Traumatic Brain Injury and Its Effect on Students

A Dissertation

Submitted to

The Temple University Graduate Board

In Partial Fulfillment

Of the Requirements for the Degree

DOCTOR OF EDUCATION

By

Stacy B. Rosenthal

May 2012

Examining Committee Members:

Corrinne A. Caldwell, Ph.D., Advisory Committee Chair, Educational Administration
Steven Jay Gross, Ed.D., Advisory Committee Member, Educational Administration
Joseph DuCette, Ph.D., Advisory Committee Member, Educational Psychology
Michelle Chaplin Partlow, Ph.D., Examining Committee Chair, Educational Administration
S. Kenneth Thurman, Ph.D., Examining Committee Member, Special Education

ABSTRACT

TRAUMATIC BRAIN INJURY AND ITS EFFECT ON STUDENTS

By Stacy B. Rosenthal

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Temple University, May 2012

Major Advisor: Dr. Corrinne A. Caldwell

Over one million people suffer a traumatic brain injury every year, many of whom are students between the ages of 5 and 18. Using a qualitative case study approach, I wanted to discover the specific factors that both impede and help the school re-entry process for students in grades kindergarten through twelve so that these students can return to school on a full-time basis. The theoretical base behind this problem included motivation theories, memory theories, and emotion theories including self-determination theory, self-efficacy theory, Kübler-Ross Grief Cycle, and Lezak's stage model.

Educators, including teachers, school counselors, and administrators, need to provide educational support to children with brain injuries and their families as a result of the Individuals with Disabilities Act of 1990, Public Law 101-476. However, if these individuals do not have a good understanding of what these students need to achieve optimal educational success, then the students will probably not be able to achieve their educational goals. Therefore, I searched for factors that affect the re-entry process.

I used a qualitative case study approach in my methodology to complete this study. The sample used in this study included those students associated with the BrainSTEPS team local to

my residence who were willing to participate, along with their parents, teachers, counselors, and administrators. Historical data were collected through medical and academic records. The bulk of the data came from interviews and observations I made; I then used the constant comparative method to analyze these data. I had several methods of verification in place to ensure the validity of this study and I did my best to hold the study to the highest ethical standards possible.

The factors that were found to enhance the re-entry of students with brain injuries include: education and awareness prior to the injury occurring, the scheduling of frequent breaks during the school day, a gradual transition, providing each student with a brain injury with a non-injured study buddy in the classroom, teaching the student to become a self-advocate, constant communication between all of the key players that begins as early as possible, and support provided by the administration and therapists for the classroom teachers in the form of periodic check-ups.

ACKNOWLEDGEMENT

I would like to acknowledge the support of those who made the completion of this dissertation research proposal possible. To my parents, Lynne Rosenthal and Richard Rosenthal, and my brother, Joseph Rosenthal, I am eternally thankful for their support, words of encouragement, and sacrifices that they had to make along the way. While my name is the only family member name that appears on the cover page, they deserve credit for putting up with many late nights and plans arranged around my graduate schoolwork. None of this would have been possible without them. To my parents specifically who have instilled the value of family in me. It was important to me to respect the degrees that both of them earned from Temple University and to honor their alma mater. To my mom especially, she was the inspiration of this research topic and I only hope that this dissertation helps to alleviate some of the suffering that she, and others that have experienced and may endure a traumatic brain injury in the future, has gone through.

To my grandmother, Sharon Rosenthal, who wanted a doctor in the family. While it is not an M.D., I hope that she will be satisfied with an Ed.D. and a dissertation topic associated with education and the medical field.

To my colleagues and friends, I appreciate their words of encouragement, support, and sense of humor that kept me going through this long process. Again, I could not have completed this accomplishment without you.

I would also like to extend gratitude to Professor Corrinne A. Caldwell who guided me through this entire process from defining my research questions to writing the research proposal to completing the study. Professors Steven J. Gross and Joseph DuCette also deserve my gratitude for serving on my dissertation advisory committee. These three individuals provided me with positive encouragement and much appreciated constructive criticism along the way. Professors Michelle Chaplin Partlow and S. Kenneth Thurman also deserve acknowledgement as members of my examination committee. They offered great suggestions that contributed to improving the final work. I really appreciate the work on my entire dissertation committee.

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INTRODUCTION

Introduction

According to the National Institute of Neurological Disorders and Stroke (NINDS, 2009), traumatic brain injury (TBI) is a major public health problem, especially among male adolescents and young adults ages 15 to 24. Each year in the United States alone, approximately 1.4 million people experience a TBI, approximately 50,000 people die from head injury, approximately one million head-injured people are treated in hospital emergency rooms, and approximately 230,000 people are hospitalized for TBI and survive. Those that are fortunate enough to live through their injury usually have to make adjustments to their daily routine as a result of the post-injury complications. Using a qualitative case study approach, I found out specific factors that both impede and enhance the school re-entry process so that these students can return to school on a full-time basis. The theoretical base behind this problem included motivation theories, memory theories, and emotion theories.

For school-aged children, a traumatic brain injury may affect the way they learn, which might be different from how they learned pre-injury. If the students are learning differently, then their teachers need to teach them differently. The students also cannot make the jump directly from their hospital room or in-patient rehabilitation center to being a full-time student. There are several stages the students must go through prior to attending school as they did before the injury from out-patient rehabilitation, to homeschooling, to attending school part-time, and finally to attending school full-time.

The students cannot make this transition without the support of many people including administrators, teachers, counselors, and medical professionals. These individuals need training to know how they can help the student learn best and what factors impede or enhance the re-entry process. The following sections will define the problem and research question more clearly, reflect on the literature that already exists on this topic, describe the methodology and procedures that I used to conduct my experiment, present the results of this study, and finally provide recommendations that can be used in the field based on these findings.

Problem Statement

According to the Brain Injury Association of Pennsylvania ([BIAPA], n.d.b), each year, over 4,000 of children in Pennsylvania survive traumatic brain injuries significant enough to require hospitalization. Many of these children are left with life-altering difficulties in physical, cognitive, language or behavioral functioning. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain (NINDS, 2009). Some symptoms are evident immediately, while others do not surface until several days or weeks after the injury. A person with a mild TBI may remain conscious or may experience a loss of consciousness for a few seconds or minutes. The person may also feel dazed or not like him- or her-self for several days or weeks after the initial injury. Other symptoms of mild TBI include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, bad taste in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking.

A person with a moderate or severe TBI may show these same symptoms, but may also have a headache that gets worse or does not go away, repeated vomiting or nausea, convulsions or seizures, inability to awaken from sleep, dilation of one or both pupils of the eyes, slurred speech, weakness or numbness in the extremities, loss of coordination, and/or increased confusion, restlessness, or agitation. Small children with moderate to severe TBI may show some of these signs as well as signs specific to young children, such as persistent crying, inability to be consoled, and/or refusal to eat. “Statistics show that one in 125 children between birth and age 14 are diagnosed with a traumatic brain injury, said pathologist Sarah Krusen, the BrainSTEPS team leader for Bucks and a certified brain injury specialist. As a comparison, one in 150 children is diagnosed with autism spectrum disorder” (Bentman, 2009, p. A1). Educators, including teachers, school counselors, and administrators, need to provide educational support to children with brain injuries and their families. However, if these individuals do not have a good understanding of what these students need to achieve optimal educational success, then the students will probably not be able to return to school on a full-time basis.

Purpose of the Study

While many studies have been completed on people of various ages who have suffered traumatic brain injuries and some studies have been completed about how these people learn, there is less research about how school-age students with traumatic brain injuries learn and how education professional can assist them with re-entering school following a TBI. This study sought to find out specific factors that both impede and enhance the re-entry process so that these students can return to school on a full-time basis. Those in the education field cannot support these students until they know how to support them, so this study looked to better understand the problem by illuminating these support factors.

There is plenty of research on people that have suffered traumatic brain injuries, but there is little research about TBI and students. Deidrick and Farmer (2005) state that “school re-entry programs have not been subjected to empirical study” (p. 25). There has been research on special education, but that is not specific to educating students with TBI. There has also been research about the willingness of teachers to learn about TBI and its effect on students, but this does not answer the question about what the students need. Research about traumatic brain injury and its effects on students was noticeably missing prior to this study.

Research Questions

There are several research questions guiding this study. The overarching question is:

- What factors impede or support the re-entry to school of students with a traumatic brain injury in grades kindergarten through twelve?

In order for this larger question to be answered, two secondary questions also needed to be asked and answered. These are:

  - What does the re-entry process look like for students with a brain injury in grades kindergarten through twelve and how does that process unfold?
  - Who are the principal actors are in the re-entry process?

