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A Prescription of Hope: Educational and Therapeutic Collaboration During the Rehabilitation of Adolescents with Acquired Brain Injury

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A PRESCRIPTION FOR HOPE:

Educational and Therapeutic Collaboration During the Rehabilitation of Adolescents with Acquired Brain Injury

Heather Counsell

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For Nathania,

who pointed me in the right direction all those years ago.

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Who knew exactly what I was trying to say,

Then helped me say it.

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A Prescription for Hope: Educational and Therapeutic Collaboration During the Rehabilitation of Adolescents with Acquired Brain Injury

Heather Counsell

In recent years there has been growing awareness of the unique challenges facing children recovering from an acquired brain injury (ABI). Within the literature, much has been written about the importance of a variety of therapeutic interventions throughout the rehabilitation process. However, the role of the teacher is rarely mentioned in the discussion of early-stage rehabilitation, despite the central role school plays in the lives of children.

Using a case study methodology, this study investigates the benefits of extended educational and therapeutic collaboration, facilitated through the involvement of a hospital teacher. Three cases from a children's hospital are explored, beginning at the time of each child's accident, following through several months of intensive rehabilitation, and culminating in the eventual return to the community school. Through immersion and crystallization (Crabtree & Miller, 1999) the study identifies three meta-themes emerging from the transcribed voices of student, family, hospital and school, as participants describe the rehabilitation experience from their own perspective. Results are offered in a reader's theatre style presentation (Meyer, 2001) to emphasize these contrasting perspectives.

The research offers compelling evidence that the early intervention of a rehabilitation school provides hope, normalization, motivation and a functional context for therapy for these individuals. Teamwork and communication between school, hospital and family is observed to be an effective method of establishing a baseline profile as individual rehabilitation goals are established. This teamwork approach supports teacher education and facilitates planning for success as the student returns to the community school. From the data, a socio-cultural model for paediatric rehabilitation is developed. This model provides a framework for much needed socialization and family advocacy, while addressing the need for ongoing support.

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University of Ottawa, 2008

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I thought I was dying until I met the teacher.

I didn't think they would make a dying kid go to school.

From that point on, I knew I would get better.

Brad 2004

Chapter One: Introduction and Literature Review

Acquired brain injury (ABI) is any type of sudden injury that occurs after a period of normal brain development that causes temporary or permanent damage to the brain (Kumpf, Bennett, & Good, 2003). ABI may include stroke or an infection such as meningitis, or it may happen as a result of oxygen deprivation to the brain, such as in the case of a near-drowning. It does not include congenital or developmental disabilities such as cerebral palsy or fetal alcohol syndrome. The most common form of ABI is traumatic brain injury (TBI) (Brain Injury Association of America, 2006), caused by an external force, such as impact during a motor vehicle collision. In North America, TBI is the leading cause of death in children aged 3 to 14 (Hotz, Helm-Estabrooks, & Nelson, 2001). The annual incidence is estimated to be 250 per 100,000 children, with 80% of the survivors having life-long problems in learning and language related skills (Hotz et al.).

Since September 2002, I have worked with a rehabilitation team at a children's hospital in a major Canadian metropolitan centre. As a teacher, my role is to gradually incorporate school activities into the daily schedule of children recovering from acquired brain injury. I also liaise with each child's community school to facilitate gradual re-integration. Early in my experience, while discussing the need for an Individual Education Plan (IEP) for a child with a head injury, I came to realize that ABI was not a recognized exceptionality according to the Ontario Education Act (Ministry of Education, 2001). Furthermore, I observed that in educational circles, there seemed to be a distinct lack of knowledge and experience in dealing with the unique needs of children impacted by ABI. I observed that many students fell through the cracks once they left the intensely supportive environment of the hospital, quietly slipping out into overcrowded, under-equipped classrooms. It is interesting to note that while ABI is largely ignored in educational training, the role of a teacher in ABI rehabilitation is often overlooked in medical settings. For example, ABI seminars tend to focus on the work of various medical specialists and therapists on rehabilitation teams, while the involvement of teachers and the community school are usually given only passing notice (Ylvisaker et al., 2001).

Over the last six years, I have had the opportunity to work closely with a number of schools, supporting students affected by ABI through their rehabilitation beginning in the intensive care unit and culminating in school reintegration. Although each child with ABI is distinct from any other (Glang, Singer, Cooley, & Tish, 1992), there have been observable trends in both needs and interventions across the population (Warschausky, Keuman, & Kay, 1999). In a child's world, attending school is one of the most normal, predictable aspects of life. Offering therapy in a school-like format and coordinating rehabilitation goals with curriculum goals, however modified they may be, seems to provide a rational, meaningful and motivational environment for the pediatric patient.

As my practice evolved with the rehabilitation team, it became interesting to watch the on-going effect of direct teacher involvement, not only during early rehabilitation, but also throughout community reintegration. Turning to the literature I discovered that the level of educational and therapeutic collaboration offered by our team was quite unique in practice, but not unsupported in theory. A growing body of information exists with respect to the issue of pediatric ABI but most of it is addressed to medical and therapeutic professionals. Whereas some authors recognize the need for a holistic approach to pediatric rehabilitation, the direct involvement of a teacher during early stage rehabilitation is not given consideration in any of the models encountered during my research.

After surviving an injury or illness, children afflicted with ABI face numerous obstacles. In order to explore how these obstacles relate to the challenges presented during rehabilitation and school reintegration I have organized my literature review around the following themes: The diverse and dynamic nature of the ABI profile, the need for a holistic treatment model, the need for teacher awareness and education, and the need for on-going advocacy and support.

1.1 The diverse and dynamic nature of the ABI profile

The literature addresses a broad spectrum of ABI needs from the psychosocial (Lewis, Morris, Morris, & Foster, 1998) to the physical (Emanuelson, et al., 2003). Because of the ability of the brain to compensate after a loss of function (referred to as plasticity) and the variability in children's development, it is challenging to predict even individual outcomes (Watanabae, Miller, & McElligott, 2003). Indeed Hotz et al. (2001) suggest that there is great disagreement about the long-term affects of pediatric ABI. While some authors suggest that the plasticity factor enhances potential for recovery, others (Abouhamad, 1999) feel that very young children with brain injuries face greater risk as they grow into deficits. Goldberg (1996) identifies two broad categories of variables that will affect the outcomes: patient-related factors and injury-related factors. Patient-related factors include age, health, personality and pre-morbid intelligence. Injury-related factors include the quality of the first aid response and the severity of the injury, where severity is often measured using the Glasgow Coma Scale (GCS). A GCS score of less than 8 points is considered to be severe.

An important concept in pediatric ABI known as *growing into a disability* is the phenomenon of a new disability appearing years after an injury because the brain has not called upon the injured area to perform up until that time (Kumpf et al., 2003). Typically the onset of adolescence can trigger issues in social problem-solving as peers play an increasing role in the child's life. Higher cognitive functioning and more complex organizational skills are expected as students make the transition from elementary to high school, making deficits in these areas more pronounced. Thus, children that appear to have fully recovered from brain injury may, over time, demonstrate deterioration in cognitive, behavioural and/or socio-emotional functioning (Van't Hooft, Andersson, Sejerse, Bartfai, & von Wendt, 2003).

Despite possible variations, there are certain similarities that all children with ABI share, the most common being fatigue. The effect of fatigue can quickly and drastically exacerbate areas of need from the cognitive, physical, behavioural and emotional realms (Zinga, 2004). In the span of one hour, a student can range from appearing on-task and capable, to disruptive and unintelligible simply due to cognitive fatigue. Physical fatigue often makes daily school attendance impossible for months following an accident or illness.

A student with ABI will present with many cognitive deficits that can negatively impact on classroom learning. Attention, motivation, and initiation are foundational skills required for students of any age. As grade level increases, processing speed, abstract thinking, and expressive/receptive language skills become essential for academic success. Memory, reasoning and strategic thinking ability are key ingredients for classroom survival. Without self-monitoring skills, students may face profound social consequences. A student with ABI will be lacking in some, if not all of these critical areas (De Pompei, Epps, Savage, Blosser, & Castelli, 1998). Because of a previous history of school success, some changes in children with ABI may seem mild initially, but can have a devastating cumulative effect (Ylvisaker & Feeney, 1998).

In the school setting, many students with ABI are mislabelled as learning disabled, developmentally delayed or behaviourally challenged (Kumpf et al., 2003). Although some interventions may appear to initially meet superficial needs, they will likely fail to meet the more complex challenges. Unlike learning disabled students, a child affected by ABI may remember and utilize prior knowledge but have trouble attaining new concepts. The resulting knowledge gaps can make assessment difficult. Academic performance may constantly change due to pain and fatigue. Additionally, children with ABI have short-term memory issues that may be misinterpreted as comprehension issues. In such cases, the student may be moved to a lower level of programming when what is really needed are different teaching techniques to help the learner contextualize learning (Oberg & Turkstra, 1998).

Similar to other behaviourally challenged children, the student with ABI may experience social difficulties, anger management issues, and lack of self-awareness. Failure to initiate can be misinterpreted as oppositional defiance when a child appears to understand instructions but is unable to begin the sequence of steps required to fulfil the task (Kumpf et al., 2003). Social inappropriateness/unawareness can be mistaken for intentional misbehaviour. Mottram and Berger-Gross (2004) found that these disruptive behaviours, which included non-compliance, inattention and aggression, are often secondary to the cognitive and emotional difficulties following a brain injury. The teachers involved in the

Mottram and Berger-Gross study reported that behavioural issues represented the most significant strains on school reintegration. As educators, they felt they had inadequate preparation for managing students with ABI.

According to Ylvisaker and Feeney (1998), misuse of behaviour modification may result in confusion and withdrawal. Some of this confusion is related to misunderstanding of *executive function*. Keeley (2003) describes executive function as "a collage of cognitive activities that encompass the ability to design actions toward a goal, to handle information flexibly, to realize the ramifications of behaviour, and to make reasonable inferences based on limited information" (p. 10). Specific techniques for assisting executive function are often required in the classroom, but are rarely explained to the teachers.

In review, the student affected by ABI will have many cognitive and emotional sequelae that have the potential to negatively impact on school success. Secondary factors such as fatigue, developmental level, and inappropriate use of behaviour modification can quickly change the student's profile, and increase risk factors for failure in both social and academic spheres.

1.2 The need for a holistic treatment model

A common treatment model for pediatric rehabilitation after ABI is broken into three stages (Singer & Nixon, 1996). Stage One occurs in an acute care hospital, beginning at the time of injury and continuing until the child is medically stable. During this stage the focus is almost entirely on medical, life-sustaining issues. Once stabilized, children recovering from ABI wait for placement in an in-patient rehabilitation centre such as The Bloorview MacMillan Children's Centre in Toronto. This period of active rehabilitation is recognized as Stage Two, where an increased focus is given to regaining physical and cognitive abilities. Children work with a variety of therapists in a one-on-one setting, and often begin to spend some time in a classroom setting with a special teacher. Stage Three, which may not begin until several months post-injury, refers to the time of community and school reintegration, during which children return home and gradually begin to include normal daily activities in their routines.

In his 1996 phenomenology, Singer identifies the need to "humanize" the system of therapy delivery surrounding pediatric ABI rehabilitation. He notes the lack of ability of social institutions to recognize the child as a whole. His study focuses on the importance of a child's self-perceptions, and the need to recognize identity as part of a family unit. However, a great deal of a child's identity is also found through school experience, especially during adolescence as peer relationships grow in prominence. Thus a more complete holistic approach should not only include the child as part of the family unit, but should also encompass the socio-cultural interactions in the child/school relationship.

De Pompei et al. (1998) posit that the student's return to school can be devastating if the health care facility and the child's home school do not interact quickly and frequently. They suggest that as soon as a child is admitted into a health care facility, the school reintegration process should begin. Unfortunately, their study shows the reality is all too often the opposite and children are reintegrated with little, if any support service in place.

Mark Ylvisaker (personal communication, 2007) talks about the need for therapists to share their expertise so the routines of everyday life can be carried out and organized by everyday people, such as the parent, the teacher, or the coach. He describes *accordion-like* *supports* that can increase or decrease as needed during the child's daily regime. Cohen (1991) also describes the importance of the rehabilitation team reaching out and educating the community school prior to reintegrating a student with ABI. He suggests that this communication between the hospital and school not only allows the therapists to equip the teachers with effective strategies, but allows rehabilitation team to gain a valuable understanding of the pre-morbid functioning of the child. Both Cohen and De Pompei et al. (1998) suggest that school-site visits by therapists can help customize the strategies and routines to fit the reality of the community school situation. Furthermore, in-service of teaching staff helps address potential problems for reintegration before they occur.

A holistic model for pediatric rehabilitation must acknowledge the child's perceptions of self as a child, a student and a friend. Including the school early in the rehabilitation process helps ensure that these established identities are not overshadowed by the child's new identity as a patient, and provides a framework for communication and future school success.

1.3 The need for teacher awareness and education

The development of new medical practice has reduced mortality rates for children with a severe brain injury, while at the same time progress in first aid response has improved the projected outcomes of such injuries (Singer, 1996). Thus it is a fairly recent phenomenon that educators are experiencing an influx of children with such unique cognitive, sensory and neuro-motor challenges. It was only in 1990 that the U. S. Department of Education passed legislation recognizing traumatic brain injury as an area of exceptionality (Individuals with Disabilities and Exceptionalities Act, 1990), resulting in a growing body of literature addressing the need for teacher education and support. In their resource designed for educators, Glang, Singer and Todis (1997), describe approaches that have been effective in improving the experiences of students with ABI as they return to the community school. However, the role of a teacher in pediatric rehabilitation may be overlooked from the medical perspective. For example, a literature search of the Medline database, spanning the years 1980 to 2007, revealed 5,858 articles with the keywords *brain injury* and *children*, however only 16 of these articles (0.2 %) contain any reference to *teacher.* In the Psychinfo database, where greater emphasis is given to the cognitive and behavioural issues, rather than the purely medical concerns of ABI, only 1.6 % of the articles addressing pediatric ABI include *teacher(s)* or *special education* as a keyword. These studies focus on the need to communicate with the community school teacher in preparation for reintegration, rather than the on-going involvement of a teacher as part of the rehabilitation team.

In Ontario we have not yet politically recognized the uniqueness of ABI. Within the province there exist eleven categories through which students can be identified as exceptional. These include Behaviour, Autism, Deaf and Hard-of-Hearing, Language Impairment, Speech Impairment, Learning Disability, Giftedness, Mild Intellectual Disability, Developmental Disability, Physical Disability, Blind and Low Vision, and Multiple Exceptionalities (Special Needs Ontario Window, 2007). Although some consequences of ABI may fall into one of these categories (for example, Physical Disability), the unique cognitive and behavioural sequelae of ABI are not currently included within these eleven. Without formal identification, students with no outward physical disabilities often fail to receive ongoing educational support and review (Bennett, Good, Zinga & Kumpf, 2004).

Bennet, Good, Zinga and Kumpf (2004) acknowledge that regular classroom teachers are rarely provided with any training addressing the educational needs of children with ABI. A review of three texts used in pre-service and specialist certification for teachers supports this statement. ABI is not even mentioned in Schulz, Carpenter and Turnbull's text *Mainstreaming Exceptional Students* (1991). Two other current texts, *Children with Exceptionalities in Canadian Classrooms* (Winzer, 1999) and *Teaching students with special needs in inclusive settings* (Smith et al., 2006), include only short discussions of ABI as a low-incidence disability, even though ABI is the most common cause of death and disability of school aged children (Keyser-Marcus et al., 2002).

While the topic of adult rehabilitation following ABI has been addressed in a recent thesis (Smith, 2003), Canadians have focused little academic study with respect to the ongoing educational needs of children recovering from ABI. Not surprisingly, many students with ABI in Ontario's schools may be erroneously identified as "learning disabled" or "behaviourally challenged." Consequently, they do not receive the support appropriate to their distinct ABI-related needs related to executive function, language processing, and fatigue (Feeney & Ylvisaker, 2003). Once a child's brain injury is identified, practical in-service is required for most teachers and support staff to understand the varied consequences of the ABI before they can apply successful classroom strategies (Farmer & Johnson-Gerard, 1997). Glang, Singer and Todis (1997) acknowledge that

> despite the abundance of literature documenting the challenges involved in meeting these students' diverse learning needs, there has been little empirical research on the effectiveness of particular instructional strategies that would help guide teachers in designing instructional programs for the students with ABI (p. 94).

Through the combined efforts of the Ontario Brain Injury Association and Brock University, resources for teachers are becoming available, but the authors of *Educating Educators about ABI: Resource Book* (Kumpf et al., 2003) acknowledge that the strategies will go unused if teachers have little awareness of the presence of ABI in their classrooms.

The poor or improper identification of children affected by ABI is challenging because the brain itself frequently takes a much longer path of healing than the more outwardly obvious body components (Ylvisaker et al., 2001). Consequently, some students display no physical signs to alert an observer to a significant brain injury resulting in underreported TBI incidence and prevalence. In 1998, more than 50 percent of all students identified with special needs under IDEA (1990) were served under the category of Learning Disability. During this same time period only 0.2% had a TBI classification, yet the incidence of TBI in school age children during that same time period was 180 per 100,000, with at least 32% of these injuries expected to leave lasting deficits (Ylvisaker et al.).

Kumpf et al. (2003) describe the concept of *walking wounded,* a term used to define individuals with an acquired brain injury but no visible outward signs (i.e., physical disability) that alert others in their social or academic milieu of their disability. Included in this category are children experiencing closed head trauma that are unnoticed not only by school personnel, but also by the medical team (Kumpf et al.). Sometimes it is because other visible physical traumas (such as fractured limbs) are treated and the patient is discharged before hospital staff notice the more subtle signs of head injury. Depending on the age of the child it could be months or even years before the child's behaviour or school performance alerts teachers to a possible problem. According to Jantz and Coulter (2007) if the symptoms that these children display are misconstrued as common behaviour or academic issues, they are at high risk for school failure. Jantz and Coulter's study echoes the need for teachers to be taught how to recognize the manifestations of ABI in the classroom.

The review of the need for ABI education in the schools tells us that schools are receiving increasing numbers of children in their classrooms who have survived a severe ABI. The fact that ABI remains an unrecognized exceptionality and the reality that ABI sequelae are not routinely addressed in teacher training, results in a poor prognosis for appropriate and effective intervention. Children returning to school following an ABI are often mislabelled or receive interventions inappropriate to their needs, contributing to a poor prognosis for school success.

