Traumatic Brain Injury
Challenges and Considerations for the School

A Thesis

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DEDICATION

As anyone who has completed a thesis would know, it is a huge under-taking and it can consume your life for months, if not years. I would not be in the position I am in now if it were not for a number of very special individuals. Therefore, I find it only appropriate to dedicate this thesis to the following:

Case Study Parents: *Thank you so much for opening your hearts for this study. I believe that I have represented your stories to the best of my ability and that your belief in this research will be beneficial not only to our school system, but also for parents who may be going through similar experiences.*

Dr. Vianne Timmons: *I have learned so much from this experience and I cannot thank you enough. You have been a constant support throughout this whole project. I have enjoyed each and every meeting with you and have always left your office with a plan. With your guidance, time lines, wisdom and feedback, you have instilled a confidence in myself which I am most grateful for. It has been a pleasure having you as my thesis supervisor. I could not have asked for a better mentor or friend.*

My Mother: *I do not have the words to say how much I appreciate you. You have been a steady anchor for me throughout all of my educational experiences. You have spent countless hours helping me throughout my degree, especially when it came to the thesis. You are my confident, my sounding board, my editor and my role model. You always have words of wisdom for me and just enough push to keep me going when I feel like giving up. I am very lucky to have you as such a wonderful support.*

My Husband: *We have spent countless evenings and weekends apart and I am sure that you thought that this was never going to end, as did I. Thank you for your love, support, humor, and patience as I complete my Master Degree and this thesis. I look forward to this next chapter in our lives where we can spend more quality time together and raise a family.*

ABSTRACT

This qualitative study profiles two families on Prince Edward Island who have a child with a traumatic brain injury (TBI) currently in the school system. It explores the changes that the students, their families and their school communities experienced during their recovery and reintegration to school. The purpose of this research was to determine the challenges for a school when a child who has incurred a TBI returns to the classroom, and to provide school personnel with considerations to maximize a successful transition from home to school.

The research is based on a number of in-depth interviews with parents, medical professionals and school personnel. During the course of the interviews, a number of issues evolved which are consistent with findings from a review of the literature. The results of acquiring a TBI affects all aspects of the individual's life – cognitively, physically, behaviorally, and socially. These changes have a significant impact on the home, the school and the social environment of the child and need to be considered by school personnel during the reentry process. Key elements to consider for successful reentry planning include: educating school personnel on the extent of the injury and how it has impacted the child; collaborating with medical professionals, parents and the student to share information and provide a support team; planning for realistic and flexible goals and appropriate interventions; preparing students for the child's return in order to establish a peer support system; and seeking additional support both within and outside the school system to address the individual needs of the child. If schools use the guidelines outlined above to prepare for a child's return to school, they can become well equipped to provide effective services to students with a traumatic brain injury.

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CHAPTER 1

One mistake, one forgetful moment can change, not only your life, but all of the lives around you forever. Two such students, their families, and their social network are experiencing this first hand on Prince Edward Island. Both students were involved in accidents that left them with severe traumatic brain injury. One was not wearing a seatbelt and the other was not wearing a bicycle helmet. This thesis is an account of the far reaching impacts of these accidents. It explores the changes that the students, their families and their school communities experienced during the recovery and reintegration process to school. It is hoped that the learning resulting from these experiences will raise awareness of the rippling implications of a traumatic brain injury.

DEFINITION OF TRAUMATIC BRAIN INJURY

Traumatic Brain Injury (TBI), a form of Acquired Brain Injury, is an injury to the brain caused by the head being hit by something or shaken violently. TBI was defined in 1992 in the Individuals with Disabilities Act (United States Constitutional Definition) as an "injury to the brain caused by an external force, resulting in total or partial functional disability or psycho social impairment, or both, that adversely affects a child's educational performance." This term applies to both open and closed head injuries (Definition from 57 Fed. Reg. 189(1992), p. 44802). The web site from the Brain Injury Association of Nova Scotia <www.3.ns.sympatico.ca/bains1/injury.htm> describes TBI in the following way:

> Traumatic Brain Injury is an insult to the brain caused by an external physical force, that may produce a diminished or altered state of consciousness, resulting in an impairment of cognitive abilities or physical functioning. These impairments may be either temporary or

permanent, and cause partial or total functional disability or psycho-social maladjustment

INTRODUCTION

OVERVIEW

The following thesis is a qualitative study that profiles two families on Prince Edward Island who have a child who has returned to school with a traumatic brain injury.

The purpose of this research is two fold:

- to determine how Prince Edward Island school personnel (defined as administrators, teachers, teacher assistants, school counsellors) prepare to assist with the reentry into the educational system of students with traumatic brain injury;

- to provide teachers and administrators with considerations regarding re-entry planning for a student with TBI.

SIGNIFICANCE & POTENTIAL CONTRIBUTION

Based on statistics (Kehle, Clark, & Jenson, 1996; Clark, 1996; DePompei & Blosser, 1987; Pieper, 1991; Tyler & Mira, 1993), it is highly possible that at some point in a teaching career, a classroom teacher will teach a student with TBI. There is no specialized training on Prince Edward Island to assist educators with the unique special educational needs of these students. Teaching children with TBI is very different from teaching children with other disabilities. The biggest distinction between children with TBI and children with other disabilities is that the injury – and subsequent disability – occurs “overnight”. With other cognitive disabilities, the child and his or her parents may have had some time to deal with the disability emotionally and develop strategies to cope (CEC Today, March 2001). This became apparent to me the first year when I coordinated a program called the *Education Coalition Continuous Skills Development Summer Program.* This is an Island wide summer tutoring program designed for children with disabilities. The program was implemented so that students would be able to retain and maintain the skills they had learned throughout the year. Instructional assistants are hired to tutor students one-on-one throughout the summer months. As the summer progressed, I was able to visit students who had sustained TBI and observe them as they worked with their instructional assistants. During these visits, it appeared that, at times, the students, parents, classroom teachers and instructional assistants were over-whelmed and frustrated, and seemed to be at a loss as to how to handle different situations. Students were frustrated because they were unable to do many of the things that they previously had been able to do. They also displayed signs of anger and/or hurt feelings regarding many issues around their friends. One of the most common feelings they expressed was that they couldn't understand why their friends were not coming around anymore. Parents expressed frustration and pain at "losing" the child they knew and for not having a way to grieve that loss while, at the same time, learning to accept the new child in his/her place. Parents also described guilt or anxiety, wondering if they were doing everything that they could for their child to help him/her regain prior skills both cognitively and socially. Most often, one parent was now needed at home for full time care of the child and the added strain on family income became an issue. Classroom teachers were challenged with developing new programming and trying to maintain some sort of consistency in daily routines. Many of them felt the need to counsel the class as well as the student with TBI to attempt to explain the challenges associated with TBI, while not entirely understanding this themselves. The teachers struggled to find some sort of explanation to help each of the students understand certain situations (Clark, 1996; CEC Today, 2001; Clark, Russman, Orme, 1999; Tucker & Colson, 1994). Instructional assistants, in many cases, had an advantage when working with the students because they had not known the student before the accident and no expectations had been developed. The instructional assistants were looked upon as "Saviours and Experts" when, in fact, they too expressed feelings of helplessness and looked to me for support. I needed to become more knowledgeable in this area, so I began to do some research hoping to find some strategies to assist the instructional assistants. What I found was quite alarming. There is a lack of Canadian research available to assist any of the individuals involved.

This knowledge, or lack of, really made me take a look at myself and my profession. I currently teach grade six in a rural school. Presently, we have no policy or procedures in place if one of our students were to reenter our school with a head injury. In fact, in a discussion in the staff room one afternoon, it became evident that our staff knew very little about TBI and many didn't even know what TBI stood for. If TBI is the leading cause of an acquired disability, I believe educators require more knowledge in this area. When I return to school tomorrow, one of my students may have been in a car accident; or checked head first into the boards playing hockey; or had a bicycling, diving, or snowmobiling accident and suffered a head injury as a result. As educators, we need to be knowledgeable about TBI in case such an event occurs.

The potential significance of this research is to broaden knowledge and increase teacher awareness of TBI, to outline academic, social and behavioural concerns specific to students with TBI and to suggest considerations for school personnel when a student with TBI returns. As a researcher, it is my intent to address some of these gaps that I found while reviewing the literature.

STRUCTURE

Two families who have a child with a Traumatic Brain Injury, agreed to participate in this study. Both children returned to the school system in Prince Edward Island since their accident. When interviewed, parents were asked to provide a list of school and medical personnel who had worked or are currently working with their child. Parents felt that these individuals would be the most helpful to interview for the purpose of this research. From this list, school and medical personnel were contacted and interviewed with similar research questions. Although the research questions directed the study, at the same time they allowed for flexibility. With this approach, it allowed the study to explore and discover the shared reality of all participants involved.

LIMITATIONS

As Patterson (cited in Marshall & Rossman, 1999, p. 42) says, "There are no perfect research designs. There are always trade-offs." The following is a list of the possible limitations of this study.

- *Small sample size.* Only two families were interested in participating in the study.
- *List of names provided by parents.* This list could reflect bias of the parents on who was most (un)helpful.
- *Special Education Database.* Neither the Department of Education, the Eastern School District or the Western School Board maintain a database of students with TBI. This may have limited the number of families who received the introductory information package.
- *Needs of the students with TBI.* This study looks at the needs of the students as they are perceived from adults (family and professional). The student voice is absent.

- *No student voice.* Ethical considerations prevented the students from being interviewed.
- *Emotional Aspect.* The emotional aspect of the parents' experience may cloud their objectivity.

CHAPTER 2

LITERATURE REVIEW

TRAUMATIC BRAIN INJURY: CAUSES

Traumatic Brain Injury (TBI) is the most common cause of acquired disability in childhood and adolescence (Kehle, Clark, & Jenson, 1996; Savage & Wolcott, 1995). A car or bicycle accident, a fall from a tree, a football injury, or a blow from an abusive adult are a few incidents that, in an instant, can cause a life-disabling head injury. Of these, the most common cause is car accidents (Clark, Russman, & Orme, 1999). A brain injury is caused when the head is slammed against a stationary object resulting in the brain being crushed against the inside of the skull at the point of impact. The brain then keeps moving back and forth within the skull after impact, crashing against the inside of the skull at the opposite side from the point of impact, tearing apart the brain substance. Because the inner surface of the skull contains a number of sharp, bony protrusions, bleeding and further contusion occur as the brain rubs against the skull (Mira & Tyler, 1991). In addition to contusions from the slamming following an impact, the forces within the skull pull, stretch, and rotate the brain along various planes and surfaces (Mira & Tyler, 1991). This not only further disrupts tissue and blood vessels, but also affects individual brain cells as fibres are stretched and often torn. A significant feature to note is that such rotational and stretching forces occur widely throughout the brain resulting in injury that may be far removed from the original site of impact. Medical advances are enabling a larger percentage of these children to survive what would once have been fatal head injuries.

TRAUMATIC BRAIN INJURY: EFFECTS

In TBI, widespread damage may be done beyond the point of impact. The stretching and tearing result in diffuse changes, which are not often visualized by procedures such as CT scans. The implication is that the effects of TBI are generalized; they affect more than one area of the brain and, therefore, affect more than one or two skills (Mira & Tyler, 1991). Rotational shearing effects, which are permanent, occur even in mild head injuries. This primary damage represents permanent effects of the trauma on the brain; the damaged cells will not regenerate (Mira & Tyler, 1991).

Secondary effects of the trauma to the brain further influence the individual's condition after injury. Bleeding and accumulation of blood may be present within the brain. Build-up of fluids in the tissue will result in swelling. This swelling causes increased pressure within the brain, which may further restrict blood flow throughout smaller vessels, leading to further cell damage. These secondary effects of trauma will subside when treated; as they do, the patient's condition will improve. This early, relatively rapid improvement is often erroneously interpreted as an indication that subsequent recovery will be as rapid and complete.

Children who have sustained acquired or traumatic brain injury fall under a broad category ranging from very mild to very severe. Although no uniform system exists for classifying the severity of TBI, a frequently cited system follows:

Minor: *Common bumps on the head with no evidence of concussion; generally, these cases are not seen by a physician.*

Mild: *Only brief loss of consciousness, if any, with accompanying symptoms of concussion such as vomiting, lethargy, or lack of recall of the injury.*

Moderate: *Evidence of concussion; loss of consciousness, less than 5 minutes.*

Severe: *concussion or skull fracture; loss of consciousness 5-30 minutes.*

Serious: *Loss of consciousness more than 30 minutes; concussion or skull fracture and notable neurological sequelae.*

(Mira & Tyler, 1991)

In least severe forms, the brain injury may produce only mild problems which resolve with limited medical attention. Children are sometimes admitted to hospital overnight for observation or may be examined in the emergency room and sent home. Changes to attention, concentration, memory and mood may occur following a minor brain injury (Vriensen & Wheeler, 2002). Some of the most common effects are headaches, dizziness, irritability, fatigue, problems with sleep and blurred vision. Typically, these symptoms do not last for more than three months (Vriensen & Wheeler, 2002). However, of the approximate one million cases of TBI each year in the United States, sixteen thousand to twenty thousand will be serious enough to cause lasting effects, and one in five hundred will be severe enough to cause hospitalization (CEC Today, March 2001).

Since children, and adults alike, can frequently make a good physical recovery, outwardly they will appear normal in all respects. However, a traumatic brain injury can cause changes in one or more areas of the child's behaviour, cognitive and physiological development. Changes may occur with the child's thinking and reasoning skills, understanding, remembering, paying attention, problem solving, and thinking abstractly. Other changes could occur with the child's speech, vision, hearing and motor development (Bennett, Good, & Kumpf, 2004).

A traumatic brain injury can also change how a child learns and behaves in school. Common cognitive problems, for example, include problems maintaining attention, slowed processing speed, poor judgement, lack of anticipation skills, poor perception, difficulties with problem solving, inability to transfer new learning to different situations, poor memory, cognitive fatigue, and lack of initiation (Bennett, et. al., 2004). Persistent behavioural and emotional problems are also observed such as agitation, increased impulsivity, sudden outbursts of anger, and difficulty in the monitoring and control of emotion. Bennett and her colleagues (2004) also note other difficulties that could occur, which include: difficultly experiencing empathy, resulting in egocentric perspectives; difficulty relating to peers; being unaware of the impact one's behaviour has on others; social inappropriateness through behavioural disinhibition; and an inability to read social/nonverbal cues. Bennett and her colleagues (2004) state that these difficulties will often influence the way others will perceive and interact with the student with TBI and this therefore contributes to the tendency for the student to become socially withdrawn or isolated. Furthermore, notable problems may not be apparent for a year or more after injury.

TRAUMATIC BRAIN INJURY: IDENTIFICATION

Current United States statistics estimate that approximately one million school aged children will sustain a traumatic brain injury each year and that 90% of all children and adolescents with TBI return to the school system (Clark, 1996). Canadian statistics in this area are scant. Dr. Ellen Vriesen, a neuropsychologist, along with members of the Paediatric Acquired Brain Injury Team of the London Health Sciences Center, London, Ontario, Canada estimate that 50 000 Canadians sustain a brain injury every year, and more than half of those injured are younger than 20 years of age (Vrienses & Wheeler, 2002). However, the web site of the British Columbia Brain Injury Association <www.brainassociation.com> claims that 14 000 British Columbians acquire new brain injuries each year and the Brain Injury Association of Nova Scotia web site <www.3.ns.sympatico.ca/bains1/injury.htm> states that each year approximately 1000 Nova Scotians suffer a traumatic brain injury. The web site for the Ontario Brain Injury Association <www.abieducation.com> estimates that approximately 27 000 children sustain a TBI yearly . To date, the Brain Injury Association of Prince Edward Island is inactive and there are no current or official statistics on the number of students with traumatic brain injury who are in the public school system in Prince Edward Island. However, the Directors of Student Services in the Eastern School District and the Western School Board and the Special Education Coordinator at the Department of Education, estimate there to be a dozen students with TBI currently attending school in Prince Edward Island.

Part of the reason for the inconsistency regarding statistics on the number of people with TBI could be explained by the difficulty in identification. TBI is regarded as a low-incidence problem, with many school administrators reporting no occurrence in their school. Nevertheless, one in 500 school-aged children will be hospitalized each year because of a head injury and, by the age of 15, 3% of the student body will have sustained a head injury (Mira & Tyler, 1991). A metropolitan district can expect 90-100 children a year to incur head injuries that will have an impact on their education needs. In a small rural community three or four children may be injured annually (Mira & Tyler, 1991). Thus, TBI can be a significant problem within the schools. Savage (2001) debunks the myth that TBI is a low incidence injury. He refers to TBI as a "silent epidemic" that is poorly identified by the medical profession and misidentified in the educational system. TBI is frequently identified and classified as a learning disability (Bennett, et. al., 2004). Many symptoms of a mild head injury mirror those of a learning disability, such as short term memory problems, slower thinking, difficulty with information processing, shortened attention span and word finding difficulties (Bennett, et. al., 2004). These symptoms may vary and become more obvious over time.

Parents, teachers, and the students may not associate them with a past injury (Bennett, et. al., 2004). In fact, often educators are not notified of the child's injuries and therefore the injury is often overlooked as the relevant correlate or cause of difficulty. As such, any behavioural problems may be misinterpreted and considered a learned conduct or social issue independent of any underlying organic basis.

TRAUMATIC BRAIN INJURY: HOW IT DIFFERS FROM OTHER DISABILITIES

Traumatic Brain Injury is often mislabeled and, on the surface may, present like a learning disability or a developmental delay. Bennett and her colleagues (2004) state:

> In cases that are confused with learning disabilities in particular, the assumption that, because many of the types of strategies that are successful with [TBI], the label of LD will suffice in terms of identification. However, this label fails to recognise the specific need of children with [TBI]. Student with [TBI] unlike those with learning disabilities may:
>
> - have a preinjury history of successful school experience,
> - have the ability to remember and utilize information learned prior to the injury but have difficultly attaining new knowledge,
> - learn well in isolation but be unable to be successful when skills are integrated,
> - be difficult to assess as standardized and informal measures of assessment provide information on previous learning not on how students learn,
> - experience pain and fatigue issues related to physical recovery, have a constantly changing profile as the result of cognitive development and recovery period,
> - experience social difficulties reintegrating to a peer group or even family that has expectations that the child will be unchanged,
> - have difficulties with anger management and levels of frustration that were not existent pre injury,
> - lack awareness of the effect of their injury and the degree of impairment.

Bennett and her colleagues (2004) also claim that similar difficulties arise with the mislabeling of students with TBI as developmentally delayed or having behavioural challenges.

The biggest distinction between students with TBI and students with other disabilities is that the injury, and subsequent disabilities, occurs suddenly and without warning. With other cognitive disabilities the student and his or her parents have had some time to adjust emotionally and learn how to cope with the disability.

Understanding the consequences of head injury in childhood is complicated by the development of the central nervous system and the changing nature of the traumas to which children are exposed (D'Amato & Rothlisberg, 1996; Kehle, Clark, & Jenson, 1996). The nature and timing of the injury can cause unpredictable consequences, as the trauma disrupts the normal development of the central nervous system. However, in some cases, especially if the student suffered the injury at an early age, the educational effects of TBI may not show up immediately. The student may not experience problems in school until intermediate or high school when higher-level thinking and more complex tasks are performed (CEC Today, 2001).

Thus, students who have sustained TBI are often very different from their peers with learning disabilities or other special needs. It is not uncommon to find that prior to the injury, these individuals typically experienced success in school. Often, upon return to the school, both the student and teacher have set unrealistic goals that are no longer appropriate for their current level of functioning. The resultant failure is frustrating and difficult to comprehend for the student and the teacher. Plans, goals and programming must be modified appropriately and realistically to assist the student in experiencing success.

TRAUMATIC BRAIN INJURY: IMPLICATIONS & CHALLENGES FOR SCHOOLS

Ultimately, schools end up being the largest provider of services to children with brain injuries (Savage & Wolcott, 1995). A majority of the children who have sustained TBI do return to school, and schools are increasingly involved with working with hospitals and rehabilitation facilities to help students with brain injuries reenter school and plan appropriate educational services (Savage & Wolcott, 1995). The educational system is an important resource to promote recovery and redevelopment of the central nervous system, since this neurodevelopment is particularly enhanced by experience and interaction. Although the physiological central nervous system neurodevelopment is particularly extensive from conception to age 15, it continues at a more limited, but important, pace up to approximately age 25. Most schools, however, are not prepared to meet the changed educational needs of the student (Clark, 1996; <u>CEC Today</u>, 2001; Clark, Russman, & Orme, 1999). When children with traumatic brain injury return to the educational system, their educational and emotional needs are very different from before the injury. Their disability has happened suddenly and traumatically. They can often remember how they were before the brain injury. This can bring on many emotional and social changes. The child's family, friends and teachers also recall what the child was like before the injury. These other people in the child's life may have trouble changing or adjusting their expectations of the child. Educators' lack of knowledge regarding how TBI can affect a student's academic and social functioning can be a barrier to providing the services that meet the needs of these students (Savage & Wolcott, 1995; Glang, Singer & Todis, 1997).

Children with such injuries are by no means new to the educational system; however, the number of severely injured students is on the rise and they are returning to the classroom. With the advancements in medical technology and care, children who once would not have survived severe injuries are getting prompt care, are recovering, and are retuning to school. Thus, it can be anticipated that the number of TBI children returning to school will increase as medical services become more sophisticated. Current estimates are that 90% of all children and adolescents with TBI can be expected to live, and 65% of those with more severe injuries will survive the insult to the brain (Clark, 1996). Since recovery takes months (in the case of concussions) or years, schools and school personnel have the potential to play a crucial role in helping the student adjust to what will most likely be a changed relationship to his or her environment (Clark, 1996; D'Amato & Rothlisbery, 1996). Because many will have long-term problems as a direct result of their injuries, these children will often require educational concessions and program modifications. Educators who understand what happens in a TBI are in a better position to address cognitive issues in children returning to school following a head injury. Given the structure that schools provide, and the variety of specialists represented, schools may be in one of the best positions to provide services to these children (Clark, 1996).

Educators have only recently begun to attend to this population and they do not yet have a repertoire of tested techniques or educational modifications from which to draw (Clark, 1996). However, educators' early involvement with the hospitalized child, careful planning for reentry, and a willingness to make the necessary educational modifications seem to be key techniques necessary for planning and providing for the educational needs of children with TBI.

Currently, there has not been professional development programs for Prince Edward Island school personnel that acknowledges a TBI designation. Without the necessary awareness and training in TBI, it is common for classroom teachers to address and/or confuse the needs of a student with TBI with those students who have other special needs issues such as developmental delays, learning disabilities, lack of motivation or behavioural problems (Clark, Russman, & Orme, 1999). Without specific and targeted interventions and strategies, teachers are less able to effectively assist the students who have a brain injury.

When school personnel working with a child with TBI seek information on teaching children with TBI, they will discover articles in the research literature, almost all of which are United States based, written by specialists in rehabilitation, that lean toward application in a clinical setting <www.abieducation.com>. There is a need for TBI research relevant for the school personnels' professional development in order to enhance reintegration of students with TBI into the classroom. An awareness of the cognitive, academic, and behavioural needs is obviously important in enabling teachers to appropriately work with that individual.

Equally important, however, is awareness of the fact that the teacher will also experience emotional and/or behavioural changes as a result of interacting with the student. The child with TBI is not the only one to experience the effects of the head injury, the entire family suffers. Caregivers attributed their own anxiety, depression, and impairment in social adjustment to the survivor's social isolation and negative emotional behaviours (Clark, Russman, & Orme, 1999). Educators need to be aware of the needs of the child and the child's family if interventions are to be effective.