Definitions

The following is a list of terms whose definitions the reader should know to understand the study:

BrainSTEPS – is a child and adolescent brain injury school re-entry program created in 2007 by the Brain Injury Association of Pennsylvania, under contract from the PA Department of Health and partnered with the PA Department of Education. BrainSTEPS (**S**trategies **T**eaching **E**ducators, **P**arents, and **S**tudents) is working to make sure that those who provide educational support to children with brain injury have a good understanding of the effects of the injury, the resulting challenges, and supports and interventions that will help these students achieve educational success through graduation.

Compulsory School Age – refers to the period of a child's life from the time the child enters school as a beginner which may be no later than at the age of 8 years, until the age of 17 or graduation from a high school, whichever occurs first. A beginner is a child who enters a school district's lowest elementary school grade that is above kindergarten (PA Code, Title 22, http://www.pacode.com/secure/data/022/chapter11/s11.13.html). All of the subjects in this study are of compulsory school age.

Individualized Education Plan (IEP) – is a legal document associated with Individualized Education Program under the Individuals with Disabilities Education Act (IDEA) that promotes more effective progress through a standard public school curriculum for a student who meets the criteria for special education services (The Goldberg Center for Educational Planning, 2012).

Individuals with Disabilities Education Act of 1990 (IDEA), Public Law 101-476 – is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. This law was previously known as Education for All Handicapped Children Act of 1975 (EHA), Public Law 94-142. The most recent version of this law is 2004 (United States Department of Education, http://idea.ed.gov/).

Least Restrictive Environment – is one of the assurances that must be proven to the Secretary of Education by the State that, to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (United States Department of Education, http://idea.ed.gov/).

Section 504 of the Rehabilitation Act of 1973 (504 Plan) – extends civil rights to students with a physical or mental impairment in order for them to more equitably access their public school curriculum (The Goldberg Center for Educational Planning, 2012).

Americans with Disabilities Act (ADA) – prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications (U.S. Department of Justice, 2005a).

Rehabilitation Act – discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors (U.S. Department of Justice, 2005b).

	IEP	504
Definition	Individualized Education Program: student program or curriculum that is essentially different from what peers utilize – fundamentally a special education program at its core	Section 504 of the Rehabilitation Act of 1973: equal opportunity for those students with disabilities – fundamentally a general education program at its core with supports extended to access it
Purpose	Specialized instruction with modification of actual program or curriculum materials	Accommodations for accessing standard program or curriculum materials
Eligibility	Only under specified disability categories: Autism, Emotional, Specific Learning Disability, Sensory (Hearing, Vision, Deaf-Blind), etc.	Less discriminatory – available to students with physical or mental impairment substantially limiting at least one major life activity, have a record of such impairment or regarded as having such an impairment
Oversight	Individuals with Disabilities Education Act (IDEA) – Education Law	Americans with Disabilities Act (ADA) – Civil Rights Law
Contents	Disability listing, vision statement, progress impact, short-term goals, accommodations/modifications, behavior and/or social skills plan if applicable, summer services, transport needs, placement recommendation	Plan objectives, definitions, care and self-care details, resource access, health/medical monitoring, emergency planning, testing and classroom dynamics, communication and notification instructions, additional contact details
Funding	Federal funding	No federal funding
Reciprocity	A student covered under IDEA on an IEP is automatically covered under ADA's Section 504	A student covered under ADA's Section 504 is not necessarily covered by education law under IDEA
Testing	Standardized testing accommodations available	Standardized testing accommodations available
Tracking	Progress reporting	No progress reporting

Figure 1: A Support Plan Comparison © 2007 The Goldberg Center for Educational Planning™, LLC

Plasticity – is the ability of the brain to adapt to deficits and injury (Monfore, 2005).

Re-Entry – means a second or new entry (Merriam-Webster Online Dictionary, http://www.merriam-webster.com/dictionary/re-entry).

School Age – is the period of a child's life from the earliest admission age to a school district's kindergarten program until graduation from high school or the end of the school term in which a student reaches the age of 21 years, whichever occurs first (PA Code, Title 22, http://www.pacode.com/secure/data/022/chapter11/s11.12.html).

Traumatic Brain Injury (TBI) – is a form of acquired brain injury that occurs when a sudden trauma causes damage to the brain. The damage can be focal - confined to one area of the brain - or diffuse - involving more than one area of the brain. TBI can result from a closed head injury or a penetrating head injury. A closed injury occurs when the head suddenly and violently hits an object but the object does not break through the skull.

A penetrating injury occurs when an object pierces the skull and enters brain tissue. Traumatic brain injury is a type of acquired brain injury since the person experiencing the injury was not born with it (NINDS, 2009).

Acquired Brain Injury (ABI) – is any injury to the brain after birth, including all types of traumatic brain injuries. ABIs often occur as the result of a stroke. Often times, TBI and ABI are used synonymously (Brain Injury Association of America, 2012; WebMD, LLC, 2012).

Delimitations and Limitations of this Study

Since BrainSTEPS is "based on a successful brain injury school re-entry model implemented in other states" (BIAPA), I focused on the successful re-entry of students with a brain injury in Pennsylvania (n.d.b). More specifically, since there is a BrainSTEPS team local to my residence, I focused on students with brain injuries from that county. As a case study researcher, I became immersed in my study to collect and then analyze the qualitative data. I could not have taken a snapshot of my subjects and expected to walk away with the complete picture. While I would have liked to more fully immerse myself into my project, and feel that intensive, long-term, and widespread involvement could be valuable for the research, taking a leave of absence from my full-time job to follow some of the students with brain injuries through their rehabilitation and re-entry process was not feasible, nor was it practical to travel long distances. This study will in itself, despite the logistical limitations, provide an important contribution to understanding the field; and although it may apply to other settings, generalization was not the goal.

Choosing a local sample is typical of case studies such as this where I conducted personal interviews and observations. I relied on previous studies in different geographic locations to fill in any blanks that I felt existed due to the geographic limitation. I could also have extended my sample into neighboring counties if the need had arisen; however, I decided not to do that in order to keep the variables to a minimum. The sample used was selected primarily for logistical reasons and also for its ability to provide an adequate population and sample to respond to the research questions.

Significance of the Study

Between 1991 and 2001, the number of students educated with traumatic brain injury increased steadily from very few to approximately 15,000 according to data provided by the U.S. Department of Education (Bullock, Gable, & Mohr, 2005, p. 8). TBIs have the potential to significantly disrupt a student's cognitive, academic, social, emotional, behavioral, and physical functioning, as well as their long term growth and development (Bowen, 2005; Mayfield & Homack, 2005; Pieper, 1991; Stavinoha, 2005). The student, as well as those involved in his or her education including family, medical personnel, teachers, counselors, and school administrators, must understand the effects of the student's TBI on his or her learning, need to set attainable goals, and then should work together to develop a plan to reach those targets. Since each TBI affects each student differently, the plan needs to be tailored to fit the specific needs of each individual. One student re-entering school after suffering a TBI may or may not be able to accomplish the same tasks as another student that has suffered from a similar TBI. Therefore, an assessment of each student's strengths and weaknesses needs to be done prior to defining the goals and developing a plan. Detailed information on specific assessments can be found in Appendix B, which begins on page 141. The educators should rely on the expertise of those from the medical field to determine the consequences of the injury, but the doctors, nurses, and therapists should rely on the educators to determine specific accommodations that need to be made in the school setting. The student and his/her family should be involved to add additional insight. This study looked at each piece of this puzzle. Together, the hope is that each student that suffers a traumatic brain injury will be able to re-enter school on a full-time basis, with the support of others.

"Successful school re-entry following TBI is critical to recovery. Early intervention has the potential to improve academic outcomes and promote effective coping with any persistent changes in functioning" in the short- and long-term (Deidrick and Farmer, 2005, p. 23). This study was designed to determine what factors impede or enhance the successful school re-entry of students with a brain injury. "Even children who have suffered "minor" or "mild" head injury may have sustained physical damage to their brains which will change their lives. This kind of damage to the brain is often overlooked. Such brain damage may go completely unrecognized until changes and problems surface" (Pieper, 1991, p. 1). If these problems are detected sooner and treated appropriately, perhaps the student, his/her family, and his/her educators will avoid a cycle of frustration and failure that might otherwise occur.

Although the numbers of school-aged children and adolescents suffering traumatic brain injuries are staggering, I was only able to locate two studies, both performed in the past decade in Australia, on the student and family perspectives of the school re-entry process. Since the educational system in Australia differs from that of the United States, there is a need for further research in this area. After developing a conceptual framework to support their study, Sharp, Bye, Llewellyn, and Cusick (2006), who focused on the family perspective, stated that "further research is required to understand in more detail the perspectives of adolescents themselves, their peers, the rehabilitation team, and schoolteachers" (p. 777). Mealings and Douglas (2010), who did focus more on the adolescents, feel that "as clinicians and educators, we need to explore this dimension of success/satisfaction in more detail" (p. 14). The purpose of the present study was to respond to this need.

