINE**

Do **NOTHING**

There **WILL NOT** be a fire.
What would you **DO:**

If you were **SICK**?

- **Take MEDICATION**
  - ![Medication Image]
- **Go SHOPPING**
  - ![Shopping Image]
- **CALL OUT** for help
  - ![Calling Image]
- **Press LIFELINE**
  - ![Lifeline Image]
- **Do NOTHING**
  - ![Nothing Image]
  - ![Not Sick Image]
- **PHONE someone**

**I WILL NOT** get sick.
4. Able to appreciate consequences of REFUSING proposed Long Term Care placement

If you **DO NOT** go to a Long Term Care Home
WHERE will you LIVE?

- **HOME**
- **HOSPITAL**
- **HOTEL**
- **FRIENDS’ HOUSE**
- **WITH FAMILY**
- **RETIREMENT HOME**
- **Do not know**
If you live at **HOME**

**WHO** would **HELP** you on a **DAILY** basis with ___________________________?

---

PARTNER/SPOUSE

FOURTH/SPOUSE

CHILDREN

FRIENDS

FAMILY, BROTHER OR SISTER

CAREGIVER OR NURSE

NEIGHBOUR

---

**I do not know**

**NEED HELP**

**Someone else?**

**I do NOT**
If you can **NOT** look after yourself

and you **DO NOT** have enough **HELP** at **HOME**

**WHAT WILL YOU DO?**

**PAY** someone to **HELP ME**

**$$$**

I have money

I have private Insurance

Something else?
5. Able to appreciate consequences of ACCEPTING proposed Long Term Care placement

What would a Long Term Care Home HELP you with . . . ?

Getting **in** and **out** of **bed**

**Walking** or getting around

**Getting dressed**

**Going to the BATHROOM**

**Having a shower or bath**
What will a Long Term Care Home **HELP** you with . . ?

<table>
<thead>
<tr>
<th>Taking <strong>MEDICATION</strong></th>
<th>Preparing and eating <strong>MEALS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>![Medication Image]</td>
<td>![Meal Image]</td>
</tr>
</tbody>
</table>

**NOTHING,**

I **DO NOT** need help.

So do you think you should **MOVE** to a Long Term Care Home **NOW**?
Communication Aid to Capacity Evaluation CACE

Response sheet

Last Name: ____________________________  First Name: ____________________________

Date of Birth: ________________________  Health card #: ______________________

<table>
<thead>
<tr>
<th>Question</th>
<th>Response verbal</th>
<th>Response non-verbal</th>
<th>Capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose of the assessment process</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CONSENT TO ASSESS</strong></td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td>Consent to assess</td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td><strong>ORIENTATION - OPTIONAL</strong></td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td>Person</td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td>Place</td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td>Time</td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td><strong>1. ABLE TO UNDERSTAND CARE NEEDS</strong></td>
<td></td>
<td></td>
<td>○ Yes ○ No ○ Unsure</td>
</tr>
<tr>
<td>Health needs</td>
<td></td>
<td></td>
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<tr>
<td>Care needs</td>
<td></td>
<td></td>
<td>○ Yes ○ No</td>
</tr>
<tr>
<td>Question</td>
<td>Response verbal</td>
<td>Response non-verbal</td>
<td>Capacity</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>---------------------</td>
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</tr>
<tr>
<td>Who helps?</td>
<td></td>
<td></td>
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<tr>
<td>Frequency of help</td>
<td></td>
<td></td>
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<tr>
<td>Page - 17</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Who lives in Long Term Care Facility</td>
<td></td>
<td></td>
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<tr>
<td>Page - 20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. ABLE TO UNDERSTAND PROPOSED LONG TERM CARE PLACEMENT</td>
<td></td>
<td></td>
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<tr>
<td>Knowledge of Long Term Care Facility</td>
<td></td>
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<td>Page - 19</td>
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<td></td>
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<tr>
<td>2. ABLE TO APPRECIATE PROPOSED LONG TERM CARE PLACEMENT</td>
<td></td>
<td></td>
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<tr>
<td>Agree or disagree to placement</td>
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<tr>
<td>Page - 21</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3. ABLE TO UNDERSTAND PRESENT CONDITION</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Consequences of staying at home – safety</td>
<td></td>
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<tr>
<td>Pages 22 - 24</td>
<td></td>
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<tr>
<td>4. ABLE TO APPRECIATE CONSEQUENCES OF REFUSING PROPOSED PLACEMENT</td>
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<tr>
<td>Alternate living situation</td>
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<td>Page - 25</td>
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<td></td>
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<tr>
<td>Who will help</td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>Page - 26</td>
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<td></td>
<td></td>
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<tr>
<td>What will you do?</td>
<td></td>
<td></td>
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<td>Page – 27</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. ABLE TO APPRECIATE CONSEQUENCES OF ACCEPTING PROPOSED PLACEMENT</td>
<td></td>
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<tr>
<td>How a Long Term</td>
<td></td>
<td></td>
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<td>Page - 16</td>
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</tbody>
</table>