Children who sustain brain injuries encounter numerous problems as they make the transition from medical and rehabilitation settings to home, school, and community. When these students reenter the school setting, educators are especially challenged by the learning and behavioural difficulties that children often demonstrate (Blosser & Pearson 1997). School personnel can help students and their families learn to manage these difficult transitions by implementing several key strategies. Those strategies include building collaborative teams, gaining critical knowledge about brain injury and teaching techniques, and establishing a common philosophy for teaching (Blosser & Pearson, 1997). Schools are well equipped to provide effective services to students with brain injury when school personnel understand its potential implications. Educational goals can be accomplished by providing alternative options for learning, preparing the student for multiple transitions, adapting the school curriculum to meet the student's unique needs, and establishing an individualized education plan that is flexible and responsive to the student's unique characteristics.

Children with TBI within the school system have an excellent opportunity for compensatory recovery through their direct access to teaching professionals with expertise in cognition (learning, problem solving), physical growth (physical education, nutrition), and social development (group interactions). Children with TBI who are able to access the school system will typically have sustained mild to moderate severity in injury, and therefore , are the ones who can most benefit from cognitive and educational interventions.

TRAUMATIC BRAIN INJURY: CONCLUSIONS AND INTERPRETATIONS

A promising aspect of this research is that the educational system in Prince Edward Island already has in place a strong program directed at working with students with special needs. In both the Eastern School District and the Western School Board, special education/resource teachers meet monthly throughout the school year. This venue can be utilized to provide these educators with information on how to better address the needs of students with TBI. They, in turn, have the opportunity to provide leadership within their own school to better prepare school personnel and students for the unique transitional needs that arise, should a student in their school community return to school following a head injury.

Since the beginning of this research, the Department of Education has revised their special needs data collection form to include a category identifying students with TBI within the Island's school system. This is a significant step in recognizing the unique challenges of addressing the special educational needs of these students.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

INTRODUCTION

The purpose of this research is to assist school personnel with planning the return of students with Traumatic Brain Injury (TBI) to school. The information received from the participants in this study may help school personnel in several ways: to understand the implications of a TBI; to construct appropriate teaching strategies; to implement necessary adaptions and modifications; and to provide valuable information for a successful reintegration. This chapter will outline the research design and rationale employed. It will also discuss the selection process for the participants, site selection, data analysis, data collection methods, and ethical considerations.

RESEARCH DESIGN

Qualitative research methods are used in this research to allow for a "rich, thick description" of the topic being researched (Lincoln & Guba, 1985, p. 178). Qualitative research has been defined as, "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (Strauss & Corbin, 1990, p. 17). Denzin and Lincoln (1998) define qualitative research as: "a complex interconnected family of terms, concepts, and assumptions...including the traditions associated with positivism, post-structuralism, and the many qualitative research perspectives, or methods, connected to cultural and interpretive studies"(p. 117). Merriam (1987), also identified some features that involved qualitative research. She discusses them in this way: "The world is not an objective thing out there, but a function of personal interaction and perception. It is a highly subjective phenomenon in need of interpreting rather than measuring. Beliefs rather than facts form the basis of perception" (p. 17). Qualitative research unravels and emerges as a study progresses through its research questions.

This study of Traumatic Brain Injury and possible implications for schools was completed by methods of qualitative research; in particular, two case studies. The methodology involved an in-depth interview with parents of students with TBI, as well as with relevant professionals who work(ed) with the student (ie. teachers, school counsellor, medical personnel) [Appendices A, B, & C]. Based on the literature review, the questions were open ended to allow the participants to describe their feelings, views, and perspectives on the questions asked. It was felt that in-depth interviews would be the best possible method for uncovering information that was needed for this study because of the participants' knowledge of the case studies prior to and/or following the accident.

There are many views as to why case study research is valuable. Shank (2002), states "Case study, by its nature, turns us away from the typical to the unique. To understand the 'typical', you really should do survey research. To understand an individual in depth...you really need to sit down and talk and listen to that person"(p. 53). Stake (1995), outlines how complex a single case can be and that the purpose of case study research is not to evaluate nor generalize to a larger population. The case study has to make its own case:

> A case study is expected to catch the complexity of a single case. A single leaf, even a single toothpick, has unique complexities--but rarely do we care enough to submit it to a case study. We study a case when it itself if of very special interest. We look at the detail of interaction with its contexts. Case study is the study of the peculiarity of a single case, coming to understand its activity within important circumstances (p. xi).

Merriam (1987), emphaszes the following criteria when case study research is involved:

> Qualitative case studies can be characterized as being particularistic, descriptive and heuristic. Particularistic means that case studies focus on a particular situation, program or phenomenon. The case itself is important for what it reveals about the phenomenon or about what it might represent. This specificity of focus makes it an especially good design for practical problems– for questions, situations, or puzzling occurrences arising from everyday practice...Descriptive means that the end product of a case study is a rich, 'thick' description of the phenomenon under study...Heuristic means that case studies illuminate the reader's understanding of the phenomenon under study. They can bring about the discovery of new meaning, extend the reader's experience, or confirm what is known (pp. 29-30).

PARTICIPANT SELECTION AND SITE SELECTION

The population on Prince Edward Island, Canada, is approximately 138 000. There are two English school districts; the Eastern School District has 43 schools with a population of approximately 14 900 students, and the Western School Board has 21 schools with a population of approximately 7 200 students. There is one French Language School Board for the six French first language schools across the province that services approximately 3 000 students.

The case study participants were recruited through the Eastern School District and the Western School Board [Appendix D] of Prince Edward Island. The researcher sent a letter outlining the nature of the research and research procedures to the Eastern School District and the Western School Board. This letter was followed up with a telephone call to confirm their willingness to notify potential case participants. To ensure confidentially, the Eastern School District and the Western School Board sent out the Research Information Letter and the Informed Consent directly to the parents/guardians of students with TBI [Appendices E & F]. Should the parents/guardians chose to participate, the consent form was sent directly back to the researcher in a self addressed, stamped envelope. The researcher provided the Eastern School District with twelve forms and stamped envelopes and the Western School Board with six forms and stamped envelopes for the mail out to parents/guardians. The Eastern School District and the Western School Board requested more forms than were required for a couple of reasons; the first reason being that neither school district knew the exact number of forms needed for the mail out and the second reason was due to confidentiality. This ensured the researcher would not know how many forms were sent out and therefore how many families did not respond. From the time of the mail out, possible participants were given ten business days to decide if they wished to participate in the research. Two families indicated that they would like to participate in the research. One family was from the Eastern School District and the other family was from the Western School Board.

With permission from the parents of the case study individuals, additional participants involved with each case study were contacted either by telephone or by mail with a Research Information Letter [Appendix G] and an Informed Consent Form. These participants included school personnel and medical professionals.

CASE STUDY INDIVIDUALS

The following is a description of two students who acquired traumatic brain injury as a result of an accident. Pseudonyms are used to protect the identity of the children and their families. However, due to the small population of the province, it is impossible to ensure anonymity.

Each case synopsis discusses the child's family dynamics, the accident, the subsequent injuries resulting from the accident and an overview of rehabilitation.

SUSAN

Susan was sixteen at the time of her accident. She lived at home with her parents and her two younger siblings. On her last day of summer employment, 2001, she was travelling with a group of co-workers when their car was hit by a transfer trailer. Susan was sitting in the middle in the back seat and was not wearing a seat belt. Susan was unresponsive at the scene of the accident and was taken to the Emergency Department at the Queen Elizabeth Hospital (QEH) in Charlottetown, Prince Edward Island, where she was diagnosed with a traumatic brain injury. She was subsequently airlifted to the Queen Elizabeth II Health Sciences Centre in Halifax, Nova Scotia. She remained in a coma in the Intensive Care Unit (ICU) for two weeks and was then transferred back to the QEH in Charlottetown, where she remained as an inpatient for six weeks. Her mother describes Susan's injuries in the following way:

> Susan suffered a serve traumatic brain injury. The head injury was on the frontal lobe, right front lobe, with two spots on the back as well. She also had other fractures and, other than the fractures, she looked very good. There were no marks on her body whatsoever. She ended up with a fractured pelvis, shoulder, punctured lung, and broken ribs, but the main injury was the right front lobe. It caused paralysis on her left side right down to vocal cord paralysis. So it was extensive on the left. She also had third nerve damage to the brain...the third nerve controls the dilation and the movement of her left pupil...being [Susan], she had crossed eyes when she was younger and had surgery to correct it so all of her life she has used her two eyes independently...it never caused any vision impairment...She had zero mobility, she couldn't do anything. After the accident, right, left, it didn't matter, there was not one part of that child that was moving at first...I mean there was nothing that worked right after the accident. There wasn't any part of her body functions that worked at all...Slowly the right side came back...She had no way of communicating and she couldn't speak... but probably by a two week period she was able to respond with her right side by writing. It was

> pretty hard to read sometimes but she would answer by writing down stuff, and in probably three weeks she spoke in just a whisper...She couldn't hold her head up...She had absolutely no muscle control, nothing...if she sat in a wheelchair, she would be completely plunked over and you had to keep her back and keep her upright.

When Susan was out of ICU, she was transferred back to the QEH in Charlottetown where she started her rehabilitation. Her mother described how slowly her rehabilitation progressed in the beginning.

> Time was the only thing that was going to do any good, so there was no point in being in Halifax...We started trying to get her balance back just trying to get her to sit on the edge of the bed, to get some control of her upper body, to control her head...We started speech rehabilitation...All of those things probably started week five after the accident...and until she was able to move enough, we didn't really do the whole physiotherapy upstairs in the gym at the hospital for quite a while...She started moving her left hand first and that probably started about week five and things happened very quickly once she started recovering...We were probably a little better than seven weeks in Charlottetown [QEH] and at that point she was walking on her own, without the walker and she could stand by the time we left and she was able to talk some.

JACK

Like Susan, Jack sustained a severe traumatic brain injury as a result of an accident. On Victoria Day weekend of 2000, Jack, age 10, was riding his bicycle, without a helmet, down a very steep hill with some of his friends, when he lost control and was thrown over the handle bars. He hit his head on the pavement and was knocked unconscious for a few moments. Jack's older sibling was babysitting at the time while his parents ran a quick errand in the community. When his parents first saw Jack, he was conscious and crying. Because Jack did lose consciousness at the time of the accident, they took him to the Prince County Hospital in Summerside, Prince Edward Island where he stayed the night for observation. Jack was released the next morning and his mother recalls the events that followed:

> We were released the next morning by lunch time and we had a very quiet Sunday afternoon. I wouldn't allow him to go outside and play. I just wanted him to lay quiet for 24 hrs. He ate a full supper, I bathed him and tucked him into bed and within an hour he screamed, 'Mommy, my head, my head, my head hurts!' We [Parents] went in and it was only minutes 'till I couldn't get one eye open and we gathered him up and headed back for Summerside and as soon as we got there they got him ready to go to Moncton [New Brunswick] and we left right away.

In Moncton, the true extent of Jack's injuries were realized. His mother recalls:

> [Jack] suffered an epidural hematoma and subsequent brain injury. The vessel busted on the left side of his head and with every pump of his heart, the blood clot kept getting bigger and bigger and bigger and by the time we got him to Moncton, they took him right to surgery...[Jack] remained in a coma for three and a half weeks and we were at Moncton City Hospital for seven and a half weeks...Then we spent six months in Charlottetown [QEH] in rehab...When [Jack] first came out of the coma he couldn't talk, he couldn't sit, he couldn't roll over, he couldn't do anything by himself....he was still fed liquids. He was on the lung machine for quite some time. As he came closer to a full awakening out of the coma, he would take seizures. His fever would shoot up to 44 degrees Celsius and one particular night he vomited and it seemed to be almost a turning point for him....he seemed to become more conscious all the time after that...They started putting him in a chair with a high back and arm support...he couldn't hold his head up, he had no body support. He was conscious, but that was it. He couldn't sit up by himself, he couldn't do anything...We had to do everything all over again. It was just like he was a baby. He had to have diapers. He had to be toilet trained all over again. He had to be spoon fed; everything was pureed and liquified. He had a speech therapist. He had to learn how to form his words all over again...He had physical therapy, two forty-five minute sessions every day. He had a half hour of speech therapy every day. He had two half hour sessions of occupational therapy every day and everything else just exhausted him...It started in July and it went 'till the end of December. December 20th he was home.
>
> [Jack] suffered a right side semi-paralysis. It's just as if he suffered a stroke...because of the brain injury, his body suffered 'tone'; that's

> a medical term that they used for tightness and rigidness with his muscles...His muscles went so stiff and so tight...He had a drug treatment called botox...This is his third leg brace, and he has a knee brace that he wears to bed at night to help him. We're in the process of trying to straighten his foot so that he can walk as normal as we do and try to get his heel down to the floor, plus keep his knee straight. Right now he presently has his right side half bent, his right knee is partially bent as he walks. His right arm, he has limited use of his right hand. If he goes to do something, his right arm constricts and draws up uncontrollably. He can't control, he can't stop that arm from coming up and coming forward. His brain wouldn't tell him his stomach was full. He always felt hungry...He was 83, 86 pounds, somewhere in there, when he had his accident and within the year he weighed 150 and he weighs 200 now. He's 13 and weighs 200 pounds...We were only back in Charlottetown probably only a week and all of a sudden, like just over night, he had body odour, he started to grow pubic hair and it just kept coming and coming and growing and, because he grew so fast, it was hard for the physiotherapist to keep up with the physio aspect of it because his body was growing faster than his muscles could develop from the injury. It [the brain injury] brought on an early puberty.

DATA COLLECTION AND ANALYSIS

In total, nine interviews were conducted. The first two interviews were held with the parent(s) of each case study. The second phase consisted of six interviews with school personnel that had been identified by the parent(s). The final phase of the interview process was an interview with a medical team, consisting of a physiatrist, an occupational therapist, a speech language pathologist, a social worker, a home care support worker, a rehabilitation nurse and a physical medicine nurse. The researcher led all the interviews. All the participants were interviewed in a locale of their choosing. This was done to ensure the comfort level of the participant as he/she would be in familiar surroundings and would not have to endure any unnecessary inconveniences to meet with the researcher. It was very important that the participants felt as comfortable as possible, and that the surroundings were as warm and inviting as they could be. Face to face interviews further allowed for visual observations of the participants, which were insightful. Making written notes on the interview guide captured these visual observations. Each participant was interviewed only once, with the actual length of interviews lasting between 1 ½ - 2 ½ hours for the parents and ½ hour to one hour for the school personnel and medical personnel.

The majority of the interviews were audio-taped unless the participant requested otherwise. In such a case, the interviewer took hand written notes. Some of the medical personnel who were not from Prince Edward Island, participated in either a telephone or email interview, whichever they preferred. All the interviews were transcribed and then sent out to each participant involved in the study to be verified for accuracy. Once the transcribed interviews were returned to the researcher, they were then edited as requested.

When the data collection was completed, the interviews were analysed and themes were identified for interpretation (Kvale, 1996). The researcher analysed the data for common themes by comparing the interviews of the parent(s), school personnel and medical professionals. The researcher also integrated these findings with those of other studies that had been reviewed in the related literature.

This study spanned a nine month period from start to finish. Research began in January of 2003 and interviews began in March. The study was completed at the end of September, 2003.

TRUSTWORTHINESS

An integral part of all research is trustworthiness (Marshall & Rossman, 1999). A researcher's log was kept throughout the study. It was very important that the study's progress be recorded in detail. If such items were not written in the log, details may have not have been recalled at a later date. The log aided memory and made the information gathered during the study more reliable. Interviews were taped, recorded and transcribed with the permission of participants. The responses were voluntary and any section of their transcript could have been amended if participants had so desired and in some cases this happened. Denzin and Lincoln (1998) state:

> Time-honored procedures such as triangulation and negative case analysis and newer procedures such as member checks, peer debriefers, and audits are all utilized by interpretivist evaluators to enhance credibility of their inferences. This work can make no contributions unless it is perceived as credible and trustworthy. (Denzin & Lincoln, 1999 as cited in Wood, 2001, p. 48)

Trustworthiness was exercised in the form of member-checking, peer debriefing, and the creation of an audit trail. Member-checking was completed by providing participants with a copy of the interview questions before the actual interview, if they so desired, and a copy of the transcripts, which they could amend. As well, each participant was offered a summary of the findings. Peer debriefing was done by consulting with the researcher's thesis supervisor to discuss the progress of the research and to check for any evolving bias. An audit trail was kept by keeping a researcher's log, audio-taped and transcribed in-depth interviews, and all abstracts and articles used in the literature review. All tape recorded data has been kept in a locked cabinet to ensure confidentiality. This raw data will be kept for two years and then destroyed. As previously stated, all participants received a transcript of their interview to confirm their responses and to add or omit data if they wished; this procedure helped to increase validity. These methods ensured the trustworthiness of this study.

ETHICAL CONSIDERATIONS

This study received ethical approval by the Ethics Review Board of the University of Prince Edward Island. The Eastern School District, the Western School Board and the Department of Education were contacted via letter to request permission to conduct this study. Permission was granted before proceeding with the research. The study did not proceed until the researcher received written confirmation from the participants. The researcher met with participants on a one-to-one basis to ensure they fully understood the study. Other ethical consideration safeguards were provided to each participant. These included informed consent forms, a discussion of the interview agenda and time frame, and a utilization of a tape recorder to insure accurate transcribing of the responses of the participants. Participants were asked if they required clarification about any of the interview questions before the interview began and could pass on any questions they did not wish to answer. Participants were able to withdraw from the study at any time up to a specified date. As well, the researcher provided a debriefing for the participants after the study was completed. The researcher kept all agreements that were made with the participants. Finally, the names of the participants were held in the strictest of confidence. Their names are protected in the study by the use of pseudonyms. Additionally, no reference was made in the study to a particular area of the province or a specific school. A great deal of care and creativity was taken to ensure confidentiality for all involved. All possible precautions were taken to protect the rights of the individuals involved in the study. However, due to the small size of the population in the province, total anonymity cannot be assured.

CHAPTER 4

FINDINGS

In this chapter, the findings that emerged from the in-depth interviews with the parents of children with a traumatic brain injury and the school personnel and medical professionals who have worked with these children are discussed. The comments and reflections of those interviewed reiterated many common observations and reflected similar concerns. Through an analysis of the transcripts, three major themes have emerged. The first theme explores the ways each child has changed personally since the brain injury. These changes are discussed under the sub-themes of academic changes, social development changes, behavioural changes and physical changes. The second theme examines the sociological impact the brain injury had for the child. These can be categorized under the sub-themes of the impact to the child's school community, the impact to the child's family, and the impact to the child's friends. The third theme centres on the preparations for the child's return to school. The sub-themes identify issues that need to be considered from the perspective of the parents, the medical professionals and the school personnel.

CHANGES IN THE CHILD SINCE THE TRAUMATIC BRAIN INJURY

When a child sustains a traumatic brain injury, many aspects of the child's life are affected. This was the case for both Susan and Jack. The following sections will discuss the academic, social development, behavioural and physical changes in both Susan and Jack after their accidents.

ACADEMIC CHANGES

According to the parent and school personnel for both Susan and Jack, each student developed academic challenges after acquiring a traumatic brain injury.

SUSAN

Susan's mother indicated that, prior to the accident, Susan had some academic difficulties and struggled throughout her elementary and intermediate education. Susan had repeated grade two, had numerous academic assessments. She was involved in the school resource program, which made modifications to her academic subjects, and required extra support from her teachers. Susan's determination, organization and maturity level are credited by both her parent and teachers as the reasons she made it through to high school as an average student. Her mother describes Susan's academic struggles as follows:

> Her cognitive abilities were somewhat impaired before the accident. That was the area that was always brought up in any testing that she had before the accident. In fact, probably she was lucky that it [the brain injury] was in that area as opposed to another area in the brain, where she had compensated for a lot of things that were happening in that side of the brain. She learned a lot of stuff and habits and every thing else to deal with the deficiency before the accident. [Susan] was very capable of handling school. She knew that she had to get her act in gear and buckle down and ger her work done. She knew that from the time she was in grade three and up. The child would come home from school and I would say to her, 'Go and do your homework', and she would say, 'Mom, it's already done'. She was extremely responsible. I think that came from repetition, knowing that she had to organize herself, knowing that she wasn't able to get everything done unless she did do it. She was very mature that way. It's a funny twist; she knew that, that's what had to be done to get what she needed done, and she wanted it done. She wanted to do well, she always wanted to. We spent hours studying, her and I; hours, upon hours, upon hours, just so she could get the grades that she wanted. All kinds of testing was done prior to the accident that scored her well below average, in the low average range of the scale...yet, she scored by herself a 75% percent average across all of her elementary years, but it was because of determination and she just beat it to death.

A teacher Susan had prior to the accident, also noted her struggles in intermediate school and, in particular, during her class.

> [Susan] struggled in grade nine. I think she had some other learning disabilities and some difficulties doing things and what not, the writing and not understanding what had to go on. I remember sometimes I'd assign something and I'd have to go and explain it to her just exactly what she had to do, but academically she really was in the sixties and seventies and did her best.

When this teacher was asked what she thought was Susan's greatest success, without hesitation she stated:

> I think getting through [intermediate school]. I think for her making it through...and the friendships that she had made and how she blossomed a little bit. She was shy and...I know it must have been hard sitting back and letting other people take the lead...but definitely getting through grade nine. She was pleased with her marks and her mom was pleased with the effort that she had put forth. Seventies are not bad for a grade nine student or for anybody. She worked hard and tried to get through here with a positive attitude and she could go through and do it on her own and didn't need any extra assistance and stuff like that.

Susan started high school in February of 2002. Since the accident, Susan's educational needs, according to her mother, didn't seem to change a whole lot. Her determination and stubbornness continued to get her through.

> [Susan] took a full semester. Again, this stubborn streak that she has would not allow her to accept that this was too much to handle. She took academic English, academic math, academic geography and physics. I was trying to talk her into taking two credits and looking at herself in two months. She passed two credits, geography was modified for her and gym was modified for her. She has a peer helper, not a TA. She absolutely refused the TA. So, she's had peer helpers whenever required. I don't think that they [educational needs] are probably that much different, other than the peer helpers, which she never had before. That certainly is different. When she went back into the school system, her principal stopped me one day and he basically said that she was an absolute inspiration for any

> student that was there because she gave it one hundred and ten percent again. All of that old determination; she wasn't ready to take the easy road just because of what she has been through.

During the 2002 and 2003 school year, Susan's mother stated that she continued to succeed with modifications to her course load.

> She's very pleased with being able to go back to school and pass her credits, she was extremely pleased with herself. She passed all four last semester. She's very independent in some ways; in some ways more independent. We started talking about a TA at first and particularly in February when she came back; it was just not an option, but the peer helping program works. [Susan] doesn't feel segregated from the rest of the class that way. She's doing the same work as everybody else. She gets excused from speed tests and all of those types of things that's just physically impossible. The exams were what hurt her. There was too much information at one time. They were always a problem. That was always part of her problem with dealing with exams, was the physical atmosphere around her. Now they [teachers] modified her courses but only to the extent there is someone there when she writes her tests or whatever. The material hasn't changed; its just that the modification is there for testing.

One of the teachers that Susan had her first semester after the accident, described Susan as a "gem of a student", "wanting to do well and to succeed ", "determined" and "very independent". The teacher recalls the support needed for Susan.

> I did not modify it [course]. I made some adaptations but I didn't modify anything. [Susan] was very determined. She wanted to make sure that she was treated equally. There was a peer helper in the classroom and it was suggested that she work with [Susan], but [Susan] was really adamant that she would not be singled out. She wanted to stand on her own two feet, do her own thing and therefore it ended up that she got very, very little help from the peer helper and a lot of other students got more help than [Susan] did. Adaptations were very, very simple. Reading questions to her, but orally you would read the questions, but she would still write it down, her response. So other than that, that was basically all I did. I didn't do anything else. Academically she put more into her school work than I have ever seen anybody do in my life. She wanted to do well, she

> wanted to succeed. Her memory obviously was a major hindrance for her. Her short term memory was very, very limited. You could tell her something and she would never remember it. I found that difficult on a test because I knew that she knew the stuff, but because she didn't want me to give her an oral exam and she didn't want much help with the exam, it ended up that she, academically, didn't do very well.