This study provides additional insight into those students that have suffered a TBI to the students themselves, their families, and their educators. Through a literature review and the close investigation of students with a brain injury at various stages of the re-entry process, this study determined what factors impede or enhance the re-entry to school of students with a brain injury. This study concluded that some of the accommodations thought to be helpful in the past are still useful, but this study also illuminated new ideas that can and should be implemented to help the student make a successful transition back to school. This transition process cannot be made without the cooperation of the student, his/her family, individuals from the medical field, and educators including teachers, counselors, and administrators.

This study is also significant because traumatic brain injury has been recognized as its own category for children with disabilities in federal special education laws. Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA), added the category of traumatic brain injury in 1990. "The regulations governing implementation of the IDEA were amended to define this category as follows:

> 'Traumatic brain injury' means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma [34CFR§300.7(b)(12)] (Bohmann, 2007, p. 13; Bowen, 2005, p. 37; Bullock et al., 2005, p. 7; McCaul & Osher, 1993, p. 1-2).

Previously, "students with TBI (were) entitled to special education services through provision of the Education for All Handicapped Children Act of 1975 under the heading of 'other health impaired'" (Bullock et al., 2005, p. 7). The seriousness of the effects of a TBI on a child's education necessitated the change. Just as educators need to know about other disabilities, they now must also be familiar with TBI.

Everything comes at a cost. According to a conservative estimate made by the Centers for Disease Control (CDC), as reported by the National Brain Injury Research, Treatment and Training Foundation, "TBIs cost the U.S. economy over $56.3 billion annually" ([NBIRTT], 2007). According to Finkelstein, Corso, Miller and associates (2006) "direct medical costs and indirect costs such as lost productivity of TBI totaled an estimated $60 billion in the United States in 2000" (p. 136). Perhaps working to prevent TBIs can lower both the cost of direct medical attention and lost productivity, but this study found some factors that could lead to lowering the indirect costs. Once the factors that are found to enhance successful re-entry are implemented and those that are found to impede progress are removed, then perhaps lost productivity can be recouped.

Theoretical Base

While there are many theories that could be applied to this aspect of the research including motivation theories [cognitive evaluation theory (Deci), intrinsic vs. extrinsic motivation (also Deci), expectancy theory (Vroom), goal-setting theory (Locke), self-determination theory (Deci), investment model (Rusbult), and self-efficacy theory (Bandura)], memory theories such as network theory (Bower), theories based on emotion such as Mood-Congruent Judgment (Isen et al.), the Kübler-Ross Grief Cycle, a similar cycle developed by Lezak, and Cognitive Behavioral Theory (Beck & Ellis), social identity theories (Turner) such as Self-Discrepancy Theory (Higgins) and the Theory of Personal Construct Psychology (Kelly); this study will only take a look at a few that have been directly applied to traumatic brain injury.

Since, according to Stavinoha (2005), “social, emotional, and behavioral disturbances following TBI may severely interfere with educational success”, I will focus on these three categories (p. 14). Self-Determination Theory, Self-Efficacy Theory, Kübler-Ross Grief Cycle, and the Lezak sine wave model will describe how the internal thoughts and feelings reflect on how the student with the brain injury, his or her family members, and other members of the support team act outwardly. The basis presented here begins with how motivation affects behavior.

Self-Determination Theory, a motivation theory proposed by Deci and Ryan (1985) posits that we all have a perceived locus of causality (PLOC), internal or external.

> Researchers on this topic have pointed to some key skills associated with self-determination: self-regulation, self-knowledge, self-reflection, problem solving, goal setting, self-monitoring, and decision making. Obviously, many students learn these important skills without them being formally taught. Moreover, these are critical skills for all students” (Marks, 2008, p. 55-58).

“For people with severe disabilities, limitations in personal ability, opportunities, the perceptions of others, and the environments in which they live, learn, work or play limit the degree to which they can become more self-determined” (Wehmeyer, 2005, p. 119). Students that perceive that their behavior is stemming from their own decisions have a higher internal PLOC and are more intrinsically motivated than those with a higher external PLOC. Therapists and teachers will need to evaluate if each student has a higher internal or external PLOC and assign tasks accordingly.

Similar to Self-Determination Theory, Self-Efficacy Theory focuses on internal and external factors that stimulate a person. Self-Efficacy Theory, also associated with motivation, was originally developed by Bandura (1986) to explain how clinical interventions can affect anxiety. According to Simon Driver (2006), “this has implications for people with brain injuries” (p. 150). Driver applied self-efficacy theory to traumatic brain injury through physical activity. Through his study, Driver found that feelings of efficacy, or confidence, associated with specific tasks "may increase enjoyment and motivation to participate" in certain activities, especially "in the face of barriers" (p. 150-151). Conversely, "individuals may avoid" certain activities that "exceed their coping abilities without supports". Barriers play a critical role in shaping an individual's feelings of efficacy. Driver concluded that since individuals with brain injuries

> may be faced with a greater number of barriers, their feelings of self-regulatory efficacy (will) decrease. Research indicates that individuals with increased self-efficacious feelings display greater effort and persistence, whereas people with low feelings of efficacy are more likely to discontinue participation. Thus, it is suggested that self-efficacy theory offers potential as an appropriate theoretical framework to understand the behaviors of people with brain injuries (Driver, 2006, p. 152-153).

Driver broke his theory into four categories.

> Self-efficacy theory predicts that there are four main antecedents to an individual's feelings of self-efficacy, including past performance accomplishments, vicarious experiences, social persuasion, and physiological arousal. These sources are listed in order of their impact on self-efficacy with past performance exerting the strongest influence followed by vicarious experience, and so forth. The first antecedent is past performance, which refers to the amount of success or failure an individual has previously experienced with a particular activity. The individual's appraisal of previous events will then influence expectations for future success, as they perceive that they did it once, so they can do it again. Research has shown that positive previous experiences enhance feelings of self-efficacy (Driver, 2006, p. 152).

Although students with a brain injury may have memory problems, letting them know how they did in the past may or may not be helpful.

Driver continued with the idea of demonstrating where a non-injured person such as a peer or a teacher shows the student with a brain injury how to do something.

> The second antecedent, vicarious experiences (modeling), involves watching someone else complete the activity. When the model is successful then self-efficacy is increased, but if the model is unsuccessful then self-efficacy beliefs decrease. Findings from the modeling literature indicate that self-efficacy and performance can be increased through the use of successful models. (In Driver's study), results indicated that individuals exposed to the peer model group were more self-efficacious and performed better at post intervention and follow-up assessments. Findings from the modeling literature also indicate that the impact of the model is increased when there is similarity between the model and view (e.g., ability, age, gender). For

> example, a male with brain injuries will relate better to a male model that has similar disabilities (e.g., spasticity, balance issues) than to a female without a disability. Thus, if individuals view a similar model completing a task successfully then their feelings of efficacy to complete the same task will be increased. This will cause them to feel greater enjoyment. Research reinforces this tenet of the model (Driver, 2006, p. 153).

This second precursor will dictate the classes the students with brain injuries are placed in, and the teaching methods used by the instructors. For example, placing students with a brain injury in inclusion classes with other students with special needs will help them see that they can overcome their disability. Also, the teacher may want to use a lot of demonstration in his/her technique rather than predominantly using the lecture approach.

The next influence that Driver calculated would be helpful to students with a brain injury is verbal coaxing, but this can also have a negative effect if the person providing the prompts does not maintain a positive approach.

> The third antecedent, verbal persuasion, involves verbal or nonverbal cues from a significant other. Persuasion can be either positive or negative and both statements have a differential effect on an individual’s self-efficacy, affect, and motivation. For example, if individuals receive negative persuasion from a family member (or teacher), then they will have lower feelings of efficacy. Consequently, they will not participate because they do not think (cognition) or feel (affect) that they can (accomplish a task). Conversely, individuals who receive encouragement from a friend will have higher feelings of self-efficacy and thus be more likely to (complete a task). Research has shown a link between positive persuasion, self-efficacy, and behavior. Positive persuasion (is) associated with greater feelings of efficacy. The credibility, expertise, and assumed knowledge of the source of persuasion will impact the interpretation of the (positive or negative) statement (Driver, 2006, p. 153).

Thus, the school might want to consider implementing a peer mentor program, which will pair up a good, positive student with a student with a brain injury to reinforce his/her accomplishments and provide encouragement for continuation of their efforts.