1.4 The need for on-going advocacy and support

Without an ongoing treatment protocol supported in the classroom, many children with ABI will not experience school success (Luiselli, Dion, Hammil, Potoczny-Gray, Savage, and Sherak, 2000). A study of 25 families trying to advocate for their children's needs when returning to the community showed that 100% of the participants expressed a high degree of frustration with the educational support services offered by the community school (Singer and Nixon, 1996). After discharge from an intensive rehabilitation program where students and their families have access to regular counselling support with psychologists and social workers, they found it challenging to return to a school setting where educators acknowledged they were only minimally aware of the social and emotional impacts of the trauma on the family. The teachers in the Mottram and Berger-Gross study (2004) felt ill-equipped to handle the ongoing behavioural and cognitive sequelae of a child with ABI. The subject of one case study (Hawley, 2005) showed marked deterioration in behaviour at both home and school during five years post-injury, largely attributed to long-term failure to use appropriate instructional strategies resulting in secondary behavioural consequences. Kumpf et al. (2003) suggest that when the student's apparent physical recovery overshadows the changes in their ability to process information, it increases the chances that the student's ABI will be overlooked in the classroom. Because of the less visible nature of cognitive disability and the transitional nature of school experience, important information and training is often not passed on to subsequent teachers after a child's initial return following an injury or illness (Shaughnessy, Greathouse, Neely, & Wright, 2006).

During the first two years post-injury, the healing brain can continue to make significant progress. According to Hotz et al. (2001) about 66 percent of children with TBI have returned to the school one year after an injury. Failure experienced during early school reintegration not only contributes to a negative school experience; it also results in a drop out rate of over 50 percent for older teens (National Dissemination Centre for Children with Disabilities, 2006). Students returning to the social and academic demands of a classroom without the appropriate supports risk resigning to failure before abilities have stabilized.

For most students with ABI, a lack of self-awareness makes self-advocacy a challenge (Wiseman-Hakes, Stewart, Wasserman, & Schuller, 1998). Even when individuals affected by ABI are given direct instruction and opportunity to practice advocacy in a learning environment, their memory difficulties can hamper the transfer of skills from classroom to real life (Beardmore, Tate & Little, 1999). Usually it is the parent who must take on the role of advocating for the educational needs of the child, a role that repeats itself every school term as the child's teachers and needs continually change (Singer & Nixon, 1993). Without formal identification, the need for advocacy is even greater. In the wake of little professional awareness about ABI, it can be a daunting task.

On-going advocacy and support is a constant and exhausting reality for the families of children with ABI. The lack of awareness in the community setting is compounded by the inability of many children with ABI to self-advocate. A parent of one such child summed up the challenge quite articulately, "It is hard to have the energy to fight for your educational rights, when you have just finished fighting for your life" (personal communication, 2004).

In summary, in response to improved survival rates following ABI, there is a growing body of literature aimed at increasing the awareness of ABI in various communities of practice. While many of these authors recognize the need to share this knowledge with the school system, none have explored the benefits of the direct involvement of a hospital teacher during in-patient therapeutic intervention. This study explores how this specific form of educational collaboration during early-stage brain injury rehabilitation promotes a holistic approach to treatment, while addressing the important issues of teacher education, ongoing advocacy and support.

Chapter Two: Purpose and Conceptual Framework

The purpose of this study is to explore the benefit of extended hospital teacher involvement through all stages of pediatric rehabilitation following acquired brain injury. There are a number of different classification systems describing the different stages of rehabilitation. This study adopts the stages identified by Singer and Nixon in their 1996 “Report on the Concerns of Parents of Children with ABI.” These stages include: (a) the period of coma, (b) the period of intensive rehabilitation, and (c) the period of reintegration into the home and school. First, I examine the therapeutic benefits of teacher involvement during the first two stages of rehabilitation, and how this relationship contributes a hopeful, holistic, and functional context to the therapeutic environment. Secondly, the socio-cultural impact of early-stage community school involvement is explored, while considering the benefits this collaboration brings to the issue of teacher awareness and education. Finally I investigate how this model can provide a framework to meet the need for on-going advocacy and support throughout the student’s educational career.

The major ABI issues identified in the literature review have been further explored through three case studies involving adolescent students affected by an acquired brain injury. The students, as well as family members, hospital and school personnel are interviewed and resulting conversations transcribed. Through immersion and crystallization (Crabtree & Miller, 1999) transcriptions are analysed to identify recurring themes. These themes have then been organized into meta-themes, which serve as a guide to discuss future model development.

The conceptual framework of this research has been greatly influenced by Vygotsky's perspectives on socio-cultural theory, John-Steiner's writings on collaboration, and Bakhtin's ideas of multi-voiced discourse.

2.1 Socio-cultural theory and the healing brain

Vygotsky's theories around the social origins of mental functioning (Wertsch, 1991) offer support to a school-focused therapeutic delivery model. A key idea of socio-cultural theory is that higher order functions of the individual develop out of social interaction. Vygotsky (1981) argues that in order to understand a child's individual development we must focus our study on the social world in which that individual developed. Tharp and Gallimore (1988) state, "through participation in activities that require cognitive and communicative functions, children are drawn into the use of these functions in ways that nurture and 'scaffold' them" (pp. 6-7). Kublin et al. (1998) state that "Vygotsky described learning as being embedded with social events and occurring as a child interacts with people, objects, and events in the environment" (p. 287).

A socio-cultural approach to how the mind learns includes the idea that "any functioning of the child's cultural development appears twice, or on two planes. First it appears on the social plane, and then on the psychological plane" (Vygotsky, 1981, p.163). A socio-cultural approach to paediatric rehabilitation following acquired brain injury must recognize that the community school setting provides an ideal laboratory for the internalization of familiar social routines. Executive function, an often-impaired cognitive activity following a brain injury, could be described as the base of intra-mental functioning. The role of the therapist or teacher can be seen as an external support to executive function, modelling problem solving on a social plane. One of the greatest challenges to children with brain injuries is their inability to transfer modelled social relations to higher mental functioning (Selznick & Savage, 2000). From the child's perspective, it appears invaluable to have the opportunity to be involved in the familiar social milieu of a school setting while seeking to reconnect the fractured intra-mental functioning of the injured brain.

Vygotsky is considered to have a unique approach in that he perceives disability as a socio-cultural developmental phenomenon (Kozulin, Gindis, Ageyev & Miller, 2004). He theorizes that many symptoms associated with an organic disability are considered to be secondary handicapping conditions because they are acquired in the process of social isolation. Expectations and attitudes of society "influence the access of a child with a disability to socio-cultural knowledge, experiences, and opportunities to participate in shared or joint activities with peers" (Kozulin et al., p. 203).

The research of Taylor, Yeates and Wade (2002) supports the ideas of Kozulin et al. (2004), suggesting that behavioural outcomes in children with ABI actually worsen following the environmental challenges during the years after the injury. Often the social isolation and educational exclusion caused by challenging behaviour produces a negative feed-back loop of increasingly greater gaps in age-appropriate behaviour leading again to increasing isolation and exclusion for students with ABI (Gardner, Bird, Maguire, Carreiro, & Abenaim, 2003).

A socio-cultural model for children involved in ABI rehabilitation would pro-actively support social inclusion by the early involvement of a social support system including peers, teachers and family, as well as the typical medical and therapeutic professionals. It is ideal to deliver interventions and supports within the child's everyday routines of life from the beginning of the rehabilitation process and to use everyday people, such as teachers and family members, as primary deliverers of the interventions (Feeney & Ylvisaker, 2003).

2.2 Educational and therapeutic collaboration

Collaboration, by its very nature, involves a variety of tensions as the lines distinguishing areas of responsibility and expertise can quickly become blurred. In her text *Creative Collaboration,* John-Steiner (2000) identifies three key elements in effective collaboration. The first element, a willingness to tackle differences, describes how "collaboration thrives on diversity of perspectives and constructive dialogue between individuals negotiating their differences while creating their shared voices and visions" (p. 6). The second element is described as *mutual appropriation,* a term which John-Steiner refers to as "a fascination with one's partner's contributions" (p. 64). This can only be realized through an investment of familiarity between team members and a shared knowledge base. Finally, shared trust and risk-taking is identified as a critical element in successful collaboration. Wallace and Gruber (2000) reflect, "What collaboration does for you is, by spreading the risk a little bit, it encourages you to take more chances" (p. 13).

A collaborative model in education is practiced in most school settings on a number of levels. For example, a child's education is divided up into courses and programs that are taught by individuals possessing expertise in specific subject areas. The special education teacher may act as a consultant to equip the subject teacher with strategies to appeal to different learning strengths represented within each class. These teachers work together in collaboration to help the student reach the shared goal of graduation. In the health field, Enhancing Interdisciplinary Collaboration in Primary Health Care (EICP) is a relatively new initiative designed to develop a framework to describe how primary health care professionals can deliver services more effectively and efficiently (Enhancing Interdisciplinary Collaboration in Primary Health Care, 2006). Teamwork is an inherent concept of collaboration. The EICP identifies the differences between multidisciplinary teamwork and interdisciplinary teamwork. The former includes several disciplines with various knowledge and skill bases that are drawn together into one structure to provide services. Interdisciplinary teamwork includes the integration of a group of individuals with diverse training and backgrounds who work together as one unit. A key difference in the interdisciplinary approach is that team members collaborate to solve problems that are too complex to be solved by one discipline alone or by many disciplines in sequence (Soever, 2006).

The interdisciplinary teamwork experienced in the rehabilitation setting is unique in that it includes collaboration not only between a variety of professions, but also between two different institutions; the hospital and the school. The type of collaboration experienced in a rehabilitation setting could be described as *complementary collaboration,* which includes a division of labor based on expertise, knowledge, role and temperament. "Participants negotiate their goals and strive for a common vision" (John –Steiner, 2000, p. 198). The diverse selection of stakeholders involved from the intensive care unit to the community school can only hope to work effectively when they focus on a shared vision. Indeed a holistic approach (Singer, 1996) involves much sharing of knowledge and constructive communication between disciplines in order to support the affected individual, who must be seen at all times as a patient, a student, and most importantly, a child.

From the hospital perspective, I have observed how partnering with schools from early in the acute stage (to create a clear baseline picture) through to classroom integration promotes a high degree of communication and teamwork between medical and educational professionals. Figure I provides a visual representation of the framework for collaboration. Outlining our facility's current model for an extended partnership between the community school and the rehabilitation team, it begins with the acute injury and in-patient rehabilitation. It continues during outpatient rehabilitation, while the patient lives at home with therapeutic support, and culminates with the return to school. The square boxes indicate the site of primary care at each stage of the rehabilitation. Arrows indicate the input of off-site, secondary or tertiary care providers.

I have already noted that De Pompei et al. (1998) point to the need for educational and therapeutic collaboration. In fact, they suggest that as soon as a child is admitted to the health care facility, the school reintegration and transition process should begin. The sharing of information about the long-term rehabilitation needs of children with existing community services, especially schools, is essential to the continued growth and development of the child (Savage, 1997). Blosser and Pearson (1997) suggest a six-step approach (see Appendix B) that includes the necessity of building a team linking the hospital, school and community that shares a common philosophy. As in John-Steiner's (2000) concept of common vision, this shared philosophy will help guide differences in opinion when looking at medical and educational perspectives.

Family members, friends and familiar support staff are the ideal vehicles for the delivery of interventions and supports in order to support successful long-term maintenance (Feeney & Ylvisaker, 1998). These supports should be incorporated into the child's everyday routines of life. This approach advocates collaboration with children affected by the disability in order to offer them choices and decision making opportunities.

2.3 Multi-voiced discourse

Over the last decade, qualitative research has ventured into less traditional forms of representation. Eisner (1997) advocates for the use of more realistic forms of data representation in qualitative inquiry while Richardson (1997) incorporates a variety of performing art forms to represent aspects of learning, understanding and individual growth. Leland and Harste (1994) discuss the notion of *transmediation*, "the movement between communication systems such as language and art" (p. 338) as an effective means of addressing the issue of multiple intelligences (Gardner, 1983) and multiple literacies. A specific example of this approach is found in Meyer's (2001) exploration of *theatre as representation* (TAR) as a teaching and presentation medium for qualitative research. TAR is a teaching medium that employs a live performance or reading of an original dramatic scenario (either in full out theatrical performance or in a reader's theatre setting) based on a true-life incident. Meyer describes traditional case study as "an external documentation that requires a passive reading and linear analysis" (p. 151). The TAR approach involves the viewer at a higher level, "from simply describing the case to exploding its language into an emotional reality" (p. 151). Bakhtin (1981) characterizes this process of active and engaged understanding as one that

> assimilates the word under consideration into a new conceptual system, that of the one striving to understand, establishes a series of complex interrelationships, consonances and dissonances with the word and enriches it with new elements . . . it is in this way, that various different points of view, conceptual horizons, systems for providing expressive accents, various social *languages* come to interact with one another (p. 282).

Reader's theatre is one form of TAR in which selections of the actual words of participants are read aloud by actors in a storytelling fashion to emphasize the contrasting perspectives of the different voices involved. Because there are no props, costumes or sets, the emphasis is on oral expression; no physical acting is involved. Borrowing from the style of reader's theatre, I have tried in this thesis to dramatically capture the interaction between family members, hospital staff, school personnel and the students themselves during each stage of rehabilitation. I believe that through the actual reading of (and hence interacting with) the voices of the participants we gain a richer understanding of both the internally persuasive discourses (pre-existing beliefs) and the discourse encountered through the rehabilitation journey. The dramatic component of voice aids in the experience of *intertextuality*, the message that "lingers in spaces between the words" (Bruce, Feng, Nishizawamiko, Palulis, Russel, & Worthing, 2003). Bruce et al refer to the "potential offered by re-cognizing notions of text" as one that allows both researchers and teachers the opportunity to "step into a space of intertextuality that at once expands the notion of text – from book to school to community to spaces between the words" (p. 2). The reader's theatre presentation style of the research data helps all stakeholders hear-through-the-ears and see-through-the-eyes of their partners in the rehabilitation journey, creating a powerful intertextual experience.

2.4 Research question

Ultimately, the goal of the rehabilitation team is to see the child settled happily and productively in the world outside the hospital doors. With this goal in mind, the study's central question is: *How can the involvement of a hospital teacher support an extended partnership between health and education professionals to meet the diverse and dynamic needs of an adolescent with acquired brain injury during rehabilitation and reintegration in to the community school?*

Chapter Three: Methodology

3.1 Tradition of inquiry and research method

Using a case study methodology (Creswell, 1998), this study explores the potential for educational and therapeutic collaboration during pediatric rehabilitation following an acquired brain injury. A case study approach has been used in pediatric rehabilitation research in both medical and educational settings (Glang, Todis, Cooley, Wells, & Voss, 1997; Mottram & Berger-Gross, 2004; Selznick & Savage, 2000; Slifer et al., 1997).

Each of these studies looks at a selection of three adolescents at various stages in the rehabilitation process, specifically addressing behavioural issues. Settings include an in-patient rehabilitation setting (Slifer et al., 1997), a private school for students with brain injury (Selznick & Savage, 2000), a community school setting (Glang et al., 1997) and an after-school program for adolescents with severe health problems (Mottram & Berger-Gross, 2004). The time frame of each study varies from six weeks to four months of observation. All studies employ the use of a customized behaviour rating scale (designed to measure the effectiveness of a specific behavioural intervention over time). Each study also uses information gathered through one-on-one consultations with medical or therapeutic staff to situate the individual needs of each participant. The focus for each study is primarily on the effects of a specific intervention on disruptive or anti-social behaviours.

Similarly to the above-mentioned research, the present study examines three individual cases, generating a significant volume of data given the qualitative nature of the design. The length of time described within the bounded system varies for each student between two to four years, beginning at the time of each child's accident, following through several months of intensive rehabilitation and continuing through school reintegration. As an instrumental case study (Creswell, 1998), the focus is on the specific issue of educational and therapeutic collaboration, rather than on each case itself.

The methodology, or process of research, is comprised of digitally recorded and transcribed vignettes gleaned from interviews with multiple sources of information “to draw the reader into the case” (Stake, 1995). Besides interviewing each student, I spent time in directed conversations with an additional family member who remained most present throughout rehabilitation. In each case this happened to be the mother. While it is interesting to note the consistent presence of the mother as the principal nurturing adult from the family structure, it falls outside the scope of the present study to further study the causal explanations for this.

A representative from the pediatric rehabilitation team was also selected. Our rehabilitation team is headed by a pediatrician/physiatrist (physical medicine specialist) who works closely with a psychologist and nurse case manager. Other team members include physiotherapists, occupational therapists, speech and language pathologists, social workers, chaplain, hospital teacher, child life specialist, dietician and discharge planning nurse. For each study, the nurse case manager was selected as the participant. Her responsibilities span all aspects of the in-patient rehabilitation program giving her the broadest range of first-hand knowledge of each case. It is interesting to note that our facility includes acute care, active rehabilitation, and out-patient follow-up all under one roof, allowing the team members that meet the family in ICU to continue to be directly involved with the patient through all stages of rehabilitation. A majority of rehabilitation facilities are housed in separate locations from acute care hospitals where medically stable patients may be sent home to wait for an available bed at a rehabilitation centre.

Finally, a teacher from the community school was selected for each case. This special education teacher is responsible for arranging the Individual Education Plan for all exceptional students. He or she is the main communication link between the hospital teacher and the school for each case.

Each participant was given an advance copy of an interview guide developed to assist them in reflecting on each stage of the rehabilitation experience (Appendix A). The descriptions gleaned from these one-to-one interviews focus on the psychosocial journey rather than on the purely physical issues of the case. "Personal narratives and life histories are prominent forms of qualitative work that explore the lived experiences of people with disabilities" (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005, p. 199). By using the actual words of all participants, I have tried to capture the multi-layered texture of each story and the contrasting perspectives of individuals involved, including those who have been historically marginalized (Brantlinger et al.).

3.2 Philosophical framework

This study takes the ontological stance that social reality differs from group to group and even individual to individual. From a constructivist perspective (Guba and Lincoln, 1994), I acknowledge that the participants understand and experience the issue in their own unique way. It becomes apparent that the students have limited first hand recollection of the early stages of injury, due to their level of consciousness at the time. Photographs and stories from family, friends and therapy staff may have augmented their memories. However, their perspectives remain valuable in that they show how they attempt to make sense of the new reality they awaken to after a life-threatening accident. Family insights contribute to the dialogue as extremely vested observers to the rehabilitation process who must ultimately incorporate this new world into their everyday life.

Conversely, in the eyes of the medical specialists, participation in rehabilitation practice is a normal daily experience. They do not need to reconstruct meaning and rationale with every new patient, yet they need the flexibility to respond to the unique abilities and challenges presented by each child. Community school teachers must find a way to reconcile their teaching style and classroom management to meet the behavioural and cognitive needs of the reintegrated student. My own sense of reality as the researcher is equally distinct because my role in the rehabilitation process spans all three "places" in the system (hospital, home and school).

Epistemologically speaking, my study is a kind of reflection of my own practice. Acknowledging my bias, the reality of my unique involvement with each student, it was difficult to analyse the data without a set of pre-existing themes in mind. I believe however, that my personal insight into each case allowed me to interact with participants on a deeper level, revealing issues that would otherwise go unnoticed through casual questioning and review. Working from the premise that knowledge is a human construction (Hatch, 2002), the participants and I co-constructed our understanding of the role of educational collaboration during rehabilitation. Throughout the research process my relationship with each participant shifted according to the varied roles and responsibilities I had in relation to them; teacher, teammate, peer, mentor, and friend.