○ Yes
○ No
○ Unsure
<table>
<thead>
<tr>
<th>Care Facility helps</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pages 28 - 29</td>
<td></td>
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</tr>
<tr>
<td>Now move to a Care Facility</td>
<td></td>
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<tr>
<td>Page- 29</td>
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</tr>
</tbody>
</table>

○ No  ○ Unsure  ○ Yes  ○ No  ○ Unsure

Summary Comments:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Capacity to Make Admission Decisions

- [ ] CAPABLE
- [ ] INCAPABLE
- [ ] REFUSED EVALUATION

Rights Information

- [ ] APPLICANT INFORMED OF INCAPACITY
- [ ] RIGHTS INFORMATION SHEET GIVEN
- [ ] FINDING OF INCAPACITY TO BE APPEALED
Evaluator’s Signature: __________________________

Co-evaluator’s Signature: __________________________

Date: ________________
Appendix 5

Panel of Experts Survey

Instructions
Please read the original ‘Capacity to make Admission Decisions’ questionnaire and the adapted ‘Capacity to make Admission Decisions’ questionnaire. Then please complete the following survey. A line is included after each question should you have a specific comment. Thank you for your participation.

Definitions
1) **CAPACITY** - A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to **understand** the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to **appreciate** the reasonably foreseeable consequences of a decision or lack of decision. (Health Care Consent Act 1996, c. 2, Sched. A, s. 4 (1).)

2) As a construct, to "**understand**" refers to a person's cognitive abilities to factually grasp and retain information. To the extent that a person must demonstrate understanding through communication, the ability to express oneself (verbally or through symbols or gestures) is also implied. (Capacity Assessment Office, Ministry of the Attorney General 2005)

3) The "**appreciate**" standard attempts to capture the evaluative nature of capable decision-making, and reflects the attachment of personal meaning to the facts of a given situation. (Capacity Assessment Office, Ministry of the Attorney General 2005)

Survey
A) Compliance with the current ‘Capacity to make Admission Decisions’ questionnaire

1) The adapted version reflects the **content** of the original ‘Capacity to make Admission Decisions’.

   - **4** Strongly agree
   - **3** Agree
   - **2** Neither agree nor disagree
   - **1** Disagree
   - **0** Strongly disagree

   Comment: _______________________________________________________

2) The adapted version allows the evaluator to assess whether a patient **understands** the information.

   - **4** Strongly agree
   - **3** Agree
   - **2** Neither agree nor disagree
   - **1** Disagree
   - **0** Strongly disagree

   Comment: _______________________________________________________
3) The adapted version allows the evaluator to assess whether a patient appreciates the reasonably foreseeable consequences of his or her decision or lack of decision.

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither agree nor disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

Comment: __________________________________________________________

**B) Compliance with the Health Care Consent Act**

Does the ADAPTED ‘Capacity to make Admission Decisions’ version reflect the following components of the Health Care Consent Act (1996)?