JACK

In contrast to Susan whose academic problems were intensified following the accident and where her teachers had already made adaptations for her programming, Jack's academic history was much different. Before the accident, Jack was described as being a "straight A student" by his parents and teacher. He was a conscientious student and an avid reader and a great support to his classmates and friends. He experienced no difficulty in school. His parents describe Jack's academic background as follows:

> Smart as a whip. He was a straight A student. He was in grade four reading at a grade 6/7 level. He was a very avid reader. He had his own library card when he was nine and he would go to the library and get books. Read them all and couldn't wait to go back. He was a peer mediator in school; he was a peer tutor in school. Families would get computers and things and he would he would set up their e-mail address and give them an e-mail name and everything; he was very smart on a computer. He'd get home here at 10 to 4 off the bus, and lay down on the floor, do [his] homework while I was getting supper ready. [Jack] would be done in 15 minutes. It just seemed he liked doing homework. Loved it, he wanted to do it; he wanted to get it done 'cause he wanted to be able to, summer or winter, he wanted outside. Didn't matter, rain, sleet, snow, he liked outside. He was a real outdoor kid.

Jack's grade 5 teacher didn't have Jack in her class until after his accident, but she recalls knowing Jack from being around the school. She remembers him as a "bright, above average student, top of the class", "very neat", and "he academically wanted to do well". She recalls wanting to have Jack in her class because of the prior experience she had with his family, had observed Jack on the playground and interacting with the other students and "he just seemed to be a keen student and really enjoyed school".

This little boy, who seemed to enjoy and excel in school, had his educational and academic needs dramatically changed after his brain injury. While Jack was still in the hospital, his hospital team wanted to have tutoring provided so he could continue with his school program. The school psychologist was asked to administer academic testing. This turned out to be a difficult process. The school psychologist explains:

> We wanted to do testing with him to get a base line of where he was functioning now so that we could measure his progress at the time. So I did some preliminary academic screening with him using the WIAT, which is the Wechsler Individual Achievement Test, but when I administered that test there were some modifications made. There was something wrong with his vison, which made the testing difficult, so I felt my results were not very valid at the time because of that, and because it was after that...he got corrective lenses for it. I readministered another achievement test just to get a sense of where he was functioning and what we found was that he was around the average level. So that was positive, but it was hard to say because we didn't have a base line of how he was functioning before the accident, but we know he was, from the reports from school, he was an A student and he was a very intelligent boy, but we have nothing to compare it to.

A full psychological assessment was never completed and when Jack first returned to school, almost a full year after the accident, the regular academic program proved to be too difficult. He needed constant support from a teacher assistant (T.A.). Resource support was provided and an Individualized Education Program (I.E.P.) was developed. His teacher recalls the struggle:

> We went right back to grade one things-patterns, sequencing, playing of tapes, a lot of grade one things, a lot of tactile things. His fine motor skills, pencil work, was not well [developed], very poor. We

> kept trying it though. We couldn't pin point areas; he could read, just didn't want to so it was hard to find out exactly what level he was at. We then moved to grade 3/4 stuff.

Now that Jack is in grade seven, his parents and current teacher agree that Jack has progressed, but he has not yet attained the academic level of performance he had prior to the accident. His parent's state:

> He's in a basic regular grade seven program and enjoying it. He takes computers, he takes math, he takes English, and he takes science and social studies, very normal. He is not doing regular grade 7 math, where he's still doing basic math skills; addition, subtraction, division, multiplication. He still uses flash cards...He can't read as much or as well at where his age and grade level should be...He is starting to pick up with his reading now. He is starting to pick up the paper and look at the funnies. He reads if he has to, and if it's something that he's interest in, but he doesn't just pick up a book and read it like you or I would and just curl up with it...His educational needs are very different. He doesn't presently take resource, the resource teacher at the junior high level does not feel that he requires it at this time. They adapt and modify. His [work] is multiple choice, true or false, matching and that's how they modify and adapt his program. He is doing the same work, but not as much of it.

In grade seven, Jack has a number of teachers working with him including the same teacher assistant he had in elementary school. His home room teacher/science teacher describe's Jack's academics as follows:

> I only see [Jack] three days in the cycle...I have him on special projects, where much of the material is the same but on a lower level; something that he can easily work at and understand. He does do some of the things in class with the other students. [Jack] enjoys getting [assignments] back to see what ones he had right and what ones he had wrong. He does enjoy when he does do well as do most students do and that's always nice to see. Although if you say to him, '[Jack] you are not going to do well in this assignment because you are goofing around when you should be working in the lab'...he does have that 'who cares' attitude...but you know that he does care. Where as the other junior high kids can cover that they don't, you can

see that he does because you can see all the expressions on his face.

SOCIAL DEVELOPMENT CHANGES

With both Susan and Jack, social development changes occurred. This was evident in each case when they would interact with their peers, school personnel and family members.

SUSAN

Susan's grade nine teacher indicated prior to the accident how Susan was developing like a "normal teenager". She describes her as being "quite shy" and "having a couple of good friends". According to her grade 9 teacher, "[Susan] hit a stage where she liked the boys. Boys were becoming very interesting to her and she really didn't know how to get their attention and it was because she was really, really shy". However, her mother feels that Susan was very "out spoken". She recalls:

> Socially she definitely had a lag. I would probably think she was somewhere a couple more years less mature than her peers; the aspect of mature in terms of how to behave normally in a social situation, those kinds of things. She needed to dominate conversations. She was hard to deter even before her accident. If she had something to say she had to say it. She was very determined and when she needed to get something across, not to the extent of course after the accident, but it was definitely there. On the other part, she would do the strangest things that would make me think that she was so much more mature than some of her peers as far as what she was going to do with her life...She had friends, but no close friends. She didn't have a best friend ever. Probably one of the hardest things a parent can watch in a child is not to have a best friend. She had a group, never close friends, but there was a group.
>
> [Susan] has been very, socially, very aggressive, to a certain degree. Her impression of a guy is that she will need to be very close. I mean right in there, in their face and I keep telling her they need their space and she just can't get that close to some people's face without offending them and, again, ninety percent of the time people are fine with it. She would probably take it to the extreme. Just the way she

> talks to guys or touches, or and I don't mean anywhere inappropriate, I just mean, she would hold their arm, things she wouldn't have done before the accident. She doesn't know the limitations of where to stop; doesn't know when to just say, 'Hello', and, 'How are you doing?' It's hard to explain. Between all of us repeating, 'You can't do that', and again it wasn't inappropriate or sexual to that degree, I think she's gotten very, very strong boundaries of what she would allow to happen. She would put her head on his shoulder or sit very close but there's a very, very clear boundary as far as sex. Probably to the extreme again. She has a very mature point of view about that. She wouldn't try to do any of that until she's completely ready and she has probably more old fashioned sense about all of that than most people do.

Since Susan has returned to school, her teacher and school counsellor see that Susan is trying to "fit-in" as much as possible. The school counsellor states:

> [Susan] was certainly quite apprehensive about high school, like many, many people that start here. Didn't really know her way around, a little overwhelmed by the numbers of people that were here, but she was certainly very determined to go, very determined to be here, to get around, to make eye contact with people, and to fit in socially, that kind of thing. I think at the time, looking back at September, she was probably still struggling with that whole concept of fitting in and I don't know what went through her own mind in terms of feeling different, or anything like that, and of course I have a feeling that some of her peers kind of saw her in a different situation, or saw her differently, if I could say that, so I'm sure that, that had to have an affect on her as well; but through out the year, it has been very plain to me that she has certainly evolved socially...She's been in a group of general courses and got all her credits in grade ten so she has moved on to grade eleven as she should be, but it's the social aspect that's more hard. As the year progressed she dressed better, wore more make-up, really attempted to talk to people and be out there socializing and trying to really be in the center of things. In some sense, perhaps trying too hard...She is doing everything in her power to be as 'normal', if I can use that word, as she ever was.

Susan's first semester teacher described her social development as follows:

> She was very, very sweet, very pleasant. She required a lot of

> interaction I found. I always made a point to say, 'Hi [Susan], how are you? How was your weekend? How was your day?' and she responded very positively to any of that. I don't know if she was getting a lot from other people, and I am not just speaking of teachers, but people in general, and her face would light up like a candle. She was always very, very pleasant. She, socially, I think she was below the age of her body. She would often treat the boys like you would if you were in grade six rather than you would if you were in high school. She was immature in that regards. So I'd say mentally that definitely hurt her. Her mental capacity was not to the age she actually was.

JACK

In contrast to Susan, Jack was very outgoing before his accident. Unlike Susan, however, his social development underwent significant setbacks.

Prior to the accident, Jack's parents described him "as a very sociable little boy. He was involved in 4H, Sunday School and always had a group of friends around". After the accident, his parents indicated that just about everything changed.

> He made friends with everybody in the hospital. We used to go for a walk through the hospital and he got to know a guy who worked in the utility room, the laundry guy, the garbage man, everybody, it didn't matter where you went. Everyone would say , 'Hi [Jack]. How are you today?', the ladies in the kitchen and the cafeteria, everybody!

> He lost all his friends and they told us it would happen. He just can't do the things that other kids do and it doesn't matter whether you're 10 or 100, you will eventually lose your friends ...and that's happened. It's been that way for a year and a half now. Some of his friends came at first and, in most cases, kids are more accepting than adults, but with the physical disability and being in a wheel chair and not having the ability to do most things, it's hard on young ones. And there were behaviour problems...he was impulsive, lack of control, anger and resentment and eventually the children got so they didn't want to come. He'd call somebody to come and as soon as they got here he would start to punch them. It was like he resented them because they could walk and he couldn't; or they might get here and

> then they would do...he wanted somebody, but he can't do anything with them. He would get his best friend here and then he couldn't play and he would get very frustrated, very angry and he would end up laying in this chair here watching TV or watching them and then he would fall asleep. I have seen his friends get here and by the time they get here, he would be asleep in the chair and I'd have to say that he fell asleep and could you come back in an hour? Ya, well then when the hour was up or when he wakes up well then he'd say, 'Did ----- come?' 'Yes dear, ----- was here, but you were asleep', and then he gets angry again. Just a vicious circle.
>
> Socially, still has a great sense of humour and still wants to be social with everybody but because of the impulsiveness and the lack of control, you never know what he's going to say or what he's going to do and some of the kids get really turned off by it.

Jack's home room teacher describes some of Jack's social behaviours in her class.

> Socially he wants to work with other students. He wants to be part of the group. He wants to be involved, even if we are doing something alone, he wants to be part of a group. He's interesting. He comes up to me in the hallway and he wants to chat in the hallway, but he always wants to be right in my space and I'm not comfortable with that with any student, and that kind of makes me nervous a little bit. [The students] react better to him sometimes than maybe I would.

PERSONALITY CHANGES

Susan and Jack both experienced changes to their personalities. In some instances, Susan's changes were somewhat more subtle than Jack's.

SUSAN

Susan's mother and grade nine teacher both indicated that Susan's personality was affected by her brain injury; however, Susan's mother reported more subtle changes than did her teacher. Susan's mother has described her daughter as being determined, stubborn, responsible and in some cases, mature. She really didn't see much of a difference in her after the accident.

> She had just turned sixteen in May and wanted to work, and the job and the whole independence that she gained from that...she has really gained a whole lot of maturity from it; she gained her independence, her self confidence, a real change. The summer of her accident was probably the biggest growth I saw in [Susan] in her entire life. That eight week period.
>
> [Susan] did not cry after her accident probably for at least four or five weeks. There was no tears. There was no emotion. There was anger. There was no sadness, there was not a thing even remotely close to that side of the emotion. Frustration was there and anger. It was probably five weeks after the accident that she actually cried for the first time and she was good then.
>
> She was such a shit and beyond. I had asked her when she wrote for the very first time, 'Do you know who I am?' and she wrote, 'No', exclamation mark. I looked at her and said, 'What?', and she looked as me as if to say, 'Why are you asking me this?' That's when I knew that [Susan] was back.
>
> [Susan] in many ways is still very much who she was before. Now knowing that, and I say that quite often, some people say that she'll never be gone, or independent, or any of those things, but she's going to be independent. She may not be that far away but she'll get there in her own state. I think she probably will eventually become independent, maybe to a level, maybe not the same level as the rest of the world. Her determination, I think, is going to take her there, I really do. She wants to take the early childhood course, she wants to keep going and I'm certainly not going to stop her.

Susan's teacher before the accident saw significant changes in her personality when she would meet Susan in the community. Prior to the accident, she described Susan as being " very shy, very, very shy, very quiet". She recalled a time when her class was making a grade nine video and Susan would always shy away from the camera. However, Susan's teacher also recalls that Susan "was spunky; she was a fighter and you just knew that she had that fighting attitude and you just don't get her mad, or don't get her angry". When asked if she saw any changes in Susan's personality since the accident, she stated:

> Big time...even her laugh has changed. Like she's much more out going, much more. Maybe out going in a negative way where she doesn't quite understand. I can remember I was talking to her one day in church and she just wanted to talk, talk, talk, talk, talk and that was really odd because she would never say more than what she had to. Her mom would say, 'Okay [Susan] ----- has gotta go', and then she would think of something else she just had to tell you. She would just go on and on and on and she would say the same thing, she wouldn't realize she had told you and she would repeat it later on in the conversation, you know, that kind of thing. Much more outgoing that way, it was hard to believe that the accident could do this to her. She became very interested in boys, didn't shy away from them, made contact with them, would go up and talk to them, go up to them at a hockey game, go down and watch a hockey game, you know, just totally different than what she was in school. I know that afterwards, after the accident, her mom would say that she's totally different and that she's never displayed this kind of temper, this fighting, much more of a fighting attitude then she had before [the accident].
>
> It's an awful way for anybody to have to become out going to go through what she did and maybe lose a few other things that she had going for her but, and, in some cases, it's a good thing and, in some cases, its kind of a bad thing. She's out going to the point where she might repeat things and it's hard to say, 'Yes, [Susan], you already told me that'. She still wants to talk but it was very positive and negative. I mean from where she came from, it just seems to be a positive. You hate to say that, but it [the accident] did enhance who she was. She is totally out going and I don't know if that would have changed over the summer, it could have been work that helped her too. I know people who knew her at work and would say, 'She's so quiet. She hardly says anything', and now to see her, it's like, 'Oh my gosh!' What she's gone through and how she's come through, it is just amazing. I don't think she would have changed that drastically over a summer, maybe over a few years, but not as quickly as she did.

When Susan started high school the winter after her accident, neither the school counsellor nor the teacher who was interviewed knew her prior to her attending their school. Her teacher described Susan as, "very positive to have in the classroom and bubbly and smiley. I never saw her out of sorts ever, ever at all. She was always an extremely upbeat person". The school counsellor had this to add:

> I think she was very, very good at putting out the whole notion that she was attempting to be just like she was, and hence, 'Don't treat me any differently'; but my expectation was that she was dealing with the whole notion with not just fitting into a new school, but just fitting in among her peers again. I imagine that she knows that she is not exactly as she once was and the worry would be how she's perceived. I suspect that in some cases that some of the so called 'friends' that she had at first, disappeared and some haven't. That is pretty heavy for anybody to deal with. My guess is that when she started school here, she was in the midst of really starting to live life again and learning a lot of stuff all over again that most of us don't have to learn again. Once we learn it, we have it and she was coping with that while at the same time being in school and handling all this stuff that school throws at you on a daily basis. She probably had a pretty full plate. Again, I am not sure how she perceived that but whether she perceived it in total or whether she's been very good at coping with it all and carrying that load, she truly has come a long way. I think her biggest success has been the management of her life or the overcoming of the obstacles. I am just amazed at her, that she is out there and meeting people and being social and in no way have I seen where she gets herself down or has a gloomy attitude. I just haven't seen that. Her mother did tell me at one point that she did have some of that, particularly around having a boyfriend and not having a boyfriend and sort of being fixated on certain individuals, but I see her everyday in the hallway or in the corridor and interacting and I haven't picked up on any gloomy attitude. In fact, it's just the opposite. She's out there and as time passes, you see more interaction, more smiles, more laughter, so I think it has been fabulous. I'm not saying that the school needs to take any credit for that; I put all the credit with [Susan], with what ever attitude she has, or what ever she has taught herself or trained herself to do or perceive, believe or whatever, it is great.

JACK

Interestingly, while Susan's personality became more outgoing and assertive following her accident, the most notable impact of the accident on Jack's personality was that his social judgement became significantly impaired.

Jack's parents reported they definitely saw a difference in his personality after the accident; however, there were signs that some aspects of his personality didn't change so much after all.

> He's not the same little boy. Not at all. They [medical professionals] told us that in Moncton, they [brain injury victims] are never the same and he's not...no he's not the same person at all. He has a different personality, but [Jack] has a terrific sense of humour, always did. Picture a little ten year old boy, in a private room on a ward that held probably twenty-five other people that suffered stroke, loss legs, and there was a lady there that couldn't talk, she had suffered a stroke and that lady had a sign on her door , 'No Admittance, Family Only', and the only exception was [Jack]. [Jack] suffered a brain injury, and he was in a wheel chair himself, and he still had compassion for elderly people. He even made terrific friends with a gentleman who had lost both of his legs...unbelievable. It was just hard to believe how a little boy fit in and he became so 'adultified', they called it, that he had a hard time fitting back into school.

Although Jack's grade seven home room teacher didn't know him before the accident, she thinks that his personality doesn't seem to match someone who was once so eager to succeed in school.

> It doesn't seem to bother him that he doesn't finish an activity, he doesn't see it through to the end. We might start a lab one day and the next day we'd finish it and he's not here, he never says to me, 'Well, what happened to that?', where as a lot of the other students would come back the next day and say, 'Well, I didn't get to see what happened'. He doesn't have that continual.

BEHAVIOURAL CHANGES

According to both Susan and Jack's parents, the behaviour in both children changed. With the significant changes to both of their social development and to their personalities, behaviour became an issue.

SUSAN

According to all of the school personnel interviewed regarding Susan's behaviour, Susan was a "delight to have" in the school and in the classroom. Not one of them ever witnessed Susan "out of sorts" or behaving inappropriately. However, according to Susan's mother, it was a different story at home.

> There were certainly behaviours [before the accident] and again that came to the fact that she was so determined to get her point across. She would interrupt, she would do a lot of stuff, very much a lot of this whole social deficiency that she sort of did have and after the accident it amplified ten times, maybe more, but it was always bad before. That's the only behavioural issue, real issues that she was having. She was not a difficult child. She would be in your face a lot and sometimes you would have to get cranky, but that was about it. There have been definite improvements since the accident, there's no doubt, no doubt whatsoever. Probably today we are maybe, maybe about seventy percent back to where she was before. She still requires a lot of attention, she still requires to be heard. She still needs to get her point across. Right after the accident it was hard. She would repeat, she had what they called perseverence, where she would say something, repeat it; it didn't seem to matter. She knew, according to her neuro-psychologist that she was doing it, but her brain was hitting a wall. He described it as a little marching toy that just hits the wall and can't stop. That was quite severe after the accident. You couldn't change her mind, could not get her to stop her thought process. Today, we're probably, most of the time, certainly at home, able to have a fairly normal life for the most part. She would stop and take some time. In public, it's probably at lot worse with her than at home, depending on the amount of people and what's happening, whether or not she's herself.

Susan's Speech Language Pathologist also recalls her inability to change focus while in conversation.

> I recall [Susan] being, as most teenagers, fascinated with boys in her life, and that was an easy avenue, I think, in the initial stages, to engage in conversation, which is what I do. However, her ability to place that in a sensible compartment and talk about other things in her

> life was not evident, especially in the early stages, even in the later of her time here, but not really all that easy for her to compartmentalize and sort that out. She was forever wanting to bring back the activity that she might be engaged in that weekend. She had a really difficult time, and probably still does, giving priority to things and that's a reasoning skill, I guess, a judgement skill.

According to Susan's mother, before the accident Susan had a temper and that too seemed to amplify after the brain injury.

> She would get to a level where she's very explosive, extremely explosive. Before the accident she wouldn't have dared try to hit me or anyone. It wouldn't have even crossed her mind and now her temper has amplified but it's rare. I mean, probably it may happen four times in a year, max. You know, it's probably every three months, she's in a level of frustration. We've spend some emotionally times like, 'Why did I live?' and all of that. She's on anti-depressants and she has been since the accident but I think it's more of just, just venting, like, 'How could this have happened?'

JACK

While the accident seemed to amplify Susan's behaviour, for Jack there was a dramatic reversal in his behaviour. According to Jack's parents and the school personnel, Jack's behaviour after the accident changed a great deal. Prior to the accident, Jack was involved in a number of physical activities and always had a circle of friends around him. His mother stated:

> I'm not trying to brag, but both my [children], teachers in schools, all their teachers would say that they were the most polite little children they have every seen. Everything was, 'Yes, please', 'No, thank you', but now you don't know what [Jack] will say. He could say, 'Please', or he could say [pause], he's too unpredictable; it's what ever comes in his mind.

After the accident, the once "happy, go-lucky, normal little boy", is reported to suddenly become "bitter", "angry", "depressed" and "violent". Jack's parents state:

> We have had our ups and downs. We have had days when he was bitter, angry, depressed. The first year he fought with me, he would hit me, bite me, pinch me, take almost like a temper tantrum type and he would go to the floor and lay on the floor. Before, he would do what you wanted him to do and the psychologist told us that it is because he is angry. [Jack] knows what has happened to him. He knows. He can remember things that happened when he was four and five years old. They [medical professionals] tell us that that is the biggest part of [Jack's] problem, his attitude. He's on various medications; he's on anti-depressants, ritilan, and he is on two different types of muscle relaxants to keep his muscles from getting so tight and tense that he can't move. His medication has made a mass difference, I believe, in behaviour, in his temperament, his emotional state.

The changes in Jack's behaviour, especially his impulsiveness, made it difficult for his teacher and teacher assistant to deal with his behavioural challenges. His elementary school teacher explained that there were "more behavioral issues than cognitive issues to deal with". Because of Jack's escalating behavior when he first returned to school, he was removed from the classroom more and more due to "foul language", "sexual behaviors", "using his cane and wheel chair as a weapon" and "hitting a couple of kids". For the school, it was a safety issue. In the beginning , transitions were also a difficult time for Jack and it took a few months for both the teacher and the teacher assistant to "learn when to back off and when to pick the battles". Both the teacher and the teacher's assistant felt that they may have added to some of Jack's behavioral challenges because "it was hard to know what was the injury or what he [Jack] just didn't want to do. We were never sure what was the 'true' [Jack]".

The school psychologist described Jack's behavior during the rest of his elementary education and his progression up to and through grade seven:

> I understand that [Jack] was very depressed, really grieving and he would often be heard saying things like "Why didn't I wear my

> helmet". It was really, really hard for him and he was very agitated and his behaviour was quite challenging. He would get really angry and I guess you would call it throwing temper tantrums. He was explosive, aggressive and it was how to manage his out of control behaviour [that] was an issue. Hitting others, hitting objects, throwing objects, damage to personal or school property, refusing to comply to the teacher, yelling profanity so there were a lot of very serious, extreme behaviour which was not characteristic of him. He was very prone to fatigue so this affected his ability to retain, which increased frustration. He just couldn't do the things that he used to be able to do. It must have been extremely frustrating, frustrating for him, and just trying to cope with the physical changes. You could say initially it was very, very, difficult for him.
>
> In terms of his behaviour at school,...we made some recommendations and these recommendations were based on brain injury and what's recommended. I met with them [school personnel] and we went over it all together and at this point he had a TA so that was built into it. As for now, I see him here and there and he seems to be doing a lot better. We don't hear from him and that's a good thing! No news is good news.