The values that shape the rhetorical structure have been formed through my experiences in the education system at many levels, both as student and teacher. My values are greatly affected by the unusual role I play in the field of education; my involvement straddles both the health and education professions, offering unique insights into two differing paradigms. The hospital paradigm, seeing the child as a collection of parts, focuses on the need for reconstruction or repair in order to function effectively as a single unit. The school paradigm, seeing the child as part of a collection, focuses on the need for cognitive performance and appropriate social interaction with other students.

3.3 Site and sampling

The cases are comprised of narrowly conceptualized bounded systems detailing a period of two to four years. Each of the three young adults was selected from the convenient population of students treated over the past four years in the rehabilitation program in which I work. While effort was made to select a student sample diverse in age, gender and socio-economic status, the available sample was limited due to ethical considerations such as age at the time of interview. All candidates share the common experience of a motor vehicle accident resulting in a severe acquired brain injury requiring several months of hospitalization, followed by a lengthy stay at home prior to a gradual return to school. Bounded in time from September 2002 to March 2007, these cases are by definition *within site* (Creswell, 1998), with three places included in the system, each representative of the students' progression: the hospital, the home, and the school.

Potential student candidates were identified and contacted by the rehabilitation case manager. All candidates initially contacted agreed to participate in the research. At this time students also gave consent for other stakeholders in their rehabilitation journey to be approached. Additional interviewees were selected as a convenient, purposeful group, recognized as those individuals who were principal participants at the three sites of rehabilitation: from the hospital, the nurse case manager; from the home, the mother; and from the school, the special education coordinator.

3.4 Instrumentation

Data collection occurred through digitally recorded, informal, one-to-one interviews. In an effort to avoid any manipulation of the participants' responses, I intentionally avoided including any of my own recollections in the taped sessions. Likewise, I did not refer to my personal journals to verify details; however participants were allowed to bring personal records and notes to the interview if so desired. Interview times lasted between eighteen and forty-five minutes, and were guided by the use of the questions outlined in Appendix A. These guiding questions were given to participants in advance of the interview times in order to allow time for recollection and reflection. It should be noted that these questions were developed through an unpublished pilot test carried out on a similar sample in October of 2004. At that time these questions were successful in helping the participants reconstruct and reflect on experiences that were personally meaningful and motivating, rather than eliciting predetermined response.

3.5 Data analysis

The use of a digital recorder allowed me to focus more on the interview process, giving opportunity for me to clarify meaning through more specific questioning in the emerging discussion time. Interviews were transcribed into more than one hundred pages of notes. Using the transcribed notes from each interview, I purposefully organized the data in two separate ways. First I organized the comments in a chronological manner in such a way as to tell the story of each case, picking meaningful, representative statements allowing each participant to have a voice in reader's theatre format. The goal of this first collection of narratives is to give the reader opportunity to experience the unique story within each case and begin to visualize the key players involved.

Secondly, I analysed the data for specific themes using the immersion and crystallization approach (Crabtree and Miller, 1999). This process involved immersing myself in the data in order to absorb the text. Through hours of listening to, and careful rereading of transcriptions, and coding of recurring words and phrases, specific themes began to crystallize. The following five sub-questions derived from the study's central question served as a framework in which to initially organize these themes:

- How can the school best support rehabilitation during the acute phase?
- How are therapeutic goals combined with curriculum goals at the high school level?
- How can the rehabilitation team support the community school during reintegration?
- How might the spectrum of hospital and school collaboration be described?
- What other themes emerge from gathering information about the case?

When organizing the data to address these five questions, three meta-themes clearly emerged related to Early Intervention, Teamwork and Communication, and On-going Support. The second collection of narratives is organized around these meta-themes, allowing the reader to experience the convergence of themes and the tension arising during the interaction between differing persons, perspectives and practices.

Chapter Four: Three Stories

Each of the following case studies provide a multi-voiced description of each story, shared in the actual words of the student, a family member, a member of the hospital team, and a teacher from the community school. Students' names have been changed, as have other minor details that could potentially compromise the anonymity of each case. Other participants are recognized only by the designations: family, hospital and school. I have not included any of my own words in an effort to allow each reader to respond to the un-edited voice of each participant and thus become a fifth player in the dialogue.

4.1 Brad's Story

a. Injury and acute care

Family – It was Sunday evening in the fall. He went out for a drive in the neighbourhood with some friends of his. We got a call at 8:30 from another friend who was out with them saying that Brad was in an accident. We thought it was a fender bender so we were getting ready to ground him for a very long time.

Brad – Uh, I was supposedly driving down the street with my friends, I was a passenger in the car, and we were going down the street I guess a little too fast and lost control going around the corner.

Family – Fire trucks went by our house and we followed the fire trucks, and when we got there, he was still in the car – trapped in the car, there was gasoline on the ground, potential fire explosions, the whole bit, and as a parent I was looking at the fire hoses wondering, why are they going to wash the car? That was all I was thinking.

Hospital – They had to use the Jaws of Life to get the passenger, Brad, out of the vehicle. His GCS was less than 7. The saying goes 'Less than 8 – you're too late.'

Family – The police stay around to make sure the victim is still living. The psychologist stays around to make sure the parents don't flip out. And they tell you "if he makes it through five hours," or "if he makes it through ten." If he just makes it through.

Family – He had a seizure on the table in ER. Plate and pins in his wrist and upper arm. Ruptured bladder, damaged urethra, broken pelvis, broken ribs, and those are the good parts of the injury. The other part was the head injury. His head was injured in the lower left, rear quadrant of his brain.

Family – There are two kinds of damage. There is immediate damage and secondary damage. The secondary damage happens because of the swelling and bleeding inside.

Family – They put medication in his body to cool him down and they laid him on a bed of ice as part of the hypothermia study. They didn't cool him way down, but he was cooled down enough that before you touched him you had to remind yourself that he wasn't dead.

Brad – I don't remember anything from the ICU.

Family – He doesn't realize it, but he did hear things. At one point we put a music tape on his ears and whenever we played it, his heart rate would go up. All the medical indicators were that there was some kind of input getting through.

Hospital -- Physiotherapy started working with him during his significant state of comatose, to try to keep some range of motion.

Family – The scariest thing for us was the day the school sent in the school chaplain and didn't tell us. We thought he was getting last rights.

School – Apparently the ICU nurses were getting inundated with calls. The parents had to go into the school and ask the principal to stop the calls because Brad needed his rest.

Family – When he first started waking up in emergency it was not like waking up. He started coming conscious one piece at time. It started with his toe.

Hospital – The nurses would say, "Oh Brad is awake," because his feet would start crawling up the medication poll and his toes would feel around and then they would come back down.

Brad – I remember waking up mid-October and seeing . . . a wrap around my hand to prevent me pulling out the feeding tube out of my nose, and um, yeah, it was pretty foggy for the first couple days that I remember.

Family – In ICU, and before Brad was ready for rehab, there were so many people doing so many different things. You take the body and you divide the body into multiple mini-parts, and there is somebody there for every part. It got to the point where someone would come in and I would say, 'Okay, so what body part are you here for?'

b. Rehabilitation

Hospital – When he was coming out of coma and he was becoming more oriented and his parents were sharing things and we were hearing about his schooling and academic performance prior to the accident . . . what we were hearing about was a child, teenage boy, who had a real lack of caring and he wasn't putting the time or the energy or the potential forward that everybody knew he could. Our team was faced with the very real concern of whether or not he could actually pull the rehab part of this off . . . but Brad really came to the plate for most therapy times.

Family – I asked a lot of questions. The more I understood as a parent the more I could convince my child of what he needed to do.

Brad – I had a hard time finding the words. I had a hard time . . . thinking of what to say. I had a hard time . . . getting it out. I knew what I wanted to say, but I couldn't say it. It was very frustrating.

Family – The difference with the rehab team is that they don't just look at parts, they look at the whole. Whereas they may work on the parts, but they do it more as a team on the whole. They have more of a balance.

School -- Interaction with the hospital was almost immediate. I did visit Brad very soon after the accident, so I did see his progression from the accident right through his rehabilitation.

Family –When you are in acute care it is "What can I move that isn't broken." It keeps you at status quo. When you move to rehab it is about progress. "Let's see how far we can go."

Rehabilitation: Physiotherapy

Brad – Physio-terrorist!

Family – It was a lot of hard work.

Hospital – Physio was significant due to brain injury, multiple fractures and one-sided weakness.

Brad – Oh man, WOW! Big part, big part of my rehabilitation. They got me out of bed. They got me up walking again. They helped me do a lot of things on my own again that I had relied on other people to do for me.

Family – I remember the physiotherapist taking off her shoes, climbing on the bed and feeling the body with her eyes closed. It was the most bizarre thing. You watched her and it was as though she was stripping off the skin, the muscles and getting down to the bones.

Brad – It was a pretty motivating activity because I was really tired of lying around, I mean literally lying around, and I wanted to get up and get out as fast as I could.

Rehabilitation: Occupational therapy

Hospital – The role of OT is to improve function and strength in the upper extremities and fine motor movement. They also work on cognitive, visual perceptual, memory and concentration tasks. The activities of daily living.

Family – The purpose was life-skills. You used to write with your right hand before, now how can we establish the same goal using your left hand? How to put on a shirt and button it up without mom helping.

Brad – I didn't much see or feel the need for an OT, but um, I guess she kind of did help me by testing what I could do so they could classify me or something.

Family – OT is what taught me to shop differently. Short socks versus long socks. Very, very practical.

Brad – She did teach me to use my left hand instead of my right, like to pick up a glass of water.

Rehabilitation: Speech pathology

Hospital – Our Speech Pathologist began by giving the parents strategies on how to communicate with this child who was very disoriented. They worked on communication issues.

Family – She made us a pictorial speech guide. Brad started speaking the next day. Once he started speaking Speech helped me to understand what he really meant.

Brad – They went through a bunch of exercises to help me get my words out.

Family – One day Brad was really, really frustrated. And I came in and he kept saying to me, "Untie my breakfast." And I thought, "What in God's name is he talking about?" Well, he had a banana he wanted me to peel. Speech helped me to think outside the box.

Brad – I remember reading the same thing day after day after day after day in the hospital. More strategies, more reviews, more tests. The tests, the tests, the tests.

Rehabilitation: School

Hospital – Although not part of the medical team, the teacher is definitely part of the rehab team. . . I especially remember her working with Brad, and while his school was studying one novel, the teacher found an abridged version to work on so he could complete his English Credit.

Family – At first I thought, what in God's name are these people doing? Are they idiots?

Brad – I remember thinking “Bummer” when I heard I was going to have a teacher in the hospital. I thought it would be a mini-vacation with no homework. It wasn’t, but she made it easy to succeed.

School – I think the connection to the school, he knew what was being studied at school, an experience he knew had relevance, the fact that it is a normal activity, that was what he needed at that point.

Family – And eventually I figured out what it was about, that school with these kids is normal. None of the other therapists is normal, because they never had to do anything with it. But school is.

Brad – It helped reintegrate me back into my school. And into the world.

c. Community reintegration

Family – I think a big reason why Brad never thought of NOT going back to school is because school started in the hospital. You had school because you are sixteen. And sixteen year olds go to school. It’s real life.

Brad – When I first got home I had this home instructor. I was open to the idea but she ended up talking a lot. The non-stop jibber jabber, it tired me out really fast.

School – We actually started this two to three months before he officially came back. He was coming back for one period unofficially and he was getting support through our home-tutoring program.

Brad – The tutor spoke a lot, she spoke quickly, she spoke about nonsense – it got me prepared for real school.

Family – When we had the first meeting at the school the whole team was there. It was the OT who talked to the teachers about the wheelchair, the emergency exits, that kind of stuff. The Speech Pathologist talked about the language stuff.

School – There was more concern around the physical layout of the school, how will we get him into the classroom, do we have room to put the wheelchair and the desk, if there is an emergency do we have a way of getting him out . . .?

Brad – I think it was all wonderful. The first team meeting that we had back at school was with me, all my therapists, my parents, and my teachers at the same time. All I heard was praise from every single person, and that was an unbelievable feeling right there.

Family – Brad's school, when we explained the issues, found a way to work around it. . . the things that really worked well were the gradual integration back in to school. . . working with the school and with the parents, finding those special classes. That's the key to success.

Brad – I don't really remember the first day back at school. I was only there for one class that day, and it was overwhelming I think -- just seeing everyone and everyone wanting to say "Hi!" and wanting to talk.

School – It was really helpful for the hospital and parents to relay concerns to us prior to him coming back because Brad would not, could not, have communicated a lot of things to us. Because his temperament, his personality was proud, he didn't want to appear that he was different, he wanted to sort of just roll right back into the school like he always had.

Brad – I was in a chair for the first couple of weeks and then I started walking because I figured I could do it. My parents would have rathered that I had stayed in the chair, but who are they to say what I can do?

School – The biggest thing for Brad was that he didn't want to access help. He wanted to do it on his own. And the rehab team gave us strategies about what to notice physically in Brad if he was over-tired or it was just going to be too much for him that day.

Family – Having a school that was behind you was key. We hand picked the courses first based on what he needed, then we hand picked the teachers from the ones that were available, based on their teaching and communication styles.

Hospital – He had a wonderful advocate as a parent and a wonderful guidance counsellor. The school was very understanding at the beginning, in setting up the types of courses he needed to get him going back to school. His first while back to school he felt successful. And that is what we want for these kids. We want safety and success.

School – There were a lot of successful indicators. He continued to develop with regards to his speech. He had a girlfriend with him at prom. He did go on to graduate, so all of those things that everybody else did he continued to do.

Brad – I go to college now and they have a centre for students with disabilities and they are phenomenal. Their support is there if you need longer test hours, a different location for tests, they have so many more accommodations available.

School – He won the principal's award. We always nominate a student who has gone through a traumatic event but still overcame that event or rose above it to graduate and meet their goals. He also became a voice for the children's hospital, which was interesting because he took control of the situation, in some sense and sort of turned it into a very positive, sort of social change kind of thing.

Brad – I am definitely more involved with absolutely everything. I understand where someone is coming from with a disability because I myself have been there. I am definitely all for charity. I jump at the chance to lend a hand wherever I can.

Family – At 21 years old I always thought I would have a lot less involvement in his life. When he started college I really tried to see what would happen in his life if I backed off. Well, he got a B and a C and a D-, another D- and an F. The hardest thing is asking yourself at this age "What is the injury and what is the 21 year old?"

Brad – Ten years from now I want to be working, with a nice car of course, maybe in a relationship, definitely living on my own and away from my parents. Working full time at a government job or anywhere in computers because, yes, I am a nerd. But I am the cutest darn nerd you've ever seen.

4.2 Adam's Story

a. Injury and acute care

Family – Adam was coming back from a movie one evening in December. It was winter and there was snow left on the road. He had the right of way at the intersection and I believe he thought he had enough time to get through.

Hospital – He was the driver of a smaller car and T-boned at an intersection with a pick-up truck. They had to get the Jaws of Life to get him out of the car. He was airlifted up to the hospital.

Family – When we arrived at the hospital at first they told us he was just getting stitches. Then they asked again for his name. The nurse at the desk said, “Just by the description you have given me, I know its him.” And right away I knew there was something more, something wrong. He couldn’t talk and he couldn’t tell them who he was.

Hospital – There was a prolonged period of decreased level of consciousness and diffuse injury – both the brain injury and other injury as well.

Family – I thought coma, okay, when he wakes up it’s gonna be “Oh Mom! Where am I? What happened?” but it was completely the opposite. It seemed like in the trauma unit they didn’t have enough resources to fully tell us how he was going to be. He would get a little bit of one eye just a little bit open. After that it got to be a little bit more. Maybe a little twitch on the finger, a little on the foot, the one foot because the other side was completely paralyzed.

Adam – I know little bits of chunks of little things. But I don’t necessarily remember much.

Family – He stayed at one hospital for six weeks. He was in a coma for approximately three weeks, then it took him another three weeks of slowly coming out of the coma. He was in the ICU for nine of those days and then they spoke to us to ask if it was okay if they put a tube in. We felt he would be a lot more comfortable so we agreed to that.

Hospital – He had a tracheotomy, was ventilated and spent a fair bit of time in the trauma unit dealing with some medical issues.

Family – One day he was in the wheelchair with Velcro around the forehead, and I was clipping his hair. He had wanted me to cut his hair about a day before the accident and I always use clippers. So after I clipped his hair he had the biggest yawn – and it was so, you know it was so – it was the greatest thing I had ever seen! And every time he would yawn I would think okay, okay. Wake up! And slowly it got more and more.

b. Rehabilitation

Hospital – On the 25th of January he was transferred to our hospital for rehabilitation.

Family – He started saying his first couple of words at about the six-week mark. "Oh no!" "Oh God!" You know, things like that.

School – There was an early contact from the hospital to get an idea, an educational baseline of what Adam's history had been so once he came out of the coma they could decide what his abilities were and try to ascertain what the dysfunction was, how much of it was caused by the accident and how much of it was pre-existing.

Family – Once we started rehab there were a lot more people interacting with him. Once we got here there was just everybody coming in to say "Hi" to him at least once a day. There was physio. There was his teacher – she would come in everyday to see him even for a couple of minutes. It seemed like there was a lot more information and activity here. It seemed like they took care of the family better.

Adam – I just remember all blurs. People tell me what happened so now in my memory I tell you what other people told me what happened.

Rehabilitation: Physiotherapy

Hospital – The physiotherapist worked with movement and mobility issues with the goal of ambulation.

Family – This was a huge role. At the time Adam believed he would never be able to walk again and I think a huge part of anybody's life is just to get around walking and the physiotherapist showed him it is possible.

Adam – Physio helped to be able to do, uh, I don't know, to be able to do, like everyday things, like be able to walk and uh, stand up, to have when I stand, to have, uh, good posture.

Family – Swimming – he was so motivated with swimming. He looked forward to it every time on Wednesday. He couldn't wait.

Adam – For some reason I just remember that on Wednesday we went swimming at the uh, rehab college.

School – Adam was moving, doing some physio, again the hospital was in contact with the school to try to set up looking at some credits he could recover. I think he actually completed a phys-ed credit that was tied in with his physiotherapy.

Rehabilitation: Occupational therapy

Hospital – Occupational Therapy included the activities of daily living; grooming, hygiene, eating.

Family – OT was another huge role, you know because he needed help to uh, learn to button his own shirt, button his pants, take off his t-shirt, different techniques because otherwise I would have to help him on and off with his shirts and other clothing. But they helped him with different ways of doing things rather than doing it for him.

Adam – Uh, I didn't know the purpose of it, but uh, they taught me like, how to pick up a pencil so I could write better. Yeah, that's about the only weird thing I can remember about it. I don't really remember much.

Family – I remember the cooking with OT. He was so excited – he loved doing that. You could tell he loved his food!

Rehabilitation: Speech pathology

Hospital – Adam was very disoriented as he came out of his coma. Speech worked on orientation and communication issues.