1) “to enhance the autonomy of persons for whom admission to a care facility is proposed”

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither agree nor disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

Comment: __________________________________________________________

2) “to promote communication and understanding between health practitioners and their patients or clients”

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither agree nor disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

Comment: __________________________________________________________

3) “that a person is presumed to be capable with respect to admission to a care facility”

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>Agree</td>
<td>Neither agree nor disagree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
</tr>
</tbody>
</table>

Comment: __________________________________________________________

**C) Explanation of the Consent Evaluation Process**
1) The adapted version allows the patient with a communication barrier to understand the capacity evaluation process.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td></td>
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</tbody>
</table>

Comment: __________________________________________________________

Further Comments:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
CONSENT to 
PARTICIPATE in a 
RESEARCH STUDY

I Investigator: Alexandra Rowland, 
Doctoral Candidate (student), 
University of Toronto

Project Title: Adaptation of the ‘Capacity to Make Admission Decisions’ Assessment to an Accessible Format for People with Communication Disorders

Does the adapted capacity evaluation work? 
Does it help people with aphasia? 
I need you to help me find out.
Contact Information:

Investigator
Alexandra Carling-Rowland, B.Sc., M.Sc. doctoral candidate
Institute of Medical Science, University of Toronto,
1, King’s College Circle,
Toronto, Ontario M5S 1A8.
Telephone: 416 686 8298

Doctoral supervisors

Dr. Sandra Black,
Sunnybrook Health Sciences
2075 Bayview Ave
Toronto, ON. M4N 3M5
Tel: 416-480 6100

Dr. Aura Kagan
Aphasia Institute
73, Scarsdale Rd
Toronto, ON. M3B 2R2
Tel: 416-226 3636

Dr. Lynn McDonald
Institute of Life Course & Aging
University of Toronto
222 College Street
Toronto, ON. M5T 3J1
Tel: 416-978 0377

University of Toronto
Research Ethics
Jenny Peto, Research Ethics Coordinator
University of Toronto
McMurrich Building
12 Queen’s Park Cres
Toronto, ON. M5S 1S8
Tel: 416-946 3273
• I am **testing** a form called the

“Communication Aid to Capacity Evaluation” or “CACE”

![Communication Aid to Capacity Evaluation - CACE](image)

Alexandra Carling-Rowland M.Sc. SLP-C
Doctoral Candidate
Institute of Medical Science
University of Toronto

• CACE will be used to evaluate people with **aphasia** and other **communication barriers**.

• CACE will evaluate a person’s **capacity** to make a **decision** about **where** they will go after they leave **hospital**.

• I need people with **aphasia** and **social workers** to help me test **CACE**.

• This is **NOT** a **real** evaluation, just a test to see if **CACE works**.

• Does CACE help people with aphasia to **understand** and **answer** questions?
Then, your speech-language pathologist will meet with you and ask you **3 questions** about how it all went.

The whole process should take about **45 MINUTES**

- You will meet with a **social worker**.
- She or he will **evaluate** your capacity to **decide** where to live.
- The capacity evaluation does **NOT** apply to **you**. We are just testing the evaluation form.
- This will happen **twice** with a 2 week interval.

We will film you talking with the social worker and completing the capacity evaluation.

**A speech-Language Pathologist will watch** video tape.
• She will look at the **communication skills** of the **social worker**, and how much the social worker let you **participate** in the **conversation** and **evaluation**

**Right to Withdraw:**

- You can stop at any time.
- It is your choice.
- It is ok to stop.

**NOTHING** will change with your treatment or group if you stop

**Potential Benefits:**

- This will help **research**!

- This will help:
  - People with Aphasia to understand and decide on their discharge plans
  - Social Workers learn how to communicate with people with aphasia
  - Social workers perform capacity evaluations
Potential Risks:

× There is NO danger in participating in this study.

BUT you might find it **frustrating** not being able to communicate at times – Tell us!

✓ Everything is **confidential**.

We will not use your name

Files will be locked up.

The Videotapes and surveys will be **destroyed** in September 2011
• I will publish the results of the research in journals and at presentations.
• We will not use your name in the publications.

Do you have any QUESTIONS now?