Jack's parent's often stated their "frustration" with dealing with Jack.

> It isn't a matter of teaching [Jack] right from wrong. He knows right from wrong. He can't control right from wrong. He acts and then it's too late and then you can only sit down with him and tell him every time, every time, every time, and it's never ending. One thing we learned early on is, you can't push him. The more you push him, the more he'd push back. You're better off to give him choices or sometimes I'll ask him which one he wants to do first. He needs to do them both but when he has some of that control, it seems like he made that decision, not me, and he's in control and wants to do it his way and we haven't had near the problems with him.

Jack's home care and support worker, rehabilitation unit nurse and physiatrist all described his social/behavioural inadequacies in terms of his judgement, need to attention and his size. The home care support worker described his social behaviour difficulties this way:

> I guess when I think of [Jack], I think maybe one of his greatest handicaps is the social and behaviour in terms of adapting to that, that

> was an issue while he was a patient here. It continues to be a huge impact there in terms of his judgement, in terms of his need for attention, in terms of the higher executive functions of the frontal lobe. That is his greatest handicap in many ways because to fit into society and to make something of yourself, requires a level of social capacity that can override some physical deficit. Jack's quite handicapped.

Jack's physiatrist described him as "being a child in a big man's body". "He was 12 when I first met him and he looked like he was 16. Kind of scary for everybody because if he did misbehave, he could seriously hurt someone". Jack's rehabilitation nurse described how affectionate and social he was when he came to visit or for treatment. Changes needed to be put in place for his visits because it became increasingly difficult to handle him due to his size.

> When [Jack] comes to visit and he comes fairly often, although the last few visits have been better, he would come barging literally into the unit, the doors go flying and he'll try to get behind the desk. He wants to hug the nurses and me and the last time he hugged me, I really thought I was hurt at first. For a couple of days I had a terrible ache; he really did hurt me. So, I had to make this ground rule that, 'You could come to visit, but you are not ever going to hug again', and he had a hard time with that but now though, the last few visits, I found him to be a lot more quieter; but that was the big problem. He was getting stronger and bigger.

PHYSICAL CHANGES

After both Susan and Jack's accidents, each of them developed changes in their physical abilities. Susan's was more subtle than Jack's.

SUSAN

Growing up, Susan's physical development progressed normally, according to her mother. Susan didn't play a lot of sports or take part in a lot of athletic activity. Her mother did state that Susan did play soccer for a few year but it was more to "just hang out". Since the accident, Susan's mother noted that she has become more unstable on her feet and has some paralysis to her left side. She notes "there is a definite delay in her left arm still today". She walks with a bit of a limp and sometimes needs to hold on to things for balance. Her mother states:

> We've come a long way. If it never got any better, we'd be okay. I think it's still not time to give up on it [left arm delay]. I mean, I think if she worked at it, she'd bring it back. I think it will become more reflex. We don't think about what we do with our hands. Our brain doesn't tell us that it's time to move; for her she has to do all that now. The signals are really not all that good.

JACK

Because Jack was always so actively involved in sports prior to the accident, the physical changes have been more acutely felt. According to Jack's parents, Jack's physical development progressed at a normal rate and he was very active.

> [Jack] was very physically able. He was sports minded. He never was into any professional sports or organized sports, but loved to get his skates on and play hockey on the pond with the kids and was always playing soccer. Loved swimming. Loved the beach. We spent everyday at the beach during the summer.

Due to the injuries sustained in the accident, Jack's physical needs changed dramatically. Jack's nurse in Physical Medicine recalls that Jack was quite dependant.

> Physically he was quite dependant and is still, as far as distance walking. He can do longer distances now but at first he could only walk very short distances. He has a lot of increased tone, stiffness in his muscles bilaterally and the only reason we don't talk about his left side as much is because the right was so severe that the left seemed good by comparison. He also had decreased range in his joints, because of the tightness of the muscle.

His parents recall the need for therapy and the progress Jack has made since the accident.

> When he was discharged we went [to rehabilitation] every week,

> twice a week , then it went down to once a week and then every second week and we do exercises every day...it could be walking and if he wanted to try to use his right hand for something, we should let him attempt it. He can now play basketball, he can play *Play Station*, he can shower all by himself, but he has trouble with getting his back. He can't get his back and he can't get his left arm. He can't take the right arm and wash under the left arm, I have to do that side, the left side of him. He can wash the right side. He can get his coat and clothes on by himself. It does take him a little longer, but he can do it. He uses his right hand and ties his shoes the same as you and I would do it. It may not be as tight, or quite as fast, but he can do it. We don't allow him to use his wheel chair at all unless he's going far or across the road.

THE SOCIOLOGICAL IMPACT OF TRAUMATIC BRAIN INJURY FOR THE CHILD

The changes in the child after a traumatic brain injury not only affect the child, but also have a significant impact on the child's social environment as well. The impact on the child's school, on the child's family and on the child's friends are discussed in the following sections.

IMPACT ON THE CHILD'S SCHOOL

Both Susan and Jack returned to school after their accidents. This transition had an impact not only on Susan and Jack's families, but on their school communities as well.

SUSAN

Susan returned to school after her accident in February of 2002. She enrolled for a full, grade ten course load and started her first semester of high school. Both the school counsellor and her teacher felt that there was very minimal impact on the school and the classroom because they consider their school to be an inclusive one. The school counsellor noted:

> Well, being a small community where everybody knows everybody, of course, when the accident happened, it had a huge impact on the whole school community and the community itself. I am not really sure how it had impact on individual classrooms; I mean...with the

> people that knew her prior to and then being in the same class with her now, of course there is that daily reminder, particularly at first...there's [Susan] and she's different now than she used to be and so on and so on. I'm sure that had an affect on many of her peers. Now, to what extent, I don't know. When I look back on it, it wasn't a counselling issue. Nobody came to me with that as an issue. Teachers certainly didn't come to me. All the teachers accommodate, pretty well everybody, and we have a large number of people who categorize as special needs and the needs are just all over the place. I think what happened is that the teachers accommodated her on a one-to-one as best they could and discovered what she could do and how she could do it and put things in place so that she could be successful. Her peers, I think, accommodated her and she accommodated them, that kind of thing.

Susan's teacher also stated that having her in her class didn't cause as much as an impact as she thought it would. She recalls:

> I had to be very aware. I mean, needless to say, if you have any special needs in your classroom you have to be aware of what the needs are, and [Susan] was certainly not the only one I had in the classroom. There were a number of students, like in any classroom, that you have to pay particular attention to. I made every effort I could to ensure that I was close to [Susan] because I knew she was distracted by surrounding noise. I put her in front of the classroom and I did it in a way that she wouldn't realize that that's why I did it. I made sure that she was close to my desk so that I could interact with her. She would take some time to get her things out, to get her book out because her mobility and her movements were a little bit slower. I would kind of help her out a little bit. If I said to turn to page whatever, I would make sure that I was by her so I could help her. She was quite capable of doing it, but she was just slower than everybody else. It was to ensure that she wasn't falling behind. I would make sure she was on track in that regards. The way she interacted with the rest of the students seemed to be very positive, very, very positive, but of course I wouldn't accept anything but positive in the classroom. She had a couple of boys that she was really attracted to and they were very, very good with her, extremely good, and I think that that was a positive influence for her. As far as the class, it didn't change at all. It wasn't any different for her versus anybody else. I treated her equally and she demanded that. She did not want to be treated any different at all. So really, she didn't change

the classroom a great deal.

JACK

While for Susan the transition back to school went smoothly and was, for the most part, a positive experience, Jack's return was not so positive. Jack returned to school in May of 2001, a year after his accident and started grade five. Jack's grade five teacher and teacher assistant claimed that Jack's return had a huge impact on the school, the teachers and the classroom. His teacher stated that Jack " mainly lashed out at the staff, not the kids". "I think it was because of rules and limits. It was a power struggle and he wanted to be the boss." She indicated that not many of the staff had experience with Traumatic Brain Injury and the staff was in such "disbelief" with what they and/or their students witnessed or heard. Even though this school had special needs students before, this was all new. Jack's injury had created a whole new level of need. She remembers that, over all, the staff were excellent but since it was all new to them, they had to rely on using a common sense approach. Certain staff members were better at this than others. A number of staff meetings involved discussions regarding how to deal with Jack's behavior and trying to get some understanding of how to best meet his needs. She remembers that she relied on her co-workers for support, but it was difficult; she didn't want to breech anything around the code of ethics and she was conscious of the need to maintain professionalism. She found it a real challenge because she would often "need to vent and to laugh and just be human".

His teacher had to move her students and her classroom to the main floor when Jack returned because he was unable to maneuver the stairs. The school had to build a bench outside the building for him to sit on during recess and noon hour. She recalls that having the bench was " very tough sometimes, because Jack liked to perform and show off. He loved the attention and sometimes we couldn't get him to come in". His teacher indicated that, in the beginning, she thought like a parent. She stated:

> I thought like a parent and thought that [Jack] needed to go out at recess time...he was going to do what everyone else does. But I soon had to back off and I allowed him to play games-cards or board games or listen to music. We would try to get him to exercise in the gym. In the end, he rarely went out. It was a very difficult time...we would try to find incentives for him. The phone and the office was a special time.

The school psychologist recalls it being a very stressful time as well.

> I recall for the teachers it being very stressful. I don't think they understood how to address his needs and I think it was very difficult because they wanted to but they didn't know how to. There would be frustration going around behaviour and just not knowing how to manage the student and feeling really bad for him and empathic. You can understand why, but yet, how do we manage his behaviour? His teacher, as I recall, she seemed really devoted to doing every thing she could to help him out. I know that the school was really looking for information, so I know between myself and [the school counsellor] we were giving the school information about brain injury, as much as we could come up with and find at the time. The truth of it is, we didn't have a whole lot of resources, like material, or information on that topic. We've never had a student like this before. Then there were structural things that had to happen. They had to build a bench outside and they had to change their classroom location for him in order to accommodate him and his wheelchair.

Jacks transition to intermediate school seemed to go more smoothly. His grade seven home room teacher reported that Jack certainly made an impact in her classroom, but not so much on the school. The school is an inclusive school and students and teachers are used to having students with special needs in the halls and in the classrooms.

> We have an inclusive school, so they're [students] used to having somebody who may be a bit more [pause] or whatever, so in terms of

> the impact on my classroom itself, I don't find it's been a major impact. He blurts out in class and you tell him that that's not appropriate. Somebody usually has to be sitting with him at all times. I think it was a bigger impact on how maybe I deal with things rather than how the students dealt with things. I think that maybe [there were] only a couple of students in the classroom that did not have [Jack] in their classes before...The kids pretty much are accepting. I haven't seen too many people say, 'Get away from me'...or that idea...There are a couple of students that he [Jack] likes to work with and a couple of them will actually say, 'Well, I'll work with [Jack]' and they do that. [Jack] adapted remarkably well coming here, changing classes, getting use to having seven different teachers or how ever many he has. I think he's adapted remarkably well to that and I think a big part of it is [his teacher assistant], having that consistency there. I think that the biggest challenge was the apprehension of the unknown and hearing the stories of what he [Jack] did and of course, you only hear the bad things of what happened.
>
> [Jack] does have a full time teacher assistant... we have a resource teacher...we also have PD [Professional Development] time and an innovations grant that we also have, so then we can take some time for planning if I did want to meet with [the teacher assistant] or if I wanted to meet with the resource teacher or time for myself to plan and sit down to do that. We also have the guidance counsellor so that if there were things that we needed to talk to him about, we could do that.
>
> We knew that [with Jack] coming... there were a lot of difficult problems [with students] in the grade six classes. There were three [classes] so we made the effort to make them into four classes here. The classes were smaller...and we didn't have nearly the problems or issues.

IMPACT ON THE CHILD'S FRIENDS

Susan and Jack both experienced similar predicaments with their friends. Susan, although very shy prior to the accident, maintained a small network of friends. Jack, on the other hand, had a huge circle of friends prior to his accident. With the significant changes in both personality and behaviour since the accident, both Susan and Jack have been left without a social group.

SUSAN

Susan's mother stated that Susan did have a group of friends that she could get around with. However, Susan's brain injury had an impact on that friendship group. She stated:

> She had friends, and her friends were with her up until about a year after the accident. Then they went their own way. It started before that really, not able to deal with it and that is understandable. Right now she doesn't have anyone. She will go to school, and is quite happy to go to school everyday but there is not even a group anymore. She goes in and she's on her own. She says that she's okay with it but I don't believe it. People are great at school, they stop and they let her talk, they give her time too. For the most part, there hasn't been any incidents. Everybody's been really, really good as far as all that goes. I'll take her to a dance and she'll go and talk to people, she'll get out of the car. She's seventeen years old and walks into that dance all by herself and I think that there's no way in hell, when I was seventeen, I was going in that door by myself. No, the more you had around you the better off you were. [Susan] doesn't appear that she needs that. I say that though. She seems to be okay with it and she comes back from the dance and I'll hear every detail. She's very detailed in everything she says now. She can't seem to just focus her thoughts to the general side of everything. But, she has her days where it hits her.

In school, Susan's friendship group in the beginning became very supportive. Her grade nine teacher recalls how her classmates reached out.

> The kids were really good with her. I mean, when they saw her, and realized, and even some of the boys that were in her class that year that she had a crush on, they kind of understood and would talk to her, kind of reached out. I mean afterwards she thought that was great. She had a group support system around her and the kids were fabulous...Maybe some of the kids, now that they know she's better, may not give her the attention or time that she would like them to give. I think that maybe she would be very frustrated when students had to go to class and she wanted to talk to them and she wouldn't quite understand that. 'I gotta go [Susan]', maybe be abrupt and that

> may might frustrate her a bit.

During the interview with Susan's high school teacher, a discussion around her educational needs came up. The teacher felt that Susan's social needs were being met inside the school, however they were probably lacking outside the school. The teacher questioned whether or not she met Susan's academic needs, however she thought the social aspect was more important and would have liked to have seen more emphasis placed on that rather than the academics.

> Academically, I couldn't be sure I met [her needs]; socially, I think yes, and in [Susan's] case, socially was more important than academic so I think her social needs are being met because she certainly had lots of friends. The students are very, very positive around her. They don't poke fun or say anything or do anything that would be negative. So, socially, I think she has a really good network; academically, I could only pass judgement... I would take less emphasis on the academic and more on the social.

JACK

Jack's experience with his friends was similar to what happened with Susan's friends. According to Jack's parents, his grade five teacher and the school psychologist, Jack's friends were all very supportive in the beginning; however, it was difficult on most of them to see the changes in Jack, especially the behavioral ones, and many of them found it very difficult to continue friendships with him. His parents recalled:

> At first everyone flocked to him and nobody knew that he wasn't the same [Jack], other than the physical aspect of it and him being in his wheel chair. Others were timid and didn't know how to approach him and didn't know what to do because he couldn't play soccer and he couldn't play basketball...the kids just stopped coming around...he has no friends...he even told his principal that he wished he had friends...we have had incidents because of his hormones changing, because of him going through puberty, and the major part of it is due to his injury. He is fixated on sex. We've had, not so much this year

> as in the first two years, we had a lot of incidents where he was grabbing at women and I guess, with being a teenage boy, and with raging hormones and everything else, and his injury, we don't let him out of our sight. At the school dance there are two doors and he's [father] posted at one and I'm posted at the other so we can see where he's at. There are some girls that will dance with him and he'll get up, he'll stand out of his wheel chair and he dances and if he gets tired he sits back down into it. We've seen him waltz and I've seen him give one girl a kiss on the cheek and I thought, 'Oh, God, please don't go any further' and he didn't and he just gave her the kiss on the cheek and I asked him about it on the way home and he wouldn't talk about it...Last time we were at a dance, I had a hard time with it really.

Jack's grade five teacher and teacher assistant recalled that, when Jack first returned to school, the kids were so excited to have him back. The class had set up a peer program to be with Jack and, in the beginning, most of the students "loved to go with [Jack]". His teacher remembers that a few of the students were very dedicated and stuck by him to the end of elementary school, but others saw the changes in Jack and "couldn't handle it, so left." The peer program eventually branched out to other classes for "buddies", but slowly dwindled off. She indicated that students were fearful of Jack. Everyone had really mixed feelings. The teacher also recollects that the students in her class questioned Jack's actions and her and the teacher assistant's reactions. She recalls how one student would actually hide from Jack; "This particular student seemed to have a very hard time around Jack because that student was with Jack at the time of the accident. On the other hand, some of the students really benefitted with having him in the class; it humbled them".

IMPACT ON THE CHILD'S FAMILY

Major impacts to the family system were revealed in both families participating in this research. The physiatrist explained:

> They both now are teenagers and should be cutting the cords and moving on and becoming more adult independent, but they are still totally linked, still attached to their parents. They can't really be independent and that's a big impact on the parents almost as much as it might have been on the child. They likely will be with them for years to come, where they normally would have moved on.

The physiatrist and the social worker also referred to the lack of outside support and additional costs involved in raising and educating a child with a traumatic brain injury. The social worker stated that "there are a lack of resources and that increases the stress while families are trying to cope with a life long injury". The physiatrist had this to add:

> We all know that if you have a traumatic brain injury, it is very costly if you are going to get the proper treatment. The alternative is to, say, ship the whole family to another province for six months while the child gets treatment and the family gets the education; they deserve that. If you don't invest now, it is going to cost more for everyone in the long run.

SUSAN

Susan's brain injury impacted her immediate family and her extended family in many ways. Her mother recalls the effect it had on her marriage, on Susan's siblings and on the extended family.

> [The impacts] are probably not as big as they could have been. We've had some changes in her [Susan's] life; her father is no longer with us and he left in March which was six months after her accident. In a way, if I go back to the accident, prior to the accident, her father and I would have been separated anyway. There were a lot of issues that he had that we just weren't going to get together on and I think the accident only brought it to the point. It only made all of us recognize that it just wasn't going to be. If we can't do it now when we really, really need to get it together, it's not going to be. So that's been quite an impact. Her [siblings] have been extremely good. [Her siblings] were great right from the get go. They still are today. They have their moments where it's difficult to understand what's happened to her and why is this happening and why is she allowed to get away with this, but they are very minimal. [The oldest], being

fifteen, and being that [the father] is not there and has stepped into that roll and tries to help her along. He gets down to a real battle and they've had battles. At one point after the accident he said, "The behaviour can't go on, you know it can't". He's sort of the one that can go into the situation when her [Susan] and I have had a battle and sort of just talk to her. He can get around to the other side. [The other sibling] couldn't get close enough to [Susan] after her accident. He couldn't hug her enough, he couldn't hold her enough, he couldn't get close enough. I think it was just a big step back. He needed to have her, and [Susan], after the accident couldn't be touched for a very long time. It was just too much of a whole sensory thing. She just couldn't physically or mentally deal with the touching. They had had quite a volatile relationship since the accident; yet, ninety percent of the time, [he] understands what it is. It's been quite a challenge for them [siblings] but, like I said, they have to deal with their sister sometime. Like my father said, he doesn't particularly know what to do with her in public. He was very old school and you have to behave yourself and the boys had to deal with her not behaving the way that we all would in public and they are beginning to adjust pretty well to that.

[Susan] had five mothers in the hospital in ICU. My father, when they were putting her in the helicopter, made me promise that she would never be alone for an hour, and she wasn't. She was, twenty four hours, there was somebody with her. So in between the five mothers and her grandfather and, you know, friends, family, the amount of support, phenomenal, phenomenal. Her father was the opposite; he couldn't deal with any of it himself. He resented probably the support that was there. Today it's still all there between my mother and father, my sister, my best friends, the two of them..., and not only that, but she has cousins that have completely stepped in and are just great.

I would say too that the roll of having an infant again at the age of forty is challenging, but looking at it, probably only a mom could be able to deal with something like this when you're a certain age in life... you know, if I thought back to being twenty-two and having this affect me, I don't know how I would have handled it...as a parent there are many of days I don't know if I'm dealing with traumatic head injury or I'm dealing with PMS, or a seventeen year old. I really have a big chore in trying to decide what she's able to process and what is just plain being miserable and what is just being a teenager...it's a real big challenge, because you still have to take this

> child forward in life, you still have to give her limitations, and at the same time, sort of, 'That's not acceptable', 'You can't be rude', 'You can't be this', and as much as you keep doing it, you're never exactly sure...I think sometime you gotta let go. I think children need that.

JACK

As in Susan's family, the accident had a profound effect on Jack's family. The impact of Jack's traumatic brain injury seemed to take a toll on his immediate and extended family. His mother recalls how difficult it was initially:

> The first seven months I spent every day at the hospital from the time he was injured at the end of May until the end of December. I missed one day of not being with [Jack]...he had a lot of rehabilitation...I didn't go back to work actually until February 2001. I took a little longer because we wanted to get him back into school and get him straightened away...At first [Jack's sibling] was left alone for three weeks. He was 15. [Husband's] mom and dad, my mom and dad and my sister came and stayed with him and our very good friends and neighbours stayed with him, but he became independent. Almost a rebel type; 'I'm going to do what I want', and he was his own boss there for seven months, and I said, 'No you're not, you're doing what we want'. So it affected him. He felt guilty. He blamed himself and he wouldn't come to church with me anymore. For a long time, he blamed God...I never dreamed that something like this was going to happen to my family and it's heartbreaking and it sure plays havoc with your family, and your marriage. My parents, his [husband's] mom and one brother just can't understand at all. She [husband's mother] just can't accept it. They can't accept [Jack]. We have had very little support from either side, and we are not people who ask for a lot. Our parents, they don't come like they used to...We can't find a babysitter. We had come to a point in our life where [the oldest] was 16 going on 17 and [Jack] was 10 and we felt OK to leave the [children] for 4 or 5 hours and go away, go to a party, whatever, and we never worried. We had the cell phone and [the oldest] knew the number and they weren't going to fight any more than two [siblings] would.

Jack's parents also recall the impact and the feelings that they had when Jack returned to school.

> [Jack] goes to school from 8:30 until 2:30. That frees up a bit of our day... It's such a relief to have him get up and come out here and have his breakfast and get ready for school and [the teacher assistant] comes and picks him up and we know that we are never going to get a phone call all day. Then he is going to come home and have a little bit of homework to do like any normal child and that's it. That is a major relief. It sure wasn't like that the first year. It was such a battle and it was a fight and a battle to get him up and out of bed in the morning. [His school] is a real change from a few years ago. It's a whole group of different teachers but the attitude is different. Before, at the elementary school, nobody wanted to handle [Jack]. I had to leave work. I would get a call at work, 'It's an emergency, come and pick him up', and I would have to leave and go and pick him up and come home and try to get a hold of [his father]. I would have to get back to work to make a living and it would be only a matter of time, as you know, what would happen to me if this kept up...We go to the school dance, we are the only two parents there because it takes both of us to get him there. He's gotten so big now that he can get in and out of the vehicle by himself now, and everything, but his chair weighs 50 pounds plus he weights 200 pounds and it's all I can do to, I can push him on flat ground like if we are in a shopping mall, no problem, but to push him up ramps, through doors and into the elevator and door ways, and things like that, I need [his father]. I can't do it all by my self.

PREPARATION FOR REINTEGRATION TO SCHOOL

Many of the interviewed participants claimed that reintegration to school is an important step in healing. However; in some instances, the reintegration process does not run smoothly. Parents, medical professionals and school personnel offer different insights and perspectives on what is needed to have an effective transition. The following sections outline their suggestions of what is important to consider when preparing to send a child with a traumatic brain injury back into the school system.