Although the last component that Driver proposed, physiological states, was supposed to have the least impact on self-efficacy according to him, prior to my research, I envisioned that it would play a large role in my population of school-aged subjects. “The fourth influence on feelings of efficacy is physiological states, which include somatic symptoms in response to a stimulus. Links between an individual's physiological state and feelings of self-efficacy have been reported for younger populations", which is the age group that I intend to focus on in this study (Driver, 2006, p. 154).

> Although physiological states are postulated as having the least influence on self-efficacy, the significance may be increased for people with brain injuries due to movement and mobility problems. Subsequently, physiological states may have a greater impact on the feelings of efficacy of individuals with brain injuries compared to the other antecedents due to the physical impairments associated with the disability (e.g., spasticity, ataxia, apraxia). Considerable research exists that supports the use of self-efficacy theory as a tool for understanding behaviors (Driver, 2006, p. 154).

Since behavior issues are one of the problems that students with brain injuries exhibit, this dynamic would probably be an important part of my study.

Now that I know what motivates students with a brain injury to act a certain way or complete a specific task, I explored the emotional roller coaster that they, and their family members, endure. While the Kübler-Ross Grief Cycle (1969) is usually associated with death and dying, it has also been linked to any negative experience beyond terminal illness from less significant injuries to loss of employment or change in family make-up. The grief cycle explains the various emotional stages that a person goes through when trying to cope with his/her unfortunate news, as described by Straker (2009). Immediately following the bad news, the person is usually in a state of shock, which offers him/her some stability. As they come to grips with the news, they are usually immobilized, which leads to denial, then anger, then escape. When the person cannot escape the situation, he/she usually becomes depressed, and then realizes that he/she needs to look for rational solutions. Over time, the person learns to accept the state that he/she is now in. Students with brain injuries will most likely go through each of the stages of the Kübler-Ross Grief Cycle. It is important for those supporting the student to know which stage he/she is in and must ultimately help him/her get to the acceptance stage, so that they can move forward. At times, this process is a non-linear one, as documented in other systems.

Robin Dock, a licensed professional counselor and disabilities services counselor at Morehouse College in Atlanta, Georgia, who "generally sees individuals with traumatic brain injury after they have been diagnosed," describes a client who appeared to go through the stages suggested by Kübler–Ross (Morkides, 2009, pp. 41-42). According to Morkides, Dock says "After the skateboarding accident he sometimes couldn't remember what to do from one moment to the next. Was he angry? Absolutely. Was he depressed? Absolutely. Did he have to grieve his loss? Yes. In situations such as these, Dock says, counselors can offer a valuable service by teaching clients coping and stress-reduction strategies and helping them normalize their feelings of anger, frustration and loss. In addition, counseling interventions might include behavioral modification, cognitive restructuring and environmental restructuring to address social skills deficits, disruptive thoughts and physical barriers. The use of training techniques to enhance attention and concentration could also be part of treatment. Psychotherapy might be necessary to address reactive depression, heightened irritability and anxiety" (p. 42). I expected to witness the subjects with the brain injuries going through these stages and hoped to see the counselors helping them cope, but instead found that those that they had personal relationships with prior to their injury, such as parents, were more helpful in their emotional recovery. This will be discussed further in Chapter Five below.

Lezak (1986) developed a six-stage model similar to that of Kübler-Ross to explain the ups and downs that the family members of the person who suffered a traumatic brain injury experience. During the first stage, the family members have a positive outlook, expecting a full recovery of their relative with the brain injury. Just like the next stage of the Kübler-Ross Grief

Cycle, reality starts to set in for the family members in Lezak's second stage. They begin to feel anxious and have a sense of bewilderment. Then, while the injured seems to regain his/her previous "strength and vigor" and "attempts to return to preinjury activities (and) perform everyday tasks", the family becomes disappointed at their relative's failures to complete those activities in Lezak's third stage (Stejskal, 2009, p. 15). They start to blame themselves and "feel guilty for not having obtained better services so that the survivor could make more improvements" (p. 15). Just like Kübler-Ross, the pendulum swings back for Lezak, as stage four is when the family members realize "that they are not at fault for the survivor's limitations" (p. 15). They also begin to recognize that the survivor may have hit his/her max recovery point. While this initial acceptance is the final stage of the Kübler-Ross Grief Cycle it is occurring during this fourth stage of Lezak's model. Following the acceptance stage of Lezak's model is the stage where "the family relinquishes hope for the survivor's recovery and a complete return to preinjury functioning" (p. 16). The final stage of the Lezak model has the same characteristics of the Kübler-Ross model, as this is a time where family finally believes what they began accepting in stage four, thus they reorganize and "find alternative means to leading satisfying lives". Lezak's model makes sense according to Bohmann (2007) because "the student and his or her family and friends remember the injured student's level of functioning before the accident" (p. 14). Bohmann feels that "this awareness can lead to grief, anger, and guilt about the injury and the loss of previous skills" (p. 14). Obviously, both models present peaks and valleys similar to those our economy goes through. Patients, as well as their families, will need a lot of support as they overcome these emotions.

Indeed Lezak (1988) was able to prove that "brain damage is a family affair". Due to the significant changes of the brain-injured patient and the roller coaster of emotions described above, family members need to adjust to their "new" relative, and also help him/her adjust socially. "Behavior problems that are direct consequences of brain damage (include) impaired social perception and social awareness, impaired control, dependency (especially) on their families or caretakers, inability to learn from experience, (and) emotional alterations" (pp. 113-118). Stejskal (2009) and Kreutzer et al. (2009) studied the impact that brain injury can have on the families through an evaluation of the Brain Injury Family Intervention (BIFI). They applied the Family Systems Theory (FST) developed by Dr. Murray Bowen and the Cognitive Behavioral Theory (CBT) developed by Beck and Ellis. "No two injuries are exactly alike" and can vary depending on the severity of the injury, what part of the brain the injury occurred in, the age and overall health of the patient when s/he sustained the injury, and other factors (Stejskal, 2009, p. 12). "Difficulties encountered by survivors do not diminish rapidly, often persisting over the course of the survivor's lifetime. Families can have a powerful impact on survivors' recovery" (p. 13). FST describes how "families are interconnected systems. The actions, communications and feelings of each family member typically influence those of their family members and the family as a whole. To strengthen family systems, the BIFI relies heavily on family therapy techniques including empathic reflections, validation, reframing and normalization of common concerns" (Kreutzer et al., 2009, p. 538). CBT is used to describe the domino effect of one change leading to another, thus understanding each change and how to respond to it, will help families limit that effect. After receiving support through BIFI, families felt that more of their needs were met; they perceived fewer obstacles to more help, and felt that their brain-injured relatives were less depressed. The support can be most effective when it is tailored to meet the specific needs of the brain-injured person and his/her family. This information is extremely important to this study, as it dictates the necessity of the school to provide support for the family. The relationship is a symbiotic one, where the school wants support from the student's family at home, but the family also needs the support of the school. The school may need to rely on outside help to provide the necessary support to the family.

It is easy to see how the Self-Efficacy and Self-Determination Theories are related to one another and how the Kübler-Ross Grief Cycle and Lezak's stage model are related, but an extra step is necessary to bring all of the theories together. The first two describe how the level of motivation in a student with a traumatic brain injury affects his or her behavior. The Kübler-Ross Grief Cycle and Lezak's stage model describe how both the injured person and his or her family respond to the injury. During certain stages, both the injured and the family members will be more motivated than at other times. They will most likely work harder and show positive behaviors during the stages of optimism, but exert far less effort during the more negative times.

Summary

Traumatic brain injury is a significant problem in our society, especially for school-aged children. However, despite the difficult path that the students recovering from traumatic brain injuries will experience the students retained the motivation to learn. This study sought to find out how the student can learn best with the help of his or her family members, educators, and counselors.

CHAPTER TWO

REVIEW OF LITERATURE

Introduction

Even though the number of brain injured people is startling and cries out for greater attention, very few people outside of the medical profession and those who know someone that has suffered a traumatic brain injury have any TBI expertise. Even those that are related to or are friends with someone that has suffered a TBI often only know about that individual's injury and ensuing disabilities. If very little is known, especially, by educators, then it will be very difficult to plan and implement recovery strategies from a traumatic brain injury leading to the best possible outcome, although there may be an inadequate number of educators prepared to support this population of students in schools (Mohr & Bullock, 2005, p. 53). While TBI patients suffer in a variety of ways, one common finding is that they will make most of their progress in the one to two years following the injury. "Longitudinal studies indicate that children typically exhibit a gradual recovery over the first few years following the injury, with the most easily observable improvement occurring in the time soon after the injury" (Stavinoha, 2005, p. 14). Bowe (2000) felt that the majority of the recovery took place during the first year (p. 141) and Chapman (2005) stated that "over time, there can be a plateauing effect, with little or no progress for long periods of time" (p. 19). However, a multitude of sources, including most of those noted in the references section of this paper, note that each brain injury is unique. The reader must fully understand TBI, teacher awareness of TBI, concerns that teachers have about educating TBI students, assessment of TBI students, and the school re-entry process. This comprehensive review of the literature is intended to provide a background to help the reader understand this particular study.