Don’t forget – you can ask questions later as well.

Project Consent:

My questions have been answered

I agree to participate in this research project.

I have been given a copy of this form.

Signature of Participant

Date

Signature of Witness

Date
Appendix 8

MEASURE OF SKILL IN SUPPORTED CONVERSATION - MSC

A. Acknowledging Competence

- **Natural talk, age & context appropriate**
  - Feel and flow of natural adult conversation, appropriate to context
  - Not patronizing (tone of voice, rate, enunciation, loudness)
  - Appropriate emotional tone/use of humour when appropriate
  - Uses collaborative talk (not teaching/testing)
  - Establishes equal roles in conversation
  - Does not over verify

- **Sensitivity to partner**
  - Incorrect/unclear responses handled respectively - correct information given in a non-punitive manner
  - Sensitive to participant’s attempts to engage in conversation, confirms contribution
  - Acknowledges competences or difficulties when participant is frustrated eg, “I know you know what you want to say”
  - Demonstrates active listening - verbal and non-verbal
  - Takes on communicative burden as appropriate, makes participant feel comfortable
  - Communicates respect for participant’s concerns, perspectives and abilities
  - Asks questions in a non-demanding, supportive manner
  - Takes appropriate conversational turns

**MSC Score:**

Not acknowledged | Minimally acknowledged | Some acknowledgement | Mostly acknowledged | Fully acknowledged
---|---|---|---|---
0 | 0.5 | 1 | 1.5 | 2 | 2.5 | 3 | 3.5 | 4

B. Revealing Competence

1. **Ensures understanding**
   - Reduces distractions, gets and maintains attention
   - Verbal - uses short simple sentences, adapts use of language appropriately
   - Non-verbal support - uses gesture, pointing, facial expression, writing and resources
   - Organizes information in the conversation to support understanding - logical sequential order of information, causality, associations, similarity and difference
   - Gives cues in a natural and conversational manner
   - Responds to given cues (facial expression showing confusion)
   - Makes connections between topics
B. Revealing Competence

2. Ensures means of response
   - Gives enough time to the participant to respond
   - Establishes equal leadership roles on conversation
   - Allows participant to take appropriate conversational turns
   - Introduces and initiates topics
   - Allows participant to initiate topics
   - Encourages use of supported conversation techniques - gesture, drawing, writing
   - Maintains the topic by adding information
   - Allows the participant to maintain topic
   - Invites elaboration
   - Helps participant express thoughts when struggle occurs
   - Uses questions appropriate to participant’s ability

B. Revealing Competence

3. Verifies
   - Responds to given verbal and non-verbal communication, infers intended message
   - Confirms understanding of what has been said by paraphrasing and checking
   - Uses clarifying questions as appropriate
   - Verifies using a different modality using writing of yes/no question

MEASURE OF SKILL IN SUPPORTED CONVERSATION - MSC Score
A. Acknowledges Competence

B. Reveals Competence
   1. Ensures Understanding
   2. Ensures Means of Response
   3. Verifies

\[ \text{average} \]
**Appendix 9**

### MEASURE OF PARTICIPATION IN CONVERSATION - MPC

**A. Interaction - social and emotional connections**

<table>
<thead>
<tr>
<th>Verbal</th>
<th>Vocal</th>
<th>Non-verbal</th>
<th>Participant shows verbal, non-verbal communicative intent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Participant shares responsibility for maintaining feel/flow of conversation</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Participant uses appropriate turn-taking</td>
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<td></td>
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<td></td>
<td>Participant adds information to maintain/expand the topic</td>
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<td></td>
<td>Participant asks questions of evaluator which relate to the topic</td>
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<td></td>
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<td></td>
<td>Participant is pragmatically appropriate</td>
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<td></td>
<td></td>
<td></td>
<td>Participant shows active listening</td>
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<tr>
<td></td>
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<td></td>
<td>Participant uses the following communicative behaviours to foster a social and emotional connection:</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>appropriate eye contact, gestures, pointing, body posture, facial expression, writing, selection of given choices, drawing, resource materials.</td>
</tr>
</tbody>
</table>