PARENTS' PERSPECTIVE

According to both parents, Susan and Jack were anxious to return to school. The following excerpts describe the different levels of emotions that each set of parents went through during the process of Susan's and Jack's transition of days spent at home to days spent at school.

SUSAN

According to Susan's mother, Susan was anxious to return to school. However, her mother felt there were several issues that needed to be addressed before she started classes. For her personally, it was hard for her to "let go again" and she had a lot of anxiety regarding Susan's mobility.

> I had gone to the school system, they were well aware of all that happened to [Susan]. They had her first year neurological assessment, they knew her limitations completely, and they also knew that I wanted and [Susan] wanted them to just stand back at first. At this point in her physical recovery she was not all that able to walk. Her balance was still impaired, and still is probably today, but more severely then. I had a real concern over taking her from point A to point B, and that whole massive amount of people, because she certainly was not prepared to use any sort of a cane or anything like that. She had one and took it home and pitched it. It just wasn't going to be. So we made an arrangement for her to leave the classroom two minutes before the bell rang so she could get herself to the next class before that rush happened, so physically that was looked after. I was, probably, had a lot of concerns at first. I got her a cell phone immediately. She had access to me at all times and she was just to call if she couldn't handle anything, if it was too much. She knew to phone and I would take care of it. So that was good and she was able to do that, but she never did.
>
> She, at that point, she still had friends that were in one classroom or another, so I was very clear that I didn't want them to feel responsible [for Susan] because I was confident enough that [Susan] was confident enough to be there and she would be alright, but if she wasn't, she had the cell phone. So, she went into all her classes like

> that with everybody knowing that that's where she was. We did walk around [the school] and we showed her her home room. She wasn't able at this point to always be able to remember what room was next. Her schedule, we made sure, was with her at all times so she knew what floor she was on and where to go, but again we had that looked after because we had someone [peer helper] to take her to the next class a little prior to the bell.

In the following excerpt, Susan's mother describes her personal challenges with Susan returning to school.

> 'Keep my sanity, dear Lord!' She's [Susan] glued to your thigh for five months and then you gotta let her go. You wouldn't believe, just not having her that close, the anxiety over the fact that I knew she was going to cross the street, that she was going to go up the street and go for lunch, knowing that...she's not real quick on her feet you know, the anxiety that she's fallen, she's tripped, she's slipped on the ice, and by Jesus, don't help her. It probably was the biggest challenge, the anxiety. Not being able to control that. However, I think it [returning to school] was a real necessary step in her recovery... It has its challenges, don't get me wrong. There were times when she came home very frustrated with the whole thing, but I think it's still important. You need to have lots of patience. Big time. Big time....I think that we've come a long way and had [Susan's] accident happened ten years ago or twenty years ago when I was in school, the acceptance level wouldn't have been where it is today, I don't think. I think that we are in a different era. It doesn't appear to be that big of a deal today with somebody, for the most part, being different with the whole picture with the school. I think that the tolerance and all of that with kids today has changed...I know that for the most part, it's a different world.

JACK

While Susan's mother was reluctant for her to return to school, Jack's parents were anxious for his academic career to resume. However, Jack's reintegration to the school system was not a smooth transition. The elementary school personnel and his parents had conflicting views on several issues, including the duration of his day, the amount of support required and appropriate learning materials. His mother recalls:

> We started tutoring in the hospital. We started his tutoring program, they [the hospital] got him a tutor last September. Well, I guess you could say that it was the social worker, our social worker set it up and got this lady. She tutored him with basic math and words and reading and spelling from September 'til December.
>
> We took him to school, we made field trips to the school, just to let him have an afternoon with the kids a couple of times. So that's how we started out with him and he was pretty excited the first time or two. We would make these field trips in the afternoon, and that was a lot of his problem too, he was so excited to see the kids, he didn't want to work. He wanted the social interaction. He wanted dinner time and recess. That's all he wanted...we made two or three attempts at that and his teacher actually spent a day with him and his tutor at the hospital before he was discharged, which went well, and it gave [the teacher] a chance to see what [the tutor] was doing with him...the principal had all these funny, we had a real battle, aspects regarding [Jack] and I had to get my therapist to come to a case conference and tell her that they would look after the therapy part of it, if she would look after the education aspect...I knew that there were books, like you could get books on tape for the blind and everything and I kept asking them, 'Why can't you get computer programs? Why can't you get reading programs? They never got anything for [Jack] in the elementary school. They never got any resources, they were more concerned about his behaviour problem in the two years that he was there, that's all they were concerned about...There was no support there at all.

Jack's mother felt that the school, in particular the principal, set up a number of road blocks for Jack to return to school.

> She [the principal] said that he [Jack] would need a special cane, a special walker, an electric chair and I have written down here that I have no idea where she got any of these ideas. They just popped into her head on her own because my support team and my case workers and all my hospital team, this wasn't coming on a recommendation from any of these people; these were her own ideas. She went on about liability and blah, blah, blah, and he couldn't partake in any of the sports, he couldn't do anything and that there were no special resources provided for [Jack] at that time and she wanted to know if

> we had a support group, the Brain Injury Support Group, that we could talk to. She said that he would need a TA and it had to be a male TA and there was no way possible that that could be done. There were no male TAs available at that time and she stated that, 'I had hit them with a lot of demands and it all takes time'.

Jack's mother stated that she felt that she wasn't getting anywhere with getting Jack back to school. She had contact with school board officials, department officials and, finally, her Member of the Legislative Assembly in order to get Jack to return to school full time in September of 2001.

> We had a case conference at the school one evening, late afternoon. It took for me to blow up and [the School Board Rep] sat at the other end of the table and told me that there would be no way that [Jack] would ever be able to return to school until he had his behavioural issues under control. And that was when I lost it. I said to her, 'You can't tell me, and there is nobody on the face of this Earth that can tell me, if my child is ever going to be any better in 20 years time than he is today. And you're telling me, because he suffered a brain injury, he can't come back to school until he has his behaviour issues under control. He can't control his behaviour. That's why there are issues. [Jack] will be attending school full time in September 2001 so you be ready'.
>
> At first when he went back to school, it was only for a couple of hours and it was only half days. I had a lot of issues with him going back to school. It was a big battle. It was a battle with the principal. I think it was just because of who it was but we'll not get into that. She didn't seem to want to have him there no more than half a day but the way we knew it, there were kids worse than [Jack] in the school system for a full day...He went part days and every time we turned around the phone was ringing. 'You'll have to come and get him.' 'You have to come and pick him up', or his TA would be bringing him home. Something had happened or he would have said something, or he had done something, there was an issue and she [the principal] would be sending him home. Well, I just decided that I was going to have to fight everyday with someone over something. And they would call and I could just see that there was no point in coming home, you might as well hold him and love him and tell him you understand 'cause it's no point in asking, '[Jack], what did you

> do that for?' He can't answer you. 'I don't know'.

The transition from elementary school to the intermediate school seemed to go more smoothly. Jack's parents credit his principal, his teachers and his TA for the success.

> He just started junior high September of 2002. He's having a terrific year. He's having a fantastic year. It's unbelievable...Somehow the junior high is just totally different. Totally different. The assistant principal is a fantastic individual. They [school personnel] want to know how much can he do, what can he do and they are trying to integrate him as much as possible. He's doing the same work, just not the same amount of it, and he does a lot of it on the computer. He has a lap top...we did not go through the same thing with [Jack] this year. That's why we think it was a principal issue. There is a different principal there this year, and he's in a different school, but at the case conference, from the move from the elementary to the junior high, the junior high teachers thought that they are going to have their hands full and at our first parent teacher they told us that this was not at all what they [elementary personnel] told us it was going to be like...Now if he has an issue, his TA , we are lucky that he has had the same TA since he's stated, just writes it down, he doesn't even tell us about it anymore... we can, as I said, ship him off at 8:30 and walk out the door here by quarter to nine and go away for the day and be back home at quarter after two, fifteen minutes before [Jack] and we always carry our cell phones, but they never ring.

Jack's mother noted that she felt that her biggest challenge was getting Jack in school on a full time basis.

> Getting [Jack] in [school] full time was my biggest challenge. I fought and fought. I would cry and cry. One night we were at a case conference... and that's the night that I lost control of my emotions. That was my biggest challenge, was just getting him in and back to school full time, and I still firmly believe that I wouldn't of had that challenge if we had had any other principal...our whole hospital team; our pediatrician, our physiotherapist, the occupational therapist, the nurse manager, everybody said [Jack] should have been in school sooner.

MEDICAL PERSPECTIVE

The medical team, (a physiatrist, an occupational therapist, a rehabilitation nurse, a physical medicine nurse, a home care support worker, a social worker and a speech language pathologist) all agreed that there should be some sort of a process in place to help the brain injured child make a smooth transition from the hospital setting to the school setting. Throughout the discussion, a number of issues regarding problems with traumatic brain injured students were brought forth for consideration. Such issues included; the role of the school in assessment and monitoring, the importance of documentation, preparing the school personnel and the child's classmates and/or friends, case conferences, and funding and support.

The medical team claimed that the school personnel really need to be aware of the brain injured child in terms of assessments and monitoring and the difficulties around assessments. The medical team indicated that there seemed to be a lack of professionals, in particular psychologists, in the school system to administer testing in terms of psychological or cognitive assessments. The occupational therapist stated:

> The biggest thing, if there would be one catch phrase, would be that problems that result after the brain injury are not necessarily motivational, although they may look like that. The, 'I don't cares', may not be that they truly don't care, they may be unable, versus unwilling. They do need an IEP and they do need monitoring because the more subtle the brain injury, the more likely they are to slip through the cracks. The academic level when they are integrated back into the school system, that really needs to be assessed. Some of the ones that I have been involved with, as they were back in the school system, although we had repeatedly requested an assessment to be done by the school psychologist, it was not done. They weren't aware, the TAs that were working with these students and the Head of the Special Needs Department, that this kid who was in grade 7 was reading at a grade 1or 2 level and that wasn't formally assessed... or he couldn't add or subtract, multiply or divide single digit

> numbers. So the people who were working with him really were not aware at what academic level [he was performing at] and were set up to fail and they didn't seem to be aware of that. So it's very important that if you are reintegrating that you are not stepping them up to a level that is too hard for them and that academic testing needs to be done as they are being reintegrated back into the school. You need to know their specific deficits whether it is physical, mobility, visual deficit, attention, memory, putting things in the right order, sequencing; you need to know what the functional implications of those are and what accommodations or modifications... and what supports are needed. So, that in a nut shell, would be what you need for a successful reintegration process.

The medical team felt that ongoing communication between the school personnel and the medical professionals was necessary to monitor progress, document issues, and identify emerging needs. The occupational therapist noted:

> The other thing that would be very helpful for us as we are doing assessment is accurate academic history and any behavioral problems documented so we know what they were before, the what's a new problem and what isn't, and follow up should be planned right from the get go, right from the first meeting... most of these [meetings] there is going to be some sort of follow up which sometimes that has been difficult to obtain, or how we're going to confirm whatever plan we put in place is working for schools; we'll evaluate that. If there is behavioral problems, if there is learning problems it needs to be clearly documented how many times did that happen that day, how many times did it happen that week, and if you are getting iffy answers, it is very difficult to make decisions on what's going to be the best way to problem solve your way through some of this and it ends up, like some of the ones that I have done, I've gone back and helped problem solve with teachers. But sometimes you are on the phone for hours trying to get the actual of what is really going on in the school. So if it is clearly documented, if you have a problem with behavior and how many times does that occur and what is the exact behavior, it is easier to come up with a strategy...Have one person at the school responsible for pulling that kind of information, whether it's the school counselor or the teacher in that class or the teacher's aide that has been assigned to that child, because when I see patients as a follow up, all I get is the parents' perspective, and it's not always

> real. There are other stressor at home... if we get that information sooner rather than later from all the players, we know how aggressive we need to be as well, and any strategies that might help. We can't help people whose brain is...sometimes we can slow them down so that they can pay attention a bit better, but you can't make them normal.

The physiatrist agreed with the occupational therapist, however, reinforced the need for additional testing and not only from the school psychologist. He stated:

> I support what you [Occupational Therapist] are saying about psychological testing but that may not be sufficient. Again, the school psychologists are used to dealing with behavioral issues or with developmental issues. They're not the same as traumatic brain injury and having a battery of tests that a psychologist can lean on to determine that this child is now a visual learner. So it is important to write things down or to repeat things you need to tell them or show them a picture. Some kids become visual or auditory or KT learners and getting that kind of information from the psychologist or the neuro-psychologist is really helpful.

The speech therapist had this to add regarding dealing with brain injured students:

> The schools are more used to dealing with very special children. Most of them are developmental injuries... so it can look a lot more bizarre sometimes when their models don't work so well or kids don't fit quite so well with a head injury...Or they filter back. I have one on my caseload now, filtered back two years...things are just not working out in the school system. I don't know if we've collected very well, but we were kind of praying that this group of particular needs would just steady and normalize, but, in fact, there was residual issues that we hoped might resolve. It didn't, and the 'hand-off' [approach] might not have been as good as it could have been.

Preparing the school personnel is very important before a child with a brain injury returns to their school. Some of the things that the medical team felt that the school personnel should know are discussed in the following excerpts.

> *Physical Medicine Nurse*
> I think that there is a need for school personnel to know that every

person is going to be very different by far, but it is affecting every single part of the person. I found that sometimes...that there are huge behavioral problems and while a person was with us, we keep trying to do behavior modification but we are not very expert at that... but I felt that we were sending them to the school where they [school personnel] were almost going to solve this by discipline and it's what we use for a normal child and it's not going to work like [the occupational therapist] says. It's not because a person doesn't want to...it is so difficult and, personally, I think you really need behavior modification. You can't just say, 'You will sit in this class and be quiet'... Another thing would be the OT's generally either the person who is working with the child here, or the OT in the community needs to makes sure that the school is accessible for the child that will be reentering... and I think that the TA should come in here and spend some days, not day, with the child because they may have to practice toileting and how to manage a wheelchair, all that sort of thing ...They need to see the hands on before they get to the school.

Home Care Support Worker

We felt that there were some assets that the TA should have, and because it sounded like it was another level of the education system, one would fund and one would pick the next person off the list... and I think that it is important to note that just because you are trained as a TA doesn't necessarily mean that you suit a particular need of the student...We ended up having to do that from this end [when looking for a TA for Jack] because we didn't feel that the school had done their petitioning for the TA, funding had been granted and they were just going to pick a TA.

I think what I would like to see is that the school personnel get to know what these [medical] conditions are... with having worked on [Jack's] team as part of a fairly sizable effort to outreach into the school as a team to create some knowledge there so that they could feel that they could take him on with some ideas. I feel that we may have mystified [Jack]. They knew [Jack] from before and they knew him as [Jack] and I wonder sometimes if, for some of those personnel, if they didn't get more scared because of the medical team's talk with ... I felt that some of the personnel were actually very open...and for some I could feel them retreating and they [were thinking], 'This isn't education, this is something else', so there was a very uncomfortable level that some people had and I wonder sometimes if we didn't mystify it for those individuals.

> *Physiatrist*
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> ...to summarize, every traumatic brain injury is different and knowing a little bit about all traumatic brain injuries might be information that you might not ever see enough of to use and having case by case knowledge and, as a teacher, you may only have one or two in your career. So there is probably not a lot of use in getting everyone to learn about it as a whole, but in individual cases I think that it is really important to get the details. The details are what is important. What we are able to do from the hospital is to coordinate an initial reentry into the school.

In order to get necessary information regarding the brain injured child to the school personnel, many medical team members take part in case conferences with the school personnel. The medical team indicated that communication between the hospital and the school is important and that the school personnel need to be better prepared before scheduling a case conference. Excerpts from the medical team's discussion is as follows:

> *Physiatrist*
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> I think that the only things that I would have liked to see differently is that there are plans with the knowledge that the child does need immediate assistance and it would be nice to have the administration with the dollars come and say , 'We are going to think about teacher assistant' or, 'Yes, we can see the needs but...',just be able to say, you know come to the meeting with something to dole out as well, and say to the family right there and then, 'There is a teacher assistant, we have found the money', or if they've got a person working half time, do what you got to do to have it full time. In the last child that I was talking about, again, our beautiful vision of the Director of the School was there, and someone from the Department of Health and/or Education, and it sounds like a beautiful holistic group. But in the end we had to have another conference with the teacher who is actually dealing with the child and we actually don't have a TA working with her full time and it's getting to be an issue. And the child pays for that. They pay dearly for not having that extra help. It should be recognized that there are certain situations that where the child reentering the school, that you are going to have to invest and you can't just draw in the pool of what of what you've got for the year and that, but you have to get some extra funds and get that child going

in the right direction.

Social Worker

The people who make that decision need to be there and be prepared to come to the meeting.

Home Care Support Worker

I remember one meeting for [Jack] and it ended up, which should have been a conference, was actually negotiations between the special ed person and the principal of the school and it was like, could you do that outside the meeting, and it was almost that everybody came to learn, but there was no prior stuff done.

Physical Medicine Nurse

We had a ton of conferences on [Jack] and I'm not sure how we could have improved them...we went out to the school, they came for rehab, we had all levels of school personnel there and, in the end, I felt we had a very rocky reintegration...They need a whole team to work with them [brain injured students] definitely, they need a team in school, and not just our team...One thing that I think works well is when we are able to have the adaptations from the school and the student can begin reintegrate gradually to the school from the hospital. I find that works well, personally anyway, but it only works when we have a student who is close to their school...Sometimes we get quite impractical that, oh yes, they are ready to start school and then we forget that they can't spend a whole day without having a nap or sleeping. Here we are..I think sometimes, can we really keep a child here when they are not even here most of the day? I think that that would be helpful for us, the child, the family and the school.

Occupational Therapist

We need, of course, personnel from the board, from school and, if necessary, from the department to make the system a little more user friendly for families and that, who are trying to reintegrate back in.

Rehabilitation Nurse

I think that maybe we professionals could do more with the class that the kid is going back into. I don't think we have done any of that, where we go in and try to maybe break a little ground before that poor kid needs to go and face the class, or maybe have some of their closest friends come in and spend some time, perhaps on the rehab unit, and see what their little classmate is going through.

> *Physiatrist*
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> We're professionals here treating traumatic brain injury and yet, when any of these types of patients enter our work life, it is difficult for us, and that is what we do. It is hard for the nurses, it's hard for the therapists, it's hard to get your head around the fact that they can't cooperate with what you would like them to do at that point. They can't think the way that they were once taught to think. So it is difficult for us. So I can see how it is difficult for the school to have that type of child to come into the school system and that's why they need 'the gravy'. They need some extra teacher assistants and people to help guide those children.

The other issue that was discussed was the lack of funding, resources and support for families with children who have sustained a traumatic brain injury. The occupational therapist stated:

> I was recently up to Montreal with the founding members of the Brain Injury Association of Canada, and Prince Edward Island is certainly behind the eight ball for anything other than acute rehab services than every other province. There are services that, after you leave the hospital, that help you reintegrate into the community, into your work, into your school, and whatever. There are Brain Injury Associations; there is no active Brain Injury Association [on Prince Edward Island] right now. Other provinces, there is government funding to have executive directors to support Brain Injury Associations, to support brain injury research in the province, to reintegrate them into recreational facilities. We have lots of expertise here on the Island, but we have lack of resources and political will to put those services into place and we're a kind of a 'have not' province here unfortunately...I think the medical people who work with brain injury would have a great love to be working in some of those areas but there are no resources for us to do that work with now.

> *Physiatrist*
>
> We've put in two proposals to government to develop services for brain injury on the Island here. The last one was in 2001 and the one before that was in 1999. They are just sitting on shelves with the proper information and we are trying to do what we can...We can't follow people as a group to the schools. We just keep doing what we do here, but we need that kind of follow up and the bigger challenge we have as a province is that most of it is rural and you can't deliver that same services to someone who is in Tignish or someone who is in Souris as you can for someone who lives right here in

> Charlottetown, or in Summerside, for that matter. That's really difficult... We end up using the school as a form of therapy because that's all we can offer. So the children who are good enough to go back to school, we are expecting a lot from the school because we don't have specialized programs. We don't have a big population, ...so we have to depend on the school.

> *Home Care Support Worker*
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> We've also enlisted the services of the psychologist, not the education psychologist, but the psychologist in mental health, in terms of managing and addressing behavior and that was very helpful to us. I'm not sure what the role is of the school psychologist. Personally, I expected it to be more in terms of the passing over from the hospital setting to the education setting and I was very disappointed in that. I don't feel that the teacher or the teacher's aide got the support that I would have expected that the psychologist would give, who would be an expert in learning in some level of the neuro-psych, but that resource should been there.

SCHOOL PERSONNEL PERSPECTIVE

In both cases, the school personnel in which Susan and Jack were to be working with had very little prior knowledge regarding traumatic brain injury. This posed a level of uncertainty and anxiety for both school communities.

SUSAN

Each of the school personnel interviewed who worked with Susan, all claimed that they did not know much, if anything, regarding traumatic brain injury and how it affects the child in term of learning. Many of them made suggestions to consider and/or implement before working or dealing with a child with a traumatic brain injury. Susan's high school counsellor stated:

> I don't know a whole lot on brain injury...I do get a heads up on, most and if not on all, of the people who come in [to high school] who I guess we categorize, if I could use that word, as special needs and she was on the list... she's in a different situation than many of our special

> needs students but I would look upon [Susan's] situation as what she can do and we'll make whatever adjustments, modification, adaptations, we can...we tried to get her courses and scheduling right and the V.P., more than myself, has been in contact with mom concerning scheduling and courses and how things are progressing and that kind of thing and he does that simply because he knows the family more than I do. He's just taken that on, but I have had a few conversations with [Susan' Mother] as well and no problems. She is very supportive of the school and certainly wants us all to work together, which I think we do...Preparations for [Susan] was talking to [her mother] and getting mom's view on how we should proceed in terms of classes and courses and where she should be placed and I guess we looked at it as [the mother] knew probably more than any of the rest of us and also could tell us more than any doctor's report could as to what her capabilities were. So we could make some decisions about some courses and placement from talking to her...Some people would say we fly by the seat of our pants, but I really think that it's a good way to go because the teachers, I think, have a really good handle as to what somebody can and can't do in terms of curriculum and they're given, as you know, complete freedom, to more or less, modify as they see fit, adapt as they see fit, what ever works. That's my own personal philosophy of education, if I had one, is whatever works and I think that that's basically what happened with [Susan]. It brings under review change and make a little change as we go and try to maximize success and find something that works and it's all on an individual basis to decide what's best for her and the education she's getting.

The school counsellor also had suggestions regarding the preparation for the integration process and how to make it run smoothly. He continued:

> It would be nice to know, if you can get a handle on it, what sort of, or at what level the student will be functioning. I think, as a counsellor, and the individual teachers, would have to know what, someone's guess as to, and an educated guess, as to what the person can do. Has reading been affected? What cognitive abilities have been affected? Memory? Anything like that. If we could get some knowledge of that from the get go, then, of course, that would help...the more information you have, the better. If we could have the heads up as to what she [Susan] can do, somebody's assessment as to what is the brain's impairment, what is the brain's function, what can this person do, what are.., you know, with her injuries, how is that,

> what impact does that have on her ability to learn and the ability to remember or whatever, and if you could have that information or as much as you can, then you can plan and modify things as you go. If you have a good relationship with home, which we have in this case, the parents, are willing to provide us with information and for us, it helps us in here...I think that as long as [Susan's] with us, we're going to continue to do what we have been doing, keeping in contact and certainly listening to [Susan] in terms of what she's telling us what she wants and the courses she wants and how she's getting along and making whatever adaptions are needed on the fly I guess...I tend to believe that the anecdotal information that you'll get from parents or somebody else who knows the case is just as valuable, if not more valuable, than the doctors who put something a little bit technical or written out in publications. That is helpful as well obviously, but, take the information and know you are wanting to do what's best for the student. If the student can communicate what he/she wants and if you can meet those desires and keeping with what the family wants, mom and dad, and so on, and it is the job of the school to take all those wishes into account and to provide what ever education that you can. You have to provide the best education you can. You really have got to tailor things for that particular student and keeping in mind what is best for the student, what the capabilities are, and what their desires and wishes are, and go from there...Some people should, most of us should, be busy and had she not come back to school, what would have been the alternative? Would the alternative be isolated and try to learn on your own and try to come to grips with what happened or what have you, in isolation? Does that create a kind of poor me, or I'm different, type of attitude? So in retrospect, I think it certainly worked to have her [Susan] here and have her fit in and try to make things as normal as possible for her.