Traumatic Brain Injury

I feel that a general knowledge of traumatic brain injury is important to the reader. This background information can be found in Appendix A on page 129. Information included consists of causes and risk factors of traumatic brain injury, signs and symptoms of traumatic brain injury, complications that occur from a traumatic brain injury, and the rehabilitation for a patient with a traumatic brain injury, which may or may not be school-based. A brief summary of each of these sections is provided here since traumatic brain injury is at the heart of this study. There are many causes of traumatic brain injury, as TBI can occur whenever the brain experiences an external and unnatural occurrence such as those that occur when a person falls and hits his or her head. Falls are the most common cause of brain injury and you will see that was the cause of the TBI experienced by two of the student subjects in this study. One of those two students showed many signs and symptoms of a traumatic brain injury including headaches, light sensitivity, and the inability to focus or concentrate. Many of the subjects exhibited fatigue, especially when first returning to school, which is another common symptom of TBI. Many of the subjects also exhibited some of the common complications including social inappropriateness. It is important to note that not every subject showed signs of his or her injury in the same way and they did not all exhibit similar consequences, so, while comparable, each case should be treated on an individual basis. As such, the rehabilitation of each of these individuals was not identical. Some required longer hospitalization, some required in-patient rehabilitation, and all of them required at least minimal rehabilitation at school. While the facts and figures provided in the appendix are vital to this study, it is assumed that those interested in the research have some knowledge of TBI, thus it was felt that due to the length of the information presented, it was a better fit for the appendix and should be referred to on an as-needed basis.

School Re-Entry Process

As stated above, there are some school based programs for children that suffer a TBI. This section of the literature review will take an in-depth look at the school re-entry process, which begins with communication between those involved with the students with a brain injury. "Regardless of the severity of the injury and length of rehabilitation services, advance communication and coordination between the hospital, therapists, family, and the school system is a critical first step in student's returning to school. The goal of this communication should be to gather medical and functional information to assist the school in developing an appropriate and individualized (education) plan" (Bowen, 2005, p. 35). "An Individualized Education Plan (IEP) will be developed with input from the parents and classroom teacher" (Pieper, 1991, p. 4). "This communication should be ongoing and the re-entry plan determined prior the student's return to school. Specific classroom interventions and accommodations required to optimize a successful school reintegration should be developed after careful assessment of students' needs, including medical, physical, cognitive, and social-emotional problems. Because a TBI involves a progressive recovery process, a student's physical mental endurances may be limited during their initial return to school and steadily improve over time. Therefore, consideration of different schooling options may be necessary, including homebound instruction, gradual increase in school attendance, or change in class schedules to a less demanding course load" (Bowen, 2005, p. 36). Stephanie Hartshorn, a student described in an *Intelligencer* newspaper article at Pennsbury High School in Bucks County who receives services through BrainSTEPS, received homebound education since her accident in December 2008, hoped to return to school part-time in April 2009 and full-time in the fall of 2009. "Stephanie actually suffered a concussion in April 2007 after a riding mishap. At the time her family did not realize she needed to be gradually eased back into her life. Stephanie went back to school, but her grades suffered and she had trouble concentrating. The second time around her family learned of the program and has taken advantage of its resources" (Bentman, 2009, p. A1). "Academic programming and scheduling must be flexible and customized to fit children's changing needs. Class enrollment and expectation should be based on students' current, rather than previous, academic performances. Rather than push students quickly through classes and require them to make up missed assignment, students should be allowed additional time to relearn concepts and regain skills. Ongoing observation and assessment of students after their return to school is usually required to develop appropriate interventions and to evaluate the effectiveness of interventions" (Bowen, 2005, p. 35). Each of these steps is extremely vital to the successful re-entry.

While most formal re-entry programs begin with a communication stage and go through a process of gradual school re-entry, it is important to emphasize the importance of each of these steps. When participants in a study conducted by Mohr and Bullock (2005) were asked to think of critical success factors for a student returning to school following the acute phase of recovery, those who were familiar with TBI mentioned some of the key points stated above as well as others:

- Establish a system of communication early between school, family, and rehabilitation centers prior to the student's discharge from the rehabilitation facility. This concept has been mentioned as being particularly important to successful school re-entry (Deidrick and Farmer, 2005; Farmer, Clippard, Luehr-Wiemann, Wright, & Owings, 1996; Farmer & Peterson, 1995; Savage, 2005). Failure to plan early and communicate decreases the probability of successful outcomes for the student.

- Obtain information about the injury along with successful interventions or strategies used in the rehabilitation setting, and use this information to help prepare staff and peers for working with the student. The chances of success upon school re-entry are increased if planning and preparation are undertaken with the specific strengths and limitations of the injured child in mind (Bowen, 2005; Mayfield, 2005; Mira & Tyler, 1991; Savage & Wolcott, 1988; Semrud-Clikman, 2001).
- Establish a schedule that allows a shortened school day to accommodate the student's need for physical recuperation. Researchers (Clark, 1996; Deidrick and Farmer, 2005; Farmer & Peterson, 1995; Schoenbrodt, 2001; Semrud-Clikeman, 2001) have emphasized the importance of structuring the student's school day so that he or she can be most productive. This may require accommodations, such as scheduling the most intensive classes at times when the child is most alert, and shortening his or her school day to provide for rest.
- Appoint a staff member to be the liaison between rehab and school staff. Appointing a person to be responsible for ensuring that information is shared among school, family, and rehabilitation personnel is an essential component to obtaining successful outcomes. Ideally this 'case manager' is someone who is specially trained in issues related to school re-entry and planning, and can facilitate a smooth transition for the injured child and family (Deidrick and Farmer, 2005; Tyler & Mira, 1999).
- Take the family's needs into consideration and empower them by getting them involved in the planning and monitoring. Family involvement is vital to the success

of the student's re-entry, and as a major part of the planning team, the family's needs and strengths should be carefully considered (Bowen, 2005; DePopei & Blosser, 1993).

- Structure the physical environment to accommodate the student's needs and be prepared to make changes according to the student's results (Bowen, 2005; Semrud-Clikeman, 2001).

As one can see, the participants that knew about TBI made suggestions that are clearly backed up by research. Unfortunately, the participants that were not as knowledgeable about TBI were unaware about the injuries and the above specific suggestions. Teacher awareness of TBI will be looked at later in this literature review.

The school re-entry process has been studied previously. Kathleen Deidrick and Janet Farmer have spent a lot of time looking into this topic and feel that successful school re-entry is critical to recovery following TBI. Citing numerous researchers, Deidrick and Farmer (2005) have defined the four key principles of the re-entry process as assessment, multidisciplinary teaming, facilitation of peer interactions, and planning for the provision and withdrawal of support. Specific assessment tools will be discussed in a later strand of this literature review. According to Deidrick and Farmer the multidisciplinary team should be made up of professionals in the school, medical and rehabilitation, and family settings, as previously mentioned above. The professionals that should make up the team from the student's school include his/her regular education teachers, a special education teacher, the school psychologist and/or counselor, a school social worker, the school nurse, therapists, and an administrator. Glang et al. (2004) echoed this sentiment through a discussion of the TBI Consulting Team Model. "Since it's founding, the Oregon TBI Consulting Team has included individuals with

TBI, parents, classroom teachers, special education teachers, speech/language specialists, school counselors, physical therapists, occupational therapists, school nurses, school psychologists, and administrators" (Glang et al., 2004, p. 223). Those representatives from the medical and rehabilitation side should include physicians, nurses or nurse practitioners, neuropsychologists or rehabilitation psychologists, and therapists. Family members should not only include immediate family members such as parents/guardians and siblings, but can also include extended family members, clergy, and friends and family since they probably knew the student best prior to the injury and will be able to best describe the changes that they see in the individual that suffered the TBI. These individuals should be in constant communication beginning as early in the recovery process as possible.