**MPC Score: Interaction**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
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<tbody>
<tr>
<td>0</td>
<td>No participation</td>
</tr>
<tr>
<td>0.5</td>
<td>Minimal participation</td>
</tr>
<tr>
<td>1</td>
<td>Some participation</td>
</tr>
<tr>
<td>1.5</td>
<td>Mostly participates</td>
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<tr>
<td>2</td>
<td>Fully participates</td>
</tr>
</tbody>
</table>

**B. Transaction - exchange of information**

<table>
<thead>
<tr>
<th>Verbal</th>
<th>Vocal</th>
<th>Non-verbal</th>
<th>Participant maintains exchange of information, opinions, and feelings with the evaluator by sharing details.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td>Participant initiates transaction e.g., introducing or referring back to a previous topic and/or spontaneously talking or using a supported conversation technique.</td>
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<td></td>
<td>Participant provides an appropriate amount of information.</td>
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<td>Content of the transaction appears to be accurate.</td>
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<td></td>
<td>Participant uses proffered conversational supports for the purposes of transaction, e.g., gestures, points to object, person, pictographs, previous key words, or given choices, collaborates with drawing uses resources.</td>
</tr>
</tbody>
</table>

**MSC Score: Transaction**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No participation</td>
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<tr>
<td>0.5</td>
<td>Minimal participation</td>
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<tr>
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<td>Some participation</td>
</tr>
<tr>
<td>1.5</td>
<td>Mostly participates</td>
</tr>
<tr>
<td>2</td>
<td>Fully participates</td>
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</table>

### MEASURE OF PARTICIPATION IN CONVERSATION - MPC Score

**A. Interaction**

<table>
<thead>
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<th>Score</th>
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</table>
B. Transaction
Social Worker Pre-capacity Evaluation Survey

You have just had a conversation with the participant with aphasia. Please answer the following questions:

In your opinion

1) Are you confident in your own communication skills to enable the person with aphasia understand the capacity evaluation process and questions?

2) Are you confident in your own communication skills to enable the person with aphasia to communicate their answers?

3) Are you confident in your own communication skills that you will be able to determine capacity in the person with aphasia?
Appendix 11

Social Worker Post-capacity Evaluation Survey - B

You have just evaluated the capacity of the participant with aphasia to make admission decisions. Please answer the following questions:

1) How did you evaluate your participant?

Has Capacity □  Does NOT have □  ** Unable to □
capacity          determine capacity at this time

2) How confident are you in your evaluation of capacity?

NOT Confident at all  NOT SURE  VERY Confident

Comments:
________________________________________________________________
________________________________________________________________
________________________________________________________________

**Please use this option as a last resort**

If you were unable to determine the participant’s capacity please indicate why: 
*Circle all that apply*

1) Unable to communicate with the participant
2) Unable to get sufficient information to determine capacity
3) Unable to understand participant’s responses
4) Need another session to determine capacity
5) Need to determine capacity with other professional. Who? __________
6) Other (please describe) ____________________________

________________________________________________________________ 
Appendix 12

Social Worker Post-capacity Evaluation Survey

You have just evaluated the capacity of the participant with aphasia. Please answer the following questions:

In your opinion

1) Did the person with aphasia **understand** the capacity evaluation process?

2) Did the person with aphasia **understand** the questions?

3) Did the person with aphasia **communicate** their answers?
Appendix 13

Did you **UNDERSTAND** the Capacity Evaluation **PROCESS**?

NONE  A BIT  SOME  MOST  ALL
Appendix 13

Did you **UNDERSTAND** the Capacity Evaluation **PROCESS**?

[Scale with options: NONE, A BIT, SOME, MOST, ALL]
Did you **UNDERSTAND** the **QUESTIONS**?
Could you **COMMUNICATE** your **ANSWERS**?

None | A Bit | Some | Most | All
Were you **frustrated** by the **level** of communication **support**?