Adam – Different kinds of sounds, like ummmm, ahhhh, ummmm, ahhhh, ummmm, ahhhh. Yeah, stuff like that. Different exercises everyday.

Family – Speech had a big role because at the time his voice was so low, it couldn't barely ever – you couldn't really hear him. It was just to help him practice to strengthen up his vocal chords and to connect his letters and words more clearly so we could understand him.

Adam – I guess maybe speech was boring, because you just kept on repeating exercises like ummmm, ahhhh, ummmm, ahhhh, ummmm, ahhhh, everyday.

Family – It seemed boring but I know it helped him. He couldn't see how it was helping him but it was, all the repetition. So it was boring but not meaningless. It was very meaningful.

Rehabilitation: School

Family – When I first saw the teacher, it was like "What are you doing here?"

Hospital – One of the things that I remember with Adam's rehab stay here at (the hospital) was when I first met the family to kind of get a feel for the child's interests and school history. And they indicated at that time that he was an OK student. We learned later, through our teacher liaising with the school that uh, a) the family may not have been as involved with the child's schooling, and b) that the child was maybe not as uh, interested a student as we had first heard from the family.

Family – At the beginning, especially when he was just coming out of the coma I was thinking, you know he can't do any work. But after the whole process you know, looking back on it now, we understand now why the teacher came in, even to say "Hello" just to let him know that she was there and once he was capable of doing work that she was able to work with him.

Adam – School, I think it was daily. Kind of hard to remember.

Family -- I remember she brought in a magazine with snowboarding because she found out he liked snowboarding and they did a little project cutting things and putting them on his board. We found out that he could actually do more things (than we thought) so it was well worth it.

Adam – I just remember doing the novel study. The novel study and then watching the movie at the end.

Hospital – I really believe that it was through the school piece that we were able to reach some of the functional rehabilitation goals, by working side by side with the teacher here at (the hospital) and the family and then liaising with the community school.

School – I think for both Adam and for his family it was important that they knew the school was supporting what the hospital was doing and that the hospital was in communication with what the school would be doing later on down the road. He was more motivated to do the school stuff actually than some of his other therapy.

Family – He was excited about school because everyday it was something different, doing math, doing the homework – most of the time before the accident he never would have bothered doing homework, but when he had homework he would be like – "Hey, we have to hurry up and do our homework before, what's her name? Oh yeah, (the teacher) comes."

Adam – It didn't seem like a normal thing to be doing at a hospital but it seemed normal because uh, that's what I'd been doing since I was like, four or five.

c. Community reintegration

Hospital – I think the child had a family that really wanted to come to bat for him, that really tried to advocate the best they knew how. At discharge, because he was 18 we had to turn him over to the adult rehab facility, but because of his brain injury he would need constant supervision, and that was a difficult thing for this family, and they really came to bat and this family has been a strong support.

Family – It would have been really tough and a harder transition into school if there had not been school in the hospital. Harder for him and harder for me. It would have been tough and he would have been a lot more behind.

Adam – After I was home, I was home for a little bit with my tutor, but I was at school shortly after. Actually the home instructor, well, like that prepared me for when I went back to real school.

Family – The home instructor went very good. Especially with Adam, a big thing was that he wanted to get his diploma for grade twelve before he turned twenty-five. It kept him busy and helped him get as many credits as he could.

School – We had a meeting in the school a month before Adam came back to school with the special education coordinator, myself, his parents, Adam, and the whole rehab team that was working with Adam. Quite a large meeting actually and we discussed what the flow of credits was going to look like, what the timeline was going to look like and we ironed all of that out so that when Adam came back to school everything was in place.

Family – The support from the hospital to the school was great. The communication was great. Everyone got set up before the transition.

School – We weren't even sure he was ready, when he came back, because his balance was not very good and he wanted to take a cooking class and we were worried about him with knives and that was one of our concerns, was his safety, and being in a hallway, and being able to walk down the hall when there are hundreds of other students walking by and going up and down the stairs.

Family – I was terrified. I was terrified.

Adam – Well, the first day, it was more like getting set up the first day. Talking to everybody, to see everyone, But, uh, it felt good. To see my friends, it was like where I left them. The last time I had seen everybody was the last time I was at school and my accident happened and it was just like kind of a pause and I came back to it again.

Family – I dropped him off five minutes after the bell would ring so that there would be a lot less people in the hall and his aide would meet him at his class.

School – Adam had a full time EA who moved with him at all times. He encouraged her to walk further and further away from him so that it didn't look like he was being escorted to class. It was his desire to return to that more normal looking environment and not be babied. But I think that his Mom was very concerned about his safety.

Family – Leaving him there, not knowing, um, what was going to happen or if somebody was gonna, because at that time he was, his balance was not very good and with so many people in the hallway it was pretty risky to have him there.

Adam – Well, at my school there is like a coordinated rotation, which is all the time – there was only one class and I only had cooking so I only went to cooking then I went back home. But uh, it wasn't that hard. It wasn't like everyday I had to get up at 7 a.m. to shower. It made a difference that it was just one class.

School – The OT would ask for curriculum guidelines of what he would be expected to do in his classes, like the cooking class, where he was going to use a knife and to mix, and she incorporated that into her therapy so that when he was at home he was working on the skills besides reading and writing, that he was using in the classroom.

Family – It wasn't just the physical issues. Agitation, getting past a short fuse, possibly snapping at someone at the school, because I had seen it with his brother, taking it out on him, you know if someone looked at him the wrong way or possibly say something to him that might trigger something.

School – Adam, pre-accident, was a young man who was very disenfranchised with school. He had not had a lot of success academically, his attitude and behaviour toward school were very negative, he spent more time trying to get out of class, and out of school;

lots of detentions, lots of behaviour, school was not at all a positive thing for him. Post-accident Adam now is saying "Let me get back to school, I need to earn these credits." It is pretty much opposite of what he had been before.

Family – Everybody and anybody in the school was excellent. Above excellent. And they modified everything for him. Extra break, leaving five minutes before the class, getting in five minutes after the class. You know, everything. And they supported him. They didn't just hang him out to dry.

School – The students accepted Adam right into the classes because he is very easy going now and he is kind of sweet and the kids really enjoy having him in the class. I think he's found some new friends. We only have grade 11 and 12 students and we have many students who return at age 20 to finish their credits, so I think that format of our school made it easier for Adam to fit in.

Family – The struggle with memory, the fatigue, his balance – those have all had a very big impact on him.

Adam – Before, when you are able to do everything all the time, you put your energy on things that are more interesting than school. But now, all I am able to do is to focus on school, and that's why I'm taking my time. I'm taking my time and I'm paying attention and I'm putting my concentration on school right now.

School – Adam was doing a project on Acquired Brain Injury and he had to present it to a group. We chose a science class of grade eleven students where Adam would go in and talk to them about his experience. He had Bristol board with pictures of himself in the hospital and he talked about the accident and a little bit about his rehabilitation. He sat on a stool at the front of the class and chatted away with the group, showing physically his ability and disability with his hands, what he could do and what he couldn't do now. He showed a short video that was taken in the hospital early on in his recovery where I guess a physiotherapist was working with him trying to get him to put on a t-shirt by himself, and in the video he has no shirt on. He is very skinny and his arms are quite disabled, they are quite seized up, and he works for about four or five minutes in the video, trying to get a t-shirt over his head. It was painful to watch. The impact – the teacher after the presentation mentioned that he had never seen his class so quiet and attentive. Many of the students were not only impressed that Adam would come and make the presentation, but after he left one girl burst into tears and said "Look at what he's had to go through just to get to school, just to get some credits, and we're all just fully able bodied and wasting our lives." The impact was so great. The classroom teacher still talks about the day that Adam did the presentation. I was there that day and it was one of those *goosebumps on your arms* kind of moments.

Adam – About once a day you just get frustrated and you want to give up. It wasn't once a day, but it was often. Because you know, my brother would go out and go and see his friends, and here I am just staying at home with my mom and dad.

School -- He has been back to school for almost two years now. Adam has found his own way of coping. He will walk the edge of the halls, he won't go in the middle so that if he gets jostled he is supported by the wall, but you wouldn't notice that. I don't think that if you came into the school today that you would know that anything had happened to him.

Adam – Actually yesterday I went to the resource room and the teacher knew me from my other school and she, yeah, said I did change, said I was a lot more social then and now I am a lot more focused on my school. I'm in Auto (shop) and it's just like we all, a couple or four, all work on one project, like rebuilding a bike. One guy, he wanted to screw around, but now I want to work.

Hospital – It is wonderful to see him come back into (the hospital) as a young adult and just be such a success! I think that the education piece was a really great benefit to his outcome because I saw that as building little successes and showing him that he could be successful, that there was a part of school that maybe he would enjoy even though he didn't know that before his accident.

Adam – No matter how you put it, I've got to say it's successful because uh, I graduate in June!

4.3 Julie's Story

a. Injury and acute care

Family – In June Julie was going hiking, and the young lady driving lost control and the car flipped and flipped and flipped. Julie was severely injured with a brain injury, and the driver was fine. She walked away from it. Julie was airlifted to the hospital.

Julie – I don't remember the accident.

Hospital – Julie was admitted to the Intensive Care Unit with significant injuries, the major one being the brain injury that she sustained as a result of a car accident.

Family – There were two fractures in her neck and several fractures in her face and her whole skull was crushed.

Hospital – I remember very early on in this young lady's hospitalization meeting with a variety of medical team and allied support team members with the mother and introducing the idea that this patient had a significant brain injury. In fact, some of the terminology used by the specialists was quadriplegic and vegetative state.

Family – She was in the ICU for a little over a month then she went upstairs and uh, she was still in a coma until October. She was bad. She would take these storms, her temperature would go to forty-two and her heart rate would go to two hundred and something.

Hospital – We were maintaining some range of motion and she was experiencing some autonomic storming which is brainstem related. We had set up a wonderful situation at another hospital, the long-term facility.

Family – My plans were always to take her home, but the doctor's feedback was that she would always be this way. She would never talk, walk, eat -- nothing ever again.

Hospital – I can remember the teacher going in and reading novels with her and there was a change in her breathing and some of her vital signs at that point that were being registered on the monitor and it was interesting, it was like a calming, it was maybe an acknowledgement of listening. I truly believe that one of the last senses to go and one of the first to come back is hearing.

Julie – I remember hearing things before I could see things.

Family – I remember one day I took the TV away and she kind of moved and I thought to myself, was she watching that? She couldn't talk, she couldn't communicate with us but when I put it back she calmed down.

Hospital – Our physiatrist had gone on vacation when multiple team members came to me to say "Just a minute, we're seeing something," and it was the same week that we were planning the transfer to the long-term facility. And uh, they were seeing things, they couldn't put their finger on it, but they sensed they were seeing a change. The mom had sensed a long time prior to this that she was seeing changes, which is not unusual for family to report. Some of that is actual and some of that is hope that they're seeing a response from their loved one.

b. Rehabilitation

Hospital – When the doctor returned we did some testing and we decided to do a trial rehab stay for a few weeks. At this point we realized that we were seeing a response from Julie and that there were some significant changes, and from that day, for a year until she was discharged home, we continued to see progress.

Family – It is kind of hard to describe Julie "waking up," it was so slowly. Every day there were little signs. Everyone worked so hard to get that consistency of a "yes" and a "no" because she couldn't go into rehab without it. The team worked so hard to convince the doctor to let her stay for rehab. I'm very thankful.

Rehabilitation: Physiotherapy

Hospital – The role of the physiotherapist was important due to the significant state of comatose and brain injury, to help maintain range of motion and bed mobility.

Family – We always had physio everyday. They worked so hard. Their role was to get her to do everything they could. To move her arms. Because her brain was so badly injured. Everything comes from the brain – how you move your arms, and she didn't have a – everything had to be re-taught.

Julie – I don't know what my physio did. Oh, she tried to help me to walk. She made me work really hard. We had fun, but not always.

Mom – So many physio experiences stick out in my mind. When she could sit up. When she didn't need a lift. When she could stand with people holding her. As of October there were always two physios working with her all the time.

Rehabilitation: Occupational therapy

Family – OT was great. She worked with Julie constantly. She worked with her everyday. At first I didn't know what they were about but they are for equipment and to get their independence. Do things for themselves.

Hospital – Occupational Therapy helped Julie use her upper extremities. They used equipment like splints, buttons and computers to help maximize her ability.

Julie – I could not talk so I had to nod my head and point. I had to learn to push a button. My OT taught me to push the button.

Family -- OT worked on the computer with her. She would come up and try to do the pointing. They took her to a restaurant to get her out. They took her to a movie, socializing and everything.

Rehabilitation: Speech pathology

Nurse – The speech pathologist's role was to develop communication strategies and that included a little bit of a communication board that we tried to set her up with. She outgrew that very quickly and in her own mind was not as interested in learning the computer board as much as learning to talk.

Family – I thought the role of speech was to work on her voice. I found that they taught her how to play cards. They taught her different objects, what was what. They taught her how to communicate without the voice because at that time they didn't think she would get a voice.

Julie – I remember feeling that I wanted to say something but I couldn't. It was boring.

Family – They also did a lot of choices with her, where she had to choose A. B. or C. Which was good because then she did get to communicate with us in some ways.

Julie – I got to learn how to eat. Pudding!

Rehabilitation: School

Julie – The first thing I really remember was the teacher. I remember her reading me a story. The Giver.

Family – The reading was great, it really relaxed her. I could see a difference when the teacher was reading to her.

Hospital – The teacher seemed to be a key part of making that decision with our rehab team, of seeing a change in Julie during those early days and making that decision with the team to continue on.

School – When the hospital teacher contacted us we were amazed but very happy to hear that Julie was improving. But at that time we really didn't think she would ever be back at school.

Hospital – Towards the end of her rehab stay we had moved to a new unit with a brand new classroom where Julie could be in the more normal environment of having other students around at the same time.

Family – Later on, when she got to go to the classroom, she enjoyed that. She looked forward to that. Even though she couldn't talk she had ways to let us know. When we would say, "Oh, you're going to school," she would light up, she would smile. She loved it.

Julie – I liked coming into the classroom at the school. Friends. I liked to see the other kids. To listen and read stories.

Hospital – Julie did her morning care and then would come down to the classroom from 9:30 until noon. It's a matter of seeing the interactions with the other kids and being a part of the socialization as well as the educational experience. Julie is a very social young lady!

Family – Julie looked forward to it because she got to be with other children her own age and she had to use her mind when she was there.

Julie – The teacher was reading about climbing Mount Everest. I was climbing Mount Everest at the same time. I made it to the top.

c. Community reintegration

Hospital – We changed schools as a result of Julie's needs and it was in walking distance so it was quite anticipated that she would be drawn into the school setting. We see that as a really important thing, to get our kids into school as quickly as possible.

Family – We went for an interview at the school. The interview was great. It was all set up by the hospital teacher to go to the school and I felt that part was just excellent. They were more than willing to take her and help her all they could.

School – Julie was very positive, she was definitely looking forward to coming back to school.

Hospital – When Julie left we anticipated that she would return to school part-time in September, but it gave her a little bit of time at home with her rehab team first. We were going to try to set up one school period and lunch. It was all set up that her peers, a volunteer group would support her there and we had a lot of teacher support and a lot of school buy-in for having this young lady back to school.

Family – We came home at the end of June. School didn't start until September. We did go that September for a meeting

School – We had an in-school meeting with the team directly before she returned to the school. It was definitely beneficial for us to get a picture of where Julie was at that time and basically what they were looking for in a school piece. It helped give us a focus for the reintegration. It wasn't perhaps as academically minded as we originally had thought, which is a relief. Often a school has pressure put on it strictly for academics when often the socialization is more important for the first part of returning to school.

Family – At that time, Julie's therapies were more important. If we went to school we couldn't have a therapy because Julie couldn't tolerate as much as she can now. If she had physio in the morning, she had to have a sleep before she had OT in the afternoon.

Julie – I couldn't go back to school right away. Physio was teaching me how to walk. I'm working so hard on walking that I haven't been able to go to school.

Family – We had an EA all set up, who is now over there and someone else is getting free benefits from.

School – I think we had all the information about Julie that we needed. The problem was we found that sometimes the school was left in limbo. We weren't sure what was going on. We weren't able to contact home for a variety of reasons and um, so sometimes the point of contact was a little bit tricky.

Family – We did go one day and it was great. We went over for a birthday party and we played bingo with them. We really think that she needs to be meeting with people who are her own age and the other things that school probably will give her.

Julie – I visited the school. I played bingo with my class. I didn't win, but maybe next time.

School – She has actually only been here four or five times.

Hospital – The longer you leave kids at home with the home-tutor and therapies, the harder to return to school, so we really like to support our kids and get them into the school. I am not sure it worked out that way for Julie, but I really do hope for her rehabilitation program that she gets back to school. This young lady has a long educational career ahead of herself.

School – I think the nature of the integration being the social events, I think she has enjoyed that. The downer is although it's a good social time, it is not social time with the kids she knew when she used to be here. A lot of the kids that she would know and remember are no longer in the building.

Julie – The most important thing about going back to school is friends.

Family – I would like to see Julie go to school. I know it won't be full time for quite a while because of her therapy, but I would like to see her go because it socializes and I would like to see her taking some courses. Her goal has always been to be a social worker, well maybe the time will come when she'll be eligible to do that someday.

School – I think her reintegration is successfully in progress. We have a basic framework for a plan. We need to be continually working on it, but uh, she's positive, we're positive. When the determination is there everyone is willing to make sure that it works.

Hospital – I really do believe that some of the healing and some of the recovery in Julie was solely due to Mom's love, dedication and commitment to this young lady. Now she is walking, talking and feeding herself and doing much, much more. It is very exciting to see!

Family – Look at her now!

Julie (when asked what the best advice she can give to another teenager in rehabilitation) – Never give up.

It is important to note that while each of these three stories have a beginning and an ending within this text, the real-life drama continues for each family. At the time of writing, Brad is making steady progress in his third year of part-time study at a local community college. He lives at home, continues to be an advocate for the children's hospital, and has finally purchased that "nice car" from his part-time employment at an office-supply store.

Adam graduated from high school last spring. The school had to reserve an entire row of seats for Adam's family and therapy team, all of whom felt highly invested in the young man who walked across the stage to receive the Principal's Award to a standing ovation.

Julie continues to progress slowly towards her goal of walking independently through daily physiotherapy sessions. She has not yet returned to her community school.

Chapter Five: Emerging Themes

Initially the three stories were reorganized to address the five sub-questions outlined earlier:

- How can the school best support rehabilitation during the acute phase?
- How are therapeutic goals combined with curriculum goals at the high school level?
- How can the rehabilitation team support the community school during reintegration?
- How might the spectrum of hospital and school collaboration be described?
- What other themes emerge from gathering information about the case?