Another group of individuals, according to Deidrick and Farmer, which needs to be involved in the communication piece, is the student's peers. Many children and young adults are probably extremely unfamiliar with traumatic brain injury, thus they need to be educated on TBI and how to interact with their peers that have sustained such an injury. According to Janus (1994), "unless peers are given information that explains why there are changes in their friend, isolation and rejection may occur. This is especially true of the student returning to school with no obvious physical disabilities" (p. 483). Ylvisaker and Feeney (1998) state that "peers need help to play their role effectively" recommend that "either shortly before or at the time of school reentry, peers should receive information about the status of the child's injury and his or her potential needs in school" (p. 377). Such information "serves many valuable purposes. First, it can eliminate potentially negative myths and fantasies about TBI. Second," the injured student can be presented in a positive light, rather than as a person with a number of weaknesses (p. 377). "Third, students can be instructed about how to interact with and offer assistance to the injured peer" (p. 377). I believe that this is an important step due to not only the lack of knowledge about TBI, but also the immaturity of these individuals. I have seen first-hand the benefits of teachers, school counselors, and administrators preparing students for the return of a classmate to school following an extended absence due to an unfortunate event such as the death of a relative. Such preparedness makes the re-entry process less awkward for both the student re-entering and his/her peers.

The final stage of the re-entry process mentioned by Deidrick and Farmer is the planning for and withdrawal of support. Obviously the student with a brain injury is going to need a lot of support, both human and environmental, upon initial re-entry, but for long-term success, this support should be gradually withdrawn over time. Ongoing assessments should test to see which supports are needed and which supports can be slowly removed "as the child demonstrates an ability to remain competent with less support. Family and school staff alike should strive to reduce extraordinary supports as quickly as possible, being mindful of the threat of learned helplessness when too much is done for students with potentially greater competence than is attributed to them" (Ylvisaker and Feeney, 1998, p. 372). Other supports not initially needed can be added as necessitated, especially at "predictability critical times (e.g., the transition from grade school to middle school", middle school to high school, and high school to graduation) (p. 372). I hoped to find out what supports both impede and enhance the initial re-entry and ensuing transitions and see if they were similar to those already proposed.

As has already been stated, school re-entry programs are in existence. Vaughn and King (2001) discuss the funding of such programs:

> Through the advocacy efforts of the state affiliates of the Brain Injury Association (BIA), state policy makers have been informed and educated about the need for assistance for individuals who may require extended rehabilitation, care, and support that is often beyond the capacity of existing systems to fund and deliver. As a result, many of the

> states have passed legislation creating programs and services specifically for individuals with TBI and their families. A very small number of states receive funding exclusively through a legislative appropriation from general revenue; others receive funding exclusively through trust funds or comparable reserves established with civil or criminal fines or fee assessments; and some states have the benefit of both. In general, these programs have been designed to fill in the service gaps by offering assistance not otherwise available through other state and federal programs. Some states have also entered into interagency agreements. The availability of U.S. Health Resources and Services Administration (HRSA) funded demonstration grants have provided states with an opportunity to examine carefully and improve their systems of services. (p. 20 & 30)

The programs "vary widely in the type of school re-entry assistance provided, amount and length of support, type of professional providing support, and the location of the support (e.g., school-based or medically based)" (Deidrick and Farmer, 2005, p. 27). BrainSTEPS, Pennsylvania's model, is "based on a successful brain injury school re-entry model implemented in other states" (BIAPA, n.d.b). According to Alexander et al., (2001), North Carolina's "Project ACCESS (Assuring Coordinated Care, Education, and Support for Survivors of Pediatric Brain Injury) has used hospital-based pediatric brain injury Community Transition Coordinators (CTCs) to identify, coordinate care, educate, support, and generally improve the lives of thousands of children with TBI" (p. 359 & 363). The Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) and the Student Centered Education Management and Advocacy (SCEMA) program use an interdisciplinary team approach to their programs. PABICOP is medically oriented, but includes a school liaison while the SCEMA program is located within the school and includes the student as a key member (Deidrick and Farmer, 2005). Oregon, Tennessee, Iowa, and Kansas have models in which teams of educators are trained "to act as consultants to facilitate school re-entry in a particular school district" (Deidrick and Farmer, 2005, p. 27). The last model discussed by Dedrick and Farmer (2005) is one where individual school psychologists are trained "as experts in TBI assessment and intervention within the school system" (p. 27). Such a system exists in North Carolina. I will determine which of the above models is the example that BrainSTEPS is based on because this may dictate different factors in the re-entry process. While Deidrick and Farmer (2005) acknowledge the variety of models, they feel that "further research is necessary to determine whether these programs promote adjustment to school after TBI. High rates of satisfaction with ACCESS have been reported", while SCEMA has received "some criticism" (p.27). Deidrick and Farmer did not provide any feedback on the other programs, so I agree with their statement that more research is necessary. However, the focus of this study was not an evaluation of the various models, but solely on the model used by BrainSTEPS, which provided me with initial access to subjects.

The Educational Leader and TBI

School administrators have an important role in the transition back to school for students with a brain injury. Administrative guidelines are set forth in several federal mandates including Education for All Handicapped Children Act (EHA) of 1975 (PL 94-142) and IDEA (PL 101-476). According to Janus (1994), these guidelines include:

> developing a plan of action for getting the information that is needed by the school system, providing opportunities and time for staff training, staying current on litigation and initiatives pertaining to special education law, monitoring and evaluating placement decisions frequently, characterizing the student by learning behaviors and individual needs rather than a general definition, facilitating access to needed materials and resources, communicating with parents and peers, initiating and supporting local prevention efforts, being a liaison to staff members, and setting an example of acceptance and commitment to finding what works. (p. 485-586)

It is crucial for the school administrator to take each of these tasks seriously and to understand the full extent of TBI and its effects on students.

The school administrator does not need to accomplish all of the preceding guidelines on his or her own. As stated above, the re-entry process should involve a team effort that includes "at least one school administrator (e.g., building principal; director of special education)" (Ylvisaker and Feeney, 1998, p. 376). Indeed, it is the principal that should orchestrate the formation of the team. According to Bohmann (2007), "School administrators can help develop partnerships with the student and family. The principal should ensure that the appropriate school specialists meet the student and family and that the lines of communication between educators and the family are open to meet needs and celebrate successes" (p. 14). Although the principal should remain a part of the team, he or she may "call on the school psychologist to prepare staff members to support (the student's) recovery and transition back to school" (p. 12). The school psychologist could educate staff and students if the principal feels that this would benefit all of the parties involved. It is important to note that according to the U.S. Department of Health and Human Services Health Resources and Services Administration (2004), "Most teachers do not receive pre-service training on the effects of TBI on school performance and very few graduate programs in special education provide training in TBI" (p. 1). Amazingly, according to Glang et al. (2004), "surveys of speech/language pathologists and school psychologists indicate that even these professionals, who are usually the school personnel most knowledgeable about neurological disorders, receive little training in assessment and intervention with students with TBI" (p. 221). Frank et al. (1997) concluded that educators "who had either received coursework or practicum experience with the TBI population or who had met the requirements for the national certificate of clinical competency (CCC) were more likely to feel prepared to serve children with TBI" (p. 50 & 57). This is an important indicator that the principal should provide in-service for teachers at schools with students with a brain injury, prior to the students' re-entry, so that they are better prepared to help with the re-entry process.

As a member of the support team, the administrator has an extremely important job. Often times, all parties involved are experiencing "pain (and) frustration and staff hours are being spent struggling with how we can respond to a student who does things that are disruptive, inappropriate and/or unsafe" according to Todd et al. (1997, p. 426). These are "challenges schools face all across the country. Long-term results are dependent on a team process, people making the effort to work together, and (people) taking the time to understand what is needed to help a person be successful" (p. 425-427). The team needs to "assess and provide support for students" (p. 434 & 436). If everyone works together in these efforts, their time invested will decrease and should result in a more effective re-entry. The principal needs to facilitate this efficient team approach.

Aside from organizing and being part of the transition team and providing in-service training to teachers, there is even more that educational leaders can do to smooth the re-entry process. According to Bohmann (2007), "Administrators (or counselors, if they do the scheduling) should try to place a student with a TBI with teachers who have consistent expectations and strong organizational skills" (p. 14), as these are supports that will help the student learn. It is not enough for administrators to help the student with a brain injury come back to school. S/he should try to make sure that the student stays in school. Obviously, one way to do this is to continue to be a part of the re-entry transition team. Another way to do this is help with the student's transition to the next grade level, which might also involve a school change. According to Bohmann (2007), "Communication between teachers and between schools when students move to a (different grade or school) will help staff members set appropriate expectations and carry over effective accommodations. Administrators can take the lead by encouraging school visits, planning conferences, and ensuring the transfer of all appropriate information about the student's health status and school needs" (p. 14-15). Janus (1994) outlines the following as administrative tasks:

> promoting awareness, providing staff in-service training and supporting pre-service training, helping to identify those students that have suffered a TBI when the parents fail

> to notify the school, facilitating the evaluation and placement of TBI students, planning the school reentry, integrating services offered by the educational and medical fields, making appropriate modifications to the school environment when necessary, providing support to the family and peers of the TBI student, helping the family find adequate funding for services, and initiating efforts to prevent brain injury. (p. 475-485)

Obviously, it is important for administrators to be leaders as much as they need to be managers in this situation, but they must also seek help from their team members to accomplish all of the necessary steps to enhance reentry.