![Survey Scale]

- **VERY FRUSTRATED**
- **FRUSTRATED**
- **SOMewhat**
- **A LITTLE**
- **NOT AT ALL**
“Thank you so much for helping us out with the research study. Remember, all of the questions the social worker just asked you *DON’T* apply to you. You were just helping us to test a form.

The last thing I need to do is ask you 4 questions about the conversation you have just had with the social worker.

I am going to ask you questions and I want you to answer using a scale, like this one (show the first question)

The social worker will never see your answers, so you won’t hurt her (his) feelings. We need your honest opinion; we really need to know how you feel to help us.

The first question is about the general information on the process of capacity testing. What the social worker said about what was going to happen.

Did you understand the capacity evaluation process? (*Point to the words as you say them*)

No, None of it, a bit of it, some, most of it, or Yes, all of it.

Can you show me on the scale? Thank you.

The next one is about the questions s/he asked you in the capacity evaluation

Did you understand ALL of the questions? (*Point to the words as you say them*)

No, None of them, a bit, some of them, most of them, Yes, all of them.

Can you show me? Thanks

This is important. This question is about *your* communication. Could get over what you wanted to. Could you communicate *everything* you wanted to say in your answers?

No, None of it, a bit, some of it, most of it, Yes, I communicated all of it.

We are on to the last question now. How frustrated were you by the level of communication support the social worker gave you? (*Point to the words as you say them*)

Very frustrated, frustrated, somewhat frustrated, a little frustrated or not frustrated at all.
That’s it we have finished! Just before you leave, do you have any questions you want to ask? I can always get Alex if you want to ask her anything.
Room Set Up

List of required items:
- Table (square, rectangular or round)
- 2 chairs (chairs should offer back and arm support, but not a reclining chair)
- OR 1 chair and a space for a wheelchair if used.
- Pad of A4 paper
- Marker
- Adequate light
- Tripod
- Camcorder

Set up
Social worker to sit on the LEFT of the participant with a communication barrier unless otherwise indicated.

Social worker to sit on the RIGHT of the participant with a communication barrier for the following:
- the participant has a unilateral hearing loss on the left
- the right ear only is aided
- The participant has a Right CVA

The social worker should have his or her body turned towards the participant so that the participant can clearly see the social worker’s face.

The light should be on the social worker’s face.

The pad of paper and marker is at the far side of the table.

The tripod and camcorder is opposite the social worker and participant.

[Diagram showing the arrangement of the room, including the social worker, the participant with a communication barrier, a table with chairs, a pen and marker, and a tripod and camcorder.]
Appendix 16

Instructions for Social Workers

Thank you for agreeing to participate in the doctoral research study to test the Communication Aid for Capacity Assessment (CACE) with training.

We are asking you to evaluate an individual's capacity to make an admission decision. You are the experts in this field; you have the knowledge, skills and training.

It is important to remember that the research study is assessing the effectiveness of CACE with training, not your skills or performance.

The participant you will be evaluating has a communication barrier.

If you feel more comfortable you can give a different name when you introduce yourself to the participant you are evaluating.

You will NOT give the results of your capacity evaluation to the participant with a communication barrier.

The participant with a communication barrier has agreed to meet with you for a conversation about where he or she lives, and to test a form.

He or she will be debriefed by a speech-language pathologist immediately after the evaluation.

1. Following a brief conversation with the participant you are evaluating you will leave the room and complete a short survey.

2. You will return and complete the capacity evaluation.

3. You will wrap up the interview as you would a conversation. The participant with a communication barrier will leave.

4. You will fill in two short surveys.

5. You will write your evaluation of capacity on the survey.

The results of your capacity evaluation will NOT be shared with the participant with a communication barrier at any time.

Please remember that we are assessing the effectiveness of CACE, but cannot do so without your expertise and cooperation.

Suggested topics of conversation:

• The weather
• The holiday season
• Conversation groups/programs
• Shopping

Thank you very much for participating in this research project.
Participant with Aphasia

THANK YOU for participating in this research study.

You are helping to TEST a FORM on people’s ability to make DECISIONS about where they should LIVE – this is called a CAPACITY EVALUATION.