However, after extended periods of listening to the recorded data and reading through the transcribed voices, it became apparent that three meta-themes better represented the emerging messages of the participants, while adequately addressing the questions raised. The following meta-themes and related sub-themes were identified as critical and recurring in each of the three case studies:

1. *Early intervention of rehabilitation school offers*
    a. Hope
    b. Normalization
    c. Motivation
    d. Functional Context for Therapy

2. Teamwork and communication between school, hospital and family is necessary to support

  a. Cognitive and Behavioural Baseline
  b. Teacher Education
  c. Planning for Success
  d. Flexibility to Accommodate Diverse and Changing Profiles

3. Educational collaboration provides a framework for on-going support by offering opportunity for

  a. Socialization
  b. Self-Advocacy
  c. Family Advocacy

In the following pages each of these themes is identified and expanded, then supported by a sample of responses from all participants in the research.

5.1 Early intervention

Early intervention refers to the involvement of a rehabilitation teacher in the acute care setting, often while the student is still in a minimally responsive state. The teacher is introduced to the family and student as a part of the rehabilitation team even before active rehabilitation has begun. DePompei et al. (1998) support the idea of early intervention in acknowledging that "the return to school can be devastating if the health care facility and the child's home school do not interact as soon as possible and as frequently as possible" (p. 88). At this stage the hospital teacher initiates the initial contact between the hospital and the community school. While the opportunity for curriculum related teaching at this point is minimal, the hospital teacher engages the student in low-level stimulation activities such as reading a favourite text or passing on messages from the community school.

Brad's Family – I think he is where he is today because they have school in there and they started out at the right point. Because if he had gone back in to school without having that piece there, they would not have been capable of starting it.

Brad's School – I think it has to be immediate.

Adam's Family – It would have been really tough and a harder transition into school if there had not been school in the hospital. Harder for him and harder for me. It would have been tough and he would have been a lot more behind.

Adam's School –I don't know if we would have felt that same way if we hadn't had that early contact with the hospital. I think if he had just showed up on our doorstep we would have been pretty concerned about bringing him back into the school.

Julie – The first thing I really remember was the teacher. I remember her reading me a story. The Giver.

a. Hope

The involvement of a schoolteacher during acute care sends a strong message of hope to the student and the family. In referring to the early stages of rehabilitation, Ylvisaker et al. (2005) remind us that "staff and family need to maintain both optimism and alertness in relation to the future, even as they deal with problems of today" (p. 208). Despite the many medical challenges to be faced, the introduction of the teacher brings the acknowledgement of an eventual return to school. School is an institution where students learn in order to prepare for their future. The daily presence of a teacher is a reminder that the student has a future to prepare for, even in the midst of a challenging present.

Brad – When they sent in the teacher I knew I was going to get better.

Julie's Family – The reading was great. It really relaxed her. We could see a difference when you were reading to her. Even though she couldn't talk, she had ways to let us know.

Adam's School – I think that early contact was important because he was able to earn some credits while he was in the hospital and school had not always been a positive thing for Adam. And those early credits gave him the hope that "Oh, I can still do this," and get on getting back to school.

Brad's School – I think the connection to the school, as he started to use his language, he did feel connected, whether or not there was a physical connection, he knew what he was studying in the hospital school, he knew that hopefully there was a connection there that those skills were being taught back at (the community school).

Brad – It definitely helped me think beyond what was happening in the hospital. It helped me think beyond to know there would be a next semester.

Adam's Family – We understand now why the teacher came in, even to say "hello." She did a little project cutting things and we found out that he could actually do more things (than we thought) so it was well worth it.

Brad's Family – You know the kids say "Ahhh, here comes the teacher!" but I still think it makes them realize that there's going to be life after.

b. Normalization

There is very little that is normal in the life of a child in an acute care setting. They are physically removed from home, friends, classmates and team mates. Although family members are often a constant presence at the bedside, a myriad of doctors, nurses, therapists and counsellors take the place of peers and neighbours. Nothing looks familiar in a world of plastic tubes, beeping monitors, and an endless parade of masked and gowned strangers. A teacher represents the most normal, daily experience, shared by millions of children world-wide: the opportunity to go to school. Even though the hospital teacher may be a stranger to the student, the role of a teacher is familiar and *everyday* (Ylvisaker & Feeney, 1998).

Brad's Family – And eventually I figured out what it was about, that school with these kids is normal. None of the other therapists is normal, because they never had to do anything with it. But school is.

Julie – I liked coming into the classroom at the school. Friends. I liked to see other kids. To listen and read stories. It was more normal.

Brad's School – The fact that it is a normal activity, in terms of an emotional support, and a lift, that was what he needed at that point.

Brad's Family – I soon saw very quickly it was the sense of normalcy. I think a big reason why Brad never thought of not going back to school is because school started in the hospital. You had school because you are sixteen. And sixteen-year-olds go to school. It's real life.

Adam – It didn't seem like a normal thing to be doing in a hospital, but it seemed normal because uh, that's what I'd been doing since I was like, four or five.

Brad's Family – So I would say the teacher is the one normal thing in there.

c. Motivation

Having an opportunity to work towards some long-term goals, such as credit attainment and graduation, appears to have a very motivating effect on children in the hospital. Ylvisaker et al. (2005) state that "sensitivity to personally meaningful activity has the effect of improving motivation for most children and adolescents" (p. 97). It has been my observation over five years of working in pediatric rehabilitation, that once a child realizes they are going to survive their illness or injury, the next biggest concern in their mind is that of failing or falling behind at school. The introduction of a teacher during early stage rehabilitation provides much needed motivation to endure the rigours of therapy so that the student can participate in school related activities. The student's successful efforts on assignments and tests as rehabilitation progresses, builds motivation to return to the community school.

Julie's School – School is a wonderful motivator and maybe when they can interact in a school environment, there are some reminders there of things they still can't do that they really want to do, so they are really motivated to work hard.

Brad's Family – The phys-ed credit and the English credit. Those were big things because he felt like he was going forward.

Julie's Family – School really motivated her because she got to get out of her room.

Brad – If you are going back to school after your rehab, then the teacher is a must, no word of a lie, a teacher is a definite must, a requirement in rehab. It got me started, you know, thinking. It got the ball rolling and without the teacher I would have been forced into a really awkward situation.

Adam's Family – He was excited about school because everyday it was something different.

Adam's School – I think him earning those credits early on allowed him to recognize that he COULD earn credits, and even though he was behind that he could come back and get back into school. If he hadn't had that school part maybe he would have felt that it was too late, "I'm already behind credits, now I've missed another whole semester, another whole year, it's gonna be too hard to go back."

Julie's Family – Definitely having school at the hospital made Julie want to go to school. She wanted to go there to be with other people.

Adam's School – It was important that they knew the school was supporting what the hospital was doing and that the hospital was in communication with what the school would be doing later on down the road and I think that when Adam saw his rehabilitation and coming back to school were all connected that was the focus of him getting better. It motivated him to work hard.

Hospital – It was very successful and a key to setting him up for a wonderful outcome. Adam got excited about what he was doing – maybe for the first time in his education life, really was able to complete homework and complete courses and work with that success.

d. Functional context for therapy

Occupational therapists and speech pathologists in paediatric rehabilitation work with their patients to develop compensatory life skills to maximize their success in the real world. School is the shared real-world experience of all children. A hospital teacher can provide curriculum related activities to therapists to increase student motivation and provide a functional context for therapy. Ylvisaker et al. (2005) recommend that "educational materials for assessment and intervention must be brought into paediatric rehabilitation facilities" (p.108). For example, by using an actual school assignment for a language therapy session, the student benefits by making progress on a credit-related task, and the therapist is able to observe the student's ability to successfully negotiate a real-life task. As rehabilitation progresses, offering therapy in the hospital classroom provides the opportunity to observe and address potential attentional or behavioural challenges that might go unnoticed in a typical one-on-one therapy session.

Hospital – We learned very quickly that our therapies have to be meaningful for our patients or they loose interest very quickly or they just don't participate.

Brad's Family – Speech and schooling and OT, I don't think anyone realizes how connected they are. I do now, because the teacher looked like normal and was something I could recognize and she helped me recognize where the therapies fit it.

Adam's School – If you have to learn how to print again, why not learn to print again and be printing the school material that you need in order to get the credit that you need?

Hospital – Julie could be in the more normal environment of having other students at the same time, with visual stimulation, sitting up, at a table in a classroom type of setting and that's really been key with our rehab kids now, that our rehab program is set up around the classroom.

Brad – The hospital definitely got me prepared. I remember going through therapies and exercises not knowing fully what to expect but they seemed to know what to expect and they certainly helped me out.

Brad's School – School in the hospital helped him feel very comfortable when he came back. He had already dealt with a lot of the things that he needed to before he actually started his courses.

Adam's School – I think for Adam it was important that he saw that OT was something that was real and it was supporting something that he was doing at school, and that school was real life because here it was supporting the stuff he was doing in therapy.

Brad's Family – School helped him work in real life situations, using the opportunities as they presented themselves.

Brad – At first it was difficult for me to understand the reason for (the other therapists) being there. But when they came at the end and explained to me the things that I had learned, then I realized the need for them to be there.

Adam's Family – Even from physio we got that credit for phys-ed and it was so great! It helped make the therapies more meaningful.

Adam's School – OT would ask for curriculum guidelines of what he would be expected to do in his classes, like the cooking class, where he was going to be able to use a knife and to mix, and she incorporated that into her therapy so that when he was working on the skills, besides reading and writing, that he was going to need in the classroom.

Hospital –I really believe that it was through the school piece that we were able to reach some of the functional rehabilitation goals.

Brad – School was therapy because it helped reintegrate me back into my community school. And into the world.

5.2 Teamwork and communication

Teamwork and communication between the school, hospital and family helps promote a holistic view of paediatric rehabilitation, by acknowledging the patient's identity as a child and student. While recognizing that communication with parents is a developed skill amongst special educators, Sohlberg, McLaughlin, Todis, Larsen and Glang (2001) acknowledge that "many training programs in the rehabilitation disciplines do not teach about the underused practice of forming professional-family partnerships" (p. 499). The role of a hospital teacher can facilitate this teamwork by acting as the communication liaison between the parents and school, as well as the school and hospital. Open communication tends to de-mystify new situations, and almost always the rehabilitation experience is foreign to families and schools. By developing a sphere of expertise in both ABI and education, the hospital teacher can answer questions in every day language, address concerns before they become issues, and when necessary, redirect inquiries to the appropriate source.

Hospital – By working side-by-side with the teacher here at the hospital and the family, and then with liaising with the community school and with the rehab team we all communicated to set Brad up for success.

Brad's School – It is key for a healthy positive reintegration back into the school that it is done immediately and that it is done as a team approach with the hospital, the school and the family.

Brad – Teamwork, a lot of it, everyone meshing together and finding the best way for me. That helped a lot.

Brad's Family – You really need to include the parents, because nobody knows the child better than the parents.

Julie's School – Part of it is goal setting and maintaining contact with the team through case conferences. Sometimes we were left in limbo, we weren't sure what was going on. We weren't able to contact home for a variety of reasons and uhm, so sometimes the point of contact was a little bit tricky. So just a point of contact somewhere else so we can say, "Is everything okay? What can we be doing to help out?"

Adam's Family – The support from the hospital to the school was great. The communication was great. Everyone got set up before the transition.

Brad's School – I think the school reintegration was very successful and I think the reason for that was the communication between the hospital, the parents and us.

a. Cognitive and behavioural baseline

It is very important for the hospital team to have an accurate cognitive and behavioural baseline when assessing a patient's response, and developing appropriate rehabilitation goals (DePompei et al., 1998). I have observed that when faced with a situation that has threatened the life of their child, many parents seem unable or unwilling to report any school failures or negative behaviour patterns recently exhibited by that child. While the family is an important source for baseline information, schools are often able to provide quantitative measures of academic performance, cognitive testing, and up-to-date reports on behavioural issues.

Hospital – Contacting the child's school at a very, very early point to try to bring back some information for the team to know and then making the connection and partnership with the community school as to where the child was and what the child needs to do while in the hospital.

Adam's School – There was an early contact from the hospital to get an idea, an educational baseline of what Adam's history had been. So we had released transcripts and some anecdotal reports about Adam's success at school and where he was intellectually that the team was going to use as a baseline once he came out of the coma to try to decide what his abilities were . . . how much of it was caused by the accident and how much of it was pre-existing.

Hospital – We learned that the child (Adam), was maybe not as uh, interested a student as we had first heard from the family.

Brad's School – I think it is important that the connection is to the school even when there are many critical medical issues, because that is a large part of who Brad was, and I think that you have to continue to do that, not only for the academic, but for the whole person, physical, emotional and social.

Hospital – We were hearing about a teenage boy (Brad), who had a real lack of caring and he wasn't putting the time or the energy or the potential forward in school that everybody knew he could. Our team was faced with the very real concern of whether or not Brad could actually pull the rehab part of this off.

b. Teacher education

As discussed earlier, classroom teachers are rarely provided with any training at either the pre-service or in-service level about the educational needs of children with ABI (Bennett, Good, Zinga & Kumpf, 2004). A hospital teacher can open the door to community school education during the first communication with the school. Introducing the members of the rehabilitation team to the teachers at the community school helps give the student's teachers an appreciation of the lengthy process ahead. Having the opportunity to hear about (and actually see) the student's progress from a coma and acute injury into active rehabilitation, helps build a frame of reference from which to understand the dynamic nature of ABI. Educational literature about ABI can be distributed at the school early on in the process. Staff in-service can be facilitated by members of the rehabilitation team as the student prepares to return to school. Long after the student has returned, the hospital teacher can remain as a valuable educational link to answer or redirect questions from the community school.

Adam's School – If there had been no early school involvement we would have been very worried seeing Adam's state when he came into the school. We would have had some big concerns about him succeeding. But because we were seeing that there was such a huge progression from the time that he was in a coma to him actually starting to acquire credits, and come to the school, to walk around – to see that progression led us to believe that the progression would continue, maybe not at the same speed but that there was going to be continued improvement that we could facilitate.

Brad's School – Interaction with the hospital was almost immediate. I did visit Brad very soon after the accident, so I did see his progression from the accident right through to his entry into the school.

Julie's School – It was definitely beneficial for us to get a picture of where Julie was at that time, and uh, basically what they were looking for in a school piece.

Adam's School – We were very limited in our knowledge about head injury and the doctor that came with him was extremely helpful in bringing us lots of print information to the teachers to read and myself, and has actually offered to come and speak to any of our staff that wants further education around head injury.

Brad's School – This was our first major integration in terms of a brain injury and a lot of teachers have not dealt with students who have had that kind of injury. The team gave us the specific strategies as to how to structure the classroom and what to tell the kids as Brad was going to be coming back in. The hospital gave us strategies about what to notice physically in Brad if he was over-tired or if it was just going to be too much for him on that day.

Adam's School – All of the teachers were given all the information that we received from OT, from speech, from the doctors. The meetings were very productive and very positive.

Brad's School – It was very good, it was enlightening, it gave us strategies that we have incorporated into his IEP so that the things he did in the classroom were accommodated right away and the teacher was aware of some of the things he could do to make sure that he was successful. The Rehab team did explain very thoroughly acquired brain injury, and went through things to watch for, including the fact that Brad wouldn't recognize when he was tired and so forth.

Adam's School – I don't think there is nearly enough information about head injury in teacher education

c. Planning for success

Because the student is still regaining cognitive skill at the time of the return to school, it is very important that the hospital, family, and school collaborate to ensure a successful reintegration. Taking the time to hand-pick flexible teachers and appropriate courses and time-tables is a critical step in ensuring a successful return. Plagued by fatigue that can drastically alter the cognitive profile, the student must have flexible attendance options and extended deadlines. The hospital teacher is able to act as a translator between the medical and educational worlds, to frame rehabilitation strategies into workable school routines that can be implemented by the classroom teacher.

> For example, a report that states, "The child has difficulty processing auditory information" may not be as helpful as one that states "The child will be slow to hear your question and formulate an answer. Extra time to respond will be helpful" (DePompei et al., 1998. p. 87).

Hospital – One of the big things with rehabilitation is that we want them to have success. We want them to reach their academic potential but we want them to have success and build on that success throughout their schooling and rehabilitation.

Adam's School – We had a meeting a month before Adam came back to school. We had a meeting in the school with the special education coordinator, myself, his parents, Adam, the whole rehab team that was working with Andrew so that when Andrew came back to school everything was in place.

Hospital – I think that the education piece was a really great benefit to Adam's outcome because I saw that as building little successes and showing him that he could be successful. And there was a part of school that maybe he would enjoy even though he didn't know that before his accident.

Brad's Family – He wasn't terribly interested in school, so he hadn't had a whole lot of success. And for him to realize that he could have success, even after this, I think this moved him much further up the line.

Brad – I think it was all wonderful. And the first team meeting that we had back at school with me, all my therapists, my parents, and my teachers at the time. All I heard was praise from every single person, and that was an unbelievable feeling right there.

Adam – Definitely start off slow then build up – cuz you know you have to do your stuff in stages, you know you start off school in the hospital, then at home, then go to school for just one quarter of the year or half the year.

Brad's School – I remember meeting on a number of occasions with the team, admin, OT, teachers, SLP, to find strategies that we could continue to do that would encourage him on his development both inside the classroom and outside the classroom.

Adam's School – Since Adam has come back we have spent a fair bit of time with Adam and his family and the support team that works with us to help us reintegrate him back into school and community and family.

Brad's Family – Hand picking the teacher, hand picking the class is very important as they start back in. We picked a course without extra homework and the teacher was specific; he didn't use a lot of extra words.

Brad – A lot of people felt that I couldn't return to school and that I was doing too much too soon, and I just can't have people telling me what to do. I had to prove them all wrong and so I did. I showed them up.

Adam's School – The team that came, the rehab team, commented on how pleased they were that the school was willing to accommodate to such a great extent Adam's program, and we were just happy to have him back even part-time earning credits.

Hospital – Brad's first while back to school he felt successful. And that is what we want for these kids. We want safety and success, in smaller measures, rather than having a failure and setting them back.

Adam's School – It was a really positive cooperation. The OT was doing work at one point looking at possible careers and jobs while Adam was doing his Careers class so he would take his resume from Careers Class to his OT and they would buff it up a little bit and then bring it back to class.

Brad's School – I also think that everybody was on board to make sure that him coming back was going to be a good experience and that he was going to feel successful.

Adam's School – We were impressed at how the rehab team was supporting him and basically the rehab team was impressed at how we were supporting him.

Adam's Family – Everybody and anybody in the school was excellent. Above excellent and they modified everything for him; extra break, leaving five minutes before the class, getting in five minutes after the class. You know, everything. And they supported him. They didn't just hang him out to dry.

Hospital – We changed Julie's school as a result of her needs.

Julie's Family – We went for an interview at the school. The interview was great. It was all set up by the hospital teacher to go to the school and I felt that part was just excellent.

Julie's School – We had an in-school meeting with the team directly before she returned to the school. It helped give us a focus for the reintegration.

Hospital – We were going to try to set up a period and lunch and it was all set up with her peers, a volunteer group, would support her up there, we had a lot of teacher support and a lot of school buy-in for having this young lady back to school.