Teacher Awareness Studies of TBI

As previously stated earlier in the literature review, educators' familiarity with TBI varies from very little to well-informed. Those educators that are working directly with students re-entering school after a TBI need to be made aware of TBI in general, and the specific injury and effects of the students in their classrooms and schools. Mohr and Bullock (2005) conducted two focus groups "to ascertain professional educators' perceptions regarding their (a) level of preparedness for working with students with TBI, (b) ideas regarding ways to improve support to students and families, and (c) concerns about meeting the diverse needs of children with TBI" (p. 53). Most educators expressed an interest in enhancing their knowledge about TBI according to Mohr and Bullock (2005) and Stahl (2008). These researchers all felt that educators expressed a desire for more professional development in the area of TBI, an increase in communication between themselves, the families of the TBI students, and those in the medical profession, and more support for the families of these students. Perhaps if these ideas were implemented, they would calm the concerns of these teachers, which are mainly that they do not have enough knowledge about the needs of students with TBI, thus they are afraid to teach these individuals. I included school personnel associated with the TBI students as subjects, and tried to provide these individuals with as much general information as possible about TBI, but I also plan on sharing the specific results of this study with them with the hope that factors that are found to support the re-entry process can be implemented immediately while those that are found to impede the process are removed as quickly as possible.

Assessment of Persons with TBI

As discussed earlier in the literature review, assessment and communication are essential components of the beginning stages of the re-entry process of students with TBI. While communication and medical assessments should take place as soon as possible after the injury, other forms of assessment and more communication should follow shortly thereafter. "Assessment that is tailored to the individual child and occurs frequently over the first few years post-TBI can help providers (a) to develop an individualized re-entry plan based on the child's personal strengths and weaknesses, and (b) to monitor closely changes in child functioning so that providers can adapt the plan in a timely and flexible manner" (Deidrick and Farmer, 2005, p. 25). "A comprehensive assessment should look to the child's pre-injury performance at home, at school and in the community. Parents should be involved in giving information and insights" (Pieper, 1991, p. 6). This section of the literature review will look at the problems associated with assessing students with TBI and the various types of assessments used with these students.

As noted above in the discussion about TBI, the consequences of the injury sometimes return a completely different student to the classroom. Due to the disabilities caused by the TBI, assessing students with TBI can be very difficult. "Because of the heterogeneity of outcomes associated with TBI and the effects of mediating variables, such as age at the time of injury, severity of the injury, and the time since injury at the time of assessment, students with TBI pose a particular challenge when assessing educational needs. In addition, variables that can be difficult to quantify, such as physical concerns, must be considered carefully in educational programming for students with TBI, as these symptoms can significantly impact the student's success in school" (Stavinoha, 2005, p. 14). "The federal regulation (IDEA) provides a listing of functional areas that can be affected by the injury. The list is both extensive and definitive covering behaviors and skills related to major life functions and learning. Any particular individual may be affected in more than one area. Therefore, the process for assessment of students who have experienced a TBI should be comprehensive enough to screen for possible deficits in all thirteen areas" (McCaul and Osher, 1993, p. 2). "All of the elements of good general assessment become crucial when brain injury is suspected or documented" (Pieper, 1991, p. 6). These assessments are a huge, but necessary undertaking. As noted above, the assessments should be part of an ongoing process with a team of individuals working together to complete and facilitate the process.

In order to provide a complete and accurate assessment, a wide range of assessment instruments and activities should be used including assessments measuring cognitive skills, behavior, and speech/language deficits. Detailed information on specific assessments can be found in Appendix B on page 141. "Because the impact of TBI is unique for each child, there is no standard approach to rehabilitation assessment. However, useful guidelines do exist. First, each child's assessment should be individualized and directed toward the goal of recovery from TBI. Second, because of the broad range and complexity of impairments that can result from TBI, a multidisciplinary team approach is needed. Third, family members and educators should be considered integral members of the rehabilitation team and important contributors to the assessment process. A final major issue concerning assessment in rehabilitation has to do with strategies for collecting information about cognitive and behavioral changes following TBI" (Farmer, Clippard, Luehr-Wiemann, Wright, and Owings, 1996, p. 532-533). Farmer (2005 and earlier) recommends a hypothesis testing approach to assessment. She feels that this approach may be particularly useful. According to Bowen (2005), "in addition to formalized assessment of cognitive skills that may be conducted, the special education team at the school (i.e., school psychologist, special educator, speech language pathologist), uses a Functional Behavioral Assessment (FBA) to examine, measure, and treat many deficits associated with TBI, particularly behavioral changes related to increased impulsiveness, inappropriate emotional outbursts, aggression, and inattention. An ABC (Antecedent-Behavior-Consequence) assessment is on simple means of conducting an FBA. In conducting an ABC Assessment, assessors record the events that occur immediately before and after the unwanted behavior" (p. 35). These are just a few of the assessment measures. The discussion about various assessments will continue below in Appendix B on page 141.

Supported Employment for Persons with TBI

There is a wealth of research on the effects of supported employment on persons with developmental and other severe disabilities. Much of this research has been conducted by the Rehabilitation Research and Training Center on Supported Employment and studies individuals aged 20 and beyond. I see an indirect relationship between the supported employment research and the research of TBI and its effects on students because both involve re-entry into the victims' pre-injury routine. In an exemplary study performed by Wehman et al. (1989), which was included in the third volume of a report edited by Kregel, Wehman, and Shafer (1990), the employment outcomes of persons following TBI were explored. The study found that all persons had a very limited or inconsistent work history post-injury due to the severity of the injury. The most significant finding of the report was that as a collective group, supported employment was able to facilitate restoration of vocational capacity from pre-injury levels. This means two things to me. First, it was important for me to find out the severity of the TBI suffered by the students in my study, as that may be a predictor of future academic success. Second, my hunch that the level of support provided in the educational setting would be a factor in the re-entry process proved to be true. This study predicted similar findings to the supported employment study.

Student and Family Perspectives of Returning to School

As stated in Chapter One of this document, there is very little research about school re-entry following a traumatic brain injury. That amount becomes even smaller if we look at returning to school from the students' perspective and from diverse perspectives that includes many of those affected from school administrators, to counselors, to psychologists, to teachers, to students, and to families. I was only able to locate two such studies that dealt with the students' perspective, both performed in Australia, so the current study is the first documented analysis of its kind in the United States. Mealings and Douglas (2010) performed a preliminary case study on three adolescent Australian males that suffered traumatic brain injuries upon their return to school. They found that "the different responses of students to their changes and the associated impact on goals and participation influenced the way students perceived the success of their school participation, that 'success' could not be measured by any one aspect of participation", and that the students valued relationships and the support that they received (p. 1 & 14). These "three key themes derived from the students' experiences can be conceptualized as an interactive, dynamic model which is shown here in Figure [2]" (p. 9-10):

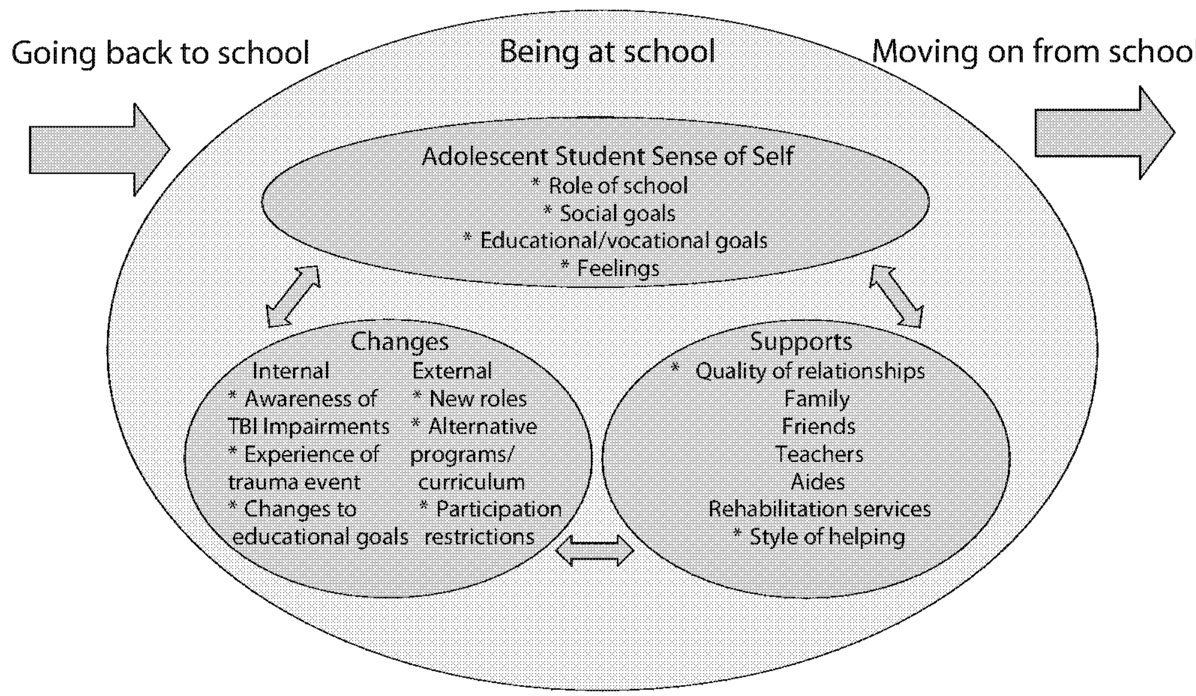

Figure 2: Adolescent Experiences of School Participation after TBI © 2010 Mealings and Douglas