This form will be used in HOSPITALS with people with APHASIA and other COMMUNICATION BARRIERS.

Today the SOCIAL WORKER will talk to you and ask you QUESTIONS to see if you can decide on the best LIVING SITUATION. Is it home or is it a long-term care home?

**REMEMBER:** These questions do NOT apply to YOU; you are just TESTING the form.

The social worker will WRITE down your responses. We will keep the paper in a locked filing cabinet.

After the interview with the social worker you will fill in a SURVEY, someone will help you with this.

You can use your OWN NAME or you can CHANGE your name for the meeting with the social worker.
What **NAME** do you want to use?
7) Instructions for administration
The first recommendation in CACE is a thorough chart review and consultation with the healthcare team. The focus is not only on gathering information about different types of communication barriers, but also on psychological and emotional issues which could interfere with a fair evaluation. The evaluator is prompted to consider both the best time of day for the patient or client, and for him or herself. People with aphasia and other communication barriers need time to process language, and their barrier precludes them from giving quick responses. CACE, as well as any thorough capacity evaluation, requires time to administer.

Patients or clients with brain injuries arising from stroke or other causes frequently have difficulties with attention. If the patient is cognitively, visually, auditorily or physically distracted he or she will not be able to process given information and formulate a response effectively. Consequently the evaluation environment needs consideration. Other strategies to adapt the process to the patient’s context are included in the subsection ‘How to Administer CACE’. CACE provides the evaluator opportunities to personalize the evaluation and offers different levels of communication support according to the person with aphasia’s needs. Tips are provided to maximize communication and focus, examples include; close observation of the patient’s non-verbal behaviours, allowing extra response time, covering some pictures on the page, and adapting language to promote comprehension. Finally, commonsense reminders are provided such as making sure the patient is wearing the correct glasses and a working hearing aid, that paper and markers are available and practice time for using a communication device.

8) Communication Techniques
Supported Conversation for Adults with Aphasia (SCA™), is a series of techniques proved to be effective when communicating with people with aphasia and other communication barriers. An abbreviated version has been included in CACE. The SCA™ techniques focus on transaction: getting information in, allowing the patient to get
information out, and verifying information. The training DVD focuses on these skills and uses examples of an evaluator interacting with a person with aphasia illustrating each technique. Effective communication can help reveal competency.

9) Response card and addendums
CACE includes cards for the patients’ and evaluators’ use. They include “YES/NO/DON'T KNOW” and “STOP, I HAVE A QUESTION/COMMENT” cards. The addendums contain more in-depth information on three legal entities should the patient with aphasia request further clarification; The Substitute Decision Maker, The Consent and Capacity Board and The Office of the Public Guardian and Trustee (see appendix 4).

10) Explanation of the Capacity Evaluation Process
The Health Care Consent Act outlines requirements for a legal capacity evaluation; these include an explanation of why capacity evaluation is taking place, presumption of capacity, what is meant by capacity, the consequences of being found lacking capacity, and process of appeal. The explanation of the evaluation process, ensuring legal compliance, makes up one third of CACE.

11) Consent to Evaluate Capacity
The patient is informed that he or she has the right to refuse to answer any questions during the capacity evaluation process. The patient is also given the opportunity to ask questions regarding the explanation before consent to evaluate is sought. Consent to evaluation is as follows; “Can I ask you the questions now? Tell me or show me”. Two pictures accompany the question with the words ‘Yes’ and ‘No’ under the respective pictures (see appendix 3 page 10).

12) Orientation
Orientation to person, place and time is a common test used by many healthcare professionals to screen for neurological disturbances. The causes of disorientation are varied, but not limited to medical and neurological complications, to adverse drug reactions, surgery, fever, hydrocephalus, subdural hematoma, seizures, and the onset of
delirium,\textsuperscript{118} all of which could affect capacity evaluation. The section on orientation is optional, but could be beneficial in some evaluation situations. Pictures, choices and text support all three spheres of orientation.

7) The Communication Aid to Capacity Evaluation Questions
The five questions contained in the Capacity to Make Admissions Decisions were adapted as follows: