EXPRESSIVE ARTS AS A SOCIAL AND COMMUNITY INTEGRATION TOOL FOR ADOLESCENTS WITH ACQUIRED BRAIN INJURIES

by

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Abstract

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Acquired brain injury (ABI) during adolescence presents even greater challenges to youth already facing complex issues in this transitory period. Studies have demonstrated that youth with ABI suffer from social and community withdrawal as a result of their injuries. However, a lack of research focusing on interventions designed to promote community integration has left the effectiveness of these programs difficult to assess. The current study aimed to collect pilot data about the effectiveness of an expressive arts-based therapeutic program in helping to improve community integration of these youth, as these therapies have been shown to be useful for individuals with similar cognitive and behavioural issues. Results over 2 stages of testing suggest that expressive arts therapy is a promising intervention strategy to help promote social and community integration skills. The findings also suggest that more research is needed to develop improved measures of community integration for adolescents with ABI.
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List of Abbreviations

ABI – acquired brain injury
CNS – central nervous system
TBI – traumatic brain injury
GCS – Glascow Coma Scale
LOC – loss of consciousness
mTBI – mild traumatic brain injury
ADHD – attention deficit-hyperactivity disorder
ODD – oppositional defiant disorder
PTSD – post traumatic stress disorder
MRI – magnetic resonance imaging
SES – socioeconomic status
RCT – randomized control trial
OCD – obsessive compulsive disorder
CBT – cognitive behavioural therapy
FAD – Family Assessment Device
BRIEF – Behavior Rating Inventory of Executive Function
HCSBC – Home and Community Social Behavior Scale
SCAIA – School and Community Activity and Integration Assessment
ICF – International Classification of Function
ICF-CY – ICF for Children and Adolescents
LIFE-H – Life Habits for Children
CASP – Child and Adolescent Scale of Participation
CAPE – Children’s Assessment of Participation Enjoyment
VABS – Vineland Adaptive Behaviour Scale
SSRS – Social Skills Rating System
COPM – Canadian Occupational Performance Measure
GAS – Goal Attainment Scaling
ABAS-II – Adaptive Behavior Assessment System Version – II
Chapter 1 Introduction
Adolescence is a time in an individual’s life that brings about an array of developmental changes. A shift occurs from a caregiver-dependent child to a fully independent adult, as an adolescent undergoes many changes in physiology, physical appearance, as well as cognitive and emotional skills. Family and community become important as an adolescent prepares for the transition to adult responsibilities and experiences, such as work or intimate relationships. Considering that even healthy adolescents struggle with this transition, having an injury or disability occur during this time frame can lead to devastating deficits and lifelong dependence on caregivers. Such can be the case for adolescents with acquired brain injuries (ABI), who suffer from social and community withdrawal as a result of their injuries (Wiseman-Hakes et al., 1998).

Having an ABI during adolescence can result in a wide array of physical, cognitive, behavioural, and emotional impairments with possible lifelong implications (Streissguth, 1997). Of particular severity are difficulties in social cognition, especially in relation to pragmatic communication skills, or the ability of a person to perceive, interpret and respond to the verbal and nonverbal contextual and situational demands of the environment (Jordan and Ashton, 1996; Wiseman-Hakes et al., 1998). Adolescents can experience difficulties with speech, language and social competence subsequent to a brain injury, all of which negatively impact the ability to learn appropriate behaviours for social interactions (Turkstra, McDonald & Kaufman, 1996). Disabilities in language-based learning, especially during adolescence when these skills are newly acquired or yet to be developed, also have a detrimental effect on the ability to use appropriate language skills for successful social interactions.

Due to these social communication problems, youth with brain injuries can suffer from social withdrawal (Wiseman-Hakes et al., 1998). In addition, changes in behaviour that occur secondary to brain injuries can be maladaptive (Lehr, 1990; Dikmen, Ross, Machamer & Temkin, 1995; Glang et al., 1997). These behavioural changes combined with social inappropriateness and cognitive challenges make it difficult for a brain injured youth to interact with peers and integrate into appropriate social networks. As a result, there is an increased likelihood that youth with brain injuries will become and remain socially isolated (Deaton, 1994; Glang et al., 1997). Therefore, it is critical to develop strategies with these youth that assist them in their integration into social networks and their participation within the community, a concept often referred to as ‘community integration’ (Minnes et al., 2003). However, currently there is a lack of research investigating such interventions for adolescents with ABI.
Expressive, or creative, arts therapy is viewed as the use of arts and artistic media to explore psychological aspects of life (International School for Interdisciplinary Studies[ISIS], 2004). This form of art can include drama, painting, sculpting, music, or even dance (ISIS). Expressive arts therapy has been shown to be useful for individuals who find meaningful verbal communication difficult, which could be relevant to the adolescent ABI population who share this similar problem (Odell-Miller et al., 2006). Theatre, or drama, has been described as the most integrative of all the arts and is thought to represent the art form that is closest to reality, leading some researchers to postulate that this aspect is what provides the innate healing function in theatre-based therapy (Snow, D’Amico and Tanguay, 2003). However, research on drama-based therapies has relied on anecdotal evidence to support findings and many studies do not describe their experimental methods or data analysis techniques (Goyal and Keightley, 2008). Though previous studies have focused on populations that share similar symptoms to that of adolescents with ABI, there is a lack of evidence that connects creative arts-based therapy directly to adolescents with brain injuries. It is believed that, because there is a close resemblance between drama and real life, the rehearsal occurring within a theatre-based therapy can be applied to actual situations adolescents may face. Thus, participation in such a program might provide a new rehabilitative strategy to improve social and emotional skills, as well as community integration of these youth.

Accordingly, the purpose of the current studies was to investigate the effectiveness of a theatre skills training program to improve social cognition and community integration. A second aim was to identify and refine methods to measure the effect of the theatre skills training program on these factors, as the lack of research on interventions has left their value difficult to assess. Chapter 2 provides background information that gave rise to the current study and details the vital role of the current study in building on the larger body of research on adolescents with ABI. Chapter 3 is a manuscript that reviews the literature on community integration interventions for youth with ABI and discusses the findings and implications of these studies. Chapters 4 and 5 are manuscripts that report the findings of 2 stages of pilot testing of an expressive arts intervention for youth with ABI, followed by Chapter 6, which provides a combined discussion of the findings from the two pilot studies.
Chapter 2  Background Information

2.1 Brain Injuries in Youth

2.1.1 Definitions and Prevalence of Brain Injuries in Youth
According to the Ontario Brain Injury Association (OBIA; 2009), an acquired brain injury (ABI) is defined as damage to the brain that occurs after birth and is not related to a congenital disorder or a degenerative disease. An ABI is non-progressive and can be the result of many different causes, including non-traumatic (e.g. tumors, stroke, central nervous system infections, epilepsy, hypoxia/ischemia, genetic/metabolic disorders, and vascular abnormalities) or traumatic mechanisms (e.g. motor vehicle accidents, assaults and recreational activities; Johnson, Dematt and Salorio, 2009).

Of the non-traumatic forms of ABI, central nervous system (CNS) tumors are the second most common malignancy among youth younger than 20 years of age [National Cancer Policy Board (NCPB); 2005]. Medulloblastomas are the most common malignant type of brain tumor and are thought to arise from precursors of the cerebellar granule cells, the most abundant neuronal cell type in the brain (Weiss et al., 2002). Another common type of pediatric brain tumor is optic nerve glioma, which can reduce the visual acuity of the affected eye even though the majority of cases are found to be benign (NCPB, 2005).

TBI’s are the most common form of brain injuries that factor in the mortality and morbidity rates of children and adolescents. From 2003 to 2004, the age category most represented in TBI cases reported to hospitals in Canada were youth from birth to 19 years of age, with the leading causes reported as falls (40%) and motor vehicle accidents (39%) [Canadian Institute for Health Information (CIHI), 2006]. Compared to a rate of 8% in adults, TBI in children and adolescents aged 12 to 19 occurred during recreational activities in 28% of cases. These injuries were mostly concussions suffered during team-based sports. In relation to motor vehicle accidents, another common cause of TBI, the highest proportion of head injuries was also found to occur in children and adolescents (33%).

The incidence of TBI is also disproportionately represented by gender. For example, during 2003 to 2004, males accounted for 67% of head injury hospitalizations for children and adolescents between birth to 19 years of age, with a mean age of 10 (CIHI, 2006). Colantonio et al. (2009) found that, among children aged 15 and younger, the rate of TBI associated hospitalization was 70% higher for males than females. This disproportion increased drastically when examining young men ages 16 – 25, as the rate was almost 160% higher. However, the
difference in rates was seen to fall after age 25 and beyond. A report by CIHI (2006) also found that the overall rate of falls resulting in TBI in children and adolescents decreased by 58% over the 10 year span of their study, from 4 661 in 1994-95 to 1 973 in 2003 – 04. This reduction has been attributed mostly to reduced cycling incidents and an increase in the use of helmets (CIHI, 2006)

2.1.2 Mechanisms and Classification of Brain Injuries

There are several ways that a TBI can be classified, such as by severity (i.e. degree of brain tissue damage), mechanism (i.e. blunt or penetrating), or morphology (i.e. skull fractures or intracranial lesions; British Medical Journal, 2007). These injuries are considered ‘open’ when penetration of the scalp and skull is involved or ‘closed’ when the head is struck or strikes an object and is shaken violently, causing rapid acceleration and deceleration forces. Due to these forces, the site of injury is not limited to where the object struck, but can affect the opposite pole of the brain or become diffuse, with the frontal and temporal lobes being most vulnerable (Koch, Narayan and Timmons, 2007). Axons and blood vessels can be sheared or torn, or blood vessels may leak and produce contusions (i.e. brain bruises), intracerebral or subarachnoid hemorrhaging, epidural or subdural hematomas (Koch, Narayan and Timmons, 2007).

Upon admission to the emergency room, the severity of a brain injury is often classified as mild, moderate or severe depending on the level of consciousness and overall dysfunction demonstrated by the individual as estimated by the Glasgow Coma Scale (GCS; Teasdale and Jennett, 1974). The GCS rates three key factors: eye opening, best motor response and best verbal response. Each of these factors is rated on a numerical scale to provide a maximum total score of 15. As a rule of thumb, a total score on the GCS between 13 – 15 and a loss of consciousness (LOC) on a scale of minutes is considered a mild injury. A moderate head injury reflects a score of 9 – 12 and a LOC on a scale of hours, whereas a severe head injury is considered a score of 8 or less, with a LOC on a scale of days (Anderson and Catroppa, 2005). For children younger than 5 years of age, a separate Pediatric GCS can be used. Within this scale, both the verbal response and motor scales are modified to reflect more appropriate scaling for this age group, such as considering vocalization as opposed to verbal responses (Simpson and Reilly, 1982). Campbell et al. (2004) demonstrated that 20% of children with GCS scores of less than 8 died upon admission to the emergency room, compared to no deaths occurring in children whose scores were above 8.
Studies have demonstrated that impairments in physical, cognitive, behavioural and emotional functions are moderated by injury severity and that more severe ABI’s in children and adolescents are associated with greater functional morbidity (Anderson and Catroppa, 2005; Asarnow et al., 1991; Catroppa and Anderson, 2002; Jaffe et al., 1992, 1993; Klonoff, Clark and Klonoff, 1993; Levin et al., 1993). For example, Todd, Anderson and Lawrence (1996) and Pentland, Todd and Anderson (1998) demonstrated that children with moderate to severe brain injuries were significantly impaired on tasks of executive functions, or the set of related skills including strategic planning and problem solving, cognitive flexibility of thought and action, and attentional control that are used for attainment of a future goal, in comparison to children with no injuries or mild TBI. Anderson and Catroppa (2005) revealed that children who had sustained a severe TBI also demonstrated greater memory impairments, compared to both children with moderate or mild injuries, 1 year post-injury.

However, more recent research suggests that even mild injuries can leave persistent negative effects that significantly impact the development of a child or adolescent months or years after the injury was incurred (McKinlay et al., 2009). Mild traumatic brain injuries (mTBI) represent the majority of head injury cases in both adults and youth. The incidence of mTBI may still be underestimated since a high number of cases go unreported when immediate impairments and difficulties are not observed, or the focus of post-injury treatment is placed on other injuries unrelated to the CNS (Thomas and Irby, 2003). Although long-term follow-up studies have demonstrated generally good outcomes for most children with mTBI, several studies have also shown that some children do continue to experience negative psychosocial, cognitive and behavioural difficulties in the months following their injury. For example, mTBI has been found to be associated with increased behavioural problems years after the injury, especially if it was incurred during early childhood (Klonoff, Clark and Klonoff, 1993; Koponen et al., 2002; McKinlay et al., 2002). A longitudinal study by McKinlay et al. (2009) found that children who incurred more severe cases of mTBI before the age of 5 were more likely to demonstrate psychiatric symptoms consistent with diagnoses of Attention Deficit-Hyperactivity Disorder (ADHD), Conduct Disorder (CD), Oppositional Defiant Disorder (ODD), substance abuse, and mood disorder during their adolescent years compared to a control group of uninjured children of the same age. Although there is currently a lack of consensus regarding the definition of mTBI, the variance in outcomes following this type of brain injury has led some researchers to suggest that mTBI be viewed as a spectrum of injuries. Therefore, impairments that are mild and transitory would be expected when the injury is towards the less severe end, but can leave long-
term problems in psychosocial functioning when the injury is towards the more severe end (McKinlay et al., 2009; Satz, 2001; Thompson and Irby, 2003).

Regardless of the label of severity that is ascribed to brain-injury in youth, any injury during this time of critical neural development has the potential to cause devastating effects. An ABI experienced during childhood or adolescence can disrupt the underlying neural processes that are involved with the acquisition and development of important cognitive, behavioural and social skills.

2.2 Neurodevelopment

2.2.1 The Course of Development of the Brain

Several synchronous processes interact in the development of the brain, some of which are complete before birth while others extend into adulthood (Lenroot and Diedd, 2006). By the age of 2, synaptic and axonal density increases rapidly and reaches a level that is 50% greater than the density found in adults (Huttenlocher, 1979). At this age, the brain has also been shown to be 80% of its adult weight, reaching 90% by age 5 (Dekaban and Sadowsky, 1978). However, the gray and white matter of the brain continue to undergo dynamic changes from childhood and into adolescence (Casey, Jones and Hare, 2008). A longitudinal MRI study by Giedd et al. (1999) followed typically developing males and females spanning ages 4 to 21 and found a linear growth pattern of white matter throughout development from childhood to adolescence, with a peak in volume of white matter seen at an earlier age in females. However, gray matter has been found to follow an inverted ‘U-Shape’ course of development and demonstrates more regional variation than white matter (Casey, Jones and Hare, 2008; Giedd, 2004; Gogtay et al., 2004; Sowell et al., 2003, 2004).

Studies with animals have shown that the overproduction of synapses and axons experienced during childhood is followed by a rapid pruning throughout the brain during early puberty (Crews, He and Hodge, 2007). Regions most notably found to undergo pruning are the amygdala (Zehr et al., 2006), nucleus accumbens (Teicher, Andersen and Hostetter, 1995) and prefrontal cortex (Andersen and Teicher, 2004). However, the growth in density of fiber connections between the prefrontal cortex and amygdala continues into early adulthood (Cunningham et al., 2002), and pruning is more prolonged during adolescence in the prefrontal cortex than the accumbens (Andersen and Teicher, 2000; Teicher, Andersen and Hostetter, 1995).
The influence of hormones is also substantial on the development of the brain, although not uniform on each area (McEwen, 1992). The adrenals, thyroid and gonads play a critical role in mediating how the external environment influences the structure and functionality of the brain during early development and adolescence (McEwen, 1992). For example, animal studies have demonstrated the effects of sex hormones, such as testosterone, that are especially critical during puberty on creating a distinct pattern of neural growth specific to each gender (e.g. Toran-Allerand, 1984). Thyroid and stress hormones have also been found to play important roles in fetal brain development (Chan, Franklyn and Kilby, 2005).

The neural developmental patterns described above also have important implications for behavioural changes observed during adolescence. For example, Casey, Jones and Hare (2008) suggest that the differences in the rate and timing of synaptic pruning and maturity of various brain regions may explain the increased risk-taking behaviour and emotional reactivity seen during adolescence, which may also help explain the increased incidence of TBI seen in this age group. It is important to note that that the majority of studies that have examined risk-taking behaviour in adolescence have been conducted in North America and may not necessarily reflect the behaviours of adolescents cross-culturally. However, recent research by Kloep et al. (2009) found that motives to take risks were similar when comparing youth from Turkey, who have been shown to engage in the same risk-tasking behaviour as Western adolescents (e.g. Bayar and Sayil, 2005; Kiran, 2003), to youth from Welsh, representing a predominately European culture. Thus, this study suggests that the motivation to take risks during adolescence, which may reflect the underlying neurodevelopmental changes described above, may exist independent of culture, although more research is needed in this area.

### 2.2.2 Neuroplasticity

Neuroplasticity, or the changing of neurons and cellular organization based on learning and experience, is one of the most important features of the CNS (Hubel and Wiesel, 1962; Johnston, 2009). The capacity for plasticity and learning seen in children and adolescents is thought to be mediated by the overproduction of synapses and synaptic connections in the developing brain. These connections are then pruned or selected and strengthened based on experience. The processes of apoptosis (programmed cell death) and neurogenesis are then carefully controlled to ensure that an appropriate number of neurons take their place in specific regions of the brain. The overproduction of neurons could also be viewed as an adaptive measure to provide protection against injury by creating a reservoir of cells (Johnston, 2009).
As a result of this type of cortical reorganization during and after an injury, structures that once took part in a certain function may no longer serve the same function or have the same interconnectedness with other structures (Bigler, 1999). Thus, injuries that are moderate to severe have greater potential to induce more significant neuropathological changes.

Previously, it was believed that because of the plasticity of the younger brain and the rapid neurodevelopment occurring throughout childhood and into adolescence, function would be most spared if a brain injury was acquired during this timeframe. However, many studies have demonstrated that this does not necessarily impart greater recovery from injuries. For example, McDonald and Johnston (1990) found that the developing nervous system is more vulnerable to sensory deprivation and abuse than the nervous system of adults, and Johnston (2009) found that this is true as well for seizures. In addition, since basic skills are still being acquired and sharpened, youth possess fewer previously established skills to draw upon for compensatory or adaptive strategies (McKinlay et al., 2009). The normal developmental trajectory of the brain is also more vulnerable to abnormalities in growth when a brain injury is acquired during youth, since prefrontal cortex and overall cerebral myelination develop rapidly within the first 5 years of age and may not reach full maturity until late adolescence (Giedd et al., 1999).

It should also be noted that the environment in which a child develops has been shown to play a critical role in the development of the brain. One particular aspect of environmental influence relates to the infant-caregiver and early social relationships, especially during the first year of life (Champagne and Curley, 2005). The early rearing environment and attachments that an infant and child forms are capable of wielding neurobiological changes that can persist into adulthood, but only recently has this research been conducted at the cellular level. Animal studies have demonstrated that plasticity has been shown to exist in relation to these environmental experiences in life, whereby social experiences or environmental enrichment occurring later in life can still alter the course of development of the brain, even compensating for early deprivation (Bredy et al, 2003). In humans, brain connectivity, as influenced by connections formed via person – environment or community interactions, has also been shown to influence a child’s capacity for self-regulation (Siegal, 1999).
2.3 Recovery from Brain Injuries

2.3.1 From the Medical Setting to the Rehabilitative Setting

Overall, recovery across different domains of function is seen in children and adolescents post-injury, although not linear and slowing down over time, with the most rapid gains made within the first 6 – 12 months post-injury (Farmer et al., 1996; Fay et al., 1994; Klonoff, Clark and Klonoff, 1993). Once the child or adolescent is medically stable, they may be transferred to a rehabilitation center if they are experiencing significant cognitive, physical or sensory deficits. To track the progress of recovery and guide rehabilitation during the first few weeks to months following a brain injury, the Rancho Los Amigos Scale (also referred to as the Rancho Levels of Cognitive Functioning) is often used and is based on observations of the individual as they respond to their environment (Hagen, Malkmus and Durham, 1979). It specifies 8 levels of cognitive and behavioural recovery stages that classify individuals based on their level of arousal and attention, responsiveness, ability to learn and retain new information, and executive functioning.

Within the rehabilitation setting, a youth can receive services from physical, occupational, education and speech-language therapists. However, a majority of children and adolescents do not experience such a transitional period and are discharged home, returning to school and leaving the individual, their parents and their educators with the significant strain of readjustment (Farmer et al., 1996).

2.3.2 Predictors of Outcome for Youth with ABI

Many of the persisting effects of an ABI beyond the normal recovery period in children and adolescents have been found to relate to several factors. As discussed previously, the severity of the injury has been shown to be related to emotional, social and behavioural problems. Whole brain volume loss has also been correlated with cognitive intelligence deficits (Hopkins, Tate and Bigler, 2005) and total number of lesions has been shown to be predictive of executive functioning 1-year post-injury (Slomine et al., 2002). Location, depth of lesion and time post-injury have also been shown to effect outcome after ABI in children and adolescents (Gerring et al., 2000; Herkovits et al., 1999; Levin, 1995; Levin et al., 1993; Levin et al., 1997; Levin et al., 2001; Taylor, 2004; Taylor and Alden, 1997). Salorio et al. (2005), however, found that the extent of damage may be more predictive of outcome than location of injury.
An ABI experienced during preschool years compared to those experienced by older children and adolescents may predict worse outcomes, such as persistent cognitive and memory deficits (Freeman et al., 2008; Levin et al., 1982). Premorbid factors may also explain some, but not all, of the problems experienced post-injury, such as a genetic predisposition to learning disabilities or ADHD, symptoms of Post Traumatic Stress Disorder (PTSD) in the individual, pre-injury emotional and adaptive behaviour problems and academic performance (Asarnow et al., 1991; Levi et al., 1997; Rutter, 1981; Schwartz et al., 2003; Taylor et al., 2001; Taylor, 2004), as well as socioeconomic disadvantage (Schwartz et al., 2003) and adverse family conditions (Thompson and Irby, 2003).

### 2.3.3 Common Outcomes of ABI Experienced by Youth

#### Physical

Physical impairments faced by youth that have an ABI include deficits in sensory abilities, such as hearing, vision, olfaction, and taste problems, muscle spasticity and contracture, impairments to fine motor control, paralysis or paresis, deficits to balance and/or gait, as well as increased fatigue (Middleton, 2001). Physical recovery has been shown to be most rapid within the first year post-injury (Sherwin and O'Shanick, 2000).

#### Cognitive

Impairments to cognitive abilities include problems with sustaining attention and concentration, increased distractibility, visuo-perceptual and spatial deficits, as well as reduced speed of processing of visual and verbal information combined with increased thinking, and verbal and motor response time (Middleton, 2001). New information may be more difficult to learn and retain, as well as to integrate into existing knowledge, as youth with ABI demonstrate problems in memory and learning (Catroppa and Anderson, 2002). Difficulties may also be present in higher-level language and executive function tasks (Anderson and Catroppa, 2005; Roncadin et al., 2004). The increased vulnerability of the frontal lobes, which are thought to mediate executive functions, to damage from acceleration-deceleration forces may explain the prominence of deficits in such skills after a TBI in children and adolescents (Bigler, 1999). The development of self-regulation may also be affected, which is fundamental to the emergence of appropriate social behaviour during childhood and adolescence (Eslinger, Biddle, Grattan, 1997; McKinlay et al., 2009).
Behavioural and Emotional

Behavioural and psychosocial problems have been found to be present in 30% to 75% of all cases of ABI in children and adolescents (Jaffe et al., 1992; Ylvisaker et al., 2007; Slifer and Amari, 2009). Irritability, inappropriate or impulsive sexual behaviour, poor anger control, aggressiveness, and behavioural rigidity (i.e. inability to change behaviour patterns in changing environments), are typical behaviour problems reported as early as 1-year post injury (Rutter et al., 1981; Gerring, 1986; Ylvisaker et al., 2007). Problems with adaptive behaviours, or age-appropriate behaviours necessary for one to live independently and to function safely and appropriately in daily life have also been noted (Slifer and Amari, 2009). Disinhibition seen after an ABI is often the most cause for concern, as this can impair the development of social skills and appropriate social behaviours (Middleton, 2001). Emotional difficulties experienced post-injury range from depression, anger, flat affect, PTSD in cases where the injury was a result of a traumatic incident, anxiety from loss of skills, and grief (Taylor et al., 1999; Yeates, 2000).

Although much of the severe cognitive, behavioural and emotional problems experienced consequent an ABI appear to spontaneously decrease to some degree during recovery and rehabilitation, certain difficulties can persist into the post-acute and chronic stages (Taylor and Alden, 1997; Slifer and Amari, 2009). One of the most pervasive difficulties experienced after an ABI in youth is within the domain of social communication. As will be elaborated on within the following sections, social communication involves a complex interaction of various abilities that are vulnerable to impairment after a brain injury. Gronwall, Wrightson and Wadell (1990) noted that the most critical characteristic that discriminates an adolescent with ABI from an adult counterpart is the aspect of social communication problems. This has important implications for the successful reintegration of adolescents with ABI into family, school and community life, which is further discussed in section 2.4.

2.4 Social Communication in Adolescence

Social communication represents a complex interaction of a variety of skills and behaviours. Included in this network are social skills, or the specific abilities that allow an individual to perform proficiently on social tasks, which underlie successful social
communication (Cavell, 1990; Turkstra, McDonald and DePompei, 2001). Social skills are reliant on goal-directed and situationally appropriate verbal and nonverbal behaviors (Wiseman-Hakes et al., 1998). In order for one to communicate their thoughts and emotions effectively and in a manner that is functional in society, applying social skills like being aware of social rules and boundaries, rapidly processing and interpreting nonverbal emotional cues, predicting and evaluating the consequences of one’s social behaviour, self-monitoring speech and language skills, and working with others to solve conversational tasks, is crucial (Turkstra et al., 1996; Dahlberg et al., 2006). This set of skills is often referred to as social cognition (Fiske and Taylor, 1991). Other cognitive skills that are not necessarily under the umbrella of social cognition, but that are important in communication, include language, working memory, initiative, inhibitory control, and declarative and procedural knowledge (Turkstra et al., 2008).

Adolescence is a transitional period when communication skills are continually evolving, as a youth is faced with increasingly complex social interactions and situations. The traditional view of social communication development puts forward that much of language development and acquisition of basic cognitive skills occurs by the age of 4, with adult-like communication skills acquired by age 11 (Homberg, Bickman and Muller, 1993; Nippold, 1998). It is likely due to this view that there is currently a paucity of research investigating social cognition in typically developing adolescents (Tonks et al., 2007a; Turkstra et al., 2008). However, future studies in this area are essential, since the drastic changes in vocational, academic and social situation demands during adolescence suggests that skill development must be occurring during this phase as well (Turkstra, 2000). What has been found by some researchers is that the emergence and development of more sophisticated communication skills is gradual and more subtle during adolescence (Nippold, 2000). This has been linked to greater conscious control over intrinsic emotional arousal and improved cognitive skills, such as working memory, executive functions and attention, which are associated with the continual development of the prefrontal cortex throughout adolescence (see section 2.2.1; Tonks et al., 2007a; Turkstra et al., 2008).

2.4.1 Emotion Recognition

Emotion recognition abilities are thought to depend on being able to read emotions from eyes, understanding gaze and vocal prosody and accurately identifying emotionality from facial expressions (Tonks et al., 2007a). Studies have shown that these abilities begin right from birth, such as the ability to discriminate happy and sad faces from surprised faces at just a few months
of age to discriminating between intensity of expression (i.e. mild versus intense sadness; Nelson and De Haan, 1997). By 6 months of age, primary emotions like surprise, anger, sadness, and fear are also present (Lewis, 2007), and by the age of 3, a child has developed a complex emotional system (Tonks et al., 2007).

Improvements in emotional recognition abilities then occur in stages that are associated with brain growth spurts. Kolb, Wilson and Taylor (1992) and Baron-Cohen et al. (2001) found significant improvements occurring at approximately ages 10 and 14, and ages 8 and 10, respectively. Tonks et al. (2007) also found a significant increase at approximately age 11 to occur in performance on facial recognition, Theory of Mind (i.e. the ability to infer other people's current mental states; Rosenbaum et al., 2007), and a test of emotion recognition from vocal prosody occurring in a sample of children ages 9 – 15.

Turkstra (2000) suggests that at approximately the age of 10, social interactions become more complex as a product of greater social awareness, independence and self-image. Thus, as demands become greater, the enhancement of these skills across the transitional period from pre-puberty and into adolescence would follow. With increasing age, children and adolescents become more insightful regarding their own emotions and display an increased understanding of mixed emotions (Izard and Harris, 1995).

Other extraneous factors beyond neural growth and situational cues that have been shown to effect the development of emotional recognition abilities include socioeconomic status (SES), as children from families of deprived SES are at greater risk for developing emotional disorders during their childhood (Caspi et al., 2000; Goodyer, 2002) and verbal IQ (Gagliardi et al., 2003). Gender-related differences in the neural correlates of emotional face processing have also been documented (McCrae et al., 2008), in addition to studies which show that gender differences are present in the performance of emotional recognition tasks (e.g. Imig, Erwin and Turetsky, 2000). For example, McClure (2000) found that females demonstrate an emotion recognition advantage that develops as early as infancy.

### 2.4.2 Language Development and Pragmatic Communication Skills

Since language is used to communicate for social purposes, it is crucial that skillful use of language be developed for efficient social communication (Wiseman-Hakes et al., 1998). Nippold (2000) describes three main areas of language that develop throughout the course of adolescence: syntax, semantics and pragmatics. Growth and sophistication in syntax, or rules
that govern how words are combined to form phrases and sentences, becomes apparent when adolescents are required to produce persuasive essays in higher grades, getting them to tap into their own competence more fully than the basic narratives and descriptive written pieces required in pre to junior school (Crowhurst, 1987; Crowhurst and Piche, 1979; Loban, 1976; Rubin and Piche, 1979). An aspect of semantics that develops throughout adolescence is the understanding of figurative language, such as proverbs (Nippold, Uhden and Schwartz, 1997; Nippold, 1998).

Pragmatics is a broad area of language and its application demonstrates subtle and gradual development across adolescence. Pragmatics is defined as the ability of a person to perceive, interpret and respond to both the verbal and nonverbal contextual and situational demands of the environment (Jordan and Ashton, 1996; Wiseman-Hakes et al., 1998). It consists of skills and abilities related to the management of conversational exchanges between two or more persons. Examples of pragmatic communication skills include behaviours such as staying on topic, asking relevant questions, making supportive comments, interrupting appropriately, turn-taking, shifting the topic of conversation gracefully, employing facial expression and body language that enhances the interaction, maintaining eye contact, initiating conversation, and being able to cohesively organize and express one’s thoughts (Burns, Halper and Mogli, 1985; Larson and McKinley, 1998; Nippold, 1998; Raffaelli and Duckett, 1989). For higher-level social skills to be developed and sustained, the establishment of fundamental pragmatics is crucial (Wiseman-Hakes et al., 1998).

Since adolescents engage more frequently in conversation with their peers as they get older (Raffaelli and Duckett, 1989), their pragmatic communication skills should also improve. In support of this, Larson and McKinley (1998) examined male and female adolescents longitudinally from grade 7, at ages 12 – 13, to grade 12, at ages 17 – 18, and found that as grade level increased, the frequency of abrupt topic shifts decreased and the frequency of both positive (e.g. “Yes, I know what you mean) and negative (e.g. “Wait, I do not understand) interruptions increased. The researchers also found that few gender-related differences emerged, with the exception of more attempts to entertain the conversational partner with humor seen in boys versus girls. Pragmatic language skills like self-regulation, abstract thinking and reasoning and the ability to adjust the content of one’s own spoken productions and speech to meet the informational needs of the listener have also been shown to improve throughout adolescence (Coleman and Hendry, 1999; Nippold, 2000).
2.4.3 Difficulties with Social Communication after ABI for Adolescents

Difficulties with communication can be devastating at any age. However, impairments to communication during adolescence are especially debilitating, as it is during this timeframe more than any other that an individual is exposed to increasingly complex social situations that will provide them with opportunities to develop their self-identity, define their morals, values and opinions, as well as present them with academic and vocational opportunities (McDonald and Turkstra, 1998). It follows, then, that a reduction in communicative competence has been established as one of the most pervasive and debilitating consequences of having an ABI during adolescence (Dahlberg et al., 2007; McDonald and Turkstra, 1998).

Having a brain injury as a child or adolescent can disrupt both the acquisition of new social skills and the performance of those previously established. To this end, several studies have reported limitations and impairments in social cognition in adults with TBI and have linked these deficits to overall communication competence (Havet-Thomassin et al., 2006; Henry et al., 2006; McDonald, 2005; McDonald, 2007; Turkstra et al., 2008). However, fewer studies have been conducted with brain-injured adolescents that address social cognition, despite the numerous psychosocial problems that have been identified (for review, see section 2.3.3.). One reason for this may be due to the emergence of these communication difficulties in the chronic (i.e. more than 1 year post-injury) phase, whereas most studies are focused on short-term outcome. Many of the studies that have been conducted previously have examined younger children, although it is thought that the same pattern of communication difficulties would extend into adolescence, but with greater severity (McDonald, 2007).

Singer and Bashir (1999) noted that the disruptions to the interrelationship between language, executive functions and self-management behaviours most likely underlie disorders of social communication. Given the impairments found in all of these factors, as well as common behavioural problems, such as impulsivity, disinhibition and aggression, experienced by brain-injured youth, impairments experienced in communication abilities and social behaviour would be expected and have indeed been demonstrated empirically (Deaton, 1987; Levin, Culhane and Mendehlsohn, 1993). Some common patterns of social communication deficits following an ABI in adolescents include overtalkativeness (Hagan, 1984) and slow, incomplete responses, with numerous pauses and a reliance on set expressions (Thomsen, 1975).

Impairments in emotion recognition abilities have also been found, though studies are limited. For example, Tonks et al. (2008) found that, compared to typically developing adolescents between the ages of 9 – 15, youth with ABI, including TBI ranging from mild to
severe, were significantly impaired on all tasks that required reading emotion conveyed by facial expressions. However, no difficulties were found in tasks involving the identification of the faces, indicating that the difficulty is more likely to lie in recognition of emotion and not general face processing. Tests of emotion recognition from vocal prosody and Theory of Mind also demonstrated that adolescents with ABI performed more poorly. In addition, Pettersen (1993) found that youth with ABI may confuse positive and negative emotions and make errors interpreting emotionally toned vignettes.

In terms of language impairments, Chapman (1992) examined children and adolescents with closed head injuries and found a pattern of disorganized discourse, similar to that seen in adults with frontal lobe lesions. Specially, they experienced difficulties with complex language tasks, developing resolutions, sequencing actions, and extracting the moral of stories. Although difficulties in basic language use, such as structuring information within a narrative and use of vocabulary relating to memory deficits, have been found in adolescents 1 year after sustaining a closed head injury (Chapman et al., 1992), research also shows a certain level of recovery with semantics and syntax post-injury (Chapman, 1999; Cicerone et al., 2000).

In contrast, the deficits found in pragmatic communication abilities appear to be more pervasive. Dennis and Barnes (2000) found that children with head injuries had difficulties producing speech acts (intentional acts performed by one conversation participant to influence the mental state of another) and that the magnitude of this deficit varied with head injury severity. Blosser and DePompei (1994) found that children and adolescents with TBI demonstrated difficulty in choosing socially correct methods for interacting. Turkstra et al. (2008) studied 9 participants with TBI aged between 13 – 21 and observed that they were significantly less able than their typically developing peers to generate context-appropriate responses in everyday pragmatic situations. Impairments in social inference, self-regulation of social functioning, social problem solving skills, and the detection of conversation skills have also been found to be impaired in adolescents with ABI relative to typically developing adolescents (Dennis et al., 1998; Dennis et al., 2001; Levin and Hanten, 2005; Turkstra, McDonald and DePompei, 2001).

Being an adolescent is more difficult today than it has ever been before. In addition to the constant battle of dealing with rapid emotional and developmental changes, today’s society has become incredibly fast-paced, necessitating the ability to handle social interactions that require increasingly complex communication skills. Unfortunately, these challenges are only compounded further when faced by an adolescent with a brain injury. The result is that these
youth can suffer from social and community withdrawal due to their injuries (Wiseman-Hakes et al., 1998). From a rehabilitative perspective, it is crucial that effective strategies be developed for adolescents with ABI; strategies that enable participation within the community and facilitate the development of appropriate social communication and emotional skills. However, the lack of research investigating community integration interventions for youth with ABI has left the effectiveness of such programs difficult to assess. This issue is the focus of the following chapter.

Chapter 3 Community Integration Interventions

3.1 A Literature Review of Community Integration Interventions

The ultimate focus of rehabilitation for brain injured individuals has shifted in recent years from physical rehabilitation to community integration (McCabe et al., 2007). In its most basic form, community integration can be defined as having something meaningful to do, somewhere to live, and someone to love (Jacobs, 1993; McCabe et al., 2007). The concept itself is multidimensional, as it can encompass one’s occupation, social relationships, leisure, recreation, community access, and productivity. Past literature demonstrates that community integration is often used interchangeably with the terms ‘social integration’ or ‘participation.’

The importance of the community, or environment, towards quality of life has been described in great detail by the International Classification of Function [(ICF); World Health Organization, 2002). For example, the ICF outlines that the physical and mental functioning of an individual acts upon and reacts to their environment, which then serves as a source of feedback and stimulation that influences further participation in activities in that environment. Successful community integration in both the adult and pediatric brain-injury populations lies in the unique set of restrictions imposed by each brain injury that can negatively affect this environment – participation interaction. For children and adolescents, barriers to community integration include age, type and severity of impairment, family functioning, as well as access to educational rehabilitation and social and recreational activities (Fay et al., 1994; Jaffe et al., 1993; Savage, 1997; Bedell and Dumas, 2004). Brain-injured youth are especially vulnerable to issues with community integration due to the underlying impairments in cognitive and communication abilities accompanying their injuries during a period of critical psychosocial development, as described below.
3.1.1 Vulnerability of Youth with ABI to Lack of Community Integration

Changes in Social Communication Skills and Behaviour

As discussed in Chapter 2.4, difficulties in social communication are one of the most pervasive problems in the chronic stage after an ABI (Dahlberg et al., 2007). Adolescents can experience difficulties with speech, language, social competence, problem-solving skills, and judgment subsequent to incurring a brain injury, all of which negatively impact the ability to learn appropriate behaviours for social interactions (Chapman, 1997; DePompei and Blosser, 1999; Farmer et al., 1996; Turkstra, McDonald and Kaufman, 1996; Goldberg, 1996; Janusz et al., 2002). These difficulties can even be experienced by youth with mild injuries (Ewing-Cobbs, Fletcher and Levin, 1997; Klonoff, Clark and Klonoff, 1993; Yeates, Luria and Bartkowski, 1999). Disabilities in language-based learning, especially during adolescence and childhood when these skills are newly acquired or yet to be developed, also have a detrimental effect on the ability to use appropriate language skills for successful social interactions (Turkstra, McDonald and DePompei, 2001).

Due to these social communication problems, youth with brain injuries can suffer from social withdrawal (Wiseman-Hakes et al., 1998). In addition, changes in behaviour that occur secondary to brain injuries can be maladaptive (Lehr, 1990; Dikmen and Machamer, 1995; Glang et al., 1997). These behavior changes combined with social inappropriateness and cognitive challenges make it difficult for a brain injured youth to interact with peers and integrate themselves into appropriate social networks. Consequently, there is an increased likelihood that youth with brain injuries will become and remain socially isolated (Deaton, 1994; Glang et al., 1997).

Participation Restrictions

Children with brain injuries face restrictions not only in their physical environments, but also in the types of activities that they are able to participate in. For example, strenuous recreational activities may not be feasible for youth with brain injuries who may have physical disabilities or are prone to experiencing fatigue. This may limit a youth’s ability to engage in athletic and free-time activities in their school environment, thus limiting opportunities for social interactions and friendship-building. Their injuries can also leave them unable to resume activities in the same manner as their friends and those close to them remember and expect them to post-injury. In fact, younger individuals often identify the reactions from their peers as the
most disabling factor to social and community integration (McCabe et al., 2007). A cycle of disappointment and further isolation may occur, as the adolescent’s social network begins to decrease when pre-injury participation patterns are not resumed as before. As a result, youth with ABI are often found to engage in more home-based activities, such as reading, computer games and watching television (Lehr, 1990; Cooley et al., 1997), further reducing opportunities to become involved in and have a sense of belonging to their community.

Participation restrictions extend beyond the functioning of a youth and may also be a result of family circumstances and functioning. For example, Beresford (1995) found that families with a disabled child are impoverished by uncompensated extra costs and restricted employment opportunities. Ehrmann, Aeschleman and Svanum (1995) compared 2 – 5 year old disabled and nondisabled children and showed that much of the disabled children’s participation were within family-oriented activities.

3.1.2 Consequences of lack of social networks during childhood and adolescence

Children who perceive that they have supportive friends have higher self-esteem compared to those who do not (Mannarino, 1976). Studies have also shown that as children reach adolescence, they increasingly depend on friends and social networks for advice and acceptance (Lerner, 1981). Adolescents view their social network and friends as a way of defining themselves and their values (Sowers et al., 1996). Long-lasting impairments, including social communication deficits, maladaptive behaviours and participation restrictions faced by youth with brain injuries, can have devastating effects on their involvement in social activities. As a result, these youth may have trouble maintaining friendships and experience an absence of social support (Glang et al., 1997; Singer and Nixon, 1996; Willer et al., 1990). For example, they may face reduced participation in typical social activities, such as attending camps and playing sports, and miss out on stage related social markers (e.g. babysitting, staying alone, learning to drive a car, etc.), as well as reduced social opportunities (Bedell and Dumas, 2004). The negative effects of decreased social integration are particularly prominent during adolescence, as socializing itself has been reported as the number one rated free-time activity for adolescents (Csikszentmihalyi and Larson, 1984). In addition, psychological and physical well-being both have been linked to social support, which is a fundamental feature of developing a positive sense of self during adolescence (Cohen, 1988; Cohen and Willis, 1985).
3.1.3 Community Integration Interventions for youth with ABI

For these reasons, it is clear that participation in community-based activities is essential for the optimal development of children and adolescents. It is from these activities that children develop the necessary skills to build upon as they get older and face increasingly complex social and environmental demands. Children with ABI have the same aspirations and needs as children without disabilities, such as having meaningful occupations and social relationships (McConachie et al., 2005). It is the responsibility of the rehabilitation community to help these youth achieve their real-life goals so that they too can participate in life and not just exist in it.

The current rehabilitation perspective suggests that children with disabilities, including brain injuries, should be able to participate in regular and typical leisure, recreational and social activities with their same-aged peers. This is in contrast to the previously held belief that youth with disabilities should interact only in social programs and activities with each other (Sowers et al., 1996). In addition, rehabilitation programs have modified their ultimate objectives to look beyond physical functioning and include interventions tailored to social and community reintegration (Simeonsson, et al., 2001; Noreau et al., 2007).

After discharge from the hospital and acute-care settings, the focus on participation for youth is geared towards school re-integration (e.g. Jantz and Coulter, 2007; Sharp et al., 2006; DePompei, 2003; Hibbard et al., 2002; Vaidya, 2002; Savage, 1997; Parkin, 1996). However, school settings provide only a small scope of experiences that are critical to developing social networks and relationships because of the restricted and planned environment imposed (Oerther 1986). Therefore, the best opportunities for developing appropriate skills come from activities and events based within community settings. These activities more accurately reflect what is encountered in real-world settings, as well as help to promote the transition from school to community; a transition of great importance to adolescents with brain injuries as they move into adulthood. Many studies have shown that participation in formal organizations within the community can help develop self-determination both in the short-term and into adulthood for youth with ABI (Hans and Eckland, 1978; Hedin and Conrad, 1981; Spady, 1970). By participating in real-life situations with others, youth can learn more appropriate and transferable ways to interact and work with others (Bedell, 2004).

However, research evaluating the effectiveness of programs focused on social and community integration beyond the school environment is currently lacking. There is a need to focus on children’s functioning in daily activities and social participation within their homes and communities, which have been recognized by many as important issues that interventions should
tackle in pediatric ABI rehabilitation (Bilbao et al., 2003, Kraemer and Blacker, 1997). The lack of evidence to support such interventions leaves program evaluators with a limited knowledge and understanding of what works and how to improve such services (Haley et al., 1992; Bedell, 2004).

Thus, given the difficulties with community participation faced by youth with brain injuries for reasons previously described, a literature review was carried out to examine the existing research on social and community integration interventions for these youth. The purpose of this was to evaluate the effectiveness of these interventions in order to provide recommendations regarding future research on this topic for brain-injured youth.

3.1.4 Methods and Procedure

A literature search was conducted to identify any studies that focused on social and/or community integration and participation of youth with ABI. Searched databases included: ACP Journal Club, AMED, CINAHL, Cochrane DSR, DARE, EMBASE, Healthstar, Medline, PsychINFO, PubMed, Scholars Portal and Web of Science. The key words used were: acquired brain injury, traumatic brain injury, brain injury, head injury, neurological injury, stroke, and head trauma. These were used in combination with the key words: community integration, community participation, community intervention, community reintegration, community re-entry, social reintegration, social intervention, social adaptation, integration, recreation, leisure, creativity, support, education, rehabilitation, and activities. In addition, journals with a pediatric rehabilitation focus were specifically targeted and systematically searched for relevant articles. Studies included in the search were published between January 1996 and March 2009 to include the most recent research and was limited to research published after 1996 because a search prior to this year on the current topic yielded no relevant studies. This initial search found 55 potentially relevant articles.

To these articles, the following exclusion criteria were applied: (1) Does not describe an intervention; (2) The intervention focuses on adult or geriatric populations; (3) The intervention focuses solely on school reintegration; (4) If outcome measures were used, they do not directly assess community integration, social competence or general participation; (5) The intervention focuses only on family members or caregivers, as this would not fully target community integration for adolescents; (6) The article is not published in English. Studies were not excluded based on their level of evidence, since research on this topic was limited.
3.1.5 Results

As outlined in Figure 3.1, 9 studies were included in the literature review after exclusion criteria were applied. These studies are outlined in Table 3.1. The total number of participants across all reviewed studies cannot be determined, as some of the included studies described existing community integration programs without specifying a distinct study population. All studies took place within Canada or the United States of America.

3.1.5.1 Study Designs and Levels of Evidence

The studies selected for review represent mixed quantitative and qualitative designs. Of these studies, there were 2 pilot studies of a pre-test/post-test design, 1 single-subject experimental design, 2 case studies, 1 quasi-experimental design and 1 randomized control trial (RCT). Two of the studies only provided descriptions of already existing community integration programs with no empirical evidence regarding the effectiveness of the interventions. Two studies employed no intervention control groups, although one was of a quasi-experimental design. Six of the nine studies reviewed could be replicated based on the descriptions given.

Drop-out rates were described when applicable, although convenience sampling or referrals were used for many of the studies and thus drop-outs were not a pressing factor. Reasons for drop-outs included lack of time to participate and inability to contact certain participants. Since the studies were largely based on small sample sizes and case studies, it is difficult to assess whether the participants described in the reviewed studies provided an accurate representation of the general population of children with ABI.

Overall, the reviewed studies provided low levels of scientific evidence. Only 1 study was a randomized control trial (RCT). Most studies were of small sample sizes or case studies, therefore limiting generalizations that can be made. One study relied on anecdotal evidence (Mallay, 2002). Another study was quasi-experimental and used non-equivalent comparison groups to assess the effectiveness of the program, with more participants in the experimental condition (McDougall et al., 2006). In addition, 1 study provided no explanation of their data analysis techniques (Sowers et al., 1996). Thus, using the Oxford Centre for Evidence-Based Medicine - Levels of Evidence (2009), 2 studies provided level 5 evidence (Gillett, 2004; Marcantuono and Prigatano, 2008), 3 studies provided level 4 evidence (Sowers et al, 1996; Glang et al., 1997; Gardner et al., 2003), 1 study provided level 3 evidence (Mallay, 2002), and 3 studies provided level 2 evidence (Wade et al., 2005; McDougall et al., 2006; Wade, Carey and Wolfe, 2006).
55 potentially relevant studies

Does not describe an intervention
  28 studies

Intervention focuses on adult or geriatric population
  8 studies

Intervention focuses on school reintegration
  6 studies

Outcome measures do not directly assess community integration, social competence or general participation
  2 studies

Intervention focuses only on family members or caregivers
  1 study

Article not published in English
  1 study

9 studies included for review

Figure 3.1 Outline of selection of reviewed articles.
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Design</th>
<th>Participant Characteristics</th>
<th>Intervention</th>
<th>Outcome Measures</th>
<th>Reported Effects</th>
<th>Authors’ Conclusions</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sowers et al.</td>
<td>Pilot study, quantitative, pre-post design.</td>
<td>N = 10 (range 7 to 17, mean age 11.7, 7 M, 3 F). Mean post-injury age of 2.4 – 9.</td>
<td>‘Building Friendships’ process delivered by outside consultants over a period of 4 months. Goal to increase quality of student’s social life. Project facilitator worked with youth to identify opportunities, goals and strategies related to social integration. (i.e. organized recreational activities by linking a student with recreational activities in the community and social events outside of school).</td>
<td>Interviews conducted by project staff of students, parents, and teachers. School and Community Activity and Integration (SCAI/A). Social validation measures to assess satisfaction with student’s social networks.</td>
<td>Average number of friendships reported from pre-to-post participation increased. Majority of students identified more friends than parents and teachers. Parents reported an increase in the number of activities child participated in with peers with disabilities. Parents satisfaction with program increased from pre- to post-intervention, although youth’s decreased slightly. Interviews revealed high satisfaction from both parents and children with process.</td>
<td>Results are encouraging. With minimal training, outside consultants can use creative approach to building social participation of students successful for youth with TBI.</td>
<td>Lack of control group. Large variability in responses. Small sample size. Quantitative data averaged for small group, but then analyzed only descriptively.</td>
</tr>
<tr>
<td>Glang et al.</td>
<td>Single subject experimental, no control subjects.</td>
<td>N = 3 (ages 13, 11, 8, all M). Participants had experienced a TBI and varied from 4 – 6 years post-injury. All participants were experiencing social isolation as noted by facilitator, parental and self-</td>
<td>‘Building Friendships’ process. Participant’s personal facilitator worked with youth to identify opportunities, goals and strategies related to social integration. Daily observations for 4 months.</td>
<td>Interviews to assess participants’ and facilitators’ reports of changes to social contacts and social validation. Weekly ratings by facilitators of degree of student integration and student satisfaction.</td>
<td>Increase in number of social interactions at school for participants. Increased parental and facilitator satisfaction during intervention phase compared to baseline. Facilitator rating of participant satisfaction decreased throughout program. Qualitative data revealed</td>
<td>Weakness of outcomes raises further questions regarding nature of changes actually produced by intervention and extent to which follow-up support is required in the future. School personnel may not</td>
<td>Gender bias. Ratings not obtained from participants. Facilitators between subjects differed in training. Confounding co-interventions for related social issues. Qualitative</td>
</tr>
</tbody>
</table>
Ratings of satisfaction with student inclusion by parents and facilitators. Observations of participants within school and playground environments. Improvements in behaviour at home and school, more cooperation, better quality of peer interactions as a function of change in attitudes of peers. Anecdotal follow-up data indicated increases in social contacts were not maintained over time.