Susan's grade nine teacher, although she didn't teach Susan after her accident, did know her on a personal level. She too, had very little knowledge of traumatic brain injury at the time of Susan's accident, but she had her own suggestions as to what she thinks is important to know when preparing for a child with a traumatic brain injury to return to school.

> What do I know [about traumatic brain injury]? Not really a whole lot, other than what she [Susan] had gone through.. didn't know a whole lot about it at all...I mean, as her teacher, I had visited [Susan] when she came back from Halifax and was staying at the QEH but

> that was the first time we had experienced something like that...if I was her teacher after the injury, I would like to know what the injury was or how it was caused and how the individual was before and what the individual is like now and what their academic successes were, where their strengths were, like it may not be totally all academic, and if there were chances of outbursts and how you could handle it that way. Kind of, maybe, prepare the other kids a bit too. I mean, we do have some special needs kids here but they're not brain trauma kids, but the other kids seem to accept them as one, and they do the best that they can, but going into it, I would like to have background information, like know what part of the brain is affected, how it's affected, what can be overcome and where the student has come from...I would hope maybe the principal or the guidance counselor would give you resources or people at the IWK or the QEH or a neurologist...I would have to know different methods of teaching, like how am I going to reach this child, what would be best for him or her and looking for different teaching resources and maybe modifying the program perhaps and seeing what the child might need. I would think that if the child had a close friend, it would be good to keep that friend close, like in the same home room.

Susan's high school teacher indicated what she and the school personnel did to prepare for Susan. She shared her views as to what she thought was important to know when teaching a student with a traumatic brain injury. Again, when asked what she knew about traumatic brain injuries, she replied:

> Very little, other than what I read in the doctor's notes and I did a few other little things. I don't know a great deal about it and, again, I think that every case is specific to the individual so, honestly, I don't know a whole lot. I didn't feel like I was prepared to meet [Susan's] needs and I'd say the major reason is that I didn't have a whole lot of time to prepare. Now I did, [Susan's Mother] gave us confidential records from the doctor. The records were pretty medical and I found that difficult to put that into something that I could use in the classroom. I mean they gave us very good suggestions on memory situations and on how to deal with brain injuries, but every situation is different, everybody is different so I didn't feel like I was prepared at all and if I had to do it again, I don't know what I would do to prepare myself, because [Susan] was very individual. She wanted to do things her own way and if I was to read something on brain

> injuries, and although I did read a few things, I don't think [Susan] fit into most of those molds because a lot of times they suggest to give lots of help, where [Susan] basically refused it. So I found that that would be the major thing... If I was going to do it again, I would have a lot more, 'What if', situations, a lot more research that would say, try this, try that, try something else but, again, I think that that is an individual situation and not everybody fits into that mold would be excellent for sure. Teaching strategies, maybe...it's difficult because [Susan's Mother] was extremely cooperative, extremely cooperative. Anything that we wanted to do she was all gunho for it. But [Susan] was the one who was the driving force behind her learning. So strategies would have helped. I don't know, I guess, for me, just knowing more about the injury, that would be about the only thing that I would say, but strategies would have helped... I think [Susan's Mother] is very realistic in what [Susan] can do and I think she kind of paved the way and we didn't really know [Susan] was coming back until, well, we really only had one little meeting to say that [Susan] was coming back and then she was there. So we didn't have a whole lot of time to prepare. Now that's not saying that I didn't or couldn't of taken the initiative to do more, but I mean, I did research a little on the Internet and few other things; but as far as preparing, I think I, probably, no, I think that that would have been it.

Susan's teacher describes the initial meeting.

> There was one meeting with the administration, [Susan's mother] and her teachers, and in that meeting she [Susan's mother] basically read us her goals and her ambitions and basically told us a little bit of what to expect...So [Susan's mother] basically told us what her concerns were and what her goals were for [Susan] and that was basically the meeting...I think that one of the things I wish we could have done with [Susan] was to have more realistic goals set out for her early and have some time to sit down and reflect on them through the term, which didn't happen. As I say, we got one meeting and that was basically it and the meeting was, here she is, and this is what the basic concerns were and we were set free and there was, not so much lack of support, but we tried to get the peer helper, for example, in my class and she had one in phys. ed. as well, but [Susan] wasn't receptive to it. I think that that was difficult because [Susan] knew that the peer helper was there for her. [Susan] is such an individual case, she was so driven. As far as school goes, I think they need to have support systems, definitely support systems, in place. If I had a concern, then I could go to someone and say, 'This is the situation,

> what do I do in this case?' You know, and needing more liaison between administration and the parent or whatever, and now I did call [Susan's mother] on a couple of occasions with concerns and questions and comments and she was great.
>
> [Susan] in this case was basically plunked into these courses because that's what they [administration] thought that she should have. I don't know whether that was the parent decision or whether it was [Susan's] decision or administration, but I think initially at first that she was thrown into too much. I would have liked to have seen her go into something a little bit lighter where she would have had some positive reinforcement rather than setting her into something where she is going to have total failure... but if I had a head injury child come into my classroom and I was teaching a pretty heavy duty academic course, I would have some reservations about that child, knowing that they would probably not have much success in my classroom. I think that success is certainly more important than being in a practical or general course, and as a school, we need to be realistic with the parent and almost forceful and say, 'Do you want the child to have positive reinforcement or do you want the child to fail?', and I don't know whether that happens enough.

Susan's teacher also made reference to what she would recommend to other school personnel before having a student with a brain injury come back to school.

> I think, in most cases, the student wants to be treated like a normal student and not to single them out. They have gone through such a traumatic thing for them. Be supportive to the teachers, have something that the teachers could go to...It sounds like I am being negative towards the school. I'm not because I don't know if they've ever had a brain injured child in the school besides [Susan], so it's not really fair to say , 'Be more supportive', if it's new to them as well, so it's kind of a catch twenty-two... goals should be set out not only with the parent, but also with the student, because we were getting [Susan's] goals via [her mother] and [Susan's] goals originally were completely different from what [her mother's] were and I think that that causes confusion... I think the goals should be realistic and say, 'What do we expect this child to have at the end of this term?' That would be my number one thing...we needed more team meetings and follow up, not just a one time shot because that doesn't do anything, you need to see if they [goals] are being met along the way... That's where I think we, as a group, fell down...I think the parent situation

> is really important and the goal setting with the parent and student involvement, the administrators and the teachers, that's where you have to start. Give the teacher some knowledge. The parent can give you some expectations and that sort of thing and so can the students. They have a voice themselves and say what they expect. You need to be prepared for the unexpected...and that is so hard to do.

JACK

As in Susan's case, the teachers involved with Jack, before and after the accident, did not know a lot about traumatic brain injury. His teacher assistant had some medical background, and had some experience working with individuals that displayed some of the same characteristics as Jack. His elementary teacher went to visit Jack while he was in the hospital and she also met with his tutor. She recalls that when she went to the hospital, she thought that she was prepared, but she wasn't. She was "shocked and grateful at the same time". She remembers that Jack was "already wheeling and dealing with the nurses", and she could see some of his behaviors right away. She also attended a meeting at the QEH, along with sixteen other people. "There was someone from everywhere that you could think of", she recalls. During that meeting, issues and recommendations were discussed for Jack's reintegration to school. Jack's teacher stated that she "prepared for some things, but it really didn't help, a lot could have gone out the window. Most of the planning was developed with the TA. We kept trying new things and we had to keep a schedule, but it was different day to day". She also recalls one of Jack's doctors coming to a staff meeting to speak to them about Jack.

Before Jack came back to school, his teacher recalls that she went to Jack's home for a visit. She prepared her class; she had her class send cards to Jack; he was included at Christmas; and she did some reading on traumatic brain injury, but not a lot. She indicated that the school was very supportive with Jack. They provided him with a full time teacher assistant, had meetings, and had support from the school counsellor. She felt that it was very much a "team approach" and they "did as much as possible within the school. I don't feel like we short changed him".

Both the teacher and the teacher assistant had suggestions on how to reintegrate a student with a traumatic brain injury, based on what they knew and experienced with Jack. They suggested that Jack's time in school should be a gradual reentry. A whole day was too much, they felt, and he should be eased back. However, they recall that his parents were very eager to have him there the whole day. Each of them prepared themselves for the "worst case scenarios" and to be honest with the rest of the students. They also suggested that a meeting with the neuro-surgeon to go over the basics is very helpful, and not to set the standards too high. It was important, in this case, to make sure that things were ready, not only within the classroom, but around the rest of the school as well. Finding out what the student's likes and dislikes are is very helpful because it enables the people working with that student to set up some sort of a reward program. Making sure that the student had "choice" seemed to work well.

Jack's grade seven teacher shares her experience preparing for his arrival.

> Until when we had our first meeting regarding him coming here, which would have been in May of last year, I didn't know him before that. [The meeting had] his grade six teachers, anyone that had had contact with [Jack] and the grade seven teachers here at our school, the principals at both schools, the guidance counsellor, anyone that would have had a role in his life there and a role in his life once he moved...here, and his T.A... we knew then that [his TA] was probably going to come with him...and that has been a God send...He [TA] knows [Jack] far better than we do and... having the TA, who's consistent, was a big thing for us. Whenever we had our first few meeting about [Jack], I will be honest, I was quite apprehensive about him coming because of the issues that were surrounding [Jack]... I probably didn't know that much [about brain injury] and I probably

> don't know a whole lot more except that it's not as hard to deal with as I thought it was going to be, and working with [Jack] is not as hard as I thought. I was very apprehensive about working with [Jack] and it has not been that at all. We knew what his ability was in math and what his ability was in language arts, and things like that, but in terms of how much he was going to understand in terms of concepts, we were unsure. I don't know how well they [the elementary school] would have been able to prepare us for him coming from the other school to here. I don't know if the IEP that we have prepared for him is meeting all his needs, if we're pushing him enough. Sometimes I wonder about that. We also saw samples of work that he had done and we were fairly prepared at the case conference, but we have also done work here on doing IEPs and on inclusion, so I think that's what prepared us as well. It wasn't like, all of a sudden, I was going to have to prepare an IEP. We've been doing adaptations and modifications here at this school for years and documenting those. So, other than looking through what I had for adapting and modifying material, probably not much more than that because I wanted to have him here to see for myself...We also had informal meetings upstairs because all of the grade seven teachers eat together and things like that so we sort of had informal meetings where we talked about what are you doing, what worked for you, but other than that, I didn't do anything extra, didn't research TBI.

His grade seven teacher was asked what recommendations she would make to other school personnel who would be working with traumatic brain injured students. She had this to add:

> Find out a more about his injury and how it might affect him and things like that. I guess that that would be the biggest thing, finding out about the injury and how it would affect him...also, any recommendations from the IWK, we went over [Jack's] file and read the recommendations that they were giving; they were helpful...One thing to keep in mind is that every student is going to be different because it [brain injury] affects personality, you know, what the personality is going to be like, so if you knew the person before hand, afterwards, the person is totally different. So you might think that you have prepared yourself, and I think that you are just going to have to be prepared to take it one day at a time.

During Jack's reintegration to the school, the school psychologist was involved. The psychologist expressed her views on what the schools and school personnel should do when preparing for a child with a brain injury. She too, did not have a lot of knowledge regarding traumatic brain injuries and how it affects students. She states:

> From my perspective, what I would like to do, is to have a better process for schools that I could take to the schools and run them through, type of thing, and be able to have information available for them right then. 'Here is some information that will be useful to you', 'This is what you are going to need to know before his enters school'. For me, that's what I would like to have. Now, of course for schools, it would be different...I think it is important to understand how the injury has impacted this child on many different levels, the physical level, cognitively, emotionally, behaviourally. I think we need to have an understanding of what is the child's difficulties right now and how is that going to impact him when he gets here. I think the school was, I think they didn't know anything. They basically didn't have a whole lot of understanding of brain injury and how that impacts him. I think they were anxious to have him back with them because he was a student of their school and they wanted him to do well, but at the same time, they were probably afraid. You know, how do we deal with it...I remember that it was getting closer to the time that he [Jack] was going to be released from the hospital and then come back to school so we had several meetings, case conferences to prepare, you know, school staff, look at what kinds of resources we will need for him, academically, behaviourally, that type of thing; so I was involved in all that process.

While the school psychologist was assisting the school with Jack's reintegration process, it became evident to her that the school personnel realized their need to become more knowledgeable about traumatic brain injury and the uniqueness of each person's injury. The school psychologist recalled:

> When he did get into school, [Jack] was having a very difficult transition into school. It was a very difficult time for him and his family and there were a lot of behaviours such as, you know, consistent with his head injury so I was involved in kind of taking a look at that and doing a functional behavioural assessment type of thing and see what kind of interventions we could implement there...I think that some of the issues are different than others, because you are dealing with so much emotional stuff, loss and grief and you know,

> it's not just impacting the child, it's impacting all of the kids in school. They all need someone to talk to. How are we going to address that with all of our students? I mean, we ended up doing that kind of hap-hazardly here and there kind of thing, but it would be nice to have that structured process to help facilitate that...I would do it differently now for sure if we had to do it again. To have some sort of a process in place...I believe strongly in helping people understand a child and that's the approach I take with all my kids that we don't understand well. At the school level, it is trying to identify the areas where they are having difficulty and really try to give the school a big picture in trying to help them understand. I find that when we have that, interventions come a lot easier...it's not that the schools wouldn't do that, but I think it is hard to do that when you don't understand the child...I think you need to educate yourself about it [brain injury]. Be flexible, be patient, not to take anything personally. Talking about it, the child is learning to adjust with it and cope with it. Educate yourself with it because when you do that you can put a lot of the behaviours into perspective and be more empathic and understanding and therefore be less stressed about it. Otherwise, if you don't understand it, you know sometimes it's hard not to take the inappropriate behaviours personally and that would increase your stress level. And I have to say to work closely with the family and to also rely on and get support from your colleagues. That would be the same thing that I would say for other particular disorders. I think people need to have in order to manage it yourself and cope with it, I truly believe that people need to have a good understanding of it and the students, and then you can separate yourself, and you can separate the child and the brain injury.

SUMMARY OF RESULTS

The result of acquiring a traumatic brain injury affects all aspects of the individual's life–cognitively, physically, behaviorally, and socially. Both Susan and Jack experienced changes in their ability to think and reason, to understand and to remember, to pay attention, problem solve and think abstractly. They experienced difficulty with speech, vision and motor development. Behavioral and emotional challenges were heightened, including, increased impulsiveness, outbursts of anger, frustration and agitation. These changes have a significant impact on the home, school and social environment of the child. Susan and Jack experience difficulties with peer relations and display socially inappropriate behaviors. Both have a lessened ability to read social and nonverbal cues and seem unaware of how their behaviors affect others. These behaviors impact negatively on all areas of the child's world and contribute to a sense of isolation, not only for him/her, but often for the family as well. The individual's needs in all of these areas have changed. It is essential to address these issues as the child prepares to return to school. This is an important part of the process in the recovery for both the child and the family.

CHAPTER 5

Note: *The following chapter will have some repetition from the previous chapters. It was written this way so that individuals whom would like a copy of the findings would have a general idea of the previous chapters. For a more in depth look a the research, refer to previous chapters.*

DISCUSSION

LITERATURE REVIEW SUMMARY

Traumatic Brain Injury (TBI) is the leading cause of acquired disability in childhood and adolescence, with the most common cause being car accidents. The effects of TBI are wide spread and can affect more than one area of the brain and therefore, more than one or two skills. Traumatic brain injury can cause changes in one or more areas of the child's behavioural, cognitive, social and physiological development. This, in turn, can cause changes in the child's physical development and how he/she behaves, learns, and interacts with others.

In Canada, it is difficult to get accurate national and provincial statistics on the number of school aged children who have a TBI. Many of the Canadian provinces which have provincial associations relating to brain injury do indicate a provincial statistic on the number of people in the province who have sustained a brain injury; however, when combined, these statistics are elevated from the estimated national average of 50 000.

Traumatic Brain Injury is often mislabeled and on the surface may present like a learning disability, a developmental delay or a behavioural issue. In some instances, especially if the student suffered the injury at an early age, the educational effects of a TBI may not show up immediately. The student may not experience problems in school until intermediate or high school when higher-level thinking and more complex tasks are required.

With more and more children surviving a traumatic brain injury, schools end up being the largest rehabilitation provider of services. However, most schools are not prepared to meet the changed educational needs of the student. Educators' lack of knowledge regarding how TBI can affect a student's academic and social functioning can be a barrier to providing the services appropriately to meet the needs of these students.

INTERPRETATION OF RESEARCH FINDINGS

The purpose of this research was two fold:

- to determine how Prince Edward Island school personnel (defined as administrators, teachers, teacher assistants, school counsellors) prepared to assist with the re-entry into the educational system of students with a traumatic brain injury;
- to provide teachers and administrators with considerations regarding re-entry planning for a student with TBI.

This chapter will examine the three different themes identified in the research findings and discuss how each theme and sub-theme relates to the current research compiled in Chapter 2, the Literature Review. Considerations will be presented for the identified themes and sub-themes. The first theme discusses the ways each child has changed personally since the brain injury in terms of academic changes, social development changes, behavioural changes and physical changes. The second theme explores the sociological impacts the brain injury had for the child in relation to the child's school community, to the child's family, and to the child's friends. The final theme focuses on the preparations for the child's return to school from the perspective of the parents, the medical professionals and the school personnel.

THEME 1: CHANGES IN THE CHILD SINCE THE TRAUMATIC BRAIN INJURY

Bennett and her colleagues (2004) stated that a TBI can cause changes in one or more areas of the child's behavioural, cognitive and physiological development. Both Susan and Jack sustained many developmental changes since their accidents. Sustaining a brain injury for both Susan and Jack has left them struggling in the areas of academic learning and behaviour, in social situations, and with their physical development.

ACADEMIC CHANGES

When a child sustains a brain injury, the injury could affect how the child learns and behaves in school. It has been noted that common cognitive changes and problems may occur following a brain injury. These may affect the child's thinking and reasoning skills; and the ability to understand, pay attention, problem solve and think abstractly. It many also result in slow processing speed; poor judgement, perception and memory; lack of anticipation skills, inability to transfer new learning to different situations, cognitive fatigue, lack of initiation and mood fluctuations (Vriensen & Wheeler, 2002; Bennett, et. al., 2004). Researchers in this field have also indicated that the symptoms associated with TBI often mirror those of a learning disability; therefore students with a TBI are often misidentified in the education system.

Before Jack's accident, academic learning was not a problem. He was a straight "A", model student who loved to read. He enjoyed school and learning seemed to come easy for him.

Susan, on the other hand, had experienced difficulty with her academic subjects. She took part in her school's resource program, was involved with numerous academic assessments and had modifications made to her academic programming. Even though school was difficult for Susan, she was determined to do well.

Since their accidents, academic learning continues to be a struggle for Susan and has become a real challenge for Jack. Because Susan struggled with academic subjects prior to her accident, Susan had developed a lot of habits and strategies to deal with her deficiency. Susan and her mother would spend hours and hours studying together in order for Susan to get the marks that she wanted. Susan was very determined to succeed in school and this determination only intensified after the accident. When Susan returned to school, she was adamant about not having a teacher assistant and did not want to be singled out; however, she did agree to participate in a peer helper program which would be a new source of assistance for her. She took a full course load her first semester back and passed two of the four credits. Many of her courses were adapted or modified. Some adaptations were minor, such as reading questions to her orally, having her sit close to the front of the classroom, and helping her turn pages in her text books to keep her on track with the rest of the class. Teachers expressed that they recommended other adaptions, such as giving her oral tests; however, Susan refused. Modifications were made to her courses where she was just not physically able to perform, such as in gym or with speed tests. Susan's short term memory was very limited and it proved to be a hindrance to her, especially when it came to testing. Because Susan did not want to be treated or do anything differently than her classmates, academically she did not do very well.

Jack was described as a bright, above average, keen student who really enjoyed school.

However, Jack had a very difficult time with his academic subjects when he returned to school following his accident. Prior to his return, Jack completed some academic testing to determine his level of functioning. The psychologist who had administered the test felt that the results were not very valid because Jack was experiencing some visual impairment at the time. Another test was administered and it was determined that Jack was functioning at about an average level; however, when he returned to school, the regular academic program proved to be too difficult. Jack needed constant support from a teacher assistant, resource support, and was place on an Individualized Education Plan. He was re-taught grade one basics such as patterns and sequencing through playing of tapes and using a lot of tactile learning tools. His fine motor skills were very poor and it was difficult to determine exactly at what level he was functioning.

Jack's academic learning has improved over the years. He is now in a regular grade seven program with adaptations in place. Jack's math program is modified as he is still working on basic math skills. In other subjects, he currently learns the same material as his classmates but content is modified and workload is adjusted. Much of his work is multiple choice, true or false and matching. He does not receive resource support; however, he continues to have a teacher assistant full time.

Having students with a traumatic brain injury return to the classroom can be very frustrating and time consuming for a teacher. Classroom teachers, parents and the child all need to have realistic expectations when it comes to academic learning. There is a need for careful planning based on an understanding of the changes in the child as a result of the brain injury. Classroom teachers need to recognize that the student with a traumatic brain injury may have developed new learning styles and/or strategies; therefore, baseline assessments and ongoing assessments are invaluable and required if continual learning is going to take place. The student's academic program needs to be constantly monitored and adjusted accordingly; and, classroom teachers need to document the student's progress carefully.

SOCIAL DEVELOPMENT CHANGES

Following a brain injury, Bennett and her colleagues (2004) note difficulties and/or changes other than academically that could occur. These include: difficultly experiencing empathy, resulting in egocentric perspectives; difficulty relating to peers; being unaware of the impact one's behaviour has on others; social inappropriateness through behavioural disinhibition; and an inability to read social/nonverbal cues. Bennett and her colleagues (2004) also state that these difficulties will often influence the way that others will perceive and interact with the student with a TBI and this, therefore, contributes to the tendency for the student to become socially withdrawn or isolated.

Prior to the accidents, Susan and Jack were very different socially. In school, Susan was described as being very shy and having a small circle of friend, but no "best" friend. She was at the age where she was becoming interested in boys, but was so shy that she wasn't sure how to interact with them or get their attention. Susan's mother felt that she lagged in social maturity by a couple of years. Susan needed to dominate conversations and get her point across; however, at other times, especially when Susan would talk about what she was going to do with her life and her plans, her mother found her quite mature. In contrast to Susan, Jack was very outgoing and was involved in many extra-curricular activities. He had many friends of all ages and made friends very easily.

Following the accidents, both Susan and Jack experienced changes in their social development. Susan became very socially aggressive. She would take social situations to the extreme, not recognizing the limits. She invaded a males' personal space and seemed to be unaware of these boundaries; however, she did have a very clear boundary when it came to sex. Susan acted younger than her body. She interacted with her male peers more like an adolescent rather than someone in high school. Susan tried to "fit-in" as much as possible. She was very determined to mingle, make eye contact and to be accepted socially. Her teachers described her as being very pleasant, but needing a lot of interaction. As her time progressed in high school, Susan began to wear make-up, dress more appropriately, and attempt to be in the centre of things. In some instances, she was described as trying too hard.

Where Susan's accident resulted in her being more outgoing and not as shy, Jack's accident resulted in significant setbacks to his social development. Jack, who once was surrounded by friends, now has none. In the beginning of Jack's recovery, his friends did come and visit; however, Jack was very resentful that they had the ability to walk or to play certain games and he would become very frustrated because he could not. Jack developed a lot of behaviours that affected his social group. He was impulsive, he lacked self control, and he was full of anger and resentment towards his peers. He would take out his frustrations on them and they soon did not want to be around him. However, in some instances, Jack's social development did not change. He still maintains a great sense of humour and continues to have the need to be part of a social group. Jack wants to work with other students even if it is individual work; however, students find it difficult to cope with his impulsiveness and lack of control. Jack, like Susan, does not seem to recognize personal boundaries. Jack often sits too close, or wants to caress the females' skin or just be in someone's personal space when chatting.

School personnel need to be aware of the social issues that students with a traumatic brain injury may be experiencing. Support groups; such as peer programs, buddy systems, and circles of friends, need to be put in place. Members of these support groups need to be made aware of the individual's social inadequacies and how to appropriately respond to situations to help the student change their behaviour. Support groups and school personnel need to be consistent when teaching social skills through social stories, modelling and role playing. It is important that there are support groups in place inside and outside of the school setting as students with a traumatic brain injury need to be involved with social groups outside of the regular school day. School personnel can recommend to parents extra-curricular activities affiliated with the school or the community that may provide additional social support for their child. School personnel need to closely monitor and supervise the social activity of the student with a TBI and make recommendations, adjustments and interventions when necessary.

PERSONALITY CHANGES

Personality changes are common in children who have experienced a TBI. In fact, research indicates family, friends and school personnel claim that personality changes are the most difficult consequence of the injury (Salvage & Wolcott, 1994; Amato & Rothlisberg, 1996). Such changes could include the child showing lack of interest in the world around him or her, a decrease in motivation, extreme and rapid changes in emotion, and/or becoming easily annoyed or aroused. The child may have difficultly inhibiting impulses and emotions, resulting in temper flare-ups, aggression and a generally lowered tolerance for frustration. The child may also exhibit social immaturity, indicated by making inappropriate or silly comments and misunderstanding social situations (Vriezen & Wheeler, 2002). The changes in personality of a child with a TBI can be directly linked to many behavioural issues, hence, many experts in the area of TBI group personality and behaviour in the same category.

Both Susan and Jack experienced changes to their personalities following the accidents. In some instances, the changes for Susan were more subtle than for Jack. Prior to the accident, Susan was described as being very shy, very quiet, determined, stubborn, responsible and, in some cases, mature. Susan also had a "spunky" side to her. Teachers recall her as having a "fighting attitude"and recognized if she was pushed too hard, she would get angry. Susan's first work experience was the summer of her accident. Her mother saw the biggest personal maturation in Susan during that eight week period. Susan's mother feels that Susan is very much who she was before the accident. She still has a sarcastic sense of humour and a strong determination. At home, her personality appeared to intensify; at school, her personality seemed to have a more significant change. She has become much more out-going, she talks non-stop and often repeats things. She doesn't shy away from boys, has much more of a "fighting attitude" and temper than before the accident, and even her laugh has changed. Many saw the changes in Susan's personality as somewhat positive. At school, she has become very good at coping and carrying the stressors of high school and never seems to get herself down or have a gloomy attitude. As time passes, Susan has displayed more social interactions, more smiles and more laughter; this is attributed to her positive attitude and her strong determination.

The most notable change in Jack's personality was that his social judgement became significantly impaired. Jack has a very difficult time in social situations, mainly due to his impulsiveness and lack of self control. Jack is described as not being the same little boy. His parents state that he has a different personality; however, he has maintained his sense of humour, his compassion for the elderly and the need for social interaction. Jack's intermediate teacher stated that Jack's personality does not seem to fit with someone who was once so eager to succeed in school. Now, it does not seem to bother Jack if he misses a class or does not get to finish an assignment or an activity in school.

School personnel need to be aware that traumatic brain injury can affect the child's personality which, in turn, could have an effect on the child's behaviour. High levels of frustration and/or anger may result from a TBI; therefore, expectations need to be appropriate when teaching the student in order to lessen the frustration and/or anger that the child may be experiencing. School personnel need to be aware of their own frustration level and not take inappropriate behaviours personally. Strategies such as teaching through modelling, social stories, and role playing are appropriate methods to help the student with a traumatic brain injury appropriately express emotions.

Behavioural Changes

Following a brain injury, persistent behavioural and emotional problems are often observed such as agitation, increased impulsivity, sudden outbursts of anger, and difficulty in the monitoring and control of emotion. Often educators are not notified of the child's injuries, especially if it happened at a young age, and therefore the injury is often overlooked as the relevant correlate or cause of difficulty. As such, any behavioural challenges may be misinterpreted and considered a learned conduct or social issue independent of any underlying organic basis.

With the significant changes to both Susan's and Jack's social development and personalities, behaviour became an issue. Susan's behavioural changes seemed to be more subtle than those Jack experienced. According to the personnel at Susan's school, they have not witnessed any behavioural issues; in fact, she was described as a "gem to have" in their classes. Susan's mother, however, believes that Susan's behaviours have intensified. Prior to Susan's accident, Susan did have typical behaviours of a teenager. She would interrupt to get her point across, she would be "in your face" a lot, she required a lot of attention; however, she was not a difficult child, according to her mother. Following the accident, Susan's behaviours amplified significantly. It was difficult to stop Susan's thought process and change her mind. It was evident that she could not compartmentalize her thoughts or things in her life, especially in the early stages of her recovery. Her temper became very explosive and violent; however, according to her mother, this is a very rare occurrence. Her temper really flares when she reaches a certain level of frustration. Susan is on anti-depressants to help with her behaviours.

Jack, who, prior to the accident, was a very, polite and "happy go-lucky little boy" became bitter, angry, depressed and violent following his accident. The dramatic changes in Jack's behaviour seem to be a result of his accident. Jack remembers very well how he "used to be" and it frustrates him that he isn't the same. In the beginning stages of Jack's recovery, he was very depressed and grieved a lot. According to his home care support worker, Jack's greatest handicap in many ways is his social capacity. Jack's lack of social judgement, his impulsivity and his need for attention have contributed to his challenging behaviours. Controlling Jack's behaviour became a real challenge for everyone involved with him. At home, Jack's parents were dealing with temper tantrums and violent outbursts; at school, school personnel and students were dealing with impulsiveness, foul language, sexual behaviours, violence, refusal to comply with the teachers and fatigue. Teacher's found it difficult to know what behaviours were caused by the injury and what Jack just didn't want to do. According to Jack's parents, it wasn't a matter of re-teaching Jack right from wrong; he already knew that. The problem was that he couldn't control right from wrong. His parents found that anti-depressants, ritilan, muscle relaxants, and giving Jack choice have empowered him, and behaviours seem less frequent at home and at school.

School personnel may need to conduct a Functional Behavioural Assessment (FBA) in order to develop an appropriate behavioural plan. All behaviour has a function; either to "get" something, or to avoid something, or to escape something. School personnel need to determine what the student gains form challenging behaviour and then teach behaviours that will allow the student to have their needs met in a more acceptable manner. A social skills inventory may need to be administered to identify "gaps" in order to teach to those gaps. Classroom teachers need to examine their academic expectation levels. Can the student do the work set before him or her? One of the most difficult task is to sort out the behaviours of the "can't do it" from the "won't do it". Students need to feel that they belong; they need to experience the "3 C's of belonging": feeling they are capable, competent, and able to contribute (Albert, 1996). Therefore, teaching should provide opportunities to enable this to happen.

One interesting observation is when Susan returned to school, it was a new school with no prior expectations of behaviour. Her transition back to school was a smooth one; however, Jack didn't have this same opportunity. Jack returned to his elementary school where all of the school personnel and students knew him as "Jack". There were prior behavioural expectations placed on him and, when Jack didn't comply, it was difficult for school personnel and students to react to the "new" Jack. It was not until Jack started intermediate school, that he seemed to get a fresh start. His time at intermediate school has seen few behavioural incidents. This change could be contributed to Jack being a year older, having a previous year at school, and having a year at school to deal with his injuries prior to entering intermediate school.

PHYSICAL CHANGES

Children, and adults alike, can frequently make a good physical recovery following a brain injury. Outwardly they can appear normal in all respects; but changes could occur with speech, vision, hearing and motor development (Bennett, et. al., 2004). Some of the most common effects of a brain injury are headaches, dizziness, irritability, fatigue, problems with sleep and blurred vision (Vriensen & Wheeler, 2002).

Prior to Jack's and Susan's accidents, both children were described as developing at a normal rate. Susan did not play a lot of sports or do a lot of physical activity as she was growing up; however, she did play soccer for a few years. Jack, on the other hand, was very active physically. He was not involved with organized sports; however, he was loved to skate, play hockey and swim. Following the accidents, both children experienced physical changes, Jack more so than Susan. Susan developed some paralysis on her left side; she has a definite delay in her left arm, walks with a bit of a limp and is unstable on her feet. Susan did take part in rehabilitation for speech and motor development. Jack, on the other hand, became very physically dependant. He had a lot of increased tone, or muscle stiffness, on his right side and he has a decreased range in his joints due to the stiffness. Jack also took part in rehabilitation and can now throw a basket ball, play "Play Station", shower himself (except for washing under his left arm and his back), dress himself and tie his own shoes. He uses a cane and only uses his wheel chair if going long distances or to cross the road.

School personnel will need to accommodate changed physical needs of students with a traumatic brain injury. Classes that require fine motor or gross motor skills may need to be adapted or modified. If there are vision and hearing impairments, school personnel may need to adapt and modify the student's program in terms of note taking and assessments. School personnel may also want to be sensitive to any speech issues that may arise as a result of the brain injury. A buddy or peer system could be put in place to assist student's with physical needs throughout the school day. For example, with both Susan and Jack, a transition period was set aside for each of them to manoeuver from one class to the other before the hallways became engulfed with students.

THEME 2: THE SOCIOLOGICAL IMPACT OF TRAUMATIC BRAIN INJURY FOR THE CHILD

The biggest distinction between students with TBI and students with other disabilities is that the injury, and subsequent disabilities, occurs overnight. With other cognitive disabilities the student and his or her parents have had some time to adjust emotionally and to learn how to manage the disability.

IMPACT ON THE CHILD'S SCHOOL

Current United States statistics estimate that approximately one million school aged children will sustain a traumatic brain injury each year and that 90% of all children and adolescents with a TBI return to the school system (Clark, 1996). In some cases, especially if the student suffered the injury at an early age, the educational effects of a TBI may not show up immediately. The student may not experience difficulty in school until intermediate or high school when higher-level thinking and more complex tasks are performed (CEC Today, 2001). Since recovery takes months (in the case of concussions) or years, schools and school personnel have the potential to play a crucial role in helping the student adjust to what will most likely be a changed relationship to his or her environment (Clark, 1996; D'Amato & Rothlisbery, 1996). However, most schools are not prepared to meet the changed educational needs of the student (Clark, 1996; CEC Today, 2000; Clark, Russman, & Orme, 1999). When children with a traumatic brain injury return to the educational system, their educational and emotional needs are very different from before the injury. Their disability has happened suddenly and traumatically. They can often remember how they were before the brain injury. This can bring on many emotional and social changes. Teachers may also recall what the child was like before the injury and may have trouble changing or adjusting their expectations of the child. Educators' lack of knowledge regarding how a TBI can affect a student's academic and social functioning can be a barrier to providing the services that meets the needs of these students (Savage & Wolcott, 1994; Glang, Singer & Todis, 1997).

Both Susan and Jack returned to the classroom after their accidents. Susan's transition seemed to be a smooth one. She started high school in February, the second semester of her grade 10 year, approximately 6 months following her accident. Jack had a full year of recovery before returning to his elementary school where he started grade 5 in May.

Susan's return seemed to have very minimal impact on the school and in the classroom. This might be credited to entering a school that is already considered to be inclusive. Teachers were already used to adapting and accommodating curriculum to meet the individual needs of their students, so Susan proved to be no different. Teachers made adaptions as they saw fit.

Because Susan demanded to be treated equally, Susan's presence did not change the classroom a great deal. Jack's return to school was not as positive an experience. Jack's return had a huge impact on the school, the teachers and the students. Jack's school had accommodated students with special needs before; however, Jack's injury created a whole new level of need for support. The school personnel had very little knowledge of traumatic brain injury and relied on a "common sense" approach when dealing with Jack. Many staff meetings and staff discussions focussed on Jack and how to best meet his needs. Due to Jack's mobility issues, his classroom needed to be moved to the ground level and a bench needed to be built outside for him to sit on during outdoor breaks. Jack was involved in daily power struggles and lashed out at the staff and students. Many incentives needed to be put in place to encourage him to cooperate.

When Jack moved to the intermediate school, his transition was much smoother. Jack seemed to have more of an impact on his individual classes than on the school as a whole. The intermediate school is an inclusive school and the students and teachers are comfortable with students with special needs. Jack had a teacher assistant with him at all times. He blurts out in class, requires a lot of individual attention and has the need to work with peers. Jack's intermediate teacher has a lot of staff support when it comes to planning for Jack. There is special professional development time set aside to meet with the resource teacher and school counsellor if need be. The school also made the grade seven classes smaller than usual to help alleviate many of the behaviour issues displayed in grade six.

IMPACT ON THE CHILD'S FRIENDS

The impact of a TBI is often most keenly experienced through the child's social network. Because of the potential changes to social development, (Bennett, et. al., 2004), many children are in danger of losing peer supports that were in place prior to the accident. The friend their peers had known before the TBI may no longer exist, and peers often have difficulty accepting this "new" person as a friend. As a result, it is not uncommon for children with a TBI to be excluded from former peer groups and experience social isolation.

Susan and Jack experienced friendship issues after their accidents. Even though Susan was shy prior to the accident, she had maintained a small network of friends; Jack, on the other hand, had a huge network of friends. Because the accidents resulted in changes to both their personalities and behaviours, Susan and Jack have been left without a social group.

Many of Susan's and Jack's friends remained in place for about a year after their accidents but, after that, many of their friends found the changes that were happening too difficult to manage and went their own way. In Susan's situation, she had a very supportive friendship group in the beginning stages of her recovery and when she returned to school. Students were very supportive and reached out to her. However, as the year progressed, Susan's social group dwindled away. It seemed that students got tired and frustrated and just didn't have time for Susan's behaviours anymore. Susan's teachers felt that her social needs were being met during the school day; however, outside of school her social needs were probably unmet. Susan's mother, on the other hand, feels that when Susan goes to school, she is on her own. Even though students do stop and listen to her, Susan attends school functions, such as dances, all by herself.

Jack, too, had a very supportive social group in the beginning stages of his recovery and upon his return to school. Many students flocked to Jack and became very dedicated, wanting to be around him and support him. A few remained friends until the end of elementary school.

When the challenging behaviours emerged and students saw a different Jack than they had been accustomed to, many of the students found it difficult to be around him. Students had mixed emotions about Jack's return. Some students became fearful of Jack's actions and hid from him; for others, it seemed to humble them, raising awareness of their own vulnerability.

IMPACT ON THE CHILD'S FAMILY

The child with a TBI is not the only one to suffer the effects of the head injury; the entire family suffers. Caregivers attributed their own anxiety, depression, and impairment in social adjustment to the survivor's social isolation and negative emotional behaviours (Clark, Russman, & Orme, 1999).

The impact of having a child with a traumatic brain injury has greatly affected the two families that took part in this research. Both families were somewhat independent from their children prior to the accidents. Their children were at ages where they could be left alone, even if it was for only a couple of hours. Now, each family has a child who has become quite dependent on them.

Susan's family went through some significant changes after her accident. Susan's parents were having marriage difficulties prior to her accident and the accident made them realize that their marriage was not going to get any better. Susan's parents separated six months after Susan's accident. Susan's mother found it quite challenging right after the accident. She described it as having an infant again at the age of forty. Now what she finds challenging on a day to day basis is whether she is dealing with the brain injury, hormonal changes, or a seventeen year old. Impact on her siblings has been somewhat positive. Her brothers have become very protective and understanding. They even step in to try to smooth things out if Susan and her mother are arguing. However, dealing with Susan in a public situation was difficult on them in the beginning because they would get embarrassed by her behaviours. Now her brothers seem to be adjusting to that.

Susan's already close extended family only became closer after the accident. Somebody was always with her while she was in the hospital. Susan's mother recalls that it was like Susan had five mothers and a grandfather as well as other family members and friends of the family rallying around with support. To this day, this support continues to be put in place.

Jack's accident had a profound effect on his family. His mother stated, "I never dreamed that something like this was going to happen to my family and it's heartbreaking and it sure plays havoc with your family and your marriage". His mother spent the first seven months at the hospital and was unable to work. Jack's older brother was left alone a lot and became rebelliously independent. He also felt very guilty because of what had happened to Jack. He has been the one babysitting at the time and for a long time he blamed himself and God. Jack's grandparents on both sides of the family are having a difficult time dealing with the aftermath of the accident and the subsequent changes in Jack. Jack's grandparents don't visit like they used to. Jack's parents feel that they have been given very little support from their parents on either side.

When Jack returned to school, it seemed to give Jack's parents some "normalcy" to their everyday lives. Jack's mother was able to return to work; however, due to Jack's challenging behaviours and size, he needed to have someone available to him at all times and it became impossible for them to find and/or hire a babysitter. Therefore, Jack's father had to become a stay-at- home parent. Jack's parents realize that they need to rely on each other to raise Jack.

Neither one of them could do it alone.

Educators need to be aware of the sociological impact of a TBI for the child, especially as it relates to the school community and the home environment. The more inclusive and accepting the school environment, the greater comfort level most students and staff have in responding to the unique needs of a varied student population. However, school personnel need to be cognizant that, despite outward displays of peer support through such venues as the buddy system and circle of friends, most children with a TBI have very few friends. Just being in school can have the effect of heightening their sense of isolation.

The opportunity to socialize outside the school can be even more limited. Families may lack outside support and experience isolation from the wider community, due to difficulty in finding respite care or due to additional expenses involved in caring for the child. Prince Edward Island's lack of resources, such as the support that could be provided through a Traumatic Brain Injury Association, increases the stressors on a family. Families may look to schools to alleviate some of their stress, be it respite, emotional support or assistance with behavioural, social or academic challenges. Therefore, educators need to be aware of the needs of the child and the child's family if interventions are to be effective.

THEME 3: PREPARATION FOR REINTEGRATION TO SCHOOL

Ultimately, schools end up being the largest provider of services to children with brain injuries (Savage & Wolcott, 1995). A majority of the children who have sustained a TBI do return to school, and schools are increasingly involved with working with hospitals and rehabilitation facilities to help those students re-enter school by planning appropriate educational services (Savage & Wolcott, 1995). Children who have sustained a brain injury may encounter numerous problems as they make the transition from medical and rehabilitation settings to home, school, and community. When these students reenter the school setting, educators are especially challenged by the learning and behavioural challenges that children often demonstrate (Blosser & Pearson 1997). Many of the interviewed participants claimed that the reintegration to school was an important and necessary step in the child's recovery. Parents, medical professionals and school personnel took what they thought were the necessary steps to ensure that the transition from home to school was smooth. However, in some instances, the reintegration did not run smoothly.

PARENTS' PERSPECTIVE

Susan and Jack were both anxious to return to school. However, Susan's mother was reluctant about Susan's return. Susan's mother had a lot of anxiety that she personally had to over come. She felt that Susan was too unstable on her feet, and she had a hard time "letting go" of being in control. Jack's parents, on the other hand, were very anxious for Jack to return to the classroom. Jack had been home for a year and his parents felt that it was time for Jack to go back to school and time for them to go back to work.

Both sets of parents took actions to help their child prepare for their return to the classroom. Susan and Jack both went to visit their schools on a number of occasions before they were scheduled to return. Susan's mother got Susan a cell phone immediately so that Susan could access her at all times if Susan needed her. Arrangements were also made with Susan's teachers to allow her to be dismissed from the classroom two minutes early so that Susan could get to her next class safely. Susan's mother also wanted Susan to have a friend in each of her classes, but was very clear that she did not want her friends to feel responsible for Susan. The peer support was to help her get safely from one class to the next. Susan's mother was pleased with the reintegration to school. Susan's mother felt she had a good relationship with the school prior to Susan attending and she maintained contact with the school on a regular basis. Any concerns Susan's mother had was recognized and addressed by the school personnel to help alleviate her personnel anxiety.

Jack's parents had arranged for a tutoring program for Jack while he was still recovering in the hospital. They, too, took Jack on a number of field trips to the school to let him spend time with peers in the afternoons. However, Jack saw this as a social time and he was reluctant to do any work. Jack's parents, felt that Jack's transition to school did not go smoothly at all. They put a lot of the blame on specific individuals within the school system. Jack's mother, from the very beginning, felt that the school, in particular the school principal, did not want Jack to return to school and therefore felt that a number of road blocks were created. Jack's mother indicated that the school principal insisted that Jack would need a lot of special equipment that the school was not able to provide and that having Jack in the school would be too much of a liability. Jack would also need a male teacher's assistant and the principal felt that none were available. Jack's mother became quickly frustrated. Ultimately, she attended a case conference with a number of school officials, insisted that Jack would be in school in September and that they were to be ready for him. Jack did return to school for half days; however, Jack's mother felt it was a constant battle with the school principal. Jack's mother felt that the school did not provide any necessary resources for Jack's academic programs and that they were too concerned about his behavioural challenges for the two years he was there. Everyday Jack's mother would be ready for a phone call for her to go to pick up Jack because there had been an "incident".

Jack's transition from elementary school to intermediate school went much more smoothly. Jack's parents credit the intermediate school's principal, Jack's teachers and Jack's teacher assistant for the success. Jack is currently going to school full time and his parents feel Jack is having a terrific year. The communication from school to home is positive and Jack's parents feel that the school is trying to do everything that they can to integrate him and to have as much success with his academic learning as possible. Jack's parents continue to carry their cell phones with them at all times; however, they never ring.

Medical Perspective

Considering the knowledge medical professionals have when it comes to the injuries and rehabilitation of a child with a TBI, they too have an important perspective to offer for the reintegration to school process. The medical professionals feel there are a lack of supports and resources for students with a TBI. There is a lack of school psychologists to administer proper psychological or cognitive testing and a lack of commitment from the school boards to obtain teacher assistant support. Medical professionals feel they need to be involved in case conferences in order to provide ongoing communication with school personnel. This, they claim, is necessary to monitor progress, to document issues and to identify emerging needs. It is important for the medical team to have consistency in school personnel attending meetings and would prefer to meet with a school based student services team rather than individual school personnel.

Medical professionals also feel that it is important to educate both school personnel and students before a child with a TBI returns to school. School personnel need to know the medical implications of the injury and the many aspects of how the child is going to be different. It is felt that the teacher assistant needs to work with the child for more than one day at the hospital before the child returns to school and, upon return, the school needs to be accessible. Students also need to be prepared prior to having their classmate return. Medical professionals feel that friends of the student should come into the hospital and the rehabilitation unit to see what their classmate is experiencing. This will better prepare them emotionally and equip them to be more supportive of the changed needs of their friend.