Julie's Family – The school was more than willing to take her and help her all they could.

Adam's School – I think it was totally successful. If you saw Adam in the hall today, first of all, you wouldn't know that he was a child with a brain injury, secondly he's happy. Thirdly, he's going to graduate and walk the stage, which uh, before his accident, I am not so sure that he would have made it.

Brad – My teachers were more than accommodating and they let me go a few minutes early from my classes just so I could beat the crowds before the rush.

Brad's School – There were a lot of successful indicators. He continued to develop with regards to his speech. He had a girlfriend with him at prom. He did go on to graduate, so all of those things that everybody else did, he continued to do.

Brad – I would say that my reintegration was very successful. I actually, before the accident, I was, y'know, just barely passing all my classes, just really because the teachers like me. Later I was actually doing the work, doing studying, y'know and getting seventies and eighties in all my classes. It felt great.

Adam's School – I'm wondering how many seats Adam is going to need at graduation, because if it's his mom, his dad, his brother, his OT, his PT . . . . if his whole support team comes we'll have to reserve a whole row!

d. Flexibility to accommodate diverse and changing profiles

Because of the diverse and changing profile of ABI, and the transitional nature of the school experience, teamwork and communication must be continued throughout the child's school career. Ylvisaker et al. (2005) found that one-day workshops alone, were ineffective in changing classroom practices. In view of the dramatic individual differences in outcome after ABI, their study recommends "support programs that offer ongoing consultation, problem solving and technical assistance to the school staff" (p. 103). One example of problem solving that has been successfully advocated for by the hospital teacher is the continued support of a flexible home-instructor (a special teacher often assigned to a child living at home who is too ill to attend school on a daily basis) while the student begins to attend daily classes at school. High schools in particular, stress the importance of regular attendance, independence and responsibility. These are noble objectives, but they are quite unrealistic for the adolescent recovering from an ABI. The hospital teacher can advocate for behavioural supports that might otherwise be deemed inappropriate, such as the use of an elevator to conserve energy (even though the student appears to be able to walk quite independently), or the assistance of an educational assistant in recording assignments in the agenda.

Hospital – With brain injury it is always different with each child – each child is unique, each brain is unique, and different parts of the brain have been injured.

Julie's School – Flexibility is a key. A lot went into getting things set up for daily or half-day school attendance, but the fact that it did not happen was not a negative. You just have to start where people are at and keep working at it.

Julie – I hope to go back to school everyday for part of a day.

Brad's Family – one thing the school system needs to do is that they need to recognize that, with most school systems you're either in or you're out. They have no recognition of the fact that today you can be in and tomorrow you need to be out, and that's the biggest thing that needs to be changed.

Brad's School – I think the biggest challenge was that we were trying to reintegrate him so that he was in a classroom setting without doing too much for him yet recognizing that he has limitations now.

Adam – At first I was spending one class at school, and then after the summer I went back to school for the first two periods, and then lunch. The next year it was for full days with a couple of courses on the side.

Brad's School – He was still getting support (from the home instructor) so we did sort of bring him back to the school informally based on his energy level. Flexibility was a big key.

Brad's Family – The OT was the one who talked to the teachers about the wheelchair, the emergency exits, that kind of stuff. The SLP talked about the language stuff.

Brad's School – There was more concern around the physical layout of the school, how will we get him into the classroom, do we have room to put the wheelchair and the desk, if there is an emergency do we have a way of getting him out?

Brad's Family – I don't think there is one area that has not been impacted by his injury.

Julie's Family – As far as using the computer and learning things, her short-term memory is starting to really come good, whereas before she couldn't remember. I would like to see her get an education and be able to set some goals. And do something she wants to do in life. Her goal has always been to be a social worker; well maybe the time will come when she'll be eligible to do that someday.

Brad's Family – Physically there are certain things he misses, because he used to play the piano and he used to play the guitar. And he just doesn't think about it, because it hurts too much to think about it.

Julie's School – I would say setting some specific goals like getting to school every second day or even once a week; getting up and getting out the door are some really good next steps.

Brad's Family – He is more emotional than he was before. I don't know yet whether that's a good thing or a bad thing.

Hospital – A lot of changes have to be put into place and the accommodations are not always easily established.

Adam's Family – Sometimes a person might have to repeat things to him, a word, phrase things with smaller words, or physically point out what you would like done and that way Adam can remember it more easily.

Brad's School – He would rush through things, and I would go back and check things over, to make sure he had not missed anything, and he was able to answer them.

Brad's Family – There are teachers that summarize first and fill in the details and those that start with the details then summarize. Brad needed the ones that summarize first. If they started with the details he was lost.

Adam – Maybe if you want to do more than one thing, like maybe one thing in the morning take a break and have lunch and one thing later, then you should think about maybe having a nap after lunch. Take a nap and then go for another outing.

Brad's School – Brad and I met on occasion whenever we needed to have some kind of an accommodation put in to place. We kept meeting with parents and teachers at the beginning of each semester to make sure that things went smoothly for him, and that teachers are aware of the injury that did occur and to support him in the classroom.

Brad's Family – There was a term we used at one point called *walking wounded* and it is very appropriate. Looking good is a positive thing in that it gets him in the doorway for a lot of opportunities. But then it sets up unrealistic expectations because when people look at him they don't understand.

Adam's Family – He needs extra caution, lots of times, you know, walking down the steps. And multi-tasking, he is not good at that. He needs to focus on one thing at a time

Adam – If you have too many things, it's easier for the kid to crash.

5.3 Ongoing support

Educational collaboration during pediatric rehabilitation for ABI provides a framework for ongoing support of student and family. In the hospital setting the role of the teacher can often diffuse some of the tensions expressed by family members at various stages of rehabilitation. For the medical team, the rehabilitation process is a normal, repeated experience, making it difficult at times for them to respond to the family's anxious perspective. The teacher can use everyday activities to highlight very gradual progress in a way that many family members can appreciate. By continuing communication with students long after they leave active rehabilitation, the teacher is able to provide a long-term perspective to in-patient families, couched in everyday language. The family inevitably becomes the front line support for the student. Ylvisaker et al. (2005) affirm that

> experienced clinicians understand that long-term family and child outcomes are reciprocally interrelated. Positive/negative child outcomes increase the likelihood of positive/negative family adjustment; similarly positive/negative family adjustment increases the likelihood of positive/negative child outcomes (p.105).

Unfortunately there is little support for the emotionally and physically drained family members themselves, although linking families with others that have been through a similar experience helps expand a valuable support network (Singer, 1996).

Adam – The things that helped me? Having a good family and even good friends. I have two really good friends and they are with me from day one and I still talk to one friend on computer and MSN

a. Socialization

As mentioned in the literature search, difficulty with peer interactions can become a secondary handicap as social isolation frequently occurs during extended rehabilitation. Glang et al. (1997) observe that "perhaps the most difficult and long-lasting effects of ABI for children and young adults are the loss of friends, decreased involvement in social activities, and absence of social support" (p. 32). Offering school in the therapeutic setting provides opportunities for students to experience socialization while adjusting to a new ability profile in a safe environment. Successful social integration is as important as successful academic integration, and must be equally well planned. Even before daily school attendance can be considered as a viable form of education, occasional school visits for socialization must be considered. Otherwise school anxiety may be added to the list of challenges the student is already facing.

Hospital – The longer you leave them at home with the home tutor and therapies, the harder (to socially integrate), so we really like to support our kids and get them into the school.

Julie's School – I think the nature of the integration being the social events, I think she has enjoyed that.

Hospital – Julie is a very social young lady and we did see changes right from the start when a couple of school chums would come in to see her. Julie just lights up with the peer interaction.

Adam – Having friends that understand is actually a really big thing. Because the other people, the other friends, they just look at you, they don't really know. It's too big of a picture for them to understand.

Julie's Family – We really think that she needs to be meeting with people who are her own age, and what school probably will give her.

Julie's School – The downer is although it's a good social time, it is not social time with the kids she knew when she used to be here. I don't know if any of them even keep in contact with her.

Brad's School – Brad was a very easygoing, likeable kid, and when he came back in, with the attention that he got, just simply because people were relieved to see him, were happy to have him back, I think generally it was very positive.

Brad – I used to go skiing, and now I can't, which is unfortunate because pretty much all of my friends have spent a couple of days up at Tremblant and I don't want to go up there just to drink.

Adam's Family – You always worry whenever they are teenagers, which way, which direction are they going to go? But because of (the brain injury) certain facts have turned him to no alcohol, no drugs and no bad groups. He has close friends that we trust him with.

Adam – My brother would go out and go and see his friends, and here I am, just staying at home with my mom and dad.

Julie –I don't miss homework or tests. I miss my friends.

Brad's Family – I think that Brad wanted to go back to school for the social aspect, and he knew that doing all of those other things was a means to an end.

Julie's Family – I would like to see Julie go to school. I know it won't be full time for quite a while because of her therapy, but I would like to see her go, because it socializes and I would like to see her taking some courses.

Brad's Family – He went back to school and realized that now those friends are gone and he has a different kind of friends. The friendships are not as tight any more. So for him the social aspect of school is not as important anymore.

Julie – Just being with friends, that's the most important thing.

b. Self-advocacy

The return to school offers valuable opportunity to develop self-advocacy skills, in a caring environment where parents and therapists are not present. School becomes an ideal next step in rehabilitation as students with ABI learn to recognize by experience, the strategies they practiced in rehabilitation that are essential for their continued success. Beardmore, Tate and Liddle (1999) observed that students who have suffered ABI "frequently fail to recognize their behavioural limitations post-injury and many display diminished awareness of their deficits" (p. 46). Because self-advocacy is typically an area of challenge for students with ABI, it is important for the family to regularly review their child's success, and offer advocacy support if necessary.

Julie's Family – Hopefully she'll be able to be her own advocate one day, but for now I have to be there for her. If I wasn't there for her she would be in a home.

Brad – I am definitely more involved with absolutely everything. I understand where someone is coming from with a disability and where they are coming from when they say they need more time, when they say they are tired, when they say they can't do anything because I myself have been there.

Hospital – Brad had a good handle on his brain injury and was able to quite nicely put it into words for us.

Brad's School – He took control in some sense, what was happening, and sort of turned it into a very positive, sort of social change kind of thing.

Adam – I'm not sure what you mean. Can you ask me that again?

Brad – Don't talk too much or I will start to phase out. If you can relate whatever you are trying to teach me through a joke then I will never forget it.

Adam – The negatives are I can't drive no more. Possibly not be able to work full time ever again, those are the only two I can remember. Oh and like uh, negative things, like it takes me a little bit longer to think things through and my memory is not quite as good.

Brad's School – The biggest things with Brad was that he didn't want to access help, he wanted to do it on his own. His temperament, his personality was proud, he didn't want to appear that he was different, he wanted to sort of just roll right back into school like he always had. So it was really helpful for the hospital and the parents to relay those concerns to us prior to him coming back, because Brad would not have communicated a lot of things to us.

Brad – The teacher support could have continued but I chose for it not to. Um, I didn't like the fact that I was involved in this accident and I didn't share it as in depth as I did at first. I liked to try to do it on my own and see if I could, and then if I needed it I would let them know. I felt I was able to advocate for myself.

Hospital – What happened here was between the teacher and the rehab team all working together and partnering with family we were able to equip the family with skills that maybe they hadn't had or drawn on before to advocate for their son.

Adam – When you are able to do everything all the time you put your energy on things that are more interesting than school, but now all I am able to do is to focus on school. And that's why I'm taking my time. I'm taking my time and I'm paying attention and I'm putting my concentration on school right now.

Brad – When people look at me and want to toss me a football, I really can't do that. Which is a bonus for me because I am pretty lazy.

Adam – I won't be able to drive and I can't shovel my driveway, but I can get people to do it for me.

Brad – I just say no. If it's a friend who knows me a little bit more, I explain why I can't, otherwise I just say no.

Brad's Family – He doesn't use his infirmity when he should.

c. *Family advocacy*

Ultimately it is the family who bears the bulk of the responsibility for life-long advocacy following ABI. If parents and educators have trouble working in partnership, conflicts arise and the student's education suffers. Glang, McLaughlin, and Schroeder (2007) recognize that parents need assistance to help school personnel understand the consequences of brain injury. Together, this team developed a multi-media presentation to help parents advocate more effectively for their children with disabilities. The emotional, physical and financial drain on the family is difficult to measure. While each family in this study was able to identify some positive impacts on their family situation brought about a sense of need and closeness to one another, the voices clearly indicate the daunting task that awaits them in the years ahead.

Hospital – Unfortunately it is not just the patient who is affected, but it is the whole family unit.

Brad's Family – We are tied into this thing for life.

Julie's Family – Now for my daughter to go to school, it is planning for when can she go there, when can she not. Who's gonna be there? It's not like saying, "Oh, she's registered, so off you go." Parking a vehicle; where do you park? You see all these people parking in wheelchair spots and they get out and they just walk away and you think to yourself, well, why are you there?

Hospital – It is a long journey. Julie will have a rehab team for the rest of her life.

Brad's Family – At twenty-one years old I had always thought I would have a lot less involvement in his life. The hardest thing is asking yourself at this age, "What is the injury and what is the 21 year old?"

Hospital – I think no mother ever anticipates having a child require so much attention and care as when they have had a significant brain injury with the care-giving and the supervision that is required.

Adam's Family – Possibly he won't be able to ever drive. Possibly, but we don't know, never be independent, and possibly never work full-time. The struggle with memory, the fatigue, his balance – those have had a very big impact on him.

Julie's Family – We wanted to get Julie a wheelchair . . . well just to get her out the door, through the door, through the snow and beyond was so much work, and then the salesman says "She should have a power chair" and we said "No – you should clean your walkway!" The (local) theatre is not wheelchair accessible. A lot of places are, but a lot of places are not. You always have to check it out before you go. I don't know. It's just everything – the simplest things in life I no longer take for granted.

Brad's Family – There were always short periods of discouragement. If Brad got discouraged and looked like he was getting depressed, we noticed it, tracked it, and tried to stop it from going off the track. We had to be very proactive.

Hospital – Because of Adam's brain injury he would need constant supervision, and the family really came to bat and he's had to have a number of rehabilitation appointments and schooling concerns and this family has been a strong support.

Adam's Family – We communicate all the time for his medication. If he hasn't communicated with me by a certain time, then I call him to make sure he has taken his medication. That way I give him a half an hour. Lots of times he never forgets, but if he is supposed to takes things at three o'clock and I don't hear from him, I call him about three thirty.

Hospital – So (the family) had to learn brain injury education as well, they had to learn about cognitive deficits, they had to learn what was the best way, and strategies and I think by working with the rehab team on a daily basis it better equipped this family for this journey and a lifetime challenge.

Julie's Family – Everything has changed, like our whole family. My immediate family has changed quite a bit. They've all come close because of Julie's accident and we don't take things for grated that we would have taken for granted.

Hospital – Brad has a wonderful advocate as a parent.

Brad's Family – You do not look at things the same way as other people because you have seen too much. You don't look at cars the same way. We don't look at ambulances the same way. You look at it informed, which is not always a good thing, but it changes your perceptions. The innocence is lost.

The theme-driven structure of this chapter serves to emphasize the uniqueness of each case while highlighting important cross-case factors that may enhance transferability to other contexts. Differences in family structure, pre-morbid functioning, severity of injury, community school environment, and time elapsed since injury, all contribute to a myriad of possible outcomes. Despite these variations, the consistent themes of early intervention, teamwork and communication, and the need for on-going support offer valuable insight into the rehabilitation perceptions of family, therapist, teacher, and student.

Chapter Six: Discussion

Emerging themes from the three case studies reflect the issues that have been previously reported in the literature. The reality of the diverse and dynamic nature of acquired brain injury (Watanabae et al., 2003) is a strong undercurrent throughout the multi-voiced discourse as parents, teachers, and the patients themselves struggle with a continuously changing profile and identity. Experiencing the divergent perspectives of parents versus medical professionals highlights Singer's (1996) call to "humanize" the system of therapy delivery through a holistic treatment model. The voice of each teacher in the study echoes the growing need for education in the area of ABI (Kumpf et al., 2003). All three stories close with a bittersweet reminder of the necessity, but exhausting personal cost, for on-going advocacy (Luiselli et al., 2000). For the purpose of discussion, the three meta-themes and their related sub-themes have been organized into three guiding statements that effectively summarize the observed benefits of educational and therapeutic collaboration during rehabilitation for adolescents recovering from ABI. Each statement is discussed in relationship to the current body of literature, followed by the implications and challenges it offers to future practice.

6.1 Early intervention of rehabilitation school offers hope, normalization, motivation and a functional context for therapy.

Building on Singer's (1996) call for holistic treatment, the introduction and involvement of the hospital teacher during acute care and early-stage rehabilitation provides a sense of hope and normalcy for the adolescents in this study and their families. All three students appreciated the introduction of the teacher as a symbol of the promise of a future.

The acknowledgement of a familiar and normal activity offered each student and family a daily anchor of stability in a very unfamiliar setting.

Beyond the simple provision of an information link (De Pompei, 1998) the early communication with the community school and rehabilitation team initiates the involvement of everyday people (Ylvisaker & Feeney, 1998). As rehabilitation progresses, the notion that students are able to continue working towards school related goals, even though they are hospitalized, is motivating, for in two of the three cases, the early intervention of rehabilitation school is identified as a primary reason for the student's eventual return to the community school. The fact that high school credits are attained during in-patient rehabilitation encourages the students to believe that continued academic success is a realistic option for their future.

An unexpected tension of early community school involvement arose when families of a child recovering from life-threatening injuries were placed in the position of acknowledging their child's pre-morbid school record – which in each case studied was below average. Taylor, Yeates, and Wade (2002) acknowledge that a higher than normal incidence of pre-morbid behaviour problems is found in adolescents experiencing ABI. The high degree of impulsivity and social disinhibition associated with behaviour problems helps explain why that population is more at risk for head injury. My experience has shown that parents may describe their children in overly positive language when relating their pre-morbid performance to therapists. While the desire to think of and recall more positive aspects of a child's personality is understandable in the situation, it is not helpful in the development of appropriate rehabilitation programming. A high degree of sensitivity is required while procuring initial parental consent for sharing of information between hospital and school.

From the therapists' perspectives, hospital school provides a functional context in which to work towards and assess therapeutic goals. The rehabilitation classroom more closely mimics real-life than the isolated one-on-one situation of a therapist's office, and discourages over-reliance on assistance for the student (Idol, 2006). The presence of other students provides realistic levels of distraction and the opportunity for un-scripted socialization, highlighting areas of individual need and competency. Combining therapeutic goals with curriculum related goals, such as in the case of physiotherapy and physical education, greatly enhanced the motivation and participation of the students in this study, especially when the opportunity for credit attainment was involved. Ylvisaker et al. (2005) support the observation that personally meaningful activities improve motivation and participation in therapy for most children and adolescents.