<table>
<thead>
<tr>
<th>Mallay (2002), Canada</th>
<th>Case Study</th>
<th>N = 1 (age 10, male). Experiencing PTSD and was being assessed for suspected ABI at time of the study. Auditory and visual hallucinations also present.</th>
<th>Fifteen in-home art therapy sessions. Drawing exercises were used to express feelings from traumatic event, objectify thoughts, emotions, and validate feelings.</th>
<th>Participant reports and observations made by art therapist.</th>
<th>Diminished psychophysiological symptomology. Participant became more involved in physical activities, school work and was actively pursuing socialization. Reduced withdrawal behaviour. Increased mastery over emotions.</th>
<th>Art therapy is valid psychotherapeutic process in pediatric trauma recovery, especially if PTSD is suspected. More sessions needed to explore and manage community integration issues.</th>
<th>Possible influence of psychotropic treatment on results. Limited generalizability. Unclear if art therapy more or less effective for ABI alone, PTSD alone or for co-morbid cases.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gardner et al. (2003), USA</td>
<td>Case Studies</td>
<td>N = 2 (ages 12 and 13, both M). One participant co-morbid with diagnoses of ADHD, OCD and severe learning disabilities. Second participant had non-malignant temporal lobe lesion of unknown etiology, as well as seizure disorder, oppositional defiant disorder, major depression and learning disabilities.</td>
<td>Assessed in residential school setting for 3 years. Applied behaviour analysis (ABA) and positive behaviour supports, combined with OT, PT, SLP services, and nursing. Functional communication training. Antecedent behaviour management strategies with reinforcement contingencies.</td>
<td>Challenging behaviours identified before entering program. Behaviour frequencies observed daily by direct care personnel and reviewed bi-weekly by clinical team. Formal structured interviews conducted with family members with Functional Assessment Interview. Direct</td>
<td>Challenging behaviours were nearly eliminated at the end of 3.5 years. Positive alternative behaviours and self-management skills drastically increased. Generalized and durable community adjustment was also observed.</td>
<td>Provides support for effective intensive and long-term interventions within natural environments, promoting lifestyle changes.</td>
<td>Intensive structure of intervention is costly and requires resources and management that may be more difficult to execute on larger scale. Multiple treatment procedures implemented make it difficult to assess causality to any single procedure. Gender bias. Generalizability limited due to case study</td>
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observations of participants’ challenging behaviours employed A-B-C data, checklists, scatterplot diagrams and detailed behavioural report.

<table>
<thead>
<tr>
<th>Methodology</th>
<th>Description of how frequency of behaviours was observed and recorded.</th>
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<tr>
<th>Study</th>
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<th>Population</th>
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<th>Challenges</th>
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<tr>
<td>Gilett (2004), Canada</td>
<td>Descriptive</td>
<td>Children with ABI (no age range specified)</td>
<td>Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). Holistic, family-centered program attempting to incorporate community in ongoing care and management of youth with ABI. Program team consists of pediatric neurologist, community outreach coordinator, school liaison personnel, psychometrist, neuropsychologist, OT, SLP. Community outreach coordinator finds community resources and programs to help deal with special needs and functional applications from therapies. Goal of program is integration in the community, achieved through collaboration, empowerment, knowledge and</td>
<td>PABICOP is an innovative program and provides a model of family/client and community centered care for youth with ABI. Further research required to empirically evaluate effectiveness of intervention.</td>
<td>Large team of facilitators involved may limit ability to provide such service to large number of youth with ABI. High financial cost. Participants may reside in communities where limited programs exist for community outreach coordinator to recommend.</td>
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advocacy.

| Wade et al. (2005), USA | Prospective pilot study of pre-test/post-test design. | 8 parents, 5 siblings and 6 children with TBI (mean age of 10.5 +/- 3.82 years for TBI group). No child was receiving medication or treatment for attention/behaviour problems. | Online Family Problem Solving (FPS) for pediatric TBI to address cognitive appraisals, coping and family communication through self-guided Web pages and videoconferencing with therapist. | Family Assessment Device (FAD), Ratings of comfort with technology and Online Satisfaction Survey (OSS). Website Evaluation Questionnaire (WEQ), Agnew Relationship Measure. Qualitative interviews to obtain opinions on overall efficacy of Web site and videoconferencing. Home and Community Social Behaviour Scale (HCSBS), Behaviour Rating Inventory of Executive Function (BRIEF). Children with TBI rated Web site content extremely helpful (OSS) and reported high overall satisfaction. However, they found videoconferencing to be less helpful and more difficult to use than other family members. Although improvements were observed on HSCBS and antisocial behaviours, these were not statistically significant. No statistically significant changes seen in general family functioning (FAD, IBQ-C) or executive functioning (BRIEF). | Web-based intervention holds promise for improving child outcomes following pediatric TBI. Videoconferencing may place too great a demand on youth with TBI and co-morbid attention deficits. Practicality of every family having time and resources to complete web-based program. No comparison group. Small sample size. High level of distress reported among group at baseline, suggesting sample may not be representative. Reliance on caregiver report for outcome measures. |
|-------------------------|------------------------------------------------|-------------------------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|
| Wade, Carey and Wolfe (2006), USA | RCT | N = 39 total caregivers of youth with ABI, N = 40 | Online Family Problem Solving (FPS) for pediatric TBI to address | FAD, CBCL, HCSBS, WEQ, and SES index to | Greater improvements in child self-management/compliance | Online FPS approach can improve child self- | Relatively small sample size. Drop-out rate |
| McDougall et al. (2006), Canada | Quasi-experimental design with non-equivalent comparison group. | N = 96, all children with ABI. Experimental PABICOP group (N = 64, 20 F, 44 M, average age of 9 years, 8 months). Control group receiving regular hospital care (N = 32, 7 F, 25 M, average age of 11 years, 1 month). Nonrandomized, samples based on area of residence. | PABICOP (as described in previous study) or regular hospital care and 3 month follow-up. | Data collected at 3 time points: 3 weeks after discharge, 3 months post and 1 year post for participants over a period of 5 years. Completed by telephone interview with primary caregiver: ABI Knowledge Quiz, Empowerment Questionnaire and Background Information Form. Completed by primary caregiver or teacher: Impact on Family Scale, Family Assessment Measure III – Brief Version. | Children with ABI and their families receiving the services from PABICOP fared significantly better than control group receiving standard care with respect to ABI Knowledge Quiz and integration of child back into family and community as measured by CBCL. Differences maintained at 1 year follow-up. | Coordinated family/community-focused interventions more useful than standard clinic-based interventions to improve outcomes for children with ABI. | Quasi-experimental design; therefore, results may not be due to PABICOP services. Ceiling effects demonstrated on outcome measures. Approximately 27% of sample did not complete measures at all 3 timepoints, leaving some statistical analyses potentially underpowered. Differences in participant characteristics emerged between both groups at baseline. Possible gender effects. |
### Marcantuono and Prigatano (2008), USA

| Description | Youth with ABI (ages 6 –12 treated in one group and 13 – 21 in another) who demonstrate neuropsychological and/or functional impairments secondary to ABI. | Day-treatment program. Children seen 5 ½ hours per day, 4 days a week in a classroom-like environment. Long-term and short-term goals identified for each child. Therapeutic activities include socialization/community group, self-advocacy group and social skills application within informal settings. | Empirical evaluation yet to be conducted. | Although no studies conducted to examine efficacy, anecdotal evidence from parents, children and school personnel suggest effectiveness in improving community integration. | Costly to families. No outcome studies yet conducted to determine effectiveness of intervention. |
However, participants were involved in the interventions from 4 weeks to 3 years, providing a more comprehensive understanding of the long-term effects.

3.1.5.2 Participant Characteristics

Study participants were all children and adolescents with an ABI. However, one study by Mallay (2002) described a case study of a child experiencing post-traumatic stress disorder (PTSD) who was undergoing evaluation for a suspected ABI at the time the study was published. In addition, 1 of the 2 participants in a study by Gardner et al. (2003) was co-morbid with attention deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD) and severe learning disabilities. The second participant in this study was also diagnosed with seizure disorder, oppositional defiant disorder, major depression and learning disabilities.

Three of the studies were family-centered and included caregivers as participants (Wade et al., 2005; Wade, Carey and Wolfe, 2006; McDougall et al., 2006), 2 of which included siblings as well (Wade et al., 2005; Wade, Carey and Wolfe, 2006). Ages of the participants with ABI ranged from 6 - 21. Post-injury years ranged from 6 months to 6 years for 4 studies where this information was specified. Four of the studies reviewed stated exclusion criteria explicitly, which included having a case manager appointed by an insurance company or having incurred additional brain injuries before the incident leading to the program referral (McDougal et al., 2006), children co-morbid with pervasive developmental disorders, autism spectrum disorders and/or intellectual disabilities (Marcantuono and Prigatano, 2008), and injuries related to non-blunt head trauma (e.g. gunshot wounds; Wade et al., 2005; Wade, Carey and Wolfe, 2006). The two studies which were conducted as case studies provided detailed information on each participant (Gardner et al., 2003; Mallay, 2002). The single-subject experimental study by Glang et al. (1997) also provided a thorough discussion of the participants. The remaining 4 studies that were experimental either provided general participant characteristics, such as age, gender and time post-injury. All of the case studies reviewed involved only male participants. The participants of the studies utilizing an experimental design were either all male or involved more male participants than females. One experimental study did not describe gender characteristics (Wade et al., 2005).
3.1.5.3 Description of Interventions

Two of the 9 studies reviewed involved cognitive-behavioural therapy (CBT) delivered in a web-based format to both the children and their families (Wade et al. 2005; Wade, Carey and Wolfe, 2006). Three of the studies applied interventions tailored to improving social networks and functioning within school settings, with the intention that the skills learned from playground and ‘free-activities’ could be transferred to community settings (Sowers et al., 1996; Glang et al., 1997; Gardner et al., 2003). For example, the ‘Building Friendships’ process delivered by facilitators (Glang et al., 1997) or outside consultants (Sowers et al., 1996) is a program which employs a team of the student’s family, facilitators and school staff to develop personal goals and strategies to expand a brain-injured student’s social network within school settings and apply these same strategies within community settings. Gardner et al. (2003) describe an intervention applied within a residential school setting for students with neurological disorders and to manage antecedent behaviours while promoting positive social responses. These strategies were combined with occupational therapy, physical therapy, speech-language pathology services, and nursing. The behaviours emphasized in sessions included those that could be generalized to community settings in order to improve community functioning and participation as well as vocational status.

Two studies described the structure and implementation of holistic rehabilitation programs (i.e. addressing other physical, cognitive, behavioural and emotional issues) for children and youth with ABI, with components of the programs tailored to community integration (Marcantuono and Prigatano, 2008; Gillet, 2004; McDougall et al., 2006). For example, the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP), described by Gilett (2004) and empirically evaluated by McDougall et al. (2006), is a holistic, parent and family-centered program attempting to incorporate the community in the ongoing care and management of youth with ABI. One of the program team members is a community outreach coordinator, who helps the family find community resources and programs to help promote integration in the community. Marcantuono and Prigatano (2008) described an outpatient pediatric day program currently in place at the Children’s Specialized Hospital in Fanwood, New Jersey. The program takes place in a simulated classroom environment where each child establishes long-term and short-term rehabilitation goals.

The theoretical backgrounds that the interventions were based on were identified in 6 of the 9 studies. These included cognitive-behavioural therapy (Wade et al., 2005; Wade, Carey and Wolfe, 2006), applied behaviour analysis and positive behaviour support (Gardner et al.,
2003), as well as holistic approaches to rehabilitation (Gillet, 2004; McDougall et al., 2006; Marcantuono and Prigatano, 2008). Although the reviewed studies had a common goal of helping to improve community integration for youth with ABI, different underlying purposes of each intervention were found between studies. For example, the Building Friendships process examined by Sowers et al. (1996) and Glang et al. (1997) aimed to improve integration by expanding the social network of the participant. Alternatively, Gardner et al. (2003) approached integration by teaching alternative communication responses to achieve lifestyle changes through a variety of methods, with the hope that these changes would lead to improved social communication skills and social integration. Art therapy was used to provide an alternate outlet of communication for overflowing emotions that would allow a brain injured youth to gain control over their emotions and promote successful social interactions, as reported by Mallay (2002). The interventions described by Gillett (2004), McDougal et al. (2006) and Marcantuono and Prigatano (2008) all approached improving community integration as a piece of an overall family-centered, holistic care model. Improving family dynamics and problem-solving were viewed as the key issues for community integration in the studies by Wade et al. (2005) and Wade, Carey and Wolfe (2006). Interventions were mostly provided in peer group settings or with family members, with the exception of 1 study that provided communication treatment on an individual basis (Marcantuono and Prigatano, 2008). Of the studies reviewed, 4 interventions viewed goal-setting, as identified by the participants, as a crucial component to the success of the social and community integration interventions.

The types of activities used within each intervention also varied. Gardner et al. (2003) attempted to identify and manage the behaviours viewed as detrimental to successful community integration, reinforce positive behaviours through antecedent management strategies and encourage and teach more beneficial strategies. The Building Friendships process (Sowers et al., 1996; Glang et al., 1997) implemented activities that were based on personalized goals of each participant in collaboration with their family, school peers, teachers, and their facilitator. The goals were created with an emphasis on including the participant in activities occurring on the school playground and to organize other activities outside of school with other students without disabilities. Mallay (2002) described artistic activities, such as drawings of pre- versus post-perceived self image, which were used to explore thoughts and feelings. In the holistic rehabilitation program described by Marcantuono and Prigatano (2008), youth with ABI took part in a variety of therapeutic activities, including a socialization/community group that focused on developing social skills and a sense of affiliation. Social application activities also took
place, where small groups met daily for 30 minutes to apply the strategies they learned in informal snack and lunchroom settings, allowing the staff an opportunity to gauge the child’s ability to transfer skills. Alternatively, in the PABICOP model, a community outreach coordinator was assigned to each child to help provide them with information regarding facilities and opportunities within the community in order to facilitate integration. Wade et al. (2005) and Wade, Carey and Wolfe (2006) used a web-based family-problem solving tool to deliver CBT-based activities in order to tailor the intervention to the schedule of the family. Two of the interventions reviewed are already delivered on a regular basis (Gillett, 2004; Marcantuono and Prigatano, 2008).

3.1.5.4 Measures

In all but 1 study, multiple outcome domains were assessed to interpret improvements in social and community integration using a variety of outcome measures. Five studies used standardized measures to assess family functioning [Family Burden of Injury Interview, Family Assessment Device (FAD), Family Assessment Measure – III – Brief Version, Impact on Family Scale, Agnew Relationship Measure, Interaction Behavior Questionnaire, Empowerment Questionnaire], executive functioning [Behavior Rating Inventory of Executive Function (BRIEF)], social behaviour [Child Behavior Checklist (CBCL)], and social competence [Home and Community Social Behavior Scale (HCSBC)]. Only 1 study used a standardized measure to directly assess improvements in community participation [School and Community Activity and Integration Assessment (SCAIA)]. Non-standardized measures were used in the reviewed studies to assess social relationships, vocational status and community participation. Four studies used qualitative methods, such as interviews, observations and surveys. Quantitative approaches included frequency counts of social contacts and social validation (Sowers et al., 1996; Glang et al., 1997), as well as negative and positive behaviors (Gardner et al., 2003).

3.1.5.5 Outcomes

Out of 7 studies that provided an empirical evaluation of a community integration intervention, all reported positive effects. Improvements were seen with respect to social relationships (Sowers et al., 1996; Glang et al., 1997; Gardner et al., 2003; Mallay, 2002), home, school and community participation (Sowers et al., 1996), initiative in seeking vocational opportunities (Gardner et al., 2003), social competence (Wade et al., 2005; Wade, Carey and
Wolfe, 2006), and social behavior (McDougall et al., 2006; Wade, Carey and Wolfe, 2006). No studies reported any negative effects for participants as a result of the interventions.

Variability was observed across the reviewed studies with respect to the definition of social and community integration and how it was measured, thus leading to a range of different outcomes. One study examining the Building Friendships process found an increased number of social contacts (interactions with peers without disabilities and without adult intervention for 10 minutes or more outside of the classroom setting) and social validation (the degree to which the participant felt a part of regular school life), although these changes were not maintained by any participant at follow-up testing (Glang et al. 1997). The study also examined the satisfaction of each student regarding their inclusion in social activities, although ratings were taken from the facilitator’s perspective. Sowers et al. (1996) also examined the Building Friendships process, although in their study the program was delivered by outside consultants. The authors also reported increases in social contacts, as well as an increase in the number of school and community activities that the participants were engaged in from pre- to post- participation, as measured by the SCAIA.

Family functioning was viewed as key to social and community integration in 3 studies, although not a direct form of community integration itself. However, neither found statistically significant improvements on this factor from pre- to post- intervention (Wade et al., 2005; Wade, Carey and Wolfe, 2006; McDougall et al., 2006). Social competence and social behaviours were observed in 3 studies, all of which reported improvements from pre- to post- participation in the interventions (Wade et al., 2005; Wade, Carey and Wolfe, 2006; McDougall et al., 2006).

3.1.6 Discussion

Previous reviews of interventions for youth with ABI have focused on cognitive and behavioural therapies that emphasize school re-integration. The current review set out to examine the evidence that exists to support interventions targeted at improving social and community integration for these youth, as it is a vital component of their development and transitioning into adulthood. The authors also sought to identify successful components and provide suggestions for future interventions or for research studying the effectiveness of interventions.
3.1.6.1 An Issue of Measurement

A key contributor to the lack of community and social participation research is a matter of measurement. Currently, a critical issue in research investigating community integration and participation in youth with ABI is developing appropriate measures that capture the effectiveness of interventions. Participation can be interpreted differently between individuals, making it difficult to establish a numerical value or scale measuring a level of integration, which inevitably would apply a societal value. As seen in the current review, across all studies the concept of community integration was interpreted in a variety of ways, from the number of social contacts one has to problem-solving and communication skills. Since various definitions were used, different methods used to assess improvements were also employed. However, only 1 study used a standardized measure directly related to community integration (Sowers et al., 1996).

To mediate these definitional issues, the International Classification of Functioning (ICF) and the later revised version for children and adolescents (ICF-CY) were created to provide a common framework for rehabilitation practitioners, health-care service providers and users (World Health Organization, 2002; Imrie, 2004; Wade and Halligan, 2003). Using the ICF-CY framework, researchers investigating participation patterns and community integration among youth with brain injuries often employ the constructs of ‘activity,’ or the execution of a task, and ‘participation,’ or the involvement in life situations, when designing their studies and evaluation methods. McConachie et al. (2005) describe the problems that arise from these definitions, as both could be interpreted in numerous ways. For example, ‘life situations’ could have a variety of interpretations that include actions such as eating or thinking, even though one would typically associate ‘participation’ with activities that are social. Many of the measures that have been created to evaluate children and adolescents’ participation in their homes and communities [e.g. Life Habits for Children (LIFE-H), Child and Adolescent Scale of Participation (CASP) and the Children’s Assessment of Participation Enjoyment (CAPE)] have also been built around these ambiguous definitions, leading to a diversity of content and dimensions of participation being assessed.

Current measures also tend to examine whether or not a child engages in certain activities, when it may be more critical to assess the frequency of activity engagement so that the perspective of what activities are actually important to the youth is considered (Coster and Khetani, 2008). A sensible solution would be to use self-reporting or observational methods to
assess what each individual youth deems important and valuable with respect to participation in their community – a form of ‘ecological inventory’ (Baine et al., 2000). However, it has been noted that individuals with brain injuries may overestimate abilities and under-report problems (Cooper-Evans et al., 2008). What is clear from the current review is the need for better measures of participation and integration specifically for children and youth with brain injuries, as existing measures have limitations in their content, relevance and feasibility across a variety of research contexts (Morris, Kurinczuk and Fitzpatrick, 2005; Lollar, Simeonsson and Nanda, 2000).

The reliance of many of the interventions on only observations and frequency counts as indicators of improvement is also troublesome. These types of measurements are built on the assumptions that what is observed is a manifestation of the youth’s actual experience and that quantity is necessarily equated with quality (Ueda and Okawa, 2003). Although important for gaining an external perspective, these methods also fail to include the perspective of the youth, which is critical in determining what improvements are meaningful to them. One possible strategy to improve on this is to use client-centered approaches. Guidance can still be provided by the facilitators to tailor the social and community integration goals to the intervention, but would still incorporate what is important to the youth. Setting-specific goals can also be created to reinforce the applicability of the skills and knowledge gained from the intervention.

Ylvisaker, Hanks, and Johnson-Green (2002) describe this type of intervention approach as the ‘contextualized’ model of rehabilitation, versus the more common ‘traditional’ approach. In the traditional model of rehabilitation, the focus is on restoration of function and compensatory strategies to eliminate or reduce underlying impairments. Conversely, a ‘contextualized’ model of intervention has a primary goal of helping an individual achieve their real-world objectives and participate in their chosen real-world activities. Carlson et al. (2006) recommended this approach after reviewing the literature for best practices and interventions to enhance participation for adults with ABI. It would take into account the perspective of the participant and work to modify their expectations and supportive behavior from people involved in their everyday life, which is especially applicable to youth with brain injuries who may deal with unreasonable expectations from friends and family when attempting to return to their pre-injury level of functioning (McCabe et al., 2007).
3.1.6.2 Intervention Setting

Overall, the studies reviewed lend support to the effectiveness of interventions at improving social and community integration within the short-term. However, only 2 studies provided long-term follow-up testing at 1 year (McDougal et al., 2006) and 3 years (Gardner et al., 2003) post-intervention, the results of which suggest that these gains were maintained after an extended period of time. Glang et al. (1997) found that improvements in social integration maintained through the intervention were not seen at follow-up testing. This suggests that ongoing support post-intervention may be required to help youth adjust more effectively to the community setting. The findings from the current review also suggest that, since many of the studies took place within an actual or simulated classroom environment, community-based interventions may provide a more appropriate setting for youth to gain directly applicable social and community integration skills. However, it has been noted that community-based service providers may not be equipped with the education and training tools regarding brain injuries to make such interventions as successful (Dumas, Bedell and Hamil, 2003). Thus, appropriate training and guidance should be conducted for intervention implementers within the community as well.

3.1.6.3 Structure of Interventions

Since family functioning has been found to be closely related to the types of participation restrictions faced by brain-injured youth, it follows that the family should be involved in the programs as well (Beresford, 1995; Ehrmann, Aeschleman and Svanum, 1995). However, the current review demonstrates that, although all 3 studies that examined family functioning found trends of improvement from pre- to post-intervention, no results were statistically significant (Wade et al., 2005; Wade, Carey and Wolfe, 2006; McDougall et al., 2006). Nonetheless, Savage et al. (2008) stressed the importance of family inclusion within interventions relating to re-integration strategies, as the family of a brain-injured youth serves a unique role in the rehabilitation process. They remain the observers and advocates through all stages of care, are experts in the pre and post-injury knowledge of the youth’s abilities and are the communicators between the intervention implementers and the youth.

Two of the studies reviewed described the delivery of community integration interventions as part of a holistic, family-centered program as soon as an adolescent with an ABI was released from an acute-care setting (Gilett, 2004; Marcantuono and Prigatano, 2008). Since only one empirical study was reviewed that evaluated this type of program (McDougall et al.,
2006), conclusions regarding the effectiveness of this type of delivery require further research. However, the benefits of outreach programs that target social and community integration issues as soon as possible could help prevent the downward spiral of social isolation and withdrawal experienced by adolescents with ABI.

3.1.6.4 Limitations

A clear limitation to the current review is the low level of evidence provided by the studies examined. The few studies that provided control comparisons were of relatively small sample sizes, therefore reducing the power of statistical analyses applied. Also, many of the study designs were uncontrolled. However, confounding variables, such as the effect of other co-occurring treatments, would be difficult to control for this population. Appropriate long-term follow up testing was conducted in only 2 of the reviewed studies, also limiting our understanding of the sustainability of any improvements on factors relating to social and community integration over time.

Although more male participants were included in the studies reviewed, this finding can be thought of as reflecting the disproportion of brain injury incidence between genders (Kade and Janzen, 2009). Among children aged 15 and younger, the rate of TBI associated hospitalization has been shown to be 70% higher for males than females (CIHI, 2006). This disproportion increased drastically when examining young men ages 16 – 25, as the rate was almost 160% higher (Colantonio et al., 2005). Also, the study samples tended to include more youth with less severe brain injuries, limiting generalizability. For several studies, ratings on social competence, participation and behaviour were obtained from the perspective of caregivers and facilitators. As discussed previously, the reliance on these types of methods does not provide insight from the youth participating in the intervention and can lead to a lack of understanding regarding what skills and improvements are truly meaningful. In addition, some of the interventions described, such as the holistic-care models, may be too intense and costly to deliver on larger scales. Some of the therapists and facilitators involved in the interventions also received extensive training and education which may not be feasible to provide in all cases.

Taken together, the limitations of the studies reviewed also limit the strength of evidence and suggestions for interventions and future research provided in the current review. The small sample sizes across the studies may not be an accurate representation of brain injured adolescents, who are a very heterogeneous population. In addition, since the design of the
current study was a literature review, the framework for evaluation of the studies did not follow a set of certified guidelines (e.g. PEDro, Downs and Black checklist, etc.). However, due to the limited research present on this topic, conducting a systematic review would further limit the amount of studies included.

3.1.7 Conclusions

It is clear from the current review that more research investigating social and community integration interventions is warranted. Although this review does not allow for any definite conclusions to be made regarding the effectiveness of such interventions, it does help provide some direction for future research. Larger sample sizes, better controls and recruitment of youth with varying severities of brain injuries should be considered. Evaluation of these interventions should include measures tailored specifically to community integration, although the development of such measures, especially in relation to the unique needs of brain-injured youth, is needed. These measures could include one or many of the several outcome domains covered in the studies reviewed and should incorporate the perspective of the youth undergoing the intervention. Treating behaviours and communication skills that affect social interactions from one context to another may be more beneficial to target and study, such as pragmatic communication skills, versus skills applicable only in certain contexts (i.e. only within regulated classroom settings).

3.2 Expressive Arts as a Community Integration Intervention

Expressive arts, or the use of arts and artistic media to explore psychological aspects of life [International School for Interdisciplinary Studies (ISIS), 2004], holds great potential as a rehabilitation strategy to improve social and community integration of adolescents with ABI. Arts-based therapies have played a role in psychotherapeutic and psychiatric therapy for many years and within several disciplines, such as geriatric, pediatric and rehabilitative settings (Waller, 1991; Borgmann, 2002; Serlin et al., 2000). ISIS (2004) established that expressive arts can facilitate opportunities for social learning through group work, collaboration, personal reflection, and the formation of a social support network when delivered in a group setting. As Wiseman-Hakes et al. (1998) reported, social difficulties associated with adolescents who have an ABI can decrease through interventions provided in a group environment that encourages peer-feedback and communication. To this end, expressive arts therapy has demonstrated
positive effects for individuals with schizophrenia, bipolar affective disorder, depression, and eating disorders (Odell-Miller et al., 2006), ADHD (Henley et al., 1988), adults with TBI (Berrol, Ooi and Katz, 1997), and adolescents delayed in socio-emotional development (Walsh, 1990).

However, there is currently a lack of research formally evaluating the effectiveness of expressive arts therapy methods on social and community integration, especially for individuals with communication impairments (Hacking et al., 2008). Several researchers have postulated that the reason for the scarce empirical support is due to a lack of appropriate instruments that are tied to the aims of the therapies, as well as limited established principles and protocols for collecting and analyzing data gathered in these projects to meaningfully evaluate outcomes (Angus, 2002; Everitt and Hamilton, 2003). The consideration of community participation as an outcome for adolescents with brain injuries is also a relatively new development (Hacking et al., 2008).

The phrase ‘expressive arts’ covers a wide range of activities, such as drawing, group writing, expressive movement, vocal exercises, and drama. Dramatic arts, or theatre-based therapies that promote aspects of play and enjoyment would be a useful form for adolescents to adhere to a therapeutic method (Goyal & Keightley, 2008). Theatre has been described as the most integrative of all the arts, as it includes singing, dancing, painting, sculpture, storytelling, music, puppetry, poetry, and acting (Snow, D’Amico and Tanguay, 2003). Theatre represents the art form that is closest to reality, or an “imitation of life,” leading some researchers to postulate that this feature is what provides an innate healing function to theater-based therapy (Emunah, 1990; McNiff, 1988; Pendzik, 1988; Snow, 1996; Snow, D’Amico and Tanguay, 2003).

Activities based on theatre could help adolescents with shedding and integrating past childhood roles while experimenting with future roles in their search for an independent identity (Emunah, 1990). For example, acting can be used to channel an adolescent’s impulse towards acting out, which may be further perpetuated as a result of the cognitive and behavioural sequelae following a brain injury (Blatner, 1973). Drama could help adolescents achieve a sense of mastery over their emotions and provide internal control by providing them with a setting in which they can explore and test real life situations with safety and distance (Emunah, 1983). With the help of a creative arts therapist, adolescents with ABI can use theatre-based interventions to help them expand their ways of perceiving and coping with the present (Emunah, 1990).
In addition, the collaboration involved in these exercises can help develop and improve social skills and provide an experience that promotes trust, intimacy and collaboration. Further key skills fostered by drama therapies include improving self-esteem and self-awareness, encouraging positive self-image, developing non-verbal communication, and developing sensitivity to the self and others (Wilkinson et al., 1998). Thus, drama therapy can provide a medium for social skills training for adolescents with ABI under the guise of plays and theatre exercises.

Goyal and Keightley (2008) conducted a search of the literature and found 10 studies of drama therapy interventions that evaluated their effectiveness for adolescents experiencing difficulties in social, emotional, cognitive and physical functioning, especially in relation to social and community integration. For example, 2 case studies by Christie, Hood and Griffin (2006) of female children with chronic pain and compromised independence and social activity participation found improvements in their social activity pursuits after they attended 6 sessions of a drama and movement therapy. McArdle et al. (2002) carried out an RCT with 112 children at a mean age of 11.4 years who presented with symptomatic behavioural and emotional problems. By using a creative-expressive and psychodrama approach, the researchers found improvements in subjective well-being and school adjustment as determined by quantitative assessments such as the CBCL (Achenbach, 1991) and the Youth Self-Report and Multidimensional Self Concept Scale (Bracken, 1992). Case studies of 2 male children, ages 12 and 10, with personality disorders and suspected ADHD, found that undergoing weekly drama therapy that included movie-making and script-writing promoted co-operation, patience and communication skills according to observations by the intervention facilitators (Novy, 2003).

Although the reviewed studies focused on populations with characteristics similar to adolescents with ABI and found that drama therapies were an effective intervention technique, Goyal and Keightley (2008) acknowledged that, overall, the studies provided low levels of scientific evidence and used anecdotal evidence to support their findings. Many of the studies also failed to adequately report the experimental procedures used in data collection and analysis. Few studies used standardized measures that focused on social and community integration to assess improvements on these factors, although currently there is no standardized measure specifically tailored for youth to assess their community integration directly (refer to review in 2.5.1). In addition, there is a lack of empirical evidence directly tying the effectiveness of drama therapy to adolescents with ABI. One study by Mallay (2002) provides a qualitative account of the effectiveness of using art therapy for the treatment of PTSD symptoms, including an inability
to communicate thoughts and feelings related to the traumatic event, for a male child with a suspected brain injury. Thus, with a lack of direct evidence, it does not necessarily hold that drama or expressive arts therapy in general would be a successful rehabilitation approach to improve social and community integration skills for this population.

What is clear, however, is that more research is needed to establish interventions that promote social and community integration for adolescents with ABI. Expressive arts interventions, especially those that are drama-based, provide a promising and unique rehabilitation strategy that could be more enjoyable to youth who would otherwise spend isolated time with a social worker, psychologist or psychiatrist. The social skills and knowledge gained by these youth could also be more adaptable to real life situations, as participation in an expressive arts program could allow the youth to form peer groups within the therapy to practice these new skills. Thus, the goal of the current study was to pilot test a theatre skills training program with adolescents who had an ABI. The program was designed to facilitate social and community integration in order to empower youth to lead meaningful and productive lives.

3.3 Global Research Objectives and Hypotheses

Multiple descriptive case studies over the course of 2 stages were carried out with the following objectives:

Objective (1): To identify and refine methods to measure the effect of the theatre skills training program on social cognition and community integration.

Specific hypotheses relating to the measures used are described appropriately within each study (refer to sections 4.2 and 5.2).

Objective (2): To collect pilot data on the effectiveness of a theatre skills training program for youth with ABI to improve social cognition and community integration

It was hypothesized that the combination of directed group activities and self-reflection within a creative learning context provided by the theatre skills training program would improve social communication skills, emotional awareness and community integration for youth recovering from ABI.
Chapter 4 Expressive Arts as a Social Cognitive and Community Integration Tool for Adolescents with ABI: Pilot Study Stage 1

4.1 Introduction
Acquired brain injury (ABI) is defined as “damage to the brain that occurs after birth and is not related to a congenital disorder or a degenerative disease” (OBIA, 2008). An ABI is non-progressive and can be the result of many different causes, including non-traumatic (e.g. epilepsy, tumours, and vascular abnormalities) or traumatic mechanisms (e.g. motor vehicle accidents, assaults and recreational activities; Johnson, Dematt and Salorio, 2009). Although an ABI at any age can have devastating effects, these effects are compounded further during adolescence. Adolescence is a time during which social and community integration skills are developing. It is a time when even healthy young people are struggling with difficult developmental issues. Having an ABI during adolescence can negatively impact the development of social skills. These skills are reliant on goal-directed verbal and nonverbal behaviors (Wiseman-Hakes et al., 1998).

In order to communicate thoughts and emotions effectively and in a manner that is functional in society, skills like being aware of the social rules and boundaries, rapidly processing and interpreting emotions conveyed by facial expressions, and working with others to solve conversational tasks, are required (Turkstra et al., 1996; Dahlberg et al., 2006). These skills are collectively referred to as social cognition and are often found to be impaired in adolescents with ABI and linked to deficits in overall communication competence (Fiske and Taylor, 1991; Havet-Thomassin et al., 2006; Henry et al., 2006; McDonald, 2005; McDonald, 2007; Turkstra et al., 2008). For example, Tonks et al. (2008) found that, compared to typically developing adolescents between the ages of 9 – 15, brain injured youth were significantly impaired on all tasks that required reading emotion conveyed by facial expressions. However, no difficulties were found in tasks involving the identification of the faces, indicating that the difficulty is in recognition of emotion and not general face processing. In addition, Pettersen (1991) found that youth with ABI may confuse positive and negative emotions and make errors interpreting emotionally toned vignettes.

Impairments in social cognition make it difficult for a brain injured youth to interact with peers and integrate themselves into appropriate social networks. Consequently, there is an increased likelihood that youth with brain injuries will become and remain socially isolated.
Studies have shown that children and adolescents with disabilities are also likely to face restrictions in their access to social and productive activities in the community (e.g. Bedell and Dumas, 2004; Bedell et al., 2002; Brown and Gordon, 1987; Bedell, 2004). From a rehabilitative perspective, it is crucial that effective treatment strategies be developed for adolescents with ABI, which facilitate the development of social and emotional skills to effectively enable community integration.

One such strategy is through the therapeutic use of expressive arts. Expressive Art Therapy is defined as the use of the arts and artistic media to explore psychological aspects of life. An expressive art (also referred to as a ‘creative art’ or ‘art’ in the literature) encompasses drama, music, painting, sculpture, and dance/movement (Smeijsters and Cleven, 2006; Odell-Miller, 2006; Walsh, 1990; Emunah, 1990; Emunah, 1983). The majority of literature relating to expressive arts focuses on the use of creativity to facilitate human relatedness, social and emotional awareness and learning.

Theatre, or drama, has been described as the most integrative of all the arts, as it includes singing, dancing, painting, sculpture, storytelling, music, puppetry, poetry, and acting (Snow, D’Amico and Tanguay, 2003). Theatre represents the art form that is closest to reality, or an ‘imitation of life,’ leading some researchers to postulate that this aspect is what provides the innate healing function of theatre-based therapy (Emunah, 1994; McNiff, 1988; Pendzik, 1988; Snow, 1996; Snow, D’Amico and Tanguay, 2003). It has the ability to enhance both group work and collaboration, as well as personal reflection, self-awareness and social integration. Drama offers group exercises and activities such as tableau (i.e. three-dimensional pictures using the human body), group writing, mirror exercises (two individuals as well as in a group), various ‘circle games’ (e.g. group storytelling, ‘hunter and the hunted’ etc.) and a plethora of others (Cameron, 1999). These activities allow individuals to explore social communication strategies through creativity. Individual activities cover a wide range of activities such as breathing exercises, yoga, expressive movement, mask building, clown work, and vocal exercises (Cameron, 1999) and give the participants, while still within a group setting, the opportunity to increase emotional self-awareness. Thus, theatre skills training has great potential to improve community integration for youth recovering from ABI, through facilitating the development and enhancement of various social cognitive skills.

To this end, several studies examining drama-based therapies for youth experiencing difficulties in social, emotional, cognitive and physical functioning, especially in relation to social and community integration, have revealed positive findings (for review, see Goyal and
Keightley, 2008). For example, improvements in pursuing social activities after attending drama and movement-based therapy was found in children with chronic pain who were previously experiencing compromised independence and social activity (Christie, Hood and Griffin, 2006). Psychodrama therapy has also been found to be effective in improving subjective well-being and school integration in children with behavioural and emotional problems (McArdle et al., 2002) and individuals with developmental disabilities (Gold, Wigram and Elefant, 2006; Snow, D'Amico and Tanguya, 2003). In addition to the aforementioned studies, clinically relevant and statistically significant changes were found in youth with cognitive communication disorders secondary to ABI after receiving peer group training on pragmatic communication skills. These results suggest that subsequent social difficulties associated with ABI can be lessened through effective intervention provided in a group setting (Wiseman-Hakes et al., 1998).

Taken together, this supports the investigation of the use of theatre as a therapeutic tool to facilitate social and community integration for adolescents recovering from an ABI. As community integration enables meaningful and productive occupational engagement, enabling opportunities for occupational engagement through increased community integration would greatly enhance the quality of life of adolescents with ABI. However, the number of studies that have investigated the use of drama therapy directly with youth with ABI are few. One study by Mallay (2002) provides a qualitative account of the positive effects of using art therapy for the treatment of PTSD symptoms, including an inability to communicate thoughts and feelings related to a traumatic event, for a male child with a suspected brain injury.

The dearth of literature also extends more generally to empirical studies evaluating community integration interventions in general for youth with ABI, which makes it difficult to determine how to measure the effectiveness of such programs on social and community participation (DiRezze et al., 2008). One widely-used method of assessment for intervention studies is to use individualized outcome measures, such as the Canadian Occupational Performance Measure (COPM) or Goal Attainment Scaling (GAS). Intervention studies of youth with disabilities have shown that this method can detect small, but meaningful, changes in relation to problems and goals that are identified by the participant (e.g. DiRezze et al., 2008; Phelan, Steinke and Mandich, 2009). Another method could be to use standardized approaches, although currently there is no standardized measure developed specifically for youth with ABI to address their unique participation challenges. One solution to this could be to use subsections from existing measures that implicitly measure participation as part of another outcome. For example, the Adaptive Behaviour Assessment System Version II (ABAS-II) is a standardized
measure that examines adaptive behaviours (i.e. age-appropriate behaviours necessary for one to live independently and to function safely and appropriately in daily life (Harrison and Oakland, 2003) and includes domains, such as leisure and social, that can be thought of as representing community integration skills.

In a recent symposium presented at the 2006 INS/SVNP/GNP Meeting: From Plasticity to Rehabilitation, Ruff and colleagues (personal communication, July 26, 2006) discussed common methodological limitations in rehabilitation research, and provided guidelines for rehabilitation research design. When introducing a new intervention they advised conducting the research across two phases. In Phase 1, the usability and feasibility of the new intervention is assessed using small numbers and evaluating the acceptability of the intervention to stakeholders (i.e. caregivers and participants), as well as the ease of implementation according to therapists and clinicians. This phase allows the researcher to refine the intervention and look for trends on their selection of outcome measures without wasting time and resources on a larger-scale study. By not including this phase, the researcher risks implementing an intervention that is not usable by the patient or administrable by the therapist (Ruff et al., personal communication, July 26 2006). Thus, the current study was implemented in a case study design in order to better explore the effectiveness of expressive arts therapy to help improve social cognitive and community integration skills for adolescents with ABI, given that it is a novel therapeutic approach for this population.

4.2 Objectives and Hypotheses

For the current study, a descriptive case study was carried out with the following objectives:

1. To identify methods to measure the effect of the theatre skills training program on social cognition and community integration from pre- to post-participation.

With respect to social cognition, it was expected that participation in the theatre skills training program would lead to improvements in identifying emotions from facial expressions, as measured by an emotion discrimination task, from pre- to post-program participation. It was also expected that community integration would improve, as reflected by improved performance and satisfaction ratings for various problem areas identified on the COPM, and improved scores on the communication, community use, leisure, self-direction, and social scales of the ABAS-II, which it was believed contained test items relevant to social and community integration.
In addition, as was found by Wiseman-Hakes et al. (1998) in their study examining a peer group training program of pragmatic skills in adolescents with ABI, it was also hypothesized that the skills gained in the program would be transferred to the home and community environments and that any positive changes observed post-program would still be observed at a follow-up assessment. In the current study, follow-up testing was conducted 8 months after the end of the program to allow for a sufficient amount of time for the participant’s to transfer any newly acquired skills to their environment.

(2) To collect pilot data examining the feasibility and usability of a theatre skills training program for youth with ABI to improve social cognition and community integration.

It was hypothesized that the combination of directed group activities and self-reflection within a creative learning context provided by the theatre skills training program would improve social communication skills, emotional awareness and community integration for youth with ABI.

4.3 Methods and Procedure

4.3.1 Design

This pilot study was conducted and analyzed as a multiple descriptive case study design to allow for the testing of the hypotheses that the theatre skills training program is effective for adolescents with ABI and to refine measurement techniques before piloting it in a larger sample.

4.3.2 Participants

All participants were recruited via Bloorview Kids Rehab’s existing NeuroRehabilitation Services Inpatient and Outpatient programs. Inclusion criteria for participants were: (a) they were recovering from a mild or moderate ABI; (b) at least 6 months post-injury to minimize the effects of spontaneous recovery and variability related to injury type on the outcome measures selected; (c) between the ages of 13 – 16; (d) identified as experiencing significant difficulties in social functioning according to self and/or caregiver reporting. Exclusion criteria included youth not reporting difficulties in these areas so that the feasibility of the program to help improve social cognitive and community integration skills could be better assessed. All participants provided informed consent and/or assent and the study methodology was approved by Bloorview Kids Rehab and the University of Toronto Research Ethics Board.
Two participants were recruited for this study.

*Participant 1*, a 17 year old female, diagnosed with a medulloblastoma at the age of 8, a nontraumatic ABI. She also experienced secondary meningitis. Due to her troubles in social functioning and desire to take part in the program, in addition to difficulties that were experienced in overall recruitment, an exception was made to allow her to take part even though she was slightly above the targeted age range for the pilot study.

*Participant 2*, a 16 year old female, was born 14 weeks premature with cerebral palsy (CP). However, for the purposes of the current study, her data is excluded since CP is not considered to be an ABI (OBIA, 2009; Toronto ABI Network, 2006).

### 4.3.3 Outcome Measures

#### Social Cognition

An emotional discrimination task was used to assess general social cognition and emotional awareness. Participants were asked to choose from a list of labels of emotional expressions (i.e. anger, disgust, fear, happy, sad, surprise, and neutral) that matched the expression displayed on a male or female face presented to them one at a time on a computer screen. Labels were available at all times to the participants while completing the task on the right side of the screen while faces were presented on the left. Faces with these expressions were taken from a stimulus set that included both genders and a mixture of Caucasian and Japanese faces that has been extensively normed in younger adults aged 18 – 21 (Matsumoto and Ekman, 1988).

#### Community Integration

**Canadian Occupational Performance Measure (COPM)**

The COPM is an outcome measure based on a client-centered approach to practice. It addresses three aspects of performance: self-care, productivity, and leisure (Law et al., 1994). Based on a semi-structured interview, this measure uses self-report data to evaluate change in performance and satisfaction with problem areas identified by the client. In this study, only the most relevant area of leisure was addressed to limit administration time. The COPM was used to identify specific concerns regarding the participant’s social and leisure functioning. Once each
concern was identified, the participants rated their current performance on a 10-point scale, with a rating of 1 representing “not doing at all” and 10 indicating “performance could not be better.” They also rated their current satisfaction for each concern, with 1 being “not satisfied at all” and 10 being “completely satisfied.” This information, in turn, was used by the theatre facilitators and therapists to guide the structure of the theatre skills training program and provide information regarding the types of activities and tasks the youth found rewarding and meaningful. Studies examining the test-retest reliability of the COPM have found intraclass correlation coefficients ranging from 0.63 to 0.80 for Performance scores and from 0.75 to 0.89 for the Satisfaction scores, reflecting acceptable to high reliability (Law et al., 1994; Sanford et al., 1994; Bosch, 1995). Criterion validity has been established in a number of studies comparing COPM scores with other measures of the same construct (Bosch, 1995; McColl et al., 1997; Pollock and Stewart, 1998), as well as significant responsiveness (i.e. ability to detect change over time; Law et al., 1994; Sanford et al., 1994). A change score of 2 points has been found to be clinically meaningful (Law et al., 1994; Chan and Lee, 1997; Cup et al., 2003).

Adaptive Behavior Assessment System – Version II

The ABAS-II Parent Form (ages 5 – 21) was used to measure children’s activities of daily living, cognition, language, play and social competency from another person’s perspective (Harrison and Oakland, 2003). Several skills are assessed and grouped together into 10 main areas. However, for the current study, we were only concerned with ratings from the subscales of: communication (e.g. looks at other’s faces when they are talking, ends conversations appropriately), community use (e.g. finds and uses a pay phone, orders his/her own meals when eating out), leisure (e.g. plans ahead for fun activities during free time, listens to music for fun), self-direction (e.g. arrives at places on time, controls temper when disagreeing with friends), and social (e.g. has one or more friends, states when others seem happy, sad, scared or angry). Each skill is rated on a Likert scale from 0 - 3 in terms of frequency (i.e. always, sometimes, never, and not able). Scores from these skill areas can be further grouped into the three broad domains of Conceptual, Social, and Practical, in addition to a General Adaptive Composite score, although, for the purposes of the current study, only the scaled scores were examined for each skill area was examined. Psychometric testing for reliability has revealed scores average reliability coefficients ranging from .85 to .97 across age groups for the skills areas and test-retest reliability in the .80s to .90s. The correlation between the ABAS-II GAC and Vineland Adaptive Behavior Scales – Classroom Edition (VABS) has been found to be .82. The manual
also contains a discussion of studies conducted by the authors of the measure that demonstrate its clinical validity for a variety of problems and disorders. For this study, the Parent Forms were used. Normative testing has revealed a mean of 10 and standard error of the mean of 3 for scaled scores (Harrison and Oakland, 2003).

4.3.4 Intervention

The experimental intervention was an intensive theatre skills training program that took place in two classrooms provided by the Bloorview School for the duration of the program. The adolescent participants recovering from ABI met daily for 4 hours over a period of 3 weeks. During each 4 hour period, regular breaks were scheduled to provide the participants with a mental and physical break from therapy. Theatre training included voice work, breathing, movement, physical warm-up, character development, script analysis, writing skills, three-dimensional awareness, group dynamics, story development, mask work and clowning among others. The group was headed by a professional theatre artist and 2 master’s level occupational therapy students completing their last clinical placement and having expressed interest in participating in the program. The artist acted as the facilitator for the group, bringing in specialists as needed for particular projects, such as mask work. Daily meetings started with a physical and vocal warm up. This warm up consisted of individual exercises done within a group setting, which allowed for self-reflection in a communal environment. Following each warm up, group exercises on a specific topic, such as story development, took place.

At the end of each day, the youth came back together to complete a Creative Tool Box exercise. The Creative Tool Box was an unobtrusive home or storage place for the work that participants completed throughout the four week session. The contents of the Tool Box were created in a number of ways; predominantly participants recorded reflections on an exercise, or created new work that evolved out of a specific exercise. Participants were asked to reflect through words or text, as well as with visual media like painting, pencils, markers and collage. The Creative Tool Box allowed participants to process changes in their bodies and minds experienced during the theatre exercises in a number of ways, allowing for multiple modes of expression. At the end of the camp, each participant thus possessed a creative record of their own process over the course of the program.

The purpose of the program was to develop a public presentation reflecting the group’s progress over the course of the program. Snow, D’Amico and Tanguay (2003) emphasize that a crucial component of theatre-based therapy is to build activities towards a performance for the
‘community,’ since this would be a test of the process of de-alienation that is emphasized throughout the entire therapeutic experience. In the current study, this presentation consisted of a scene from a play as well as other ‘works-in-progress’. These ‘works-in-progress’ included some group stories and a series of tableaus (three-dimensional pictures using the human body). Participants were asked if there were Creative Tool Box items that they wished to display in the lobby for the audience. Displaying an item was voluntary and not required.

4.3.5 Procedure and Data Collection
Following recruitment and consent, participants and their caregivers were tested at Bloorview Kids Rehab 1 week prior to program participation and 1 week post-program. Follow-up testing was completed 8 months post-program at the University of Toronto. Each program participant was administered the COPM and the emotion discrimination task and their caregivers were administered the ABAS-II. All tests were administered by trained master’s-level occupational therapy students during the 1-week pre- and post-program assessments and by the primary author at follow-up. Each testing session lasted approximately 1 hour.

4.3.6 Data Analysis
Since this was a pilot study, data analysis followed a descriptive approach. The outcome measures were evaluated from pre- to post- as follows:

1. Mean accuracy and mean reaction times were graphed for each of the emotional expressions on the emotion discrimination task using Microsoft Excel and changes were visually examined between pre- and post-program for any trends. Since no previous research has employed such a measure with youth in a pre-post intervention format, a trend was specified as any consistent increase or decrease in accuracy or reaction time that was observed from pre- to post- to follow-up assessments.

2. Differences of 2 or greater in performance and satisfaction ratings on the COPM for each identified problem area from pre- to post-program indicated clinically significant changes, as has been demonstrated in previous studies (Law et al., 1994; Chan and Lee, 1997; Cup et al., 2003).
3. Scaled scores for the skill areas of interest from the ABAS-II were graphed from pre- to post-program assessments using Microsoft Excel and were visually examined. No previous studies have used the ABAS-II in a pre-to-post manner, therefore meaningful change was assessed by using an adapted version of the 2-standard deviation (SD) band method (Ottenbacher, 1986, 1990). In the current study, the standard error of the mean (i.e. 3 scaled scores) was used as a proxy SD in lieu of a baseline SD, since only 1 baseline datapoint was obtained. Post-intervention scores were then considered clinically meaningful if they fell outside 2 SDs (i.e. change in scaled score of greater than 6). The central limit theorem posits that the distribution of a sum of independent, identically distributed variables tends towards a normal distribution (Glass and Hopkins, 1996). In this case, if data are considered to be normal, approximately 68% of the values are within 1 SD of the mean, whereas approximately 95% of the values are within 2 SD. Thus, the 2 SD band method allows for a conservative estimate of clinical significance, as the percentage outside of this confidence interval represents a value of only about 5% (i.e. less than 5% chance that the values obtained were due to chance).

4.4 Results

4.4.1 Social Cognition

*Emotion Discrimination Task*

Mean accuracy and mean reaction times on the emotion discrimination task for both participants are illustrated in Figures 4.1 and 4.2, respectively. Participant 1 demonstrated improved accuracy for anger, happy, sad, surprise and neutral faces from pre- to 1 week post-assessment. At follow-up, her accuracy improvements were maintained for angry and sad faces. Her accuracy for fearful faces decreased from guessing (50%) to 0% at both post-program assessments. Accuracy for happy, sad and surprise faces remained stable or returned to initial assessment levels, whereas her accuracy for neutral faces decreased to 0% at follow-up. Her reaction times from pre- to 1 week post-assessment decreased for all emotions and further decreases for all emotions were observed from both initial and 1 week post-assessments at follow-up.
Figure 4.1 Emotion discrimination task accuracy for participant 1. Note: Follow-up assessments were conducted at 8-months post-program participation.

Figure 4.2 Emotion discrimination task reaction time for participant 1. Note: Follow-up assessments were conducted at 8 months post-program participation.
4.4.2 Community Integration

COPM

Scores for performance and satisfaction scales for participant 1’s problem areas are displayed in Table 4.1. She identified reading, painting, knitting, and spending time with friends as problematic tasks. At the 1 week post-assessment, clinically significant improvements were noted with performance ratings in all problems identified. With the exception of knitting, these improvement ratings were either maintained or increased at the 8 months post-assessment. Clinically significant positive changes in satisfaction ratings for reading, painting and knitting skills were also noted 1 week post-program, although her rating of spending time with friends demonstrated no change from the initial assessment. At the 8 months post-assessment, all satisfaction ratings were maintained from 1 week post or improved further.

Table 4.1 Participant 1 COPM Identified Problem Areas and Ratings for Performance and Satisfaction

<table>
<thead>
<tr>
<th>COPM Problem Area</th>
<th>Performance Scores</th>
<th>Satisfaction Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-</td>
<td>Post-</td>
</tr>
<tr>
<td>Spending time with friends</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Reading</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Knitting</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Painting</td>
<td>5</td>
<td>8</td>
</tr>
</tbody>
</table>

COPM = Canadian Occupational Performance Measure
FU = Follow-up conducted 8-months after the end of the theatre skills training program

ABAS-II

Scaled scores from the ABAS-II for participant 1 are depicted in Figure 4.3. Change scores were considered clinically meaningful for skill areas when the scaled score reflected a change of greater than 2 SD, as described in section .

Visual inspection demonstrated a lower scaled score for participant 1 in the skill area of Communication at post-program (change of 1 scaled score). An increase in her scaled score at follow-up was observed compared to both pre- and post-program, although less than 2 SD. For Community-Use scaled scores, participant 1 demonstrated an increase at follow-up testing by 2
scaled scores compared to both pre- and post-program assessments. Her Leisure scores decreased from pre-program at post-program by 1 scaled score and remained stable at follow-up. An increase of 2 scaled scores at post-program for her Self-Direction score was seen between pre- and post-program, which was also maintained at follow-up assessment. For the Social skill area, participant 1’s score increased by 2 scaled scores from pre- to post-program assessment, and then by an addition score at follow-up, with a net gain of 3 from her pre-program scaled score. However, none of the changes observed for any skill area represented clinically meaningful changes using the adapted 2 SD band method.

Figure 4.3 Scaled scores for skill areas of the ABAS-II across assessments for participant 1
Note: Follow-up testing took place 8 months post-program participation
4.5 Discussion

4.5.1 Summary of Findings and Implications

Drama-based therapy as an intervention strategy to help improve social cognitive and community integration skills has been shown to be successful for youth with characteristics similar to adolescents with ABI (e.g. Christie, Hood and Griffin, 2006; Mallay, 2002; McArdle et al., 2002). The feasibility of such an approach with adolescents with ABI has yet to be fully researched. However, Wiseman-Hakes et al. (1998) showed that social impairments associated with ABI can be lessened through effective intervention provided in a group format. The results obtained provide support for using a combination of directed group activities and self-reflection within a creative learning context, as was provided by the theatre skills training program, to help improve social cognitive and community integration skills for brain injured youth. These supportive findings were revealed by our first and second objectives, to identify methods to quantitatively capture the effectiveness of the program and examine the feasibility and usability of the program, and are further discussed below.

4.5.2 Effects of Theatre Skills Training on Social Cognition

In the current study, we employed an emotion discrimination task that required the participant to identify emotional expressions from static images of faces to assess the effects of the intervention on social cognition. Emotion recognition has been found to be impaired in brain injured adolescents in comparison to typically developing peers (e.g. Tonks et al., 2007). Thus, we anticipated that participation in the theatre skills training program would promote emotional awareness through the various creative activities, and this process would be reflected in improved accuracy and reaction times in detecting basic emotional facial expressions.

Consistent trends of improvements were found in accuracy of emotion identification for only angry and sad faces over assessments, coupled with decreases in reaction time from pre- to post-program assessments and follow-up. One explanation for this may be due to more emphasis being placed on the expression of these emotions from the program activities. It may also be possible that because this task was administered 3 separate times, an effect of repetition may explain improved performance. However, McDonald, Bornhofen and Hunt (2009) found task repetition to be unhelpful in improving emotion recognition performance for adults with TBI. In addition, improvements in accuracy were not seen across assessments for all emotions, which were viewed the same amount of times as those emotions that the participant did improve on.
It should be noted that the sample set of faces used in the current study (Matsumoto and Ekman, 1988) was normed on young adults ranging from 18 – 21 years of age and may not have been sensitive enough to capture the changes in emotion discrimination abilities of the age range of participants in the current study. Since this set of images only uses adult faces, it may be possible that increased sensitivity to age-appropriate faces would boost overall performance across emotions and better capture changes from pre- to post-program (Thomas et al., 2007). More research on emotion recognition after brain injuries is needed, however, especially in relation to adolescents (Macdonald, Bornhofen and Hunt, 2009; Turkstra et al., 2008).

4.5.3 Effects of Theatre Skills Training on Community Integration

Measuring the effect of the program on social and community integration was also attempted in the current study. Currently, no measure has been designed specifically for use with youth with ABI to assess these factors. Thus, we used the COPM, an individualized outcome measure that allowed the participants to be involved in identifying their specific problem areas related to social and community activities. Participant 1 demonstrated positive changes in performance and satisfaction ratings for most identified problem areas from pre- to post-program, and these ratings either increased further at follow-up or were maintained. One exception was with her ratings of knitting skills, although this was a physical skill that was not directly part of any of the activities in the program. Overall, the positive results from the COPM provide support for the effectiveness of the theatre skills training program to improve social and community integration skills and maintain these skills over time.

The ABAS-II, a standardized caregiver report designed to examine youth’s activities of daily living was also used to examine changes in community integration skills from pre- to post-program participation. In particular, changes within the Communication, Community Use, Leisure, Self-Direction, and Social skill areas, were considered most relevant, as these skill areas contained items that were applicable to community integration. Higher scores from pre-program to follow-up assessments were noted in the Community-Use, Communication, Self-Direction, and Social skill areas, although none of these changes were clinically meaningful. However, it should be noted that much of the greatest gains on the ABAS-II were observed at follow-up assessment, supporting the idea that assessment of the effectiveness of the theatre skills training program to help improve social and community reintegration skills may be best captured during
follow-up. This would provide the youth with time to practice skills gained from program participation.

One explanation as to why little change was observed using the ABAS-II was noted when examining the individual responses to skill area items. Even when considering the skill areas most relevant to community integration, some of the items on the ABAS-II were not appropriate given the age group of the adolescents in the study. This was determined by the large number of items marked as ‘0’ within each skill area and subsequently indicated by caregivers as being a behavior that was age-inappropriate for their child to demonstrate. In addition, many of the skill areas gathered data on physical activities of daily living. While not unimportant towards participation abilities (i.e. ‘crosses the street on their own’), it was thought that these scales did not truly measure the participation of youth with an ABI within their community and assessing this factor remains a topic of further research. The creation of a standardized measure that can accurately depict the participation restrictions faced by youth with ABI in a generalized method is a challenging task, since a unique set of restrictions presents itself with each brain injury. Based on the positive results and sensitivity to small, but meaningful changes found with the COPM, it may be more appropriate to employ a measure that is client-centered and directly involves the youth in voicing what their problem areas are. However, the area of community integration research for brain injured youth is still early in development and more studies are needed to address ways to reliably and validly measure this factor.

4.6 Study Limitations
The current study was based on only 1 participant in a pre-test post-test design, limiting the strength of the conclusions that can be made from the data obtained. Also, no control groups were used for comparison to better determine the effects of participation in the theatre skills training program versus changes due to natural variation or other extraneous factors. However, given that expressive arts therapy is a novel approach to improving social cognitive and community integration skills, a case study approach is warranted and advantageous since it allows for an in depth exploration of the feasibility and usability of such a program. Another consideration is that the participant in the current study was female, therefore the effectiveness of the program may not necessarily hold for male adolescents with ABI. Participation in this program also required a significant amount of cognitive and physical effort, which may be problematic for youth recovering from a brain injury. Although breaks were scheduled, this type
of program may not be feasible for those youth recovering from an ABI that have severe physical, cognitive and speech limitations.

Taken as a whole, however, the results from the present study warrant further investigation of an expressive arts program as a social and community integration tool and to recommendations made by others that interventions delivered in smaller groups appear to be more beneficial to youth with ABI (Wiseman-Hakes et al., 1998). It should also be noted that the utilization of a creative arts technique was a completely novel approach as a therapy for youth with ABI. The lessons learned with respect to the structuring and content of the program, as well as the use of quantitative measures sensitive to therapeutic changes within this population, were invaluable and lay crucial and important groundwork for future studies.

4.7 Conclusion
Pilot data of the current study from an adolescent participant with an ABI and her caregivers who took part in a theatre skills training program support the feasibility and usability of creative arts therapy as a social and community integration tool. Quantitative measures revealed improvements from pre- to post-program in social cognition and community integration skills that were maintained or improved further over time. These findings suggest that when applied as a rehabilitative intervention in a small group format, expressive arts therapy warrants careful investigation as a novel approach to provide adolescents with ABI with the tools to live meaningful and productive lives. The current study also revealed that measurement of community integration is difficult given the unique set of participation restrictions each brain injured youth presents. Further research to examine the feasibility of expressive arts as a therapy is necessary with more participants, the use of control conditions and more sensitive measures of community integration.
Chapter 5 Expressive Arts as a Social Cognitive and Community Integration Tool for Adolescents with ABI: Pilot Study Stage: Pilot Study Stage 2

5.1 Introduction

In the previous study (refer to Chapter 4.0), a pilot study of a theatre skills training program as an intervention to improve social cognitive and community integration skills in adolescents with brain injuries was discussed. Results from this study were positive and supported the use of such an approach. Accordingly, the current study is a second pilot study that was conducted. First, difficulties in the first stage with recruitment were experienced and only 1 participant with an ABI was recruited, which did not provide sufficient data to evaluate feasibility and usability. Although useful comments regarding the structure and content of the experimental intervention were received, an increase in the pilot sample size and continued examination of the effects of the program was warranted. Thus, in the current study, inclusion criteria were expanded to include youth with more severe injuries as well. In addition, outcome measures that were used were modified based on the first phase of pilot testing. For example, the COPM, a client-centered tool which can be adapted to the individual, proved to be a feasible measure to use with adolescents with ABI. Data analysis with respect to an emotion discrimination task also revealed significant trends.

However, the ABAS-II as a measure of community integration did not prove to be sensitive enough to capture the desired social and adaptive changes, as the items focused too much on physical independence and self-care in the home and community and were age-inappropriate in some skill areas. Thus the research team decided to substitute the ABAS–II with different outcome measures to assess community integration and replicate the pilot testing in order to evaluate the feasibility and usability of the program as well as the sensitivity of the new outcome measures. In addition, a fourth time-point for data collection at 4 weeks pre-program was added. This was done in order to have two time points prior to the commencement of the program so that observations of potential changes or trends in scores independent of the program itself could be made. It was thought that this would strengthen the research design by providing increased confidence in a true baseline and help with the interpretation of the post-test data, by examining the two pre-test data points for evidence of improvement due to natural recovery or other factors unrelated to the training. Replicating the pilot testing was also done to evaluate the effectiveness of a 4 week versus 3 week program, as feedback from clients,
caregivers and therapists indicated that improvements made over three weeks would be better reinforced by a slightly longer program. Data from a waitlist control participant was also collected to better understand if changes in social cognition and community integration skills were more specific to participation in the program compared to natural variation or other extraneous factors.

Additional outcomes were also assessed in this second pilot study. First, based on observations by the program facilitators of the participant in the first stage of pilot testing, any effects that the program may have had on pragmatic communication skills were also assessed. One of the most pervasive social cognitive skill impairments faced by youth with brain injuries is within the domain of pragmatics (Dahlberg et al., 2007; Turkstra et al., 2008). Pragmatics is a broad area of language and its application that demonstrates subtle and gradual development across adolescence. Pragmatic communication skills are defined as the ability of a person to perceive, interpret and respond to the contextual and situational demands of the environment (Jordan and Ashton, 1996; Wiseman-Hakes et al., 1998). Examples include behaviours such as staying on topic, asking relevant questions, turn-taking, employing facial expression, initiating conversation, and being able to cohesively organize and expressive thoughts (Burns, Halper and Mogli, 1985; Larson and McKinley, 1998; Mayo and Waldo, 1994; Nippold, 1998; Raffaelli and Duckett, 1989). For higher-level social skills to be developed and sustained, the establishment of fundamental pragmatics is crucial (Wiseman-Hakes et al., 1998).

Studies have demonstrated that youth with ABI experience many deficits in their pragmatic communication skills. Blosser and DePompei (1994) found that children and adolescents with TBI demonstrated difficulty in choosing socially correct methods for interacting. Turkstra et al. (2008) observed that youth with TBI were significantly less able than their typically developing peers to generate context-appropriate responses in everyday pragmatic situations. Impairments in social inference, self-regulation of social functioning, social problem solving skills, and the detection of conversation skills have also been additional pragmatic communication skills that have been found to be impaired in adolescents with ABI relative to typically developing adolescents (Dennis et al., 1998; Dennis et al., 2001; Levin, 2005; Turkstra, McDonald and DePompei, 2001).

Secondly, given that the aim of the theatre skills training program was to promote social and community integration for youth with brain injuries, the effect of program participation on self-esteem was also examined. Studies have shown that as children reach adolescence, they increasingly depend on friends and social networks (i.e. smallest number of individuals with
whom an individual has a relationship with) for advice and acceptance (Lerner, 1981) and look to their peer groups as a way of defining themselves and their values (Sowers et al., 1996). It has also been found that youth who perceive that they have supportive friends have higher self-esteem compared to those who do not (Mannarino, 1976). To this end, a measure that examined the size and strength of relationships within each participant’s social network was also added to examine if either revealed positive changes after participation in the program.

5.2 Objectives and Hypotheses

Thus, for the current study descriptive case studies were carried out with the following objectives:

Objective (1): To identify and refine methods to measure the effect of the theatre skills training program on social cognition, community integration and self-esteem.

With respect to social cognition, it was expected that participation in the theatre skills training program would lead to improvements in identifying emotions from facial expressions, as measured by an emotion discrimination task, as well as improved pragmatic communication skills, as measured by the Profile of Pragmatic Impairment in Communication (PPIC), from pre-to post-program participation. It was also predicted that overall self-esteem would increase post-program, as measured by the Rosenberg Self-Esteem Scale.

In addition, community integration was also expected to improve, as reflected by improved performance, satisfaction and overall achievement towards various goals identified on the Canadian Occupational Performance Measure (COPM) and supplemented by Goal Attainment Scaling (GAS), improved scores on the Child and Adolescent Scale of Participation (CASP) and gains in ratings of closeness to significant others and social network size, as captured by the Social Networks Inventory.

It was also expected that the skills gained in the program would be transferred to the home and community environments and that positive changes would be observed at follow-up testing conducted between 6 – 8 months post-program. Follow-up assessments were initially targeted to take place 6 months after the end of the program to allow for a sufficient amount of time for the participant’s to transfer any newly acquired skills to their environment. However, based on participant availability, follow-up testing occurred anywhere between 6 – 8 months post-participation.
Objective (2): To collect pilot data on the effectiveness of an expressive arts theatre skills training program for youth with ABI to target social cognition and community integration skills.

It was hypothesized that the combination of directed group activities and self-reflection within a creative learning context provided by the theatre skills training program would improve social communication skills, emotional awareness and community integration. Incorporating modifications to the program and outcome measurements based on the first stage of pilot testing and re-piloting the program again using a case study design enabled us to reassess the hypothesis that the program was effective before executing the program in a larger study.

Objective (3): To collect data from a waitlist control participant in order to provide a comparison of scores on the emotion discrimination task, COPM, CASP, Social Networks Inventory, and the Rosenberg Self-Esteem Scale.

It was hypothesized that any changes captured by the measures completed by the control participant would not reflect improvements to the same degree as those who participated in the theatre skills training program.

5.3 Methods and Procedure

5.3.1 Design

This pilot study was conducted and analyzed as a multiple descriptive case study design to allow for the testing of the hypothesis that the theatre skills training program is effective for adolescents with ABI and to refine measurement techniques based on our previous study before piloting it in a larger sample.

5.3.2 Participants

All participants were recruited via Bloorview Kids Rehab’s existing NeuroRehabilitation Services Inpatient and Outpatient programs. Inclusion criteria for participants were: (a) they were recovering from a mild, moderate or severe ABI; (b) at least 6 months post-injury to minimize the effects of spontaneous recovery and variability related to injury type on the outcome measures selected; (c) between the ages of 13 – 16 (d) identified as experiencing significant difficulties in social functioning according to self and/or others. Exclusion criteria included youth not reporting difficulties in these areas. All participants provided informed
consent and/or assent and the study methodology was approved by Bloorview Kids Rehab and the University of Toronto Research Ethics Board

Twenty caregivers responded to an advertisement placed at Bloorview Kids Rehab. As depicted in Figure 5.1, 4 participants were excluded as they did not meet the inclusion criteria for identified social functioning difficulties. An additional 4 participants dropped out due to a lack of travel accommodations. Another 5 participants dropped out due to other commitments, scheduling difficulties or lack of interest, resulting in 6 participants who completed at least one of the pre-assessments. However, of these 6 participants, 2 more dropped out after 4- and 1-week pre-assessments due to lack of interest in the program. Therefore, the final sample size of participants in the theatre skill training program was 4. From the initial 20 families who were interested in participating, 2 participants agreed to be placed on a waitlist for the next program session and 1 took part as a control case study.

Participant 1, a 16 year old male, sustained a severe TBI at age 3 from a motor vehicle accident. He was admitted to hospital with a diffuse axonal injury and significant frontal lobe trauma, having a GCS score of 3. He has right hemi-paresis and ataxia and experiences post-injury seizures and balance difficulties, often needing physical support from others. According to parent reporting, he displays some cognitive and decision making difficulties and requires 1 or 2 attendants around him constantly to provide cues to facilitate participation. His environments are usually modified or protected to prevent self-injury.

Participant 2, a 13 year old male, was diagnosed with an optic glioma at the age of 4. As a result of numerous surgeries, he has limited vision in his left eye and no vision in his right eye. According to parent reporting, he demonstrates difficulty with executive functions and memory.

Participant 3, a 13 year old male, was inflicted with a moderate TBI at the age of 9 due to the impact of a falling soccer goal post on his head. He was admitted to hospital with skull and basal fractures, as well as some hematomas, scoring 11 on the GCS. He endured various surgeries to repair the bleeding and, as a result, had a small bone fragment removed from his skull. According to parent reporting, he demonstrated some behavioural issues, irritability and low self-esteem in the months following the incident, although it has since improved. He was also
described as currently being introverted and easily overwhelmed by new situations, often focusing on being prepared ahead of time.

**Figure 5.1** Flow chart demonstrating formation of final sample of participants who took part in the program.
Participant 4, a 15 year old male, sustained a severe TBI at the age of 2. As a result, he was admitted to hospital with bilateral subdural and retinal hemorrhaging, scoring an 8 on the GCS. He is visually impaired with very poor vision to complete blindness and experiences post-injury seizure disorder. He has limited movement in his left-hand, experiences apraxia and displays slow processing abilities. He also has severe mobility impairments. According to parent reporting, he was described as being very inhibited, having difficulties processing abstract information and requiring frequent reminders due to memory problems. He also uses many assistive devices, such as a shower chair, note-taker/scribe, daily planner and remains under constant adult supervision.

Participant 5 (Control), a 16 year old female, was struck by a moving vehicle at the age of 11 and suffered a severe TBI. She was admitted to the hospital with a GCS score of less than 8 and experienced diffuse axonal injury, frontal contusions and both a subdural and epidural hematoma. She was comatose and required ventilation for 5 days. According to parent reporting, after her injury a stark change in her personality to a more introverted, depressed and paranoid state from a more “happy-go-lucky” personality was noted. She requires repetition, constant reminders and visual cues to assist her in managing her daily schedule.

5.3.3 Outcome Measures
The results of the first pilot study revealed that some measures were not appropriate for assessing changes in community integration skills for youth with ABI. As such, changes were made to the measures used to examine social communication and community integration for testing in the second pilot study. To examine community integration, the COPM was employed again, but with the addition of Goal Attainment Scaling (GAS; Malec et al., 1999). The combination of COPM and GAS as a method of intervention evaluation for youth with disabilities has been shown to be a sensitive and effective approach in previous research (i.e. Di Rezze et al., 2008; Otensjo, Oien and Fallang, 2008). In contrast to stage 1, the COPM, with the addition of the GAS, was administered 3 days into the program to give the participants a clearer idea of the program and activities involved. This, in turn, would help in their goal creation and goal attainment level scaling. Also, the ABAS-II was replaced with the Child and Adolescent Scale of Participation (CASP; Bedell and Dumas, 2004) and the Social Networks Inventory
Changes were also made to the measures used to assess social cognition. As such, the Rosenberg Self-Esteem Scale and the Profile of Pragmatic Impairments in Communication (PPIC; Linscott, Knight and Godfrey, 1996) were added in addition to the emotion discrimination task.

Therefore, the second pilot study was conducted with the following outcome measures to assess community integration: COPM, GAS, CASP, and the Social Networks Inventory. The measures of social cognition were the: emotion discrimination task, PPIC and Rosenberg Self-Esteem Scale. All new measures are described below (refer to Chapter 3.0 for description of COPM and emotion discrimination task).

Social Cognition
Profile of Pragmatic Impairment in Communication (PPIC)

The PPIC is an objective measure of pragmatic communication skills designed specifically for use with people with TBI (Linscott, Knight and Godfrey, 1996). It includes a frequency count (i.e. not at all, occasionally, often, and almost always/always) of 84 specific positive or negative behaviour items separated into 10 feature summary subscales. The frequency counts are used to generate an overall rating per subscale on a 6-point rating as follows: normal (0), very mildly impaired (1), mildly impaired (2), moderately impaired (3), severely impaired (4), and very severely impaired (5). The subscales facilitate the identification of impairments in discrete aspects of conversational behaviour and include: Logic Content (LC), General Participation (GP), Quantity (QN), Quality (QL), Internal Relation (IR) External Relation (ER), Clarity of Expression (CE), Social Style (SS), Subject Matter (SM), and Aesthetics (AE). Appendix D contains a description of the specific behaviours falling under these categories. For the 10 feature summary scales, good reliability (i.e. coefficients between .86 to .94), and construct and face validity have been reported (Linscott, Knight and Godfrey, 1996).

Rosenberg Self-Esteem Scale

The Rosenberg Self-Esteem scale is a 10-item self-report measure of global self-esteem (Rosenberg, 1965). It is comprised of 10 statements related to overall feelings of self-worth or self-acceptance. The items are assessed on a four-point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’ and are framed from both positive and negative perspectives to allow for reverse scoring. This measure provided a quantitative assessment of self-esteem for
the current study. The scale has been widely used in various clinical populations, including individuals with brain injuries. For adolescents, good construct validity (Carmines and Zeller, 1979) and acceptable reliability (i.e. coefficients greater than .80; Yarcheski, Mahon and Yarcheski, 2003) have been found.

Community Integration
Goal Attainment Scaling (GAS)

GAS represents a flexible system of measuring outcome goals, based on a 5-point scale (Malec et al., 1999). Levels of goal attainment are expressed objectively in terms of concrete behaviours that can be observed and recorded. Goals were based on the problem areas identified by the participants on the COPM and were developed with assistance from a master’s level occupational therapy student. This helped foster self-awareness and the capacity for goal setting through use of a formal, structured process. Results from psychometric testing demonstrate reliability coefficients of approximately .90, low to moderate validity due to the individualized nature of the measure and responsiveness to change, including when used with children with disabilities (Donnelly and Carswell, 2002; McLaren and Rodger, 2003).

As is typical with GAS, the various goal attainment levels were based on the participant’s initial level in the problem area and their expected outcome by the end of the program. For the current study, the levels of goal attainment were established as follows: -2 = much less than expected outcome (i.e. ability at the time the goal was set); -1 = somewhat less than expected outcome; 0 = expected outcome; +1 = somewhat better than expected outcome; +2 = much better than expected outcome.

Child and Adolescent Scale of Participation (CASP)

The CASP is a 20-item caregiver report that assesses participation from a number of domains that pertain to home, school and community life for children and youth with and without ABI (Bedell and Dumas, 2004). It was originally developed as a follow-up survey for adolescents with brain injuries to determine outcomes and needs after inpatient rehabilitation by assessing participation. Caregivers were asked to assess the participation of their child in comparison to a healthy child of the same age on a number of items based on the following 4-point scale: age expected (4), somewhat limited (3), very limited (2) or unable (1). The items were grouped into 4 main subscales: home participation, neighborhood and community participation, school participation, and home and community living activities (i.e. household
activities, using transportation to get around in the community, etc.). In addition, the caregivers answered questions about strategies, assistive devices or modifications that may have been used or have been done to help the participant in their daily activities. High internal consistency (i.e. Cronbach’s alpha = 0.96) has been demonstrated with this measure, although further psychometric testing is ongoing (Bedell, 2006; Bedell and Dumas, 2004).

Social Networks Inventory

The Social Networks Inventory is a measure designed to assess participants’ perception of closeness or distance in their relationships with significant others (Treadwell, Leach and Stein, 1993). The measure is based on the Social Atom Theory (Moreno, 1934), which describes a social atom surrounding each individual as the smallest nucleus of all individuals that one is related to in a significant manner, constituting positive or negative emotional bonds. With the Social Networks Inventory, four quadrants are assessed: Psychological, Collective, Individual, and Ideal/Dream. The Psychological Quadrant represents family and friends, whereas the Collective Quadrant represents groups the respondent may be a member of, such as volunteer organizations. The Individual Quadrant represents the individual relationships a respondent may have with people from the groups listed in the Collective Quadrant. Finally, the Ideal Quadrant allows the participant to list any additional individuals who they may have no current relationship with, but wish they could.

Ratings of distance or closeness are then given to all individuals or groups listed within each quadrant on a 7-point Likert scale. A rating of 1 represents feeling extremely close to that person or group and a rating of 7 represents extreme distance. On this same scale, the respondent also provides a rating of how close or distant that individual or group would rate their relationship. Thus, in the current study, this measure helped identify any sources of incongruence in feelings of closeness or distance in the relationships the participants held, as well as any improvements in how the participant perceived those relationships before and after participation in the theatre skills training program. We were also interested in examining any changes to social network size (i.e. the number of individuals and groups listed) from pre- to post-program. Preliminary testing has revealed good test-retest reliability coefficients between .82 to .87 over a 2-week interval, as well as the ability to distinguish between clinical and nonclinical individuals with respect to the validity of relationships listed. However, further testing on other psychometric properties is needed (Treadwell, Leach and Stein, 1993).
5.3.4 Intervention

The experimental intervention was an intensive theatre skills training program that took place in two classrooms provided by the Bloorview School. The adolescent participants recovering from ABI met daily for 4 hours over a period of 4 weeks. During this 4 hour period, regular breaks were scheduled to provide the participants with a mental and physical break from therapy. Theatre training included voice work, breathing, movement, physical warm-up, character development, script analysis, writing skills, three-dimensional awareness, group dynamics, story development, mask work and clowning among others. The group was headed by 2 professional theatre artists and a master’s level occupational therapy student completing their last clinical placement and having expressed interest in participating in the program. For a more complete description of the program activities and daily structure, refer to Chapter 3.3.4.

5.3.5 Procedure and Data Collection

Refer to Table 5.1 for a timeline of outcome measure administration. Following recruitment and consent, each program participant and their caregivers were tested at the University of Toronto at 4 weeks and 1 week prior to program participation. One week post-program testing took place in the classrooms provided by Bloorview Kids Rehab. Follow-up testing was completed 6 - 8 months post-program at the University of Toronto, community settings and within participant’s homes. All measures were administered by the primary author, except initial administration and goal development with the COPM and GAS, which was completed by a master’s-level occupational therapy student 3 days into the program, and administration of the PPIC, which was completed by a speech language pathologist on the third and final days of the program. Data from the COPM, CASP, Social Networks Inventory, emotion discrimination task, and Rosenberg Self-Esteem Scale were obtained from the control participant and their caregiver over 4 assessments (initial, 4 weeks later, 8 weeks later, and then 6 months after the previous assessment). Each testing session lasted approximately 1 hour.
Table 5.1. Timeline of outcome measure administration.

<table>
<thead>
<tr>
<th>Timepoint</th>
<th>COPM</th>
<th>GAS</th>
<th>Social Networks</th>
<th>CASP</th>
<th>RSES</th>
<th>Emotion Discrimination Task</th>
<th>PPIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 Weeks Pre-X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>1 Week Pre-X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>3 Days into Program</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Immediately Post-X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Follow-up (6 – 8 months)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

5.3.6: Data Analysis

Since this was a pilot study, data analysis followed a descriptive approach. The outcome measures were evaluated from pre- to post- as follows:

1. Mean accuracy and mean reaction times were graphed using Microsoft Excel 97 - 2003 for each of the emotional expressions on the emotion discrimination task and changes were visually examined from pre- to post-program for any trends. Since no previous research has employed such a measure with youth in a pre-post intervention format, a trend of improvement for accuracy in emotion discrimination was considered as an increase in mean percentage accuracy from 1 week pre- to subsequent follow-up (i.e. 1 week post- and 6 – 8 months post-) testing, as any improvements from 4 weeks to 1 week pre-testing would not be related to program participation. Trends in reaction time were similarly considered, with the exception that a decrease in mean reaction time indicated an improvement.

2. Overall ratings for each of the 10 feature summary scales on the PPIC were graphed using Microsoft Excel 97 – 2003 and visually inspected for any trends of changes in the severity of impairment on pragmatic communication skills from pre- to post-program.
3. Total scores from the Rosenberg were calculated by adding the scores from individual items. A maximum score of 40 represented the highest self-esteem and a minimum score of 10 represented the lowest self-esteem. The scale has no true guidelines established to determine clinically meaningful change scores between pre- to post-assessments in case study designs or hard cutoffs for determining low versus high self-esteem. Following previous studies (e.g. Kneckt et al. 2000; Cooper-Evans et al., 2008), however, the current study used a score of 21.5 as the median, scores greater than 21.5 – 40 as indicating high self-esteem and scores less than 21.5 – 10 as indicating low self-esteem. These ranges were used to guide visual inspection of graphs of RSES scores from pre- to post-program for any trends of improvement.

4. Differences of 2 or greater on COPM ratings of performance and satisfaction for each identified problem area indicated clinically significant changes, as has been shown in previous research (Law et al., 1994; Chan and Lee, 1997; Cup et al., 2003).

5. For GAS, pre-intervention behaviours in relation to each goal were recorded as the -2 level and expected outcomes immediately post-program were established as the ‘0’ level. For analytical purposes, GAS T-scores were not used (i.e. Kiresuk, Smith and Cardillo 1994), as we were interested in observing changes for each specific goal per participant.

6. CASP summary scores were calculated by summing the scores from each applicable item, dividing this number by the maximum possible score, based on the number of applicable items rated, and multiplying this number by 100 to conform to a 100-point scale. Since this measure has never been used in a pre- to post-intervention format, we established ranges of summary scores describing different levels of participation ability. This helped guide visual inspection of graphs made using Microsoft Excel of changes in summary scores between assessments. The ranges of scores representing specific levels of participation are outlined in Table 5.2.
Table 5.2. Ranges of scores on the CASP summary scale and their corresponding description of participation restriction.

<table>
<thead>
<tr>
<th>Range</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>75 - 100</td>
<td>Age expected</td>
</tr>
<tr>
<td>&lt; 75 - 50</td>
<td>Somewhat limited</td>
</tr>
<tr>
<td>&lt;50 - 25</td>
<td>Very limited</td>
</tr>
<tr>
<td>&lt;25 - &gt;0</td>
<td>Unable</td>
</tr>
<tr>
<td>0</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

7. Ratings of self- and other-perceived closeness from each grid of the Social Networks Inventory were graphed on a Quadratic Grid of Interpersonal Relationships (QGIR). For the purposes of this study, any changes of social network size or self- and other-perceived closeness ratings across assessments were examined, especially if the changes represented more incongruence between ratings (T. Treadwell, personal communication, January 22, 2008).

5.4 Results

5.4.1 Social Cognition and Self-Esteem

*Emotion Discrimination Task*

Individual graphs for mean accuracy and reaction time are displayed in Figures 5.2 and 5.3, respectively. Participant 1 demonstrated an increase in mean accuracy for disgust and sad faces from post-program to follow-up assessment, but no other reliable trends for improvements for angry, sad, surprise, neutral or happy faces. Mean reaction time data also demonstrated no reliable trends from pre- to post-program (i.e. decreases were seen between 4 weeks and 1 week pre-program, but were either not seen post-program or were seen to decrease across all timepoints). Participant 2 demonstrated an increase in accuracy for surprise faces at post-program and follow-up, compared to pre-program accuracy. His reaction time also decreased at follow-up in comparison to all other timepoints for anger, disgust and sad faces, although this trend was not seen for sad, happy, neutral or fearful faces. No reliable trends for improvement from pre to post-program for mean accuracy or reaction time for participants 3 and 4 were observed. In addition, the task was difficult to administer and complete for participants 2 and 4 due to visual and physical impairments, whereas participant 3 appeared to perform at ceiling.
across assessments. With respect to the control participant, improvements in mean accuracy for
disgust and fearful faces across timepoints were observed, although ceiling effects were observed
for angry, sad, happy, surprise or neutral faces (refer to Figure 5.4). Also, continual decreases
across timepoints in mean reaction time were observed for anger and neutral faces, but not for
happy, sad, surprise, disgust or fear faces.
Figure 5.2 Emotion discrimination task accuracy for all program participants
Figure 5.3 Emotion discrimination task reaction time for all program participants
Figure 5.4 Emotion discrimination task accuracy and reaction time for control participant
PPIC

Figure 5.5 demonstrates changes in pragmatic communication skills as measured by the PPIC from the initial assessment (3 days into the program) to the final assessment (the final day of the program) for all program participants. Participant 1’s feature summary scales on the PPIC indicate moderate to mild communication impairment during the assessment made at the beginning of the program. An improvement was seen by the last day on several subscales, indicating mild to very mild communication impairment at post-assessment. Specifically, more fluency and less odd or bizarre utterances were observed on the LC subscale. On the GP scale, he also appeared less dominating of conversations and demonstrated better coordination among idea and more spontaneous elaboration on his ideas on the IR scale. This was accompanied by less obscure and clearer expression of ideas on the CE scale, less impolite behaviours and increased attention. Finally his use of affective expression became more appropriate and he was able to articulate words more clearly. However, it appeared as though participant 1 was exaggerating and confabulating more by the end of the program, as indicated on the QL scale.

Participant 2’s feature summary scales indicates very mild communication impairment at both the beginning and final day of the program. An improvement was seen on the QN subscale, as he provided less excessive detail in conversation. He was also able to better direct conversation, as indicated on the SS scale.

Participant 3’s feature summary scales indicate normal to very mild communication impairment during the initial assessment. It was observed that, by the final day of the program, he appeared to be normal on all PPIC scales. Specifically, he demonstrated an improved connectivity of ideas and responding to other’s social initiatives, as indicated on the GP scale. His utterances also seemed less jumbled and more coordinated, as shown on the IR scale. Lastly, as illustrated on the CE scale, his expressions were observed to be less vague and ambiguous.

The feature summary scales for participant 4 indicated an overall severe to moderate communication impairment at the initial assessment made at the beginning of the program. At the assessment made on the final day, his feature summary scales indicated an improvement on most scales to overall mild to very mild communication impairment. In particular, he appeared to be using more complex sentence structure as indicated by the LC scale, his ideas appeared more well knit and he was easier to converse with, as indicated by the GP scale. He also demonstrated more detail in his expression, shown on the QN scale, improved continuation between ideas, indicated by the IR scale, and used questions more appropriately as demonstrated.
on the ER scale. His CE scale also indicated an increased clarity of his expression as well as a
dramatic improvement in his response latency, as he took much shorter pauses in his speech.
Figure 5.5 PPIC ratings for all program participants at initial and final assessments

*Initial assessment was conducted on the first day of the program

**Final assessment was conducted on the first day of the program

Note: Absence of bars indicates performance at the ‘0’ level of severity (i.e. normal)
Rosenberg Self-Esteem Scale

Self-esteem ratings from the Rosenberg Self-Esteem scale are illustrated in Figure 5.6. All participants, including the control participant, demonstrated high self-esteem across all assessments (i.e. no scores were below the median value of 21.5) and their scores remained fairly stable across all assessments. Participant 2 and 4’s self-esteem scores remained towards the lower range of high self-esteem scores. Participant 3’s post-program and follow-up self esteem scores were slightly higher than pre-program.

*Follow-up was conducted at 6 months post- for participant 3, at 7 months post for participants 1, and 2, 8 months post- for participant 4, and 6 months from the previous assessment for the control participant. The dashed line represents the median value (21.5)

![Rosenberg Self-Esteem Scale Total Scores](image)

**Figure 5.6** Rosenberg self-esteem scale scores across assessments for all participants. Scores above 21.5 indicate high self-esteem

5.4.2 Community integration

*COPM*

Problem areas identified by each participant with respect to leisure goals on the COPM and their performance and satisfaction ratings are illustrated in Table 5.3. All participants identified ‘making friendships’ as a problematic area. Participant 1’s performance rating of making friendships showed a clinically significant increase at the 1 week post-assessment, but significantly decreased at follow-up testing. However, the net change in his performance rating
for this goal was a significant increase from pre-program to follow-up. His performance rating relating to his speech showed a clinically significant increase from pre- to 1 week post-program, but then returned to his initial pre-program rating at follow-up. His satisfaction ratings for these areas demonstrated clinically significant increases from pre- to 1 week post-program which were maintained at follow-up.

Participants 2, 3 and 4 demonstrated positive changes in their performance ratings for most problem areas between pre- and 1 week post-program, and these ratings were either maintained at follow-up or increased further. Greater clinically significant changes were demonstrated in their satisfaction ratings from pre-to post-program, which were also increased further or were maintained at follow-up. One exception to this was participant 4’s satisfaction rating of his sense of navigational direction, which significantly decreased between pre- and post-program. At follow-up testing, however, this rating demonstrated a clinically significant increase when compared to prior ratings.

The problem areas identified by the control participant and performance and satisfaction ratings as identified by the COPM are outlined in Table 5.4, who also described making friendships as a crucial problem. Significant declines in performance and satisfaction ratings were observed across assessments to minimum ratings of 1 by the last assessment for all problem areas except completing her homework. Ratings for this problem increased across assessments to reach a maximum rating of 10.
Table 5.3 COPM Identified Problem Areas and Ratings of Performance and Satisfaction for Program Participants

### Performance Scores

<table>
<thead>
<tr>
<th>COPM Problem Area</th>
<th>Pre-</th>
<th>Post-</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>5</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>▪ Clarity of speech and expression</td>
<td>5</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Participant 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>9</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>▪ Writing skills</td>
<td>5</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>▪ Reading skills</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Participant 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Visiting new places to make friendships</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>▪ Concentration during quiet recreation activities</td>
<td>7</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>▪ Time-management</td>
<td>7</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Participant 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>2</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>▪ Sense of three dimensional direction</td>
<td>5</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>▪ Reading more during spare time</td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

### Satisfaction Scores

<table>
<thead>
<tr>
<th>COPM Problem Area</th>
<th>Pre-</th>
<th>Post-</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>5</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>▪ Clarity of speech and expression</td>
<td>5</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Participant 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>9</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>▪ Writing skills</td>
<td>4</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>▪ Reading skills</td>
<td>4</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Participant 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>7</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>▪ Concentration during quiet recreation activities</td>
<td>6</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>▪ Time-management</td>
<td>5</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Participant 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Making friendships</td>
<td>1</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>▪ Sense of three dimensional direction</td>
<td>7</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>▪ Reading more during spare time</td>
<td>1</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

COPM, Canadian Occupation Performance Measure
Note: Follow-up assessments were conducted at 6 months post-program for participant 3, 7 months post-program for participants 1 and 2 and 8 months post-program for participant 4.
Table 5.4 COPM Identified Problem Areas and Ratings of Performance and Satisfaction for Control Participant

<table>
<thead>
<tr>
<th>COPM* Problem Area</th>
<th>Initial</th>
<th>8 Weeks Post-</th>
<th>13 Weeks Post-</th>
<th>6 Months Post-</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Performance Scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making friendships</td>
<td>7</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Playing the guitar</td>
<td>6</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Completing homework</td>
<td>6</td>
<td>7</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td><strong>Satisfaction Scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making friendships</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Playing the guitar</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Completing homework</td>
<td>1</td>
<td>8</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

COPM, Canadian Occupational Performance Measure.
Goal Attainment Scaling

GAS across assessments for all program participants are illustrated in Figure 5.3. Each figure is supplemented by a description of the program participant’s specific goal attainment levels in Tables 5.5 – 5.8. It should also be noted that, at follow-up testing, each participant was asked to assess their goal attainment in the context of a monthly average for the goal of ‘making friendships,’ which was shared by all participants. At the post-assessment, participant 1 reached his goal (i.e. level ‘0’) relating to speech improvement (refer to Table 5.5). At the follow-up assessment, this rating fell to his somewhat less than expected outcome. He exceeded his goal of wanting to approach new people for friendly conversation by rating his progress as much better than expected (+2 level) at the 1 week post-assessment. At follow-up testing, this rating decreased to his somewhat better than expected outcome (+1 level).

At 1 week-post, participant 2 rated himself as exceeding his socialization goal of making friendships (refer to Table 5.6). This rating was maintained at the follow-up assessment. He rated himself at the +2 level for writing skills at the 1 week post-assessment as well, although this rating decreased to the -1 level at follow-up. In addition, he rated his reading skills at the +1 level at 1 week post-assessment and this rating was maintained at follow-up assessment as well.

Participant 3 noted improvements in his time-management skills by the end of the program, as he rated himself at the +1 level (refer to Table 5.7). At follow-up, this rating fell to his expected outcome. He also exceeded his goal in improving his concentration, rating himself at the +2 level post-program and at the +1 level at follow-up. For his goal of visiting more diverse places to make friends, he noted no improvements at either post-program or follow-up assessments.

Participant 4 expressed an improved sense of direction beyond his expectations, as he rated himself at the +2 level for this goal (refer to Table 5.8). At follow-up, his GAS score fell to his expected outcome. He also rated himself at the +2 level with respect to his goal of making friends. His rating at the follow-up assessment, however, fell back to his outcome level when asked about his monthly interactions since the end of the program. In terms of his reading skills, participant 4 also exceeded the goal he had
set for himself by the end of the program, rating himself at the +1 level. This rating fell to his expected outcome level at the follow-up testing.