SCHOOL PERSONNEL PERSPECTIVE

Many students with a TBI will have long-term educational challenges as a direct result of their injuries. These children will often require educational concessions and program modifications. Educators who understand what happens in a TBI are in a better position to address cognitive issues in children returning to school following a head injury. Given the structure that schools provide and the variety of specialists represented, schools may be in one of the best positions to provide services to these children (Clark, 1996). School personnel can help students and families learn to manage these difficult transitions by implementing several key strategies. Those strategies include building collaborative teams, gaining critical knowledge about brain injury and specific teaching techniques, and establishing a common philosophy for teaching (Blosser & Pearson 1997). Educators, however, have only recently begun to attend to this population and they do not yet have a repertoire of tested teaching techniques or educational modifications from which to draw. Educators' early involvement with the hospitalized child, careful planning for reentry, and a willingness to make the necessary educational modifications seem to be key techniques necessary for planning and providing for the educational needs of children with a TBI. Without the necessary awareness and training in TBI, it is common for classroom teachers to address and/or confuse the needs of a student with TBI with those students who have other special needs issues such as developmental delays, learning disabilities, lack of motivation or behavioural challenges (Clark, Russman, & Orme, 1999). Currently, there has not been professional development training for Prince Edward Island school personnel that acknowledges a TBI designation, nor is it included in the pre-service training for teachers attending the University of Prince Edward Island or the Human Services Program at Holland College.

The school personnel involved with Susan's and Jack's reintegration to school planned extensively for their return. They demonstrated a desire to involve parents and recognized the need for input from other professionals in order to make good decisions for a reentry plan. The school personnel involved in Susan's and Jack's reintegration really felt that they had the child's best interests in mind. In Susan's case, a meeting was held with everyone who would be involved with Susan's return to school; administration, school counsellor, her teachers and Susan's mother. Susan's mother shared confidential medical reports during the meeting to give the school a better understanding of the extent of Susan's injuries. The meeting was an opportunity for Susan's mother and school personnel to express goals, ambitions and concerns. The school worked collaboratively with Susan's mother and encouraged her input concerning course modifications and changes. Susan's teachers made adjustments and modifications where they could in order to maximize success.

Jack's grade 5 teacher made a visit to the hospital and met with Jack's tutor. She also made visits to Jack's home. His teacher prepared Jack's classmates and tried to be as honest with them as she could regarding his injuries. She also tried to include Jack as much as possible by having the class make "Get Well" cards and involve him in the Christmas celebrations. She felt it was important to find out about Jack's likes and dislikes and to give him choice when he returned to school.

Jack's grade 5 teacher felt that the school took a "team approach" in preparing for Jack's return. It was decided at the school level that it would be better if Jack had a gradual reintegration. There were numerous meetings held, a full time teacher assistant was put in place; there was support from the school counsellor, Jack's doctor was invited to speak to the staff at a staff meeting, preparations were made within and outside the school and the staff prepared themselves for "worst case scenarios". The school psychologist was contacted and involved to help prepare and administer a functional behavioural assessment.

When Jack graduated from elementary school to intermediate school, it was felt that an important part of the transition was to maintain consistency with the teacher assistant. Personnel from the intermediate school and the elementary school had a number of meetings to share samples of work and develop an Individualized Education Plan.

The school personnel involved with Susan and Jack were acutely aware of their lack of understanding of the far reaching impact of a TBI. In both cases with Susan and Jack, the school personnel working with each of these students had very little, if any, prior knowledge of traumatic brain injuries and/or how a TBI affects academic learning. However, the experience of having a student with a TBI in their school has left each school with an awareness of what they deem are important considerations or suggestions of how to prepare for a child with a TBI returning to the school system. Their suggestions and considerations are similar:

- Acquire knowledge of the injury – It is important to find out the cause of the injury and the effects it has on the child. School personnel need to have an understanding of the injury; how it has impacted the child on many different levels, including his/her ability to learn; and where the child is currently functioning. It is important to know and understand that every case will be unique and school personnel need to acquaint themselves with each specific case. Determining the child's strengths and needs is crucial. The more knowledge the school personnel acquire, the easier it will be to separate the child from the brain injury and not to take issues personally.
- Collaboration is essential – It is important for schools to not only work together, but to also work closely and have a sharing of information with medical professionals, with the home and with the student. There needs to be a process for schools to obtain and share information in regards to preparing for the return of a student with a TBI. Medical documents on the child have recommendations to explain, and help deal with, the injury. It is important to work closely and maintain a good relationship with the family because the family knows their child best. In most cases, the anecdotal information that came from parents was felt to be more valuable than the more technical information that came from the medical professionals. Taking a team approach within the schools is important as well. Scheduled team meetings give the team an opportunity to have discussions, get support from each other and be accountable for follow-up. Leadership within the

school team is a key element for successful collaboration.

- Plan – It is the job of the school to take into account the wishes of the student and family and then provide the best education possible. It is important for the classroom teacher to implement and be knowledgeable in many different teaching methods and be aware of and select resources to meet the child's needs. Goals should be agreed upon by the school personnel, the family and the student. Each goal needs to be realistic. It is also important that the goals be broken down into smaller components, that they are flexible and that time is taken to reflect on the goals in place. In some cases, the goals and plans may need to be modified as they are implemented. Individualized Education Plans and Functional Behavioural Analysis are useful tools to assist in setting goals and planning appropriate interventions. Planning for crisis and any physical changes that need to occur in or around the school should be taken care of before the child returns.
- Prepare students – It is equally important to prepare the students of the school as it is to prepare the staff of the school. Students need to be given background information of what has happened and of what to expect. Students also need time to adjust, ask questions and to alleviate any fears regarding the return of a student with a TBI. If possible, close friends need to remain close, and support systems, such as the school counsellor, need to be put in place for these friends and the student with a TBI.
- Seek additional support – The whole school needs to take ownership in the reintegration process and support the classroom teacher(s). School counsellors,

school psychologists, board and department special education consultants, the medical team, and outside agencies can be beneficial when it comes to supporting the school personnel who work with a child with a TBI in terms of academic programming, special needs, behavioural challenges and social difficulties.

Students who have sustained a TBI are often very different from their peers with learning disabilities or other special needs. It is not uncommon to find that prior to the injury, these individuals typically experienced success in school. Often, upon return to the school, both the student and teacher have set unrealistic goals that are no longer appropriate for their current level of functioning. The resultant failure is frustrating and difficult to comprehend for the student and the teacher. Plans, goals and programming must be modified appropriately and realistically to assist the student's success. An awareness of the cognitive, academic, and behavioural needs is obviously important in enabling teachers to work appropriately with that individual. Equally important, however, is an awareness that the teacher will also experience emotional and/or behavioural changes as a result of interacting with the student.

CONCLUDING COMMENTS AND RECOMMENDATIONS

This chapter has examined TBI and the rippling effect such an injury has, not only for the child, but for the child's family, the child's social network and the child's school community. It has summarized the changes that may impact the child's academic learning, social development, personality, behaviour and physical development. Examination of an issue will often lead to future recommendations, as experience can prove to be the best teacher. The school personnel involved with Jack's and Susan's transition to school felt they learned much from this experience and offered several recommendations concerning what worked well and, in hindsight, what might have been helpful in the transition planning. Their considerations, coupled with those from the parents and the medical professionals, are supported by research. In both cases, the key elements suggested for successful reintegration to school are constant. They include:

- Collaborate with parents and medical professionals to share pertinent information
- Arrange meetings with the child prior to the return to school to gather necessary information and conduct assessments as required
- Provide essential information to all school personnel and utilize a team approach to plan for the reintegration
- Establish and maintain a positive working relationship with the home to ensure that parents, student and school personnel work together to create common, realistic goals
- Utilize expertise at the school, board and department levels to assist in setting and implementing realistic goals
- Utilize tools such as Individual Education Plans and Functional Behavioural Analysis in the planning process
- Plan frequent conferences to monitor and evaluate progress so that the necessary adaptions and modifications can be made to maximize success
- Prepare and educate peers on the nature of the child's injury and its impact

Children with TBI within the school system have an excellent opportunity for compensatory recovery through their direct access to teaching professionals with expertise in cognition (learning, problem solving), physical growth (physical education, nutrition), and social development (group interactions). If school personnel use the guidelines outlined above to prepare for a child's return to school, they can become well equipped to provide effective services to students with a brain injury. Educational goals can be accomplished by providing alternative options for learning, preparing the student for multiple transitions, adapting the school curriculum to meet the student's unique needs, and establishing an individualized education plan that is flexible and responsive to the student's unique characteristics. Working collaboratively can ensure the transition to school is as smooth as possible. The family, the student, the medical professionals and the entire school personnel each has a role to play in ensuring that this happens.

APPENDIX A

Interview Guide for Parents/Guardians

Briefing:

- I'd like to chat with you about your experience with your child's accident and their return to school.
- I have some questions which we will use as a guide. Please feel free to elaborate in detail on your experiences and thoughts as we proceed as well as feeling free to choose not to answer a question at any point in time during the interview.
- This interview will take about 45- 60 minutes.
- The interview will be taped. I may need to stop momentarily to change the tape. After the interview, I will transcribe it. I will use it along with the other interviews that I am conducting to help schools help students returning to the classroom after sustaining an acquired or traumatic brain injury.
- I want to assure you that your comments will be held in strictest confidence and your name will not be identified in the report that results from this research.
- Before we begin, do you have any questions?

Questions:

- How did the accident happen?
- Describe the extent of the injuries?
- Tell me about the rehabilitation process from the time of the injury to date?
- How would you describe your child before the accident? (Physically? Emotionally? Socially? Behavior?)
- How would you describe your child now? (Physically? Emotionally? Socially? Behavior?)
- What kind of impact has this had on your family?
- When did your child return to school?
- What did you do to prepare your child to go back to school?
- How has the school supported you and your child upon returning to the classroom?
- Do you feel that your child's educational needs are different now than before the accident? If so:
  - a) How are they different?
  - b) What has the school done to accommodate these needs?
- Do you feel that your child's needs are being met at school? Explain.
- What was the biggest challenge upon your child's return to school?
- What was the greatest success upon your child's return to school?
- In retrospect, do you feel that your child was ready to return to school? Explain.
- What might you have done differently to prepare your child to go back to school?
- If you could change anything about your child's school day what would it be?
- What advice would you give other parents whose children are returning to the classroom with an acquired or traumatic brain injury?
- I would like to interview other individuals who have worked or are working currently with your child such as school and medical personnel. I will be asking similar questions (provide

Medical and Educator Interview Questions). Will you provide me with a few names of possible participants that I could contact to add to my research along with written permission to do so? (Permission Slip made available)

- Are there any additional comments that you would like to share with me?

Debriefing:

- I would like to thank you for taking the time to share you experience with me. I have learned some important things from this interview including...
- I will be writing a synthesis of the interview which will be provided to you. I would appreciate any feedback or comments and a dated signature on it to confirm that the information you provided has been transcribed accurately.
- I hope to complete my work in August, 2003.
- I have no further questions. Is there anything else you want to add or ask me about before we finish the interview?

APPENDIX B

Interview Guide for School Personnel

Briefing:

- I'd like to chat with you about your experience with [student's name] accident and their return to school.
- I have some questions which we will use as a guide. Please feel free to elaborate in detail on your experiences and thoughts as we proceed as well as feeling free to choose not to answer a question at any point in time during the interview.
- This interview will take about 45- 60 minutes.
- The interview will be taped. I may need to stop momentarily to change the tape. After the interview, I will transcribe it. I will use it along with the other interviews that I am conducting to help schools help students returning to the classroom after sustaining an acquired or traumatic brain injury.
- I want to assure you that your comments will be held in strictest confidence and your name will not be identified in the report that results from this research.
- Before we begin, do you have any questions?

Questions:

- Describe [student's name] as a student prior to the accident? (Academically, Socially, Behavior)
- Describe [student's name] as a student since they've returned to school (Academically, Socially, Behavior)
- What kind of impact has this had on the classroom? Other students? The school?
- Do you feel you were prepared to meet the needs of this student?
- What do you know about acquired or traumatic brain injury and how it affects learning and behavior?
- What do you think is important to know before you have a child with acquired or traumatic brain injury in your classroom? In the school?
- What did you do to prepare yourself for the arrival of [student's name]?
- What would you recommend schools and classroom teachers do to prepare upon the reentry to school of a student with acquired or traumatic brain injury?
- How has the school supported you and [student's name] upon returning to the classroom?
- Do you feel that [student's name] educational needs are different now than before the accident? If so:
  a) How are they different?
  b) What has been done to accommodate these needs?
- Do you feel that [student's name] needs are being met at school? Explain.
- What was the biggest challenge upon having [student's name] return to school?
- What was the biggest success upon having [student's name] return to school?
- In retrospect, do you feel that [student's name] was ready to return to school? Explain.
- What might you have done differently to prepare for [student's name] coming back to school?

- If you could change anything about [student's name] school day what would it be?
- What advice would you give other school personnel about students returning to the classroom with an acquired or traumatic brain injury?
- Are there any additional comments that you would like to share with me?

Debriefing:

- I would like to thank you for taking the time to share you experience with me. I have learned some important things from this interview including...
- I will be writing a synthesis of the interview which will be provided to you. I would appreciate any feedback or comments and a dated signature on it to confirm that the information you provided has been transcribed accurately.
- I hope to complete my work in August, 2003.
- I have no further questions. Is there anything else you want to add or ask me about before we finish the interview?

APPENDIX C

Interview Guide for Medical Personnel

Briefing:

- I'd like to chat with you about your experience with [student's name] accident and their return to school.
- I have some questions which we will use as a guide. Please feel free to elaborate in detail on your experiences and thoughts as we proceed as well as feeling free to choose not to answer a question at any point in time during the interview.
- This interview will take about 45- 60 minutes.
- The interview will be taped. I may need to stop momentarily to change the tape. After the interview, I will transcribe it. I will use it along with the other interviews that I am conducting to help schools help students returning to the classroom after sustaining an acquired or traumatic brain injury.
- I want to assure you that your comments will be held in strictest confidence and your name will not be identified in the report that results from this research.
- Before we begin, do you have any questions?

Questions:

- Can you tell me about [student's name] injury(ies)?
- How did [student's name] injury impact their level of abilities (ie. physical, intellectual, social, behavior)?
- What do school personnel need to know about acquired or traumatic brain injury?
- Have you ever participated in a case conference or been involved with the child's reentry to school? If yes, is there anything that might have improved the case conference?
- What could the professionals in the medical field do to assist students, families, and school personnel with the reentry to school?
- How would you recommend school personnel, families and students with an acquired or traumatic brain injury prepare for the reentry to school?
- Are there any additional comments that you would like to share with me?

Debriefing:

- I would like to thank you for taking the time to share you experience with me. I have learned some important things from this interview including...
- I will be writing a synthesis of the interview which will be provided to you. I would appreciate any feedback or comments and a dated signature on it to confirm that the information you provided has been transcribed accurately.
- I hope to complete my work in August, 2003.
- I have no further questions. Is there anything else you want to add or ask me about before we finish the interview?

APPENDIX D

TARA DEGLAN-GALLANT

[Date]

Dear [School Board Official];

My name is Tara Deglan-Gallant and I am a graduate student at the University of Prince Edward Island in the Faculty of Education. This study is entitled: **Traumatic Brain Injury:** *Challenges and Strategies for the School.*

This research is an effort to complete the requirements of a Masters of Education at the University of Prince Edward Island and is undertaken with the knowledge and support of my thesis committee chaired by Dr. Vianne Timmons.

The aim of this research is to determine how Prince Edward Island school personnel should be prepared to assist with the reentry of a student with Acquired or Traumatic Brain Injury into the educational system. Based on the research findings, I hope to provide teachers and administrators with strategies that can be used to instruct a student with acquired/traumatic brain injury in a classroom setting.

The proposed research is a qualitative case study involving in-depth interviews to be conducted with the parents/guardian of students with an Acquired or Traumatic Brain Injury, as well as relevant professionals who work(ed) with the student, (ie. teachers, school counsellors, medical personnel) at a place of their choice. It is expected that all interviews would be approximately one hour in length and would be completed before the end of March, 2003.

It is important to note that pseudonyms would be used in published work and draft documents and confidentially would be ensured for all participants. No reference would be made in the study about a particular area of the province or any specified school and that all of the discussions will be audio-taped and transcribed. The audio-tape and transcript will be analysed and put into themes and secured safely in a locked cabinet. No copies will be made of the transcripts or the audio-tapes and all data will be destroyed upon completion of the thesis. However, due to the nature of a small province, there is a possibility that the participants may be identified from the information that they disclose.

If there are more participants than needed, then I will select a random sample from the willing participants. I will notify the participants by telephone to either confirm their participation or to thank them for their interest and let them know that I had enough volunteers for the study.

My request is three fold: first, to ask the Western School Board to grant permission to conduct this study; secondly, to request that the Western School Board approach parents/guardians of students with acquired/traumatic for possible participation; and thirdly, to ask permission to approach identified school personnel who work(ed) with the student for an interview.

To ensure confidentially, it is requested that the Western School Board mail the Research Information Letter and Consent form to the parents/guardians in a previously stamped envelop. For your information, I have enclosed a copy of each. Should they choose to participate, the consent form will be sent directly back to me in a self addressed, stamped envelope. I will provide the Western School District with the required number of forms and stamped envelopes for the mail out to parents/guardians.

I would appreciate hearing from you regarding these requests and to answer any questions that you may have with the research study. Please email me at me at:

Central Queens Elementary School-
Home–

Thank you for considering this request.

Sincerely,

Tara Deglan-Gallant

APPENDIX E

[Date]

Dear Parent/Guardian;

My name is Tara Deglan-Gallant and I am a graduate student at the University of Prince Edward Island in the Faculty of Education. I am writing to ask that you consider participating in a research study which will begin this year. This study is entitled: **Traumatic Brain Injury:** *Challenges and Strategies for the School.*

This research is an effort to complete the requirements of a Masters of Education at the University of Prince Edward Island and is undertaken with the knowledge and support of my thesis committee chaired by Dr. Vianne Timmons.

The aim of this research is to determine how Prince Edward Island school personnel should be prepared to assist with the reentry of a student with Acquired or Traumatic Brain Injury into the educational system. Based on the research findings, I hope to provide teachers and administrators with strategies that can be used to instruct a student with acquired/traumatic brain injury in a classroom setting.

The proposed research is a qualitative case study involving in-depth interviews to be conducted with the parents/guardians of three students with an acquired or traumatic brain injury, as well as relevant professionals who work(ed) with the student, (ie. teachers, school counsellors, medical personnel). The exact timetable will be determined after you have given your consent to participate. It is expected that all interviews will be approximately one hour in length and will proceed at a place of your choice. It is expected that the interview will be completed before the end of April, 2003.

If there are more participants than needed, then I will select a random sample from the willing participants. I will notify you by telephone to either confirm your participation or to thank you for their interest and let you know that I had enough volunteers for the study.

It is important to note that pseudonyms would be used in published work and draft documents and confidentially would be ensured for all participants. No reference would be made in the study about a particular area of the province or any specified school and that all of the discussions will be audio-taped and transcribed. The audio-tape and transcript will be analysed and put into themes and secured safely in a locked cabinet. No copies will be made of the transcripts or the audio-tapes and all data will be destroyed upon completion of the thesis. However, due to the nature of a small province, there is a possibility that the participants may be identified from the information that they disclose.

I must stress that your participation is entirely voluntary. Also, if you choose to participate, you may withdraw from the study at any point in time, even as the interviews are being conducted.

Additionally you will have the opportunity to view and edit the transcript of your statements.

Please return the enclosed consent form to indicate your interest in participating in this study with in ten business days upon receiving. Depending on your response, I will be contacting you to confirm your participation. I hope that you will consider my request to utilize your personal experience for my proposed thesis this year.

If you have any questions regarding this research project, please email me at
or call me at:

Central Queens Elementary School –
Home –

Sincerely,

Tara Deglan-Gallant

APPENDIX F

Informed Consent for Master of Education Research Study

☐ I agree to participate in the research study being conducted by Tara Deglan-Gallant who is a graduate student in the Faculty of Education at the University of Prince Edward Island. This study aims at discovering strategies to help school personnel assist students with Acquired or Traumatic Brain Injury returning to the school system.

☐ I understand that the information gathered will be used for her Master of Education thesis.

☐ I understand that this study involves an in-depth interview and this interview will be audio taped and transcribed. I understand that I have the freedom not to answer any question and that the excerpts from the interviews may be used and published in the thesis. I have the opportunity to review and edit the transcript up to May 1, 2003.

☐ I understand that I can view and edit the transcript.

☐ I understand that my participation in this study is voluntary and I may withdraw from the study at any time. I do not need to give any reason for my withdrawal.

☐ I understand that all information I give and all names of those involved in the study will be kept confidential within the limits of the law.

☐ I understand that the researcher will be using pseudonyms; however, due to the nature of a small province, there is a possibility that I could be identified by the information that I have disclosed.

☐ I understand that the researcher, Tara Deglan-Gallant, is the only person who will have access to the information.

☐ I understand that I may contact Tara Deglan-Gallant at (902) 964-2044 or her research supervisor, Dr. Vianne Timmons, at (902) 566-0405 at any time to discuss the research.

☐ I understand that I can contact the UPEI Research Ethics Board at (902) 566-0637, or by email at lmacphee@upei.ca if I have any concerns about the ethical conduct of this study.

☐ The researcher has agreed to answer any questions I have about the study and I may keep a signed copy of this consent form.

☐ I understand that there will be a follow up and debriefing with the researcher to ensure I have access to the transcript of my interview and the findings of the study.

☐ I have read and understood the contents of this letter and agree to take part in the study.

________________________________, ________________________

Name of Participant (print) Date

________________________________, Mailing Address: ________________________

Participant Signature

____

____

☐ I would like a copy of the research findings.

Telephone Number: ________________________

APPENDIX G

Research Information Letter

[Date]

Dear **[Professional Participant]**;

My name is Tara Deglan-Gallant and I am a graduate student at the University of Prince Edward Island in the Faculty of Education. I am writing to ask that you consider participating in a research study which will begin this year. This study is entitled: **Traumatic Brain Injury:** *Challenges and Strategies for the School.*

This research is an effort to complete the requirements of a Masters of Education at the University of Prince Edward Island and is undertaken with the knowledge and support of my thesis committee chaired by Dr. Vianne Timmons.

The aim of this research is to determine how Prince Edward Island school personnel should be prepared to assist with the reentry of a student with Acquired or Traumatic Brain Injury into the educational system. Based on the research findings, I hope to provide teachers and administrators with strategies that can be used to instruct a student with acquired/traumatic brain injury in a classroom setting. Your name was suggested as a possible contributor to this research because of your involvement with **[student]**.

The proposed research is a qualitative case study involving in-depth interviews to be conducted with the parents/guardian and student, as well as relevant professionals who work(ed) with the student, (ie. teachers, school counsellors, medical personnel). The exact timetable will be determined after you have given your consent to participate. It is expected that all interviews will be approximately one hour in length and will proceed at a place of your choice. It is expected that the interview will be completed before the end of March, 2003.

It is important to note that pseudonyms would be used in published work and draft documents and confidentially would be ensured for all participants. No reference would be made in the study about a particular area of the province or any specified school and that all of the discussions will be audio-taped and transcribed. The audio-tape and transcript will be analysed and put into themes and secured safely in a locked cabinet. No copies will be made of the transcripts or the audio-tapes and all data will be destroyed upon completion of the thesis. However, due to the nature of a small province, there is a possibility that the participants may be identified from the information that they disclose.

I must stress that your participation is entirely voluntary. If you are willing to participate, you may withdraw from the study at any point in time the interviews are being conducted. Additionally you will have the opportunity to view and edit the transcript of your statements. Please return the enclosed consent form to indicate your interest in participating in this study. Depending on your response, I will be contacting you to confirm your participation. I hope that you will consider my request to utilize your personal experience for my proposed research.

If you have any questions regarding this research project, please email me at ____________
or call me at:

Central Queens Elementary School –
Home –

Sincerely,

Tara Deglan-Gallant

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