The challenges of creating a functional context revolve around the nature of collaboration. The teacher and the therapist must not only share their space and work together towards complementary goals, but they must also be willing to learn from each other. Beyond practical training, this requires a level of personal commitment to a collaborative learning culture (Edward, Coffield, Steer, & Gregson, 2007). Senge (1990) describes the importance of encouraging all members of collaborative teams to develop their personal visions. "If people don't have their own vision, all they can do is 'sign up' for someone else's. The result is compliance, never commitment" (p. 121). In a pediatric rehabilitation setting, where the concept of *emotional labour* (Brennan, 2006) is a daily reality, compliance without commitment is unlikely to lead to a sustainable collaborative relationship.

6.2 Teamwork and communication between school, hospital and family is necessary to provide a cognitive and behavioural baseline, support teacher education, planning for success and the flexibility to accommodate diverse and changing profiles.

When the hospital, school and family all communicate with each other and work as a team from the beginning there seem to be many benefits. The first benefit is that the school can provide an objective cognitive and behavioural baseline for the rehabilitation team that can be supported by documentation from the student's school record, allowing the team to set realistic rehabilitation goals. In this study, awareness of the students' previous academic records allowed the therapeutic team to anticipate behavioural hurdles and cognitive challenges; adapting programming accordingly.

Secondly, on-going communication provides a network for teacher education and support (Kumpf et al., 2003). All three schools acknowledged that they would not have felt comfortable reintegrating the students without the support of the rehabilitation team. The opportunity to follow the student's progress beginning at the acute stage provided educators with a greater appreciation for the severity of an injury that became progressively more invisible as the physical healing progressed.

Finally, as the student progresses through rehabilitation the team can work together to plan for success and minimize potential school failure (Kumpf et al., 2003). Even after initial school reintegration, the continuation of this communication link helps facilitate the necessary flexibility to accommodate the diverse and changing profiles of students with ABI.

The positive experiences that Adam had with school in the hospital setting seemed to precipitate an increased interest in school that was sustained throughout his high school career. The school reintegration experiences of both boys in this study detail the changing levels of support required for success on many levels, from physical to academic to social. Walberg (1993), reports that in order for an exceptional learner to make academic progress, their instruction must be closely matched to their individual (and changing) needs. Adam and Brad returned to school with an Educational Assistant and a wheelchair, attending only one course per day. Although the time lines vary, they both graduated, walking independently across the stage, to receive their Secondary School Graduation Diploma.

The situation differs for Julie. Even though high school graduation remains a goal in her life, conflict between the schedules of her community rehabilitation team and the community school have sidelined her return to the classroom. This situation highlights the strong potential for collaborative tension that was not realized in the boys' cases. Ylvisaker et al. (2005) observe that an adversarial relationship can be set up between the family and school staff when medical rehabilitation goals are given precedence over psycho-social goals, instead of working towards both sets of goals in a functional context. At the recommendations of the community rehabilitation team, Julie's mother has chosen to continue daily intensive therapies in the home. She is fearful that the effort involved in regular school attendance will leave her daughter too fatigued to make progress in her physiotherapy and speech therapy sessions. The school has remained open to Julie's eventual return, but the family's decision to not return after an Educational Assistant was hired specifically to support Julie's transition, may compromise the willingness of the school to offer similar support if and when it is requested.

Other areas of potential tension include reticence on behalf of teachers to accept classroom strategy suggestions from therapists working in what may be perceived as an idealized situation. Handpicking classroom teachers who embrace a collaborative model is recommended for students returning from intensive rehabilitation. While the vast majority of teachers visualize themselves as being highly collaborative (Idol, 2006), there is a tendency to resist change when teacher input has not been involved in the formation and evaluation of change (Edward, Coffield, Steer, & Gregson, 2007). Ball (2003) suggests that changes in teaching strategies need to strike at teachers' souls in order for them to be embraced and effectively incorporated into their practice. While the inclusion of the hospital teacher in strategy design may facilitate communication between the hospital and school, care needs to be taken to include the actual members of the community school team early in the rehabilitation process. Without this exposure to the pervasive nature of ABI, subject-focussed teachers, especially at the high school level, may have difficulty rationalizing the level of accommodation required to support school success.

As the transitions between teachers occur over subsequent semesters, these tensions are best addressed through formal IPRC meetings at which the hospital teacher and classroom teachers are present. This level of support is effort intensive, translating into real concerns regarding funding and time management. Edward et al.'s (2007) study on the impact of inclusion of students with special needs in the regular classroom suggests that teachers may feel that one student with exceptional needs uses up a disproportionate amount of their time and energy, while remaining at high risk for failure. While being in favour of the idea of inclusion, many teachers questioned whether their time might be better spent supporting students who were able to attend class regularly and handle grade level curriculum. Edward et al. continued to note that teachers may be wary of creating a false sense of success; that is modifying and adapting to such an extreme that the student becomes overly dependent on the immediate attainability of success, compromising the ability to be challenged to learn new processes and products. Ylvisaker et al. (2005) observe that the need for support programs, consultation and technical assistance to school staff is "especially strong during the child's major transitions, for example between elementary school and middle school" (p. 103). Provision for staff in-service and support during these transition periods may be an important consideration in educating and training classroom teachers so they are better equipped to meet the needs of students recovering from ABI.

6.3 Educational collaboration provides a framework for ongoing support by offering an opportunity for socialization, self-advocacy, and family advocacy.

Living with an acquired brain injury usually translates into a radical and permanent change for both the child and the immediate family (Singer, 1996). Educational and therapeutic collaboration provides the opportunity for the child to return to school with the initial primary goal of socialization – a critical aspect of ABI rehabilitation (Mottram & Berger-Gross, 2004). Reflecting on her early-stage rehabilitation, Julie identified the socialization opportunities of school as a highly motivating factor, not only for school itself, but also for the completion of the arduous routines of morning care required before she would be able to join the rehabilitation classroom.

It is an oversimplification to equate academic inclusion with social inclusion in the community school setting. Brad recognized that he could no longer focus on the social aspect of school if he was going to achieve a measure of success academically. In a recent study examining the effectiveness of inclusive education, Lindsay (2007) found that the overall levels of social and emotional functioning were lower in children with a learning disability, even though they were in a favourable inclusive setting. A similar study (Gibb, Tunbridge, Chua, & Frederickson, 2007) found that students with even mild disabilities were less often accepted and more often rejected than their classmates without disabilities. Furthermore, Idol (2006) found that if a behaviour problem was part of the disability, social exclusion was dramatically increased in inclusive settings. These studies suggest that students with ABI face many challenges in the area of social reintegration.

Socialization and community school reintegration provide a real-life arena to develop and practice essential self-advocacy skills (Wiseman-Hakes et al., 1998). Once removed from the highly protective hospital environment, the necessity of speaking out prompted the students to discover and develop their own voice of self-advocacy. In Brad's case, his self-advocacy developed following a minor set-back at the college level; a real-life learning experience reinforcing his need to proactively communicate with his teachers. However, Gibb et al. (2007) caution that if students with special education needs experience rejection and bullying from peers, they may become unwilling to socially engage in the community school. In the case of a student with ABI, a negative social experience could in fact hamper efforts at self-advocacy and add to the child's disengagement with social inclusion. Therefore, careful consideration must be given to planning the child's social integration. As

Gibb et al. observed, academic and physical inclusion does not automatically result in social inclusion.

Because school, like life, is full of transitions, the continued communication between family and school provides an important opportunity to develop life-long family advocacy skills. Indeed, Gibb et al. (2007) identified *productive collaboration with parents* as one of twelve important factors necessary to facilitate successful inclusion for exceptional students. They describe the need to include parents in the planning and review of programming, and taking time to address parental concerns through regular interviews so that parents feel actively involved in the whole process. The sheer demands on time, from the school's perspective and the parents' perspective (who are juggling their child's school, therapy and medical appointments with their own employment needs) can challenge the practicality of this level of collaboration and communication. At some point the additional time and energy required for meetings and communication begins to detract from the available resources of time energy allotted to student education and parental care.

From the everyday experiences like simply getting out the door, to the major landmarks like attending college, the family members expressed a profound awareness that their nearly-adult child required significant coaching and support. In Adam's case, the communication model between school and family (using a telephone to remember important assignments) helped set up routines and strategies that have been transferred to support independence in his activities of daily life (using a cell phone to confirm taking medication). Despite the significant gains made by each student, all three families realized the daunting responsibility of the on-going care and support of their child. Dr. Terry Shaw, a professional who works with ABI survivors, and a parent of a child affected by ABI recounts that families are the second victims of ABI (Shaw, 1996). He advocates that until families of children recovering from ABI are acknowledged, and their needs addressed, any treatment aimed solely at the survivor is potentially substandard. He states,

> Family members do need treatment within their own time frame and at their own level of acceptance if they are ever going to be able to minimize the emotional impact of what has otherwise become known as the "worst day of their life" (p. 4).

6.4 A socio-cultural model

The data provides substantial qualitative evidence to support the benefits of educational and therapeutic collaboration facilitated through the involvement of a hospital teacher throughout all stages of rehabilitation. A holistic treatment model is initiated during acute care and early-stage rehabilitation. Based on our hospital's evolving model of school-focused rehabilitation, the role of the hospital teacher includes

- Introducing self to parents and student to provide hope that even though medical circumstances seem quite overwhelming, the team is planning now for the student's eventual return to school.
- Providing a semblance of normalcy in an environment that is unfamiliar to the routines and practices of daily life, and a therapeutic structure that recognizes the child's identity as a student.
- Providing a meaningful and motivating context for therapies that will allow students to understand the rationale and long-term benefits of physiotherapy, occupational therapy and speech and language pathology.

The data supports the idea that provision of a meaningful context, even during acute care, can elicit a higher level of response or involvement by the student than less meaningful activities (Goldberg, 1996). During rehabilitation, Ylvisaker argues that rehabilitation school gives meaning and application for the abstract concepts of motor skills, cognition, language, emotion, volition and behaviour (M. Ylvisaker, personal communication, 2007).

Educational and therapeutic collaboration provides a functional context for in-patient rehabilitation therapy through the provision of a rehabilitation classroom. In a broad sense, rehabilitation has been described as "whatever the child is doing while he is awake" (M. Ylvisaker, personal communication, 2007). While there is some necessity for one-on-one testing in the office of a therapist, the data suggests that the "real-life" setting of school provides an ideal context in which to observe, implement and assess cognitive, physical and behavioural strategies (Savage, 1997). The following examples have been taken from our rehabilitation practice to illustrate how the classroom setting is mutually beneficial to the therapist, student and community school:

- The development of Individual Education Plans co-ordinate rehabilitation goals with school curriculum goals, allowing students to work towards school credits while in active rehabilitation.
- The teacher provides meaningful, age-appropriate activities for therapists to use while assessing student progress.

- The classroom provides opportunity for un-scripted social interaction with peers in the safe environment of a rehabilitation classroom.
- There is opportunity for the therapists to observe the student dealing with distractions, classroom routines and other real-life issues. Strategies can then be developed, practiced and evaluated in a functional context.
- The higher student to teacher ratio provides opportunity for the student to develop increased independence and problem solving ability.

Teamwork and communication between the school, hospital and family provides a network to address the needs of teacher education in the area of acquired brain injury (Blosser and Pearson, 1997). This communication also provides an invaluable framework to support student success (De Pompei, et al., 1998). The hospital teacher can initiate contact between hospital and school during the acute stage in order to provide a subjective baseline picture of the student's academic and behaviour history. This aids in the development of realistic rehabilitation goals, in that a disability that existed before an injury will still be there, only perhaps more pronounced. (D. Collins, personal communication, 2007). This contact also allows the community school to become aware of the rehabilitation process beginning at the earliest stage, giving educational staff the opportunity to experience the degree of initial impairment and to observe the dynamic healing of the brain while feeling like part of the rehabilitation team process from the onset of therapy.

Teamwork allows therapists to share general information about acquired brain injury as well as specific strategies with the teachers who will be working with the student at the community school. Educational and therapeutic staff can meet together to set highly individualized, realistic short term goals that will allow the student to experience real success leading up to and during the reintegration process (Blosser and Pearson, 1996). Community school teachers continue to have on-going communication with the rehabilitation team members to help provide functional goals for rehabilitation and re-evaluate strategies and long-term goals in the school setting as the student's profile changes (Ylvisaker et al., 2001).

Similar to Singer's call for a holistic treatment model (1996), a socio-cultural model for pediatric rehabilitation would recognize each child's multiple identities – how the child perceives self in relationship to others as a friend, student, sibling or child. As the central social institution in a child's life, the school becomes the obvious choice for the primary setting of this model, with the classroom providing the central focus for rehabilitation therapy. Such a model can provide a functional framework from which to develop on-going advocacy and support.

Figure II gives a graphic representation of how this model might function. Similar to the structure diagrammed in Figure 1, rehabilitation team involvement begins at the acute injury stage, including the introduction of the teacher. However, as soon as the student is medically stable for even short visits outside of the hospital room, rehabilitation therapies can be delivered in the setting of a classroom. Borrowing from Vygotsky's theories of the social origins of mental functioning discussed earlier in this paper, the school-like setting allows the student more opportunity to observe interaction between peers and therapists on the social plane, increasing the potential for intra-mental transfer.

As the student's healing and response to therapy progresses, outpatient treatment would continue in the rehabilitation classroom setting. This allows relationships established during in-patient treatment to continue and support the student directly into daily school attendance (Ylvisaker et al., 2005). The necessity of a home instructor is minimized, resulting in a lower potential for social isolation during the time period between in-patient discharge and community school integration. Secondarily handicapping situations brought about from social isolation such as depression and school anxiety (Mottram & Berger-Gross, 2004), may be less likely to evolve when the student is able to transition directly from one classroom setting to another.

Once integrated into the community school, rehabilitation team members would continue to be directly involved through therapy and indirectly involved as consultants to the teaching staff. Annual formal reviews through the Identification, Placement and Review Committee (IPRC) would include the student, parents, teaching staff and therapeutic team. Informal consultation and review would occur on an as-needed basis throughout the year.

This model provides for on-going advocacy and support by:

- Providing opportunity for socialization throughout the rehabilitation process. This includes appropriate socialization with other children in various stages of rehabilitation, giving the student the chance to adjust to different levels of functioning in a physically and emotionally safe environment.
- Providing an environment to promote self-advocacy skills with the support of therapists and every-day people such as the classroom teacher.
- Allowing the student to experience some of the challenges of classroom reintegration while still under the direct observation of trained therapists, who

can then develop and assess the effectiveness of various interventions, as the student's needs change.

- Allowing students to learn from each other
- Allowing students to assist each other in problem solving
- Providing a support network of peers with a shared hospital experience

This model is designed for a rehabilitation setting that spans acute care to out-patient follow-up. However, the guiding statements used as a foundation for this model provide an important framework for future model development in all pediatric settings.

6.5 Challenges for future model development

Despite the potential benefits of this model, there are many practical challenges that must be explored and questions that remain unanswered. The first question revolves around the nature of collaboration in the highly emotionally charged hospital setting. *How can a medically focused acute care team initiate a collaborative practice with a teacher; a professional normally associated with a totally different institution?* While this study has provided reasonable justification for the implementation of such a practice, the practical challenges of funding, recruiting and training remain formidable.

In the opening pages of this study, I described the goal of the rehabilitation team as "to see the child settled happily and productively in the world outside the hospital doors" (p. 22). School attendance plays a principle role in the life of almost every child, with school attendance comprising up to 50 percent of a child's wakeful hours. With that in mind, any model for successful paediatric rehabilitation must ask: *What are the existing challenges associated with inclusion for exceptional students in the community school?* Gibb et al.

(2007) identify six specific barriers for students with special needs, including the child's lack of social competence and social disengagement, the child's low academic ability, inflexible staff attitudes, inappropriate teaching strategies and parental anxiety. All of these concerns can be clearly applied to the situations of students recovering from ABI. Gibb et al. suggest that "an important element in successful inclusion is the development of a three-way collaborative partnership between support professionals, schools and parents" (p. 120). *How can the rehabilitation team initiate this collaborative partnership?* Lindsay (2007) states that "at the heart of all education is the practice of teachers" (p. 12). *How can a pediatric rehabilitation model include teaching professionals from the onset of program development to build commitment rather than compliance; so that ultimately the teachers have a sense of ownership, bringing a change to the soul of their practice (Ball, 2006)?*

Finally, in addressing the need for family support and advocacy throughout the life of the student, there is still much work to be done. Unlike the subjects of this study, many families, whose children are victims of brain tumours, strokes or other illnesses, have no additional insurance settlements to help offset the burgeoning expenses of caring for a child with ABI. In these situations parents must frequently relinquish some employment income, as one parent must be home to care for the child. *How can rehabilitation programs assist families in developing support networks that will allow them to deal constructively with the issues of legitimate parental anxiety and life-long responsibility?*

Anecdotal evidence from this study also suggests a need for increased awareness at the post-secondary and employment levels. Organizations such as the Ontario Brain Injury Association (OBIA) have excellent web sites, which focus more on adult rehabilitation issues than paediatric ABI. Inevitably the task of sharing this information with potential employers falls on the shoulders of the student's caregivers – more often than not, the parents. As documented in the research, this life-long commitment can be exhausting and debilitating. The development of a parent network that could provide continuing support would be a valuable addition to any rehabilitation model.

6.6 Limitations of the study

The choice of a case study tradition is appropriate to research involving acquired brain injury in that, unlike many diseases or syndromes, ABI affects each patient in a distinct manner (Lewis et al., 1998, and Emanuelson et al., 2003). While similarities exist in recovery patterns, each case has a high degree of individuality and unpredictability (Watanabae et al., 2003). Due to this variability, some may argue that the identified meta-themes from only three case studies offer limited transfer to similar populations; adolescents who experience an acquired brain injury, their families and the medical and educational staff supporting their rehabilitation. However, the consistency with which the literature recognizes the support needs of adolescents recovering from an acquired brain injury reinforces my belief that despite the limited number of cases, my findings have ecological validity to conditions that are similar. These conditions include pre-morbidly, average-functioning adolescents experiencing severe ABI, receiving approximately two years of therapeutic interventions under the direction of a pediatric rehabilitation centre, with the goal of reintegration to a community school.

Possible threats to internal validity include concerns related to history and maturation. Because interviews were conducted retrospectively, it was difficult for participants to remember in detail, some of the events that occurred two to four years ago. It is also likely, especially in the case of the students, that developments in maturity over the past years have altered insight into the events. Responses are undoubtedly different than they might have been had the questions been asked while the participants were actually living through the experience. Dialogue with students currently in the midst of active rehabilitation reflects significantly less insight into the purpose and outcomes of rehabilitation therapies, and a greater expression of frustration with their relatively new challenges. However, the fact that the comments made by Brad, Adam, and Julie reflect their current state should not be undervalued. In the boys' cases, they reflect a level of acceptance and reconciliation with their physical and cognitive limitations. Julie, whose injury is more recent, and more debilitating, is far from reaching that point. It would be interesting to revisit these three young adults in five years time.