Figure 5.7 GAS scores across assessments for all program participants
Table 5.5 GAS for participant 1

<table>
<thead>
<tr>
<th>Goal</th>
<th>Attainment</th>
<th>Levels</th>
<th>Goal 1: Speech</th>
<th>Goal 2: Making friendships</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Participant 1 feels that his speech and lack of words to express feelings causes others to frequently ask for clarifications during normal conversation</td>
<td>Participant 1 feels that he lacks initiation in approaching others</td>
</tr>
<tr>
<td>Much better than expected outcome</td>
<td>+ 2</td>
<td>No clarification of speech and expression during 10 minute conversation</td>
<td>Will approach 7 new people for friendly conversation</td>
<td></td>
</tr>
<tr>
<td>Somewhat better than expected outcome</td>
<td>+ 1</td>
<td>Clarification of speech and expression 1 time during 10 minute conversation</td>
<td>Will approach 5 new people for friendly conversation</td>
<td></td>
</tr>
<tr>
<td>Expected outcome</td>
<td>0</td>
<td>Clarification of speech and expression 1-2 maximum during 10 minute conversation</td>
<td>Will approach 3 new people for friendly conversation</td>
<td></td>
</tr>
<tr>
<td>Somewhat less than expected outcome</td>
<td>- 1</td>
<td>Clarification of speech and expression 3-4 times during 10 minute conversation</td>
<td>Will approach 1 new person for friendly conversation</td>
<td></td>
</tr>
<tr>
<td>Much less than expected outcome</td>
<td>- 2</td>
<td>Speech and lack of words to express feelings causes others to ask for clarifications &gt;5 times during 10 minute conversation</td>
<td>Will not approach new people for friendly conversation</td>
<td></td>
</tr>
<tr>
<td>Goal Attainment Levels</td>
<td>Goal 1: Making friendships</td>
<td>Goal 2: Writing Skills</td>
<td>Goal 2: Reading Skills</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------</td>
<td>-----------------------</td>
<td>-----------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Participant 2 recently met an old friend who moved into his neighborhood and would like to spend time with that friends’ peers, since the old friend has them over at his house all the time</td>
<td>Participant 2 has expressed difficulty in finding words to express himself and has spelling problems</td>
<td>Participant 2 has difficulty reading for long periods of time because he gets caught on words</td>
<td></td>
</tr>
<tr>
<td>Much better than expected outcome</td>
<td>Will spend time with 3 new people from that group of friends</td>
<td>Writes one paragraph of personal thoughts in 10 minutes, 2-3 spelling errors</td>
<td>Can read for 40-45 minutes at a time</td>
<td></td>
</tr>
<tr>
<td>Somewhat better than expected outcome</td>
<td>Will spend time with 2 new people from that group of friends</td>
<td>Writes one paragraph of personal thoughts in 15 minutes, 4-5 spelling errors</td>
<td>Can read for 35-40 minutes at a time</td>
<td></td>
</tr>
<tr>
<td>Expected outcome</td>
<td>Will spend time with 1 new person from that group of friends</td>
<td>Writes one paragraph of personal thoughts in 20 minutes, 6-7 spelling errors</td>
<td>Can read for 30 minutes at a time</td>
<td></td>
</tr>
<tr>
<td>Somewhat less than expected outcome</td>
<td>Will make plans to spend time with 1 new person from that new group of friends</td>
<td>Writes one paragraph of personal thoughts in 25 minutes, 8-9 spelling errors</td>
<td>Can read for 20-25 minutes at a time</td>
<td></td>
</tr>
<tr>
<td>Much less than expected outcome</td>
<td>Does not spend time with any of the friends from that group</td>
<td>Writes one paragraph of personal thoughts in 30 minutes, 10 spelling errors</td>
<td>Can read for 15 minutes at a time</td>
<td></td>
</tr>
<tr>
<td>Goal Attainment Levels</td>
<td>Goal 1: time-management</td>
<td>Goal 2: concentration</td>
<td>Goal 3: Making friendships</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------------</td>
<td>-----------------------</td>
<td>--------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Participant 3 feels that his lack of time-management skills leaves him little to no time for leisure activities</td>
<td>Participant 3 feels he lacks the ability to concentrate and focus his mind. He will demonstrate his concentration by being able to win matches on his chess computer game.</td>
<td>Participant 3 does not visit a diversity of places where he would be able to meet new people and make friends</td>
<td></td>
</tr>
<tr>
<td>Much better than expected outcome</td>
<td>Will create schedule to accomplish tasks 2 days in advance, gaining 6-8 hours leisure time</td>
<td>Winning 6-8 games against computer</td>
<td>Will visit 3 new places to meet new friends</td>
<td></td>
</tr>
<tr>
<td>Somewhat better than expected outcome</td>
<td>Will create schedule to accomplish tasks a day in advance, gaining 4-6 hours leisure time</td>
<td>Winning 5-6 games against computer</td>
<td>Will visit 2 new places to meet new friends</td>
<td></td>
</tr>
<tr>
<td>Expected outcome</td>
<td>Will create schedule to accomplish tasks half a day in advance, gaining 2-4 hours leisure time</td>
<td>Winning 4 out of 8 chess games against computer</td>
<td>Will visit 1 new place to meet new friends</td>
<td></td>
</tr>
<tr>
<td>Somewhat less than expected outcome</td>
<td>Will create schedule to accomplish tasks a few hours early, gaining 1 hour leisure time</td>
<td>Winning 3 out of 8 chess games against computer</td>
<td>Will make plans to visit 1 new place to meet new friends</td>
<td></td>
</tr>
<tr>
<td>Much less than expected outcome</td>
<td>No set schedule, tasks completed at last minute, little to no leisure time</td>
<td>Winning 2 out of 8 chess games against computer</td>
<td>Does not visit new places beyond church and school to meet new friends</td>
<td></td>
</tr>
</tbody>
</table>
Table 5.8 GAS for participant 4

<table>
<thead>
<tr>
<th>Goal 1: <em>Spatial Navigation</em></th>
<th>Goal 2: <em>Making friendships</em></th>
<th>Goal 2: <em>Reading Skills</em></th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 4 feels that his lack of direction causes him to lose videogames because he loses his position frequently</td>
<td>Participant 4 moved to a new neighborhood and has had trouble making new friends</td>
<td>Participant 4 feels that he does not read for long enough periods of time and does not read efficiently</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal Attainment Levels</th>
<th>Much better than expected outcome</th>
<th>Somewhat better than expected outcome</th>
<th>Expected outcome</th>
<th>Somewhat less than expected outcome</th>
<th>Much less than expected outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>+2</td>
<td>+1</td>
<td>0</td>
<td>-1</td>
<td>-2</td>
</tr>
<tr>
<td></td>
<td>Does not get lost when playing videogames</td>
<td>Gets lost 1 time out of 4 game plays</td>
<td>Gets lost 2 times out of 4 game plays</td>
<td>Gets lost 3 times out of 4 game plays</td>
<td>Gets lost 4 times out of 4 game plays</td>
</tr>
<tr>
<td></td>
<td>Will approach 4 new people for friendly conversation</td>
<td>Will approach 3 new people for friendly conversation</td>
<td>Will approach 2 new people for friendly conversation</td>
<td>Will approach 1 new person for friendly conversation</td>
<td>Will not approach new person for friendly conversation</td>
</tr>
<tr>
<td></td>
<td>Reads a book for 40 minutes at a time</td>
<td>Reads a book for 35 minutes at a time</td>
<td>Reads a book for 30 minutes at a time</td>
<td>Reads a book for 25 minutes at a time</td>
<td>Reads a book for 20 minutes at a time</td>
</tr>
</tbody>
</table>
CASP

CASP summary scores and individual subscale scores across all assessments are illustrated in Figures 5.8 and 5.9, respectively, for all program participants. Figure 5.10 illustrates individual subscale scores for the control participant. At the 4 weeks pre-assessment, participant 1’s summary score on the CASP indicated that he was bordering the somewhat limited to very limited range of participation, at a score of 50. At the 1 week pre-assessment, his summary score reduced by approximately 15 points to fall within the very limited range (score of 36.8) and remained in this range at the 1 week post assessment (38.75). The decrease in his summary score from 4 to 1 week pre-assessment was observed to occur mainly in the subscales of school participation and home and community. At follow-up testing, his summary score returned to the somewhat limited range.

Participant’s 2 and 3 summary scores remained within the age-expected range across all assessments, whereas participant 4’s summary scores fell within the somewhat limited range at all 4 assessments. However, his individual subscales revealed an increase in his Home Participation score to an age-expected participation level at the 8 months post-program follow-up.

The control participant’s scores remained within the lower-end of the age-expected range across her first 3 assessments, but fell within the somewhat limited range at her final assessment. When examining her individual subscales, her Home and Community Living Activities score decreased to the somewhat limited range between her first and second assessment, and remained in this range by her final assessment (refer to Figure 5.10). At her final assessment, she indicated that she no longer attended public school, but was completing correspondence courses with a home tutor. Thus, her School Participation score fell to 0 (i.e. not applicable).
Figure 5.8 CASP summary scores for all participants from pre- to post-assessments

* Follow-up was conducted at 6 months post- for participant 3, at 7 months post for participants 1 and 2, 8 months post- for participant 4, and 6 months from the previous assessment for the control participant
Figure 5.9 CASP subscale scores for program participants
Social Networks Inventory

The QGIR’s for all participants are provided in Appendix E, with the main findings summarized below. Participant 1’s ratings of self and other perceived closeness indicated congruence for almost all individuals and groups. His Psychological Quadrant, which included his family and youth workers, was fairly large. He felt extremely close to them and believed they felt the same closeness. Changes seen within his Collective Quadrant occurred from 4 to 1 week pre-program, as he had begun volunteering in an extra-curricular club with same-aged peers. At 1 week post-program, participant 1 included all of the staff and participants from the program within his Individual Quadrant, feeling fairly close to them and rating their perceived closeness with the same level of intimacy. At follow-up assessment, he added his brother and step-mother to his Psychological Quadrant, indicating a close relationship with both. He also added a new person to his Individual Quadrant, as he made a new friend in the group he was volunteering with.

Participant 2’s QGIR indicated congruence for most individuals and groups listed on all quadrants. Changes were seen in ratings on his Psychological Quadrant from 4

Figure 5.10 CASP subscale scores for control participant
weeks to 1 week pre-training for individual ‘4’, who represented his sibling. He also felt more distant from members of school related clubs at the 1 week pre-program assessment, as indicated by the changes on the Psychological and Individual quadrants. At the end of the program, he placed participant 3 within his Individual Quadrant, considering their relationship moderately close. However, at follow-up assessment, he indicated that he no longer kept in touch with the camp participants, reflected in a changed rating of closeness to participant 3 as being extremely distant. In addition to this change, participant 2 listed 3 new friends in his Psychological Quadrant, rating all relationships with high self and other-perceived closeness. He also mentioned that at the time of follow-up assessment, he had moved to a different school and was no longer a member of the groups previously listed within his Collective Quadrant, although he still kept in touch with and felt close to certain individual members of those groups.

The QGIR for participant 3 also indicates good congruence for most individuals and groups listed on all quadrants. Changes were seen in his ratings of closeness to individual ‘7’ on his Psychological Quadrant, which represents a pet that had passed away recently. Also, changes were seen from pre- to post-program for his closeness ratings for collective group ‘7’ which represented a sports team he had begun practicing with by the time of the 4 weeks pre-assessment. At the end of the program, participant 3 listed all participants from the program in his individual quadrant with high congruence between ratings, feeling fairly close to all participants. At follow-up testing, he indicated that he no longer kept in touch with the program participants, but still felt relatively close to them and rated all members with moderate self and other-perceived closeness. At this assessment, he also added a new group to his Collective Quadrant, as he had joined a new sports team.

Participant 4’s QGIR was comparatively smaller than all other participants. ‘1’ on his Psychological Quadrant represents his mother, whom he alternated feeling close and distant to greatly from across assessments. At the 1 week post-assessment, he listed the theatre skills training program within his Collective Quadrant and included only participant 3 within his Individual Quadrant, although he still felt relatively distant from him. At the follow-up, he added his older sister to his Psychological Quadrant and indicated the same self and other-perceived closeness to her as he did with other family
members across previous assessments. He also indicated that he no longer kept in contact with participant 3, reflected in his highly distant rating of his self and other-perceived closeness.

The social network grid for the control (participant 5) indicated good congruence for most individuals and groups listed and demonstrated a fairly large social network within her Psychological Quadrant. However, her ratings of self and other-perceived closeness with friends highlighted increased feelings of distance as the assessments progressed (i.e. individuals 8 and 11 within the Psychological Quadrant). In her initial assessment, she was not participating in any extra-curricular or volunteer groups. At her second assessment, she indicated that she had joined 2 volunteer organizations, although she felt distant from the other members. At her final assessment, she indicated that she no longer was volunteering with these groups, but had recently joined a new one.

5.5 Discussion

5.5.1 Summary of Findings and Implications

Given that this is a novel approach to ABI treatment, one main objective of the current study was to collect pilot data on the feasibility and utility of an expressive arts-based theatre skills training program for youth with ABI to improve social cognition and community integration skills. It was hypothesized that participation in a program that emphasized group work and collaboration, personal reflection, self-awareness, and social integration would allow participants to explore effective integration strategies in a creative way. Indeed, findings from the current study show positive gains towards social and recreational goals identified by the participants, expanding of social networks and decreased severity of impairments in pragmatic communication skills from pre- to post-program participation. These encouraging findings were revealed in the current study by the first objective, to identify methods to quantitatively capture the effectiveness of the program. The implications of our findings are discussed below.
5.5.2 Effects on Social Cognition and Self-Esteem

Various social cognitive problems have been shown to interfere with social reintegration for youth with ABI (e.g. Pettersen, 1991). Behavioural and social abilities can also have a much greater effect than loss of physical abilities on the participation and social integration of youth with an ABI (Bedel and Dumas, 2004). In the current study, emotion discrimination skills and pragmatic communication behaviours were used to assess the effectiveness of the expressive arts therapy to improve social cognitive skills in order to improve social integration.

Although the emotion discrimination revealed some positive changes for participants 1 and 2, the task did not reveal any reliable trends of changes across all assessments with respect to accuracy and reaction time for the other program participants. In addition, the task proved to be difficult to administer for participant 2 due to vision impairments and participant 4 due to his visual and physical impairment. Participant 3 and the control participant also appeared to be fairly high functioning with respect to emotional awareness and demonstrated ceiling effects for accuracy across assessments. Thus, further research in this area is needed to support the effectiveness of expressive arts to improve emotional awareness. The different impairments that are faced by adolescents with ABI should be considered when developing this type of task.

The PPIC was used to examine the effects of the theatre skills training program on pragmatic communication behaviours, the skills that govern and describe how language is used in different contexts and environments (Wiseman-Hakes et al., 1998). Initially, participants ranged from being severely to very mildly impaired on these skills. However, considering that the current study examined individuals with brain injuries, variation in abilities is not surprising. Even with this variation, improvements were still seen from pre to post-program on several of the subscales outlined on the PPIC for all participants. These improvements were seen in behaviours such as general participation, including better coordination of ideas and meeting other’s needs in conversation, as well as literal content, including less sentence fragmentation and dysfluency.

It should be noted that this measure has no established criteria to determine meaningful change in pre- to post-intervention research. To our knowledge, only one study has used the PPIC in a pre-post-intervention format. Dahlberg et al. (2007)
administered the measure to 25 adults with a traumatic brain injury (TBI) before and after their participation in a social skills training program and compared their change scores to those obtained by adults with TBI who did not participate in the intervention. Change scores ranging from 0.54 to 0.92 were found to be statistically significant on several subscales, which is even less than the change scores of at least 1.00 obtained in the current study from pre- to post-assessment, which may suggest that participation in the program elicited meaningful changes in pragmatic communication behaviours for youth with ABI.

Review of the literature illustrates that the effects of a brain injury on self-esteem have not been investigated thoroughly (Cooper-Evans et al., 2008), but has been examined as a variable in relation to other outcomes. As such, self-esteem has been found to be facilitated by social integration (Henry, 1998; Mannarino, 1976). In the current study, self-esteem was measured with the Rosenberg Self-Esteem Scale. No true guidelines have been established to determine clinically meaningful change scores from pre- to post-test administration. Barrett, Webster and Wallis (1999) implemented a social skills training program for 51 youth aged 13 -16 with identified low self-esteem and difficulties with interactions with peers. The Rosenberg was given 1 week prior to and 1 week post-program. A change in total score of approximately 7 was found to be statistically significant for the intervention group in comparison to placebo and waitlist control groups. A change score of approximately this value was not seen for any participant in the current study, suggesting stability of the participant’s self-esteem ratings over the course of the study, even with the control participant.

The finding of stability of self-esteem ratings from pre- to post-participation in the theatre skills training program is not surprising, as previous research describes the stability of self-esteem as low throughout childhood, but increasing throughout adolescence and into young adulthood (for review see Trzesniewski, Donnellan and Robins, 2003). This trend is not explained by the reliability of self-esteem measures and is generally replicated across gender, ethnicity, self-esteem scales, nationality, and year of publication of study (Trzesniewski, Donnellan and Robins, 2003). Cooper-Evans et al. (2008) also found stability in self-esteem ratings in adult survivors of an ABI over a 2 week interval. Given the increased stability of self-esteem across adolescence, it seems
reasonable that no large changes in self-esteem would be expected over the relatively short time-period that the current study took place.

However, given that each participant was described through anecdotal self and/or caregiver-reporting as demonstrating difficulties with social skills and a subsequent lack of social integration, the finding of high self-esteem for all participants across assessments was not expected. Although one explanation may be that the items of the Rosenberg did not capture self-esteem in relation to these difficulties, it seems more likely that the use of a self-report measure for self-esteem with brain injured adolescents may not be suitable, especially when considering impaired awareness issues and under-reporting of problems that have been demonstrated in previous research on individuals with ABI (Prigatano & Fordyce, 1986; Ezrachi, Ben-Yishay, Kay, Diller, & Rattok, 1991; Hillier & Metzer, 1997; Sbordone, Seyranian, & Ruff, 1998; Port, Willmott, & Charlton, 2002).

Another possible variable that could be examined in future studies is that of self-efficacy. In contrast to self-esteem, which is thought to relate to one’s feelings of self-worth, self-efficacy represents the belief in one’s ability to succeed at a certain task and their capacity to understand the physical, intellectual and emotional resources that are required to succeed (Bandura, 1986; Maly, Costigan and Olney, 2006). Studies have demonstrated that self-efficacy is enhanced directly from social interactions, as it is these interactions that provide an individual with a better understanding of themselves (Wood, 1989). In addition, the self-efficacy of adults with brain injuries has been shown to increase after participation in rehabilitative strategies that provide direct human interactions and consequent social feedback (Man et al., 2006). Since the expressive arts intervention described in the current study utilized such a strategy, a measure of self-efficacy may be a better indicator of changes in the participant’s perception of their social skills performance after program participation.

5.5.3 Effects on Community Integration

Rather than completing the COPM prior to program commencement, the participants were given a few days to participate in the program before identifying problem areas. GAS was then applied to these problems, which provided them with a better understanding of how the activities in the program could potentially help them with
their identified social and community integration difficulties. Each participant, including the control, described making friendships as a problem area on the COPM. For this goal, positive changes in performance and satisfaction ratings were observed for all program participants from pre- to post-program, and these changes were either maintained, increased further or remained at a level higher than initial pre-program levels at the follow-up assessments. Performance and satisfaction ratings across most other goals also demonstrated positive changes from pre- to post-program participation that were also maintained or increased significantly further at follow-up assessment.

In addition to these positive results obtained on the COPM, GAS scores from pre to post-program assessments also indicated that each participant either reached or exceeded their expected outcome for their identified problem areas from pre- to immediately post-program. At follow-up assessment, however, goal attainment levels decreased from post-program standing, although attainment levels for most goals were still above or at the expected outcome level. For some goals, achievement fell below expected outcome levels. One explanation for this may be due to follow-up assessments taking place when the participants were well into a new school grade compared to pre- and 1 week post-evaluations. Thus, any increased levels of difficulty experienced in a new, higher grade may have affected the participant’s achievement ratings for certain goals. Also, the structure of goal scaling on the GAS may not have reflected more current levels of appropriate attainment. For example, on the COPM participant 2 demonstrated increased performance and satisfaction ratings at follow-up on reading skills, but identified on the GAS that it was taking him longer to write expressively and he was making more spelling errors compared to his 1 week post-program level.

Participant 1 also identified on his follow-up GAS that his attainment towards his goal of improved speech fell below the expected outcome that he had reached 1 week post-program. Considering that his COPM ratings of making friendships improved, it may be possible that the complexity of his social interactions increased at follow-up, which may have led to him experiencing more difficulties with his speech and expression. With the exception of participant 3, no participants at follow-up returned to their initial – 2 level for any goal, which provides further positive support for participation in the theatre skills training program to improve social and community
integration. Although participant 3’s goal relating to socialization remained at the –2 level at both post-program and follow-up assessments, he expressed that his commitments to school and extra-curricular activities left him with little time to visit new places to make new friendships.

In contrast to the program participants, performance and satisfaction ratings from the control participant on the COPM were observed to decrease for 2 of 3 identified problem areas. Drastic decreases were seen in her ratings of making friendships across all assessments, to a minimum rating of 1 for both performance and satisfaction by her final assessment. These findings imply that the improvements seen in goals by the participants of the program are more likely due to the beneficial effects of the theatre skills training program than the effect of goal-setting, which has been shown to influence goal achievement by itself (Malec et al., 1999). The control participant’s COPM ratings were observed to increase in her problem area of completing homework across all assessments. However, this finding is likely due to her sessions with a private academic tutor that began prior to her first and second assessments and continued up until her final assessment.

The results from the Social Networks Inventory suggest that social network sizes did not change greatly across both baseline assessments and good congruence for self- and other-perceived ratings of closeness were observed throughout assessments. At the immediately post-assessment, the program participants listed each other within their Individual Quadrants, but did not keep in touch with each other by follow-up assessment as indicated by increased feelings of distance. However, at follow-up, participants 1 and 2 had developed new friendships and felt closer to individuals within their Psychological and Individual Quadrants (refer to Appendix E). Participant 3 also indicated that he had joined new clubs at school. These positive changes may partially be due to effects of the program. Conversely, participant 4 demonstrated no changes in his social network, in contrast to the positive changes for his goal of making friendships indicated on the COPM and GAS. It is possible that, although new friendships were developed by participant 4 at follow-up, he may not have felt close enough to them to list them within his Psychological Quadrant. Although the control participant also indicated that she had joined new groups throughout assessments, she did not indicate that new friendships had
developed with individuals from these groups and at follow-up assessments had dropped out of these groups. Thus, for 3 of the 4 program participants, strengthening and expansion of their social networks was observed post-participation, which was not seen for the control participant.

Compared to the overall positive changes observed with the individualized measures after participating in the theatre skills training program, results from the CASP, a standardized caregiver report, were less clear. To our knowledge, only two studies have been conducted with the CASP, both examining brain injured youth (Bedell, 2004; Bedell and Dumas, 2004) and psychometric evaluation is ongoing. Studies using this measure in a pre-post format have not been previously reported; therefore, determining meaningful change in the current study was established by setting ranges of scores to represent participation levels that were age-expected or below. Results suggest that participation in the theatre skills program did not alter participation restrictions faced by youth with ABI, as measured by the CASP. Although we predicted that greater gains in participation scores would be expected at follow-up assessments, reflecting more time and opportunity for the adolescents to utilize any newly acquired skills gained from the program, we did not find drastic changes in scores at follow-up either.

Participant 1 demonstrated a large decrease in his summary scores from 1 week pre- to 1 week post-assessment. When examining his individual CASP subscales, it was observed that a drop from somewhat limited to unable (i.e. a score of 60 at 1 week pre-assessment and 40 at one week post-) occurred within the subscales of school participation and home and community living activities. It should be noted that, unlike the other participants, he attended an individualized learning centre for youth with disabilities where homework was not assigned and limited extra-curricular activities were available. Thus, the CASP may not have provided a valid assessment of his school participation and community activities.

A larger issue that was encountered with using the CASP to document change was that, like many measures developed to assess child participation, the CASP examined whether or not a youth engaged in certain activities, when it may have been more appropriate to assess the frequency of engagement. Also, the appropriateness of measuring participation in comparison to same-aged peers who are typically developing
for youth with brain injuries is questionable. Using this type of assessment to gauge changes in social and community participating after participation in the theatre skills training may be less sensitive. This may explain why findings from the current study on changes post-program using measures that compared the adolescent to their past performance revealed positive changes (i.e. COPM and GAS), even in comparison to the control participant, versus the results from the CASP. As Coster and Khetani (2008) suggest, the perspective of what activities are actually important and meaningful to the youth should be considered in measures of social and community integration.

5.6 Study Limitations

As previously discussed, a potential limitation of the current study is the use of self-report and caregiver measures, since it is possible that individuals with brain injuries may overestimate abilities and under-report problems (e.g. Cooper-Evans et al., 2008). In addition, the current study, like previous studies using GAS (i.e. Malec et al., 1999; Cusick et al., 2006) established initial achievement levels as – 2 for all goals. It may have been more appropriate to scale current status at – 1 for goals in order to document any deterioration or regression. However, only one participant rated themselves at the – 2 level beyond the initial assessment. Also, when designing the program, a better understanding of how the program affected social cognition and community integration may have been elucidated with a stronger framework established beforehand that assessed which activities could target specific behaviours.

Despite the advantages of the case study approach in feasibility and usability testing of rehabilitation interventions, such as having a small number to evaluate the acceptability to stakeholders, determining the ease of implementation according to therapists and clinicians and a more in-depth exploration of personal factors relevant to each participant to better understand trends in outcome measures without wasting time and resources in a larger-scale study (Ruff and colleagues personal communication, July 26, 2006), the strength of conclusions and generalizations to the broader adolescent ABI population regarding the effectiveness of an expressive arts based therapy intervention are limited. Participation in this program also required a significant amount of cognitive and physical effort, which may be problematic for youth recovering from a brain injury.
However, the current study included individuals with severe brain injuries who were able to complete activities and remain in the program with scheduled breaks. In addition, a large number of drop-outs occurred due to a lack of transportation accommodations to the program site. Considering the resources of the current pilot study, such accommodations could not be made, although this issue should be addressed in future research. The utilization of a creative arts technique was a unique approach as a therapy for improving social cognitive and community integration skills in youth with ABI. Therefore, the lessons learned in this pilot study regarding the structuring and content of such a program, as well as the appropriateness of quantitative measures to capture therapeutic changes within this population were invaluable and lay crucial and important groundwork for future studies.

5.7 Conclusions

The findings of the current study are encouraging and clearly demonstrate potential for creative arts to have a therapeutic effect on youth with ABI. A better understanding of community integration interventions and how to assess their effectiveness has also emerged. However, more research is needed in order to assess the success of creative arts therapy to effect change in community integration for youth with ABI. Future studies should continue to deliver the intervention in a small group format and utilize an individually-tailored approach to measurement that take into account what is meaningful to the youth. This research will help adolescents with ABI regain more than just social and emotional skills, but also a sense of belonging and an ability to participate effectively within the community, whether it is their community of peers, or their own family. The skills and knowledge gained by these youth will also be more adaptable to real life situations, as this type of intervention will allow the youth to form peer groups within the therapy to practice these new skills.
Chapter 6 General Discussion
The overall purpose of the current studies was to examine the effectiveness of expressive arts therapy as a social and community integration tool for youth with ABI. Given that this is a novel approach to ABI treatment, our first global objective was to identify and refine the types of quantitative measurements that would best assess any changes between pre- and post-program participation in social cognition and community integration. Our second global objective was, therefore, to collect pilot data for this purpose over the course of two stages. The lack of evidence to support these interventions leaves program evaluators with a limited knowledge and understanding of how to assess and improve such services (Bedell, 2004). These types of interventions are critical, as participation, whether at home, school or within the community, is an important aspect of development and has been linked to improved quality of life for youth with or without disabilities (Bedell and Dumas, 2004). A comparison of results from stages 1 and 2 and their implications will be discussed with respect to social cognition and community integration.

6.1 Measuring Social Cognition
The pilot studies described attempted to assess whether changes in social cognition, a critical area of impairment for adolescents with ABI, occurred from pre- to post-program participation. In the first and second stages of pilot testing, we employed an emotion discrimination task to measure social cognitive skills. However, in the second stage, we also added a measure of pragmatic communication skills, since previous research has demonstrated that improvements in these skills can occur in youth with ABI after participation in an intervention provided in a small group format (Wiseman-Hakes et al., 1998). A measure of self-esteem was also added during this stage, as it has been demonstrated that deficits in overall social competence can negatively impact self-esteem in adolescents (Mannarino, 1976).

Research has demonstrated that youth with ABI experience difficulties in emotion recognition and awareness (Petersen, 1991; Tonks et al., 2007; Turkstra et al., 2008). Thus, it is imperative that interventions, like the theatre skills training program, be
developed that address emotional awareness difficulties faced by youth with ABI. The pilot studies assessed emotional awareness in participants with an emotion discrimination task. In the first stage, improvements in reaction time and accuracy were observed for basic emotions (i.e. angry and sad faces) for participant 1 from pre- to post-assessment. Although these trends in data were not observed as consistently during stage 2, this may have been due to several extraneous factors. First, the task proved to be difficult to administer for participants 2 and 4 in the second stage due to visual and physical impairments. Secondly, participant 3 and the control participant also appeared to be fairly high functioning with respect to emotional awareness and demonstrated ceiling effects for accuracy across assessments. Thirdly, gender effects may explain the differences in results between both stages. Gender-related differences in the neural correlates of emotional face processing have been documented (McCrae et al., 2008), in addition to studies which have shown that gender differences are present in emotional recognition tasks (e.g. Imig, Erwin and Turetsky, 2000). The participant in stage 1 was female, compared to 4 males and 1 female in stage 2, although effects similar to stage 1 on this task were not observed with the female control participant in stage 2.

Lastly, the task used to measure emotional awareness was also normed on young adults and may not have been sensitive enough to capture the changes in emotion discrimination abilities of the participants in the current study (Matsumoto and Ekman, 1988). Since this task only used adult faces, it may also be possible that increased awareness of emotional expressions with age-appropriate faces would increase sensitivity to changes in emotional recognition and discrimination from pre- to post-program (Thomas et al., 2007). Overall, the benefits of participating in a creative arts based therapy to improve emotional awareness shows great potential, as demonstrated in stage 1, but further testing is required that controls for gender-effects and allows for any appropriate physical accommodations for youth with ABI.

Decreases in the severity of impairments, as measured by the PPIC, were observed across a variety of pragmatic communication behaviours in all participants who took part in the program. Although meaningful change indices have not yet been established for this measure, these positive changes are encouraging, especially since this measure was completed at the start of the program and on the final day. Changes were
most dramatic with participant 4, who was also the most severely impaired at the beginning of the program. This may indicate that the individuals who would benefit the most from a creative arts-based intervention to improve pragmatic communication skills are those who are more severely impaired.

Findings from the second pilot study relating to self-esteem revealed that participating in the program did not impact self-esteem ratings, as measured by the Rosenberg Self-Esteem Scale. However, the observation that all participants indicated high self-esteem across all assessments in contrast to anecdotal reports of difficulties with social cognitive skills and social integration puts into question whether the use of a self-report measure is appropriate when assessing self-esteem. This supports previous studies that have shown that individuals with ABI to experience impaired awareness and tend to over-report capabilities and under-report problems (Prigatano & Fordyce, 1986; Ezrachi, Ben-Yishay, Kay, Diller, & Rattok, 1991; Hillier & Metzer, 1997; Sbordone, Seyranian, & Ruff, 1998; Port, Willmott, & Charlton, 2002). For future research, self-efficacy may be a more reliable measure of changes versus self-esteem. Self-efficacy represents the belief in one’s ability to succeed at a certain task and their capacity to understand the physical, intellectual and emotional resources that are required to succeed (Bandura, 1986; Maly et al., 2006; Man et al., 2006). The self-efficacy of adults with brain injuries has been shown to increase after participation in rehabilitative strategies that provide direct human interactions and consequent social feedback, strategies that are incorporated within the expressive arts intervention described in the current studies (Man et al., 2006). Thus, a measure of self-efficacy may be a better gauge of changes in the participant’s perception of their social skills performance after program participation.

6.2 Person-centered measurement techniques

As outlined by Bedell and Coster (2008), there are currently 3 types of measures that appear promising for measuring participation: (1) measures that directly assess participation; (2) subsections from measures that implicitly assess participation; (3) approaches that are tailored to assess the achievement of person-centered goals and interventions addressing participation. With respect to the current study, we attempted to measure community integration by using a combination of all three types across the two stages of pilot testing.
Greater participation is not necessarily better if it occurs in situations that are not meaningful to adolescents and their families. Findings from both pilot studies emphasize the strength of person-centered approaches to measure changes in community integration by including the participant in determining what activities and areas are important to their participation goals. We used the COPM in both stages of the study to assess performance and satisfaction with the problem areas identified by each participant. In both stages, improvements in performance and satisfaction ratings were observed for most goals at post-program assessment, especially in the ability to make friendships, a common problem identified by all participants. Further support for the effectiveness of the theatre skills training program to help improve community integration skills was provided by the results from the control participant in stage 2. Unlike the program participants, her ratings of leisure and socialization goals decreased across her assessments.

Also during stage 2, GAS was applied to the problems identified on the COPM to provide the participants with a better understanding and sense of direction as to how the activities in the program could help with their identified social and community integration difficulties. GAS scores from pre to post-program assessments indicated that each participant either reached or exceeded their expected outcome on almost all goals, even at follow-up assessment. Given that these goals were made specific to the program, the positive results from the GAS also speak to the effectiveness of the theatre skills training program to help these youth gain confidence in their socialization abilities. Positive results at both post-program and follow-up from the Social Network Inventory, which allowed participants to list and describe the relationships in their lives that were most meaningful to them, further support the effectiveness of the intervention. For example, participants reported new friendships developed and greater feelings of closeness to existing relationships at post-program and follow-up assessments. Thus, the measures used in both studies that were person-centered appeared to be the most sensitive to changes that were meaningful after participating in the intervention and provided the most support for the program’s effectiveness.
6.3 Implicit versus explicit measures of community integration

The sensitivity of implicit versus explicit standardized measures of community participation across both stages was also examined. In stage 1, the ABAS-II was used to assess community participation. This measure does not directly assess community integration. Rather, we felt that certain skill areas (i.e. communication, community use, leisure, social and self-direction), could be used to implicitly measure changes in participation from pre- to post-intervention. Increases were observed in these skill areas from pre- to post-program, though not clinically meaningful, and greater gains were observed at follow-up testing in some skill areas, as the youth would have had more time to apply skills they may have gained from the theatre skills training program.

Despite these positive results, some of the items within these skill areas were not appropriate considering the age group of youth in the study (i.e. shows positive attitude towards job, attends work regularly). Also, many of the areas gathered data on physical activities of daily living. While not unimportant towards participation abilities (i.e. ‘crosses the street on their own’), these scales did not truly measure the participation of youth with an ABI within their community. Thus, in stage 2, the CASP was used as an explicit measure of community integration. Unlike the ABAS-II, the CASP directly assesses participation from a number of domains that pertain to home, school and community life.

The results obtained suggested that participation in the theatre skills program did not alter participation barriers faced by youth with ABI as measured by the CASP, as summary scores remained relatively stable for all participants. However, several limitations of the CASP for measuring changes in participation over time were noted. For example, the measurement of participation abilities of youth using the CASP is done in comparison to age-expected participation levels for typically developing youth. This approach may render the CASP less sensitive to change for adolescents with brain injuries given the unique cognitive, behavioural and social restrictions faced by this population in comparison to typically developing adolescents. Also, this measure assesses whether or not a participant can perform specific activities, when it may be more appropriate to examine changes in frequencies of activity engagement as a marker of improvement in community integration.
The results from both the ABAS-II and CASP demonstrate that the creation of a standardized measure that can accurately depict the participation restrictions faced by youth with ABI in a generalized method is a challenging task, since a unique set of restrictions presents itself with each brain injury. With these types of measures, additional concerns regarding how questions and items should be phrased and whether they should measure the extent of participation, restriction or satisfaction need to be explored more thoroughly in future studies.

6.4 Limitations
Aside from the limitations discussed in relation to each of the two pilot studies (refer to sections 4.6 and 5.6), the most prominent challenge faced during the course of the study was recruitment, which resulted in a small sample size across both stages of the study and limits conclusions regarding the strength of the evidence obtained. Recruitment was mainly limited by transportation issues in getting to the intervention site on a daily basis and the limited resources available to support participants with very severe injuries. Since transportation was a large barrier to participant recruitment, the participants in the current study may have been more highly motivated to participate in the program than the general population of youth with ABI. Thus, the effect of motivation as a factor of effectiveness in expressive arts therapy requires further evaluation. Overall, the utilization of a creative arts technique was a unique therapeutic approach for improving social cognition and community integration in youth with ABI, and the lessons learned with respect to the structuring, content and measurement of the therapeutic effects of the program were essential and lay the important groundwork for future studies.

6.5 Future Directions
The results of these pilot studies are very encouraging regarding the potential for utilizing creative arts as therapeutic intervention for youth with ABI in terms of social cognition and community integration skills. It is our intention to develop a model of community integration for youth with ABI that helps inform other researchers, practitioners and program developers. However more research is needed in order to build
a more conclusive evidence-base. Future studies should continue to deliver the intervention in a small group format and utilize an individually-tailored approach to measurement. Moving forward, studies should implement individualized measures, such as the COPM or GAS, with caregivers and participants on individualized goals in order to gain information from both perspectives and increase the strength of evidence supporting expressive arts therapy. Such an approach was utilized by Dawson et al. (2009) to evaluate the efficacy of an intervention for adults with TBI to help in the rehabilitation of executive dysfunction. This research will help adolescents with ABI regain more than just social and emotional skills, but a sense of belonging and an ability to participate effectively within the community, whether it is their community of peers, or their own family.
Chapter 7 Conclusions
Findings from both pilot studies provide positive and encouraging support for the use of expressive arts as a therapeutic tool to improve social cognition and community integration skills for adolescents with ABI. Despite the case study design and small sample size, these studies have laid down crucial framework that will help direct future studies on this topic. Important revelations regarding methods of measuring the effectiveness of interventions targeting community integration have also been revealed. Person-centered measurement techniques that take into account what is meaningful to the youth appear to be the most sensitive to capture any post-intervention changes, although further research is needed in this area. Developing interventions that help improve community integration can enable meaningful and productive occupational engagement, which in turn can enable opportunities for occupational engagement through increased community integration, greatly enhancing the quality of life of adolescents with ABI.
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Appendix A: Sample Parent Consent Form Pilot Creative Arts Camp

Date

Dear [name of parent],

My name is ____________ . I am part of a research team at Bloorview Kids Rehab and the University of Toronto that is developing a creative arts camp for youth recovering from brain injury. Before agreeing to take part in this study, it is important that you understand how you will be involved.

What is the study about?
Adolescence is a time when social and community integration are important. Having a brain injury can affect one’s ability to communicate socially with others. Creative arts have been shown to be an enjoyable therapeutic process. It has also been shown to improve one’s health and social integration. However there is not much information about its use with youth recovering from brain injury. Currently there is no standard of care for youth after 6 months of having a brain injury. We are looking at different ways of integrating youth with a brain injury back into the community. In order to do this, we will have a creative arts camp for youth to participate in. The creative arts camp will provide theatre training that will include voice work, breathing, movement, character development, three-dimensional awareness, group dynamics, story development, mask work, clowning, among others. The purpose of the camp is to help us refine the theatre training intervention in order to run a randomized control trial that will take place over the summer of 2009. This Summer 2009 Camp will be designed based on your feedback (i.e. what you liked, didn’t like and how it could be better). You will have the opportunity to provide feedback during a focus group session with other parents whose children also participated in the pilot creative arts camp. Youth who participate in the pilot creative arts camp will not be eligible for the Summer 2009 camp.

How will I be involved in this study?
We want to invite your son/daughter to Bloorview Kids Rehab to attend the camp with other children recovering from brain injury where they will meet with an artistic facilitator and occupational therapist. The camp will take place from 10 am to 2 pm Monday-Thursday from July to August and will include other youth recovering from brain injury. Your son/daughter will participate in creative arts. This may involve clown work, mask making, voice work and other creative arts techniques.
To measure how effective the camp is, we will ask you to complete two questionnaires 4 weeks before the camp starts, immediately before the camp starts, immediately after and 6 months after it is finished. This should take about 2 hours in total (30 minutes per session).

Your son/daughter will also be videotaped during 2 half-hour sessions twice a week, for a total of 2 hours per week. These recorded sessions will allow the researchers to better assess your child’s communication skills and observe any changes they may demonstrate over the course of the camp. As soon as the videotapes are completed, they will be stored securely in a locked cabinet at Bloorview. They will then be transported to the University of Toronto via registered Purolator for extra security, where they will also be stored in a locked cabinet and only members of the research team will have access to them.

Analysis of the videos will take place in a private room; however, the identities of the participants cannot be hidden to the research members viewing the tapes. Duplicates will not be made of any tapes and they will be destroyed at the end of the study.

At the end of the camp we will also ask you to participate in a discussion about the camp with other parents whose children also participated. This discussion will last for about 90 minutes. We want to know what you liked about the camp, what you didn’t like, and whether you think it helped your son/daughter communicate better with friends and family.

**Will anyone know what I say?**

We will use a tape recorder to record what you and your son/daughter say during the discussion at the end of the camp. We have a separate consent form for this. We need to use the tape recorder to review what you said in more detail. Only researchers on the project will listen to these tapes. The tapes will be transcribed and only the researchers will see the transcriptions. We will destroy the tapes and transcriptions at the end of 7 years. Individual speakers will not be identified in the transcriptions.

All the information we collect about you and your family will be kept confidential. Your name will not be recorded on the questionnaire. You will be assigned a unique ID that will be recorded on the questionnaire to keep your responses anonymous. We will not make public anything that might identify you or your family, unless required by law. For example, we have a legal duty to report certain infections that could spread to others. However, because of the nature of this study (i.e. a camp that involves other participants), other people will know that you are participating. Although it will be explained that what is said and done during the camp is to be kept private, the research team cannot control what participants may say outside of the camp.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to disclosure.
Do I have to do this?
If you decide not to take part in this study, that is okay. If you decide to take part, but then at any time during the study you no longer want to participate, that is okay. This will not affect the services you or your son/daughter gets from Bloorview Kids Rehab.

What are the risks and benefits?
We think that this camp may benefit your son/daughter by improving his/her sense of social integration. We think that you and your son/daughter will help improve the Summer 2009 camp we are designing. Some creative arts activities may stimulate emotional responses. Some emotional response is normal and the therapists and facilitators will be trained to handle this. Should your son/daughter experience strong negative emotions, a referral can be made to psychology services here at Bloorview.

We will pay you and/or your son/daughter’s gas, parking and/or public transit fare so you and your child can attend.

What if I have questions?
Please ask me to explain anything you don’t understand before signing the consent form. My phone number is 416-946-4004. If you leave a message, I will return your call within 48 hours.

Thank you for thinking about helping us with this project.

Yours truly,

Michelle Keightley, Ph.D., C.Psych.
Assistant Professor
Department of Occupational Science and Occupational Therapy
Rehabilitation Sciences Building (Centre for Function and Well-Being)
Faculty of Medicine, University of Toronto
500 University Ave., 9th Floor
Toronto, ON, M5G 1V7
CONSENT FORM

*Re: Creative Arts Camp*

Please complete this form below and return it using the self-addressed stamped envelope provided.

The researcher explained this study to me. I read the letter and understand what this study is about.

I understand that I may drop out of the study at any time.

I agree to participate in this study.

________________________________________________  __________________________  _____
Parent’s Name (please print)   Signature    Date

________________________________________________  __________________________  _____
Researcher’s Name     Signature     Date
Appendix B: Sample Information Sheet and Consent Form for Youth

Dear [name of child],

A Pilot Creative Arts Camp
My name is ___________. I am part of a research team at Bloorview Kids Rehab and the University of Toronto that is developing a creative arts camp for youth recovering from brain injury. Before agreeing to take part in this study, it is important that you understand how you will be involved.

What is the study about?
Adolescence is a time when social and community integration are important. Having a brain injury can affect one’s ability to communicate socially with others. Creative arts have been shown to be an enjoyable therapeutic process. It has also been shown to improve one’s health and social integration. However, there is not much information about its use with youth recovering from brain injury. Currently, there is no standard of care for youth after 6 months of having a brain injury. We are looking at different ways of integrating youth with a brain injury back into the community. In order to do this, we will have a creative arts camp for youth to participate in. The creative arts camp will receive theatre training that will include voice work, breathing, movement, character development, three-dimensional awareness, group dynamics, story development, mask work, clowning, among others. The purpose of the camp is to help us refine the theatre training intervention in order to run a randomized control trail over the summer 2009. This Summer 2009 Camp will be designed based on your feedback (i.e., what you liked, didn’t like and how it could be better). You will have the opportunity to provide feedback during a focus group session with other youth who also participated in the creative arts camp. Youth who participate in the creative arts camp will not be eligible to participate in the Summer 2009 Camp.

What do I need to do?
You will need to come to camp from 10 am to 2 pm Monday–Thursday from July to August. You will meet with other teenagers recovering from brain injury, artist facilitators and occupational therapists. You will learn creative arts skills. This may involve painting, clay modeling, acting or other creative arts skills.

To measure how effective the camp is, we will ask your parent to complete two paper and pencil questionnaires. We will ask you to complete 2 paper and pencil questionnaires as well. We will ask you to complete a structured interview that looks at your goals for social communication. We will also ask you to tell us what you think about faces on a
computer. We will ask you to do all of these things 4 weeks before the camp starts, immediately before and after and 6 months after it is finished. It should take about 4 hours in total (1 hour 4 weeks before the camp, 1 hour prior to camp, 1 hour afterwards and 1 hour 6 months later).

At the end of the camp we will also ask you and your parent to participate (separately) in a discussion about the camp. You will meet with a few other teens to tell us what you think about the camp. This discussion will last for about 90 minutes. We want to know what you liked about the camp, what you didn’t like, and whether you think it helped you communicate better with friends and family.

**What are the good and bad things about doing this?**
Some of the activities you do during the camp may make you feel uncomfortable. The people who run the camp will help you deal with the feelings if you want. If needed, they will refer you to a psychologist here at Bloorview.

The good thing about this study is that you will help us to make a better creative arts camp for youth recovering from brain injury. You may also find it improves your ability to talk to family and friends.

We will pay your gas, parking and/or public transit fare so you can attend.

**Will anyone know that I did this study?**
We won’t share anything you said with anyone who is not part of this study. No one else will know it was you who said these things. We will tell everyone participating to not share anything you said with anyone outside the group. However the other participants may forget and talk about their experiences at the camp.

We will use a tape recorder to record what you say during the discussion at the end of the camp. We have a separate consent form for this. We need to use the tape recorder to review what you said in more detail. Only researchers on the project will listen to these tapes and only the researchers will see the transcriptions. We will destroy the tapes and transcriptions at the end of 7 years. Individual speakers will not be identified in the transcriptions.

All the information we collect about you and your family will be kept confidential. Your name will not be recorded on the questionnaire. You will be assigned a unique ID that will be recorded on the questionnaire to keep your responses anonymous. We will not make public anything that might identify you or your family, unless required by law. For example, we have a legal duty to report certain infections that could spread to others.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to disclosure.
**Do I have to do this?**
If you do not want to try this camp, that’s O.K. You can tell your parents or me that you don’t want to take part in this study. That will be O.K. This will not affect how you are treated at Bloorview Kids Rehab. If you say yes now, you can change your mind later. You can still say no. That will be O.K.

**What if I am not sure?**
Your parents know about this study. Ask them questions if you don’t understand what this is about. You can also talk to me about the study before you decide whether or not you want to be involved.

Thanks for thinking about being a part of this study.

Yours truly,

Michelle Keightley, Ph.D., C.Psych.
Assistant Professor
Department of Occupational Science and Occupational Therapy
Rehabilitation Sciences Building (Centre for Function and Well-Being)
Faculty of Medicine, University of Toronto
500 University Ave., 9th Floor
Toronto, ON, M5G 1V7
Youth Consent Form
A Pilot Creative Arts Camp

I want to be in this study.

______________________________________________________
Name of participant and age

_____________________________________________________
Signature

I read this form to ___________________________________________ and s/he agreed
to participate.

____________________________________
Name of Person Who Obtained Consent

____________________
Signature

____________________
Date
Appendix C: Sample Information Sheet and Assent Form for Youth

Date

Dear [name of child],

A Pilot Creative Arts Camp
My name is ____________. I am part of a research team at Bloorview Kids Rehab and the University of Toronto that is developing a creative arts camp for youth recovering from brain injury. Before agreeing to take part in this study, it is important that you understand how you will be involved.

What is the study about?
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**What are the good and bad things about doing this?**

Some of the activities you do during the camp may make you feel uncomfortable. The people who run the camp will help you deal with the feelings if you want. If needed, they will refer you to a psychologist here at Bloorview.

The good thing about this study is that you will help us to make a better creative arts camp for youth recovering from brain injury. You may also find it improves your ability to talk to family and friends.

We will pay your gas, parking and/or public transit fare so you can attend.

**Will anyone know that I did this study?**

You will be videotaped during 2 half-hour sessions twice a week, for a total of 2 hours per week. These recorded sessions will allow the researchers to better understand your communication skills and observe any changes you may show over the course of the camp. As soon as the videotapes are completed, they will be stored securely in a locked cabinet at Bloorview. They will then be transported to the University of Toronto via registered Purolator for extra security, where they will also be stored in a locked cabinet and only members of the research team will have access to them. Analysis of the videos will take place in a private room; however, your identity cannot be hidden to the research members viewing the tapes. Duplicates will not be made of any tapes and they will be destroyed at the end of the study.

We won’t share anything you said with anyone who is not part of this study. No one else will know it was you who said these things. We will tell everyone participating to not share anything you said with anyone outside the group. However the other participants may forget and talk about their experiences at the camp.

We will use a tape recorder to record what you say during the discussion at the end of the camp. We have a separate consent form for this. We need to use the tape recorder to review what you said in more detail. Only researchers on the project will listen to these tapes and only the researchers will see the transcriptions. We will destroy the tapes and
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If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to disclosure.

**Do I have to do this?**
If you do not want to try this camp, that’s O.K. You can tell your parents or me that you don’t want to take part in this study. That will be O.K. This will not affect how you are treated at Bloorview Kids Rehab. If you say yes now, you can change your mind later. You can still say no. That will be O.K.

**What if I am not sure?**
Your parents know about this study. Ask them questions if you don’t understand what this is about. You can also talk to me about the study before you decide whether or not you want to be involved.

Thanks for thinking about being a part of this study.

Yours truly,

Michelle Keightley, Ph.D., C.Psych.
Assistant Professor
Department of Occupational Science and Occupational Therapy
Rehabilitation Sciences Building (Centre for Function and Well-Being)
Faculty of Medicine, University of Toronto
500 University Ave., 9th Floor
Toronto, ON, M5G 1V7
Youth Assent Form
A Pilot Creative Arts Camp

I want to be in this study.

______________________________________________________
Name of participant and age

_______________________________________________________
Signature

I read this form to ___________________________________________ and s/he agreed
to participate.

____________________________________
Name of Person Who Obtained Assent

____________________
Signature

____________________
Date
## Appendix D: Sample Items from the PPIC Feature Summary Scales

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<tr>
<th>PPIC Subscale</th>
<th>Sample Items</th>
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<td>Literal Content (LC)</td>
<td>Sentences fragmented, says odd or bizarre things</td>
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<tr>
<td>General Participation (GP)</td>
<td>Coordination of ideas, meeting other’s needs in conversation</td>
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<tr>
<td>Quantity (QN)</td>
<td>Talks over other’s, provides excessive detail</td>
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<tr>
<td>Quality (QL)</td>
<td>Makes up stories, boasts</td>
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<tr>
<td>Internal Relation (IR)</td>
<td>Repeats information, elaborates spontaneously</td>
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<tr>
<td>External Relation (ER)</td>
<td>Gives listener responses, uses questions well</td>
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<tr>
<td>Clarity of Expression (CE)</td>
<td>Is obscure, ambiguous</td>
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<tr>
<td>Social Style (SS)</td>
<td>Over-polite, gives excessive attention</td>
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<tr>
<td>Subject Matter (SM)</td>
<td>Overly intimate, inappropriate content</td>
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<tr>
<td>Aesthetics (AE)</td>
<td>Interrupts, restless and fidgety</td>
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Appendix E: Social Networks Inventory - QGIR

Participant 1 – 4 Weeks Pre-Assessment

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Participant 1 – 1 Week Pre-Assessment

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Participant 1 – 7 Months Post-Assessment

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Participant 2 – 4 Weeks Pre-Assessment

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## Participant 2 – 1 Week Pre-Assessment

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