An intrinsic difficulty with qualitative research is the issue of bias. In this study, the teachers and therapists were asked to tell the story of the student they were employed to teach or treat. It could be argued that they were asked to comment on how well they had done their jobs, which raises the possibility of bias, a reality that may undermine the credibility of the results. However, I feel that there were no further steps that I should have taken to reduce the unwarranted impact of bias, because I valued the rich description of the perspective (and inherent bias) of each voice in the study.

Qualitative instrumentation can also be seen as a threat to internal validity (Lincoln and Guba, 1985). Because open-ended questions were used to facilitate an inductive model of theory development, the participants' ontological perspectives inevitably prompted ideologically diverse responses. At times this reality helped paint the dramatic divergence of opposing perspectives on individual events (for example the perspectives of the parent and the student upon the initial meeting with the teacher). Instead of diluting the message, this conflict served to highlight the emerging themes. It is my belief that by including the actual sentences of each participant in the text, rather than isolating and triangulating words and phrases, the reader is able to experience the stories, summarily identifying and reconciling the themes anew, each time they are read.

6.7 Contributions to knowledge

Despite the growing body of knowledge in the area of pediatric ABI, the important role that school plays in a child's life appears to remain a secondary consideration in the development of rehabilitation services. While the need to communicate with teachers in the community school is recognized in a number of papers (DePompei et al., 1998), the role of a hospital teacher in rehabilitation is given only passing mention. In the rare cases in which a hospital teacher is included (Slifer et al., 1997), it is only after the patient is medically stable and deemed well enough to begin work on curriculum related activities. The role of a teacher seems marginalized to that of someone outside the health-care system; someone the therapists will pass on information to once they determine a patient is ready for school.

The positive impact of the involvement of a rehabilitation team teacher, beginning at acute care and following through all stages of rehabilitation, can be seen as the most important contribution of this thesis. While the identification of themes of normalcy and motivation were not big surprises during the data analysis, the strong message of hope brought about by the early presence of a teacher was an unanticipated finding. Brad articulates that the early visits by the teacher "helped me think beyond, to know there would be a next semester."

The observed correlation between long-term school success and early involvement of the rehabilitation teacher is another important contribution. Two of the three participants experienced their greatest school success after their injury. All four voices in both of these cases contributed a significant portion of that success to the fact that "they had school in the hospital and they started it out right at the beginning" (Adam's Mom).

The benefits of practicing educational and therapeutic collaboration from the earliest stages include developing an accurate base-line picture and the provision of meaningful work for the student. The nurse case manager recollects "we learned very quickly that our therapies have to be meaningful for our patients or they loose interest very quickly or they just don't participate." The normalized context of a rehabilitation classroom allows therapists to meet functional goals while naturally allowing socialization skills to develop.

The important challenges of teacher education are addressed through early-intervention by providing ample time to develop a team-approach with the community school. Brad's school identified that the immediate interaction with the hospital allowed them to experience "his progression from the accident right through to his entry into the school." Once established, the relationship between therapists and school can remain supportive throughout the student's school experience. "If there had been no early school involvement we would have been very worried seeing Adam's state when he came into school" (Adam's school).

Including the role of "teacher" as an integral part of any pediatric rehabilitation team positively impacts the patient, family, therapist and future school progression in a unique and meaningful way. Implementation of a socio-cultural model of pediatric rehabilitation provides our schools with a much-needed educational link, while offering a valuable functional context for therapists. The introduction of daily educational programming gives each student and family the opportunity to feel normal and motivated. Most importantly, in the eyes of the child, the early involvement of a hospital teacher presents itself as hope for the future.

6.8 Conclusion

Children recovering from ABI often experience life-long challenges in the cognitive, emotional and psychosocial realms. The goal of any rehabilitation program is to maximize the patient's ability to return to productive living in a normal environment. In the case of a child, the normal environment is school, and productivity represents learning new information – a task uniquely challenging for those affected by ABI. Even in the best-equipped medical facilities, the child's ultimate return to school must be intrinsically tied to all rehabilitation goals, or successful community school reintegration is at risk.

As a deeply vested interviewer, these studies evolved into a qualitative rationale for my own practice. It was difficult to analyse the data without a set of pre-existing themes, but I specifically did not include my own reflections during the telling of each story, in an effort to minimize the affect of my acknowledged bias. My hope is that readers will formulate their own versions of each story as they experience the voices, allowing the three settings to provide a rich backdrop in which to frame the emerging themes.

Future studies could attempt to compare the success rates of student reintegration (based on qualitative indicators such as the use of a home instructor, full-time reintegration, graduation, and post-secondary success) between children treated in a socio-cultural rehabilitation setting and children receiving rehabilitation therapy in a traditional hospital-based model. Looking at the long-term implications of successful community school reintegration is an important step in creating the necessary support network for students and their families. I believe that through the actual words of each of the participants in these case studies, all stakeholders in paediatric rehabilitation are brought one step closer to understanding the need for a socio-cultural model of therapeutic intervention and recognizing the vital and ongoing role of education in the life of every adolescent.

"Two years have passed and the teachers think the issue is gone.
But the issue is not gone.
Those support factors are not there and he is struggling.
We are tied into this thing for life."
Brad's Mom 2004

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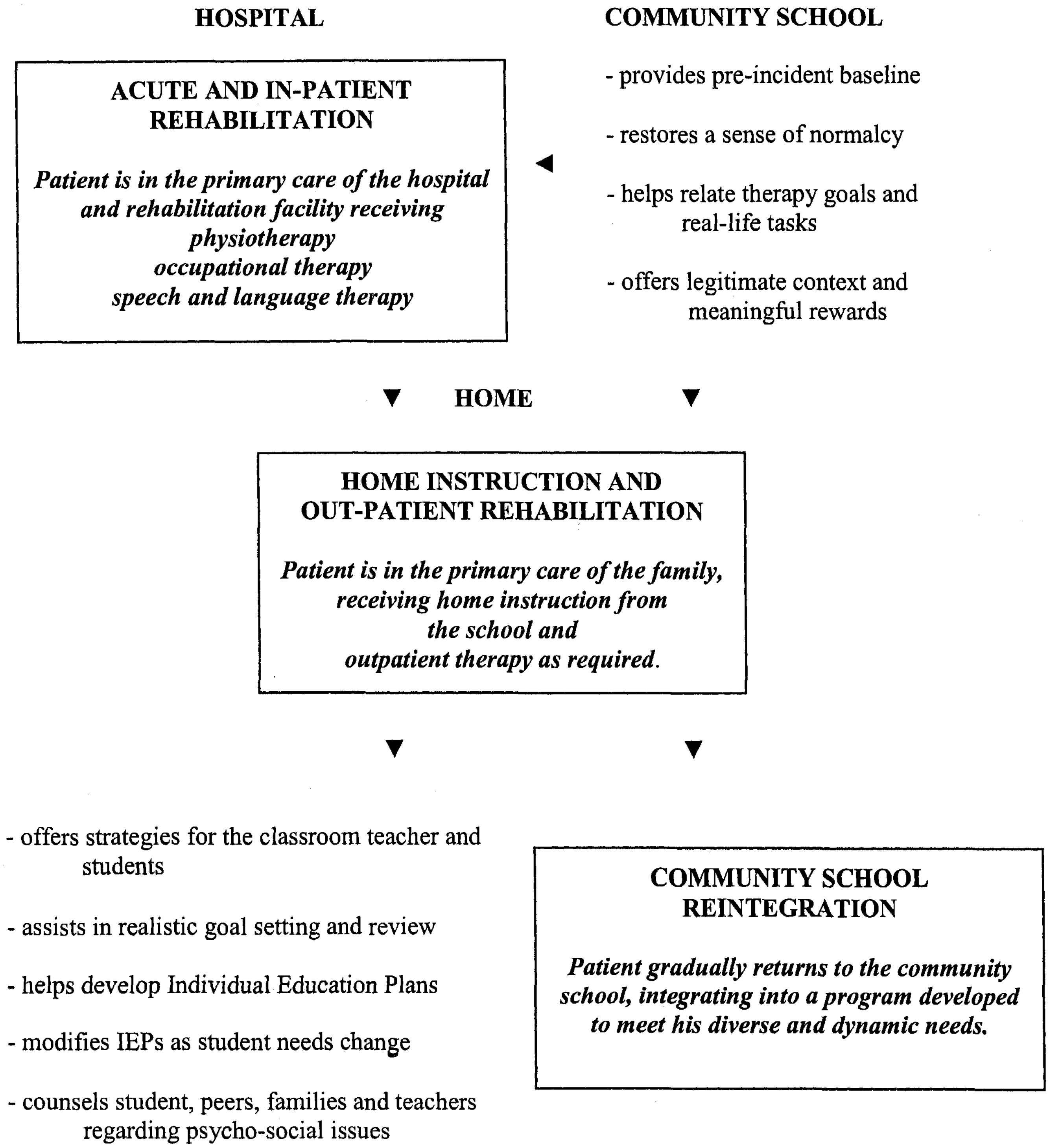
Figure 1

Framework for Collaboration



HOSPITAL

COMMUNITY SCHOOL

ACUTE AND IN-PATIENT REHABILITATION

Patient is in the primary care of the hospital and rehabilitation facility receiving
physiotherapy
occupational therapy
speech and language therapy

- provides pre-incident baseline
- restores a sense of normalcy
- helps relate therapy goals and real-life tasks
- offers legitimate context and meaningful rewards

▼ **HOME** ▼

HOME INSTRUCTION AND OUT-PATIENT REHABILITATION

Patient is in the primary care of the family, receiving home instruction from the school and outpatient therapy as required.

▼ ▼

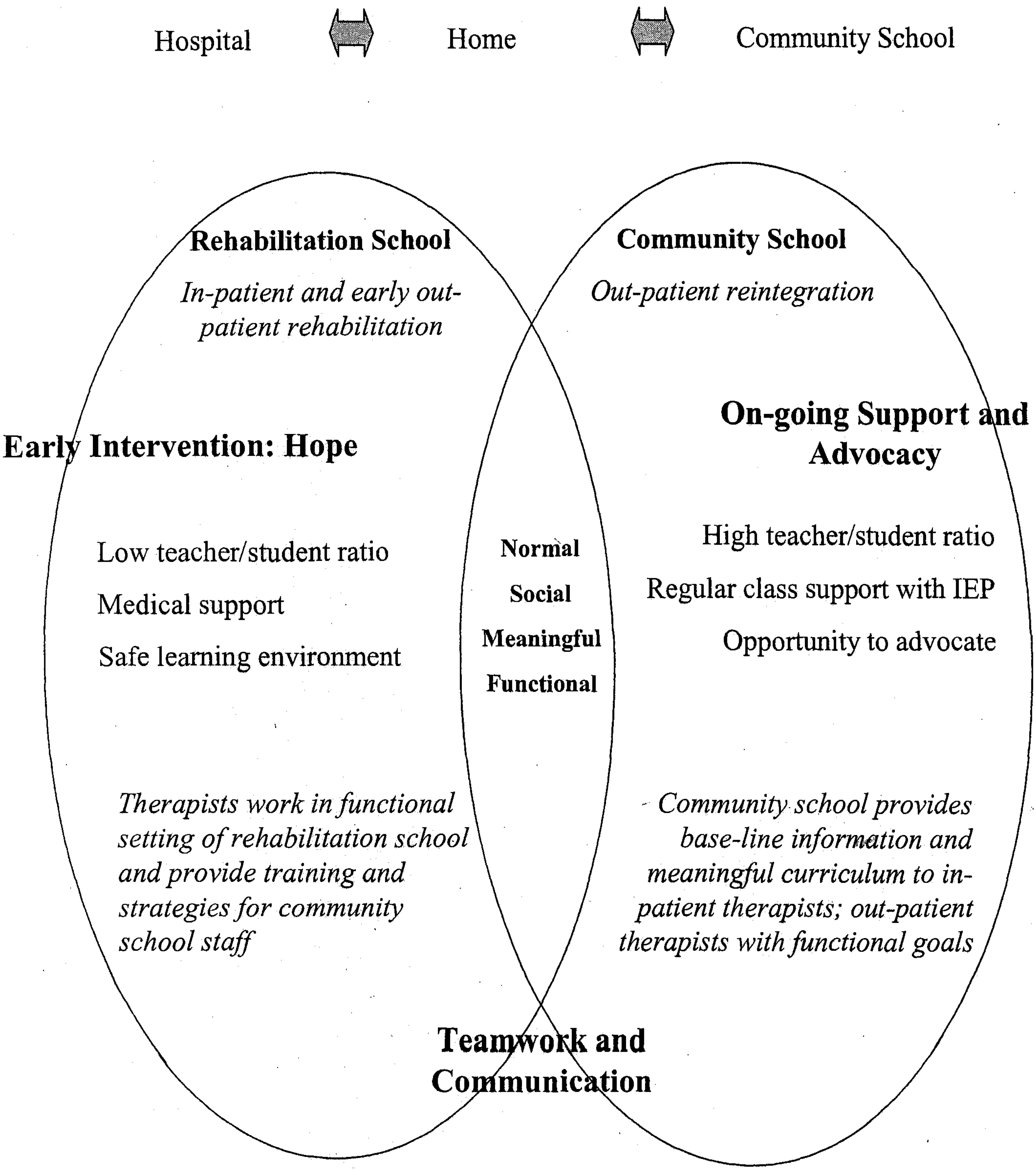
- offers strategies for the classroom teacher and students
- assists in realistic goal setting and review
- helps develop Individual Education Plans
- modifies IEPs as student needs change
- counsels student, peers, families and teachers regarding psycho-social issues

COMMUNITY SCHOOL REINTEGRATION

Patient gradually returns to the community school, integrating into a program developed to meet his diverse and dynamic needs.

Figure 2

Socio-Cultural Model for Paediatric Rehabilitation



Hospital ⇔ Home ⇔ Community School

Rehabilitation School

In-patient and early out-patient rehabilitation

Early Intervention: Hope

Low teacher/student ratio

Medical support

Safe learning environment

Therapists work in functional setting of rehabilitation school and provide training and strategies for community school staff

Normal

Social

Meaningful

Functional

Community School

Out-patient reintegration

On-going Support and Advocacy

High teacher/student ratio

Regular class support with IEP

Opportunity to advocate

Community school provides base-line information and meaningful curriculum to in-patient therapists; out-patient therapists with functional goals

Teamwork and Communication

Appendix A

Interview Guide for Participants

A. Student

1. Tell me the story of what happened to you on (date of accident).

2. Describe the role as you see it, of each of the therapists, doctors and teachers in your recovery.

3. What are your recollections regarding therapy sessions, beginning as early after the accident as you can recall, right up until discharge? Include physiotherapy, occupational therapy, speech and language pathology and any other therapeutic sessions that come to mind.

4. What are your recollections regarding school sessions, beginning as early after the accident as you can recall, right up until discharge?

5. Can you describe any events that really encouraged you or discouraged you in your experience? What, if any, activities seemed worthwhile and motivating? Why? What, if any, activities seemed boring and meaningless? Why?

6. Describe how you felt during the transition time between the hospital and attending school. Include your reflections on the role of the home instructor. What interventions made this period of time easier? What made it harder? What would you have changed if you could have?

7. Describe your return to school. Try to remember how you felt in both positive and negative ways. What aspects of your rehabilitation helped you as you returned to classes? What did the school do that was positive? What made this time more difficult?

8. Did you ever feel like "giving up" during the reintegration process? If so, please describe these feelings and explain what helped you continue each day.

9. In what ways would you describe your school reintegration as "successful" or as "unsuccessful?" Please explain your answer.

10. All of life's occurrences impact our future in one way or another. How has your head injury impacted your life and the lives of your family? Please include positive and negative reflections.

B. Family

1. Tell me the story of what happened to your (son) on (date of accident).

2. Describe the role as you see it, of each of the therapists, doctors and teachers in your (son's) recovery.

3. What are your recollections regarding your (son's) therapy sessions, beginning as early after the accident as you can recall, right up until discharge? Include physiotherapy, occupational therapy, speech and language pathology and any other therapeutic sessions that come to mind.

4. What are your recollections regarding your (son's) school sessions, beginning as early after the accident as you can recall, right up until discharge?

5. Can you describe any specific motivators or detractors in your (son's) experience? What, if any, activities seemed worthwhile and motivating? Why? What, if any, activities seemed boring and meaningless? Why?

6. Describe how you felt during your (son's) transition time between the hospital and attending school. Include your reflections on the role of the home instructor. What interventions made this period of time easier? What made it harder? What would you have changed if you could have?

7. Describe your (son's) return to school. Try to remember how (he) felt in both positive and negative ways. What aspects of your (son's) rehabilitation helped during the return to classes? What did the school do that was positive? What made this time more difficult?

8. Did your (son) ever feel like "giving up" during the reintegration process? If so, please describe these feelings and explain what helped (him) continue each day.

9. Would you describe your (son's) school reintegration as "successful?" Please explain your answer.

10. All of life's occurrences impact our future in one way or another. How has your (son's) head injury impacted (his) life and the lives of your family? Please include positive and negative reflections.

C. Hospital

1. Tell me the story of what happened to the patient on (date of accident).

2. Describe the role as you see it, of each of the therapists, doctors and teachers in your recovery.

3. What are your recollections regarding the patient's therapy sessions, beginning as early after the accident as you can recall, right up until discharge? Include physiotherapy, occupational therapy, speech and language pathology and any other therapeutic sessions that come to mind.

4. What are your recollections regarding the patient's school sessions, beginning as early after the accident as you can recall, right up until discharge?

5. Can you describe any specific motivators or detractors in the patient's experience? What, if any, activities seemed worthwhile and motivating? Why? What, if any, activities seemed boring and meaningless? Why?

6. Would you describe the patient's school reintegration as "successful?" Please explain your answer.

10. All of life's occurrences impact our future in one way or another. From your perspective, how has the patient's head injury impacted (his) life and the life of the family? Please include positive and negative reflections.

D. School

1. Describe your interactions with the hospital during the acute and early stages of rehabilitation for this student. What, if any affect, did this have on the student's reintegration?

2. Describe the student's return to school. Try to remember if the student communicated how (he) felt in both positive and negative ways.

3. Describe any changes that you have noticed involving peer interaction following the student's reintegration. Has the school done anything to facilitate the student's social development?

4. In what ways did working with the rehabilitation team help (the student) as (he) returned to classes? What did the school or hospital do that was positive? What made this time more difficult?

5. Would you describe the school reintegration as "successful?" Please explain your answer.

Appendix B

Six Steps to Facilitate Successful School Transitions for Children and Adolescents with Brain Injury (Blosser & Pearson, 1997)

1. Build a team that works to link the hospital, school and community
2. Provide the school with information about acquired brain injury in general and about the specific child at risk
3. Develop a common philosophy to help guide the differences in opinion when looking at medical and educational perspectives
4. Offer alternative options for learning. Because each ABI is unique each potential for learning is also unique
5. Prepare the student and family for multiple transitions
6. Create an educational plan that addresses curricular and life skill issues