Whereas Mealings and Douglas focused solely on the student perspective, Sharp, Bye, Llewellyn, and Cusick (2006) concentrated on the family perspective of Australian adolescents. "The main focus of this study was on understanding perspectives of parents regarding return to school for adolescents post ABI (acquired brain injury), although where possible, adolescents were also involved in the study" (Sharp, Bye, Llewellyn, & Cusick, 2006, p. 777). As far as the authors of this study were aware, theirs was the first of its kind; thus they developed the conceptual framework found here in Figure 3:

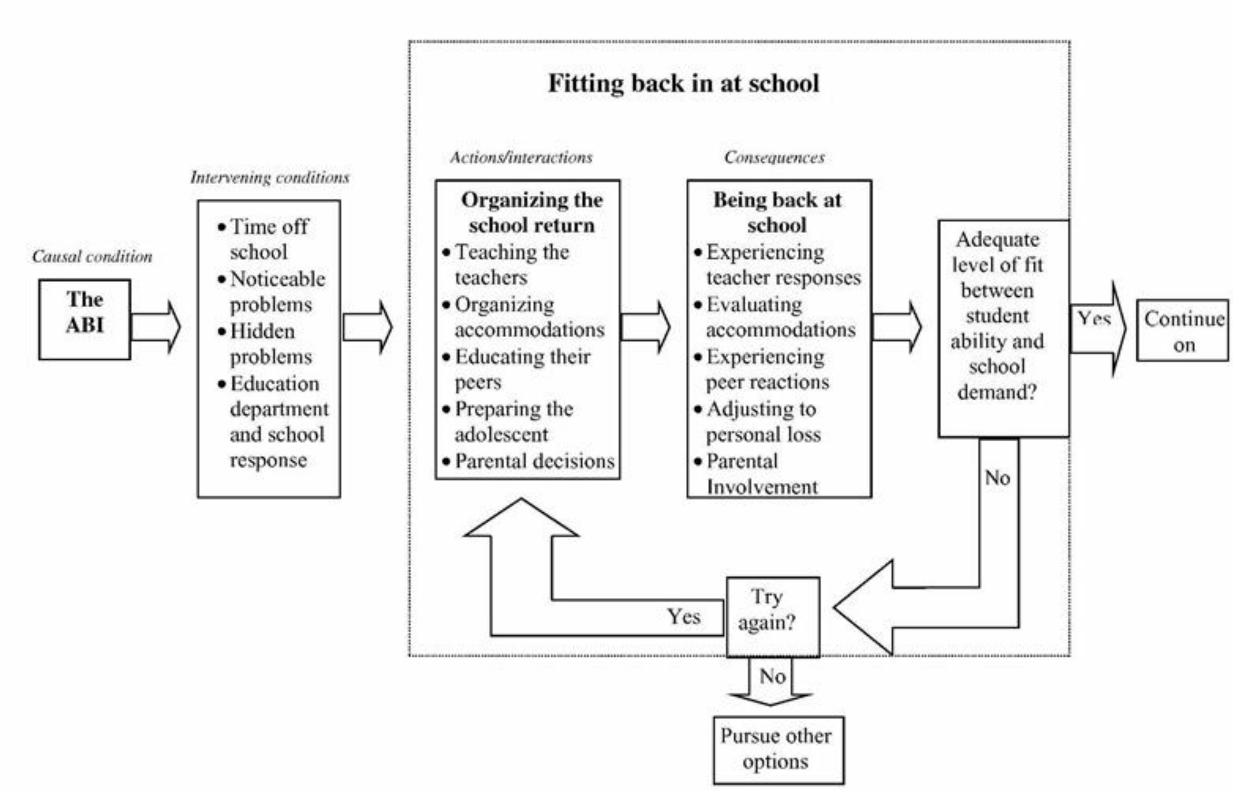

Figure 3: Provisional Conceptual Framework of the Return to School Experiences of Adolescents with Recent Severe ABI © 2006 Sharp, Bye, Llewellyn, & Cusick

Sharp et al. felt that this framework "provides a basis for future research and also a basis for further exploration and comparison of the experiences of adolescents with a variety of acquired disabilities" (p. 177). The methods used in these two studies were similar to those used in the current study; and I adapted the data matrix found in Appendix Z from Table 1 in both of these studies (Mealings & Douglas, 2010, p. 5; Sharp et al., 2006, p. 769). I received quotes similar to those found in tables two through four (p. 6, 7, & 9) and noticed similarities to Mealings' interview questions as to those provided in Appendices O through Q below. Mealings and Douglas (2010, p. 13) felt that their findings lined up with those realized by Sharp et al. (2006). This study realized similar findings to both of these studies, as anticipated. The findings of the current study are discussed in Chapter Four below.

Summary

Traumatic brain injury is a serious problem amongst school-aged children and adolescents. The medical and education fields alike cannot ignore this problem, especially when these young people prepare to return to school. While some re-entry programs exist in many states across America to facilitate the transition back to school, very little is known about their attainment and it seems that teachers remain unaware and administrators still do not understand their important role in this process. Beyond the initial assessment of these students, which should be comprehensive enough to evaluate the cognitive, behavioral, organizational, and social skills of the students, nobody seems to be sure how to work with them, and people have made very little effort to ask the students themselves. Teacher awareness studies show that educators know very little about how to work with students with a traumatic brain injury. While adults that have suffered a traumatic brain injury have been researched upon their return to work, I felt that the student perspective was lacking, especially being looked at through multiple lenses including the student him- or herself, the family members, the educators, the educational leaders, and the counselors. I hoped to gain the student perspective to fill the gaps in this research.

CHAPTER THREE

METHODOLOGY AND PROCEDURE

Assumptions and Rationale for a Qualitative Design

The voice of students with a brain injury needed to be heard and integrated with the voices of those involved in their school re-entry including their families, teachers, school psychologists, counselor, and administrator(s). I gathered all of those voices to find out what factors impede or enhance the re-entry process for all parties involved. I did not conduct an experiment, but rather conducted research on a group of identified students who were re-entering school after suffering a traumatic brain injury. I did not have any influence over the re-entry process, but rather observed and tried to understand the events as they unfolded. I could have solely looked at grades or test scores, but since they may be subjective and up to the teachers' interpretation, and they may not tell the whole picture, this study required a qualitative design in which I was able to come to my own conclusions, which would also be subjective, but would be more impartial and validated by looking through the lenses of multiple perspectives.

I personally collected data in the instructional setting. This looked different for each student, which will be described in Chapter Four below. In general, as part of the student's therapy early on, schooling started in the hospital for some of the students, then it progressed to the home, and then the student finally returned to the actual school building, usually on a part-time basis, then on a full-time basis. "Qualitative inquiry, which focuses on meaning in context, requires a data collection instrument that is sensitive to underlying meaning when gathering and interpreting data. Humans are best suited for this task, especially because interviewing, observing, and analyzing are activities central to qualitative research" and activities that I planned on completing in this study (Merriam, 2009, p. 1-2). I looked at data from interviews that

I conducted, data from observations that I carried out, and the information provided on Individualized Education Plans (IEPs) and 504 plans. "The case study's unique strength is its ability to deal with a full variety of evidence—documents, artifacts, interviews, and observations" (Yin, 2003, p.8). Although I did consider surveys as a means of collecting demographic data, my dissertation chair, an experienced qualitative researcher, felt that I would collect richer data if I asked these same questions during my interviews with the participants, which I did. As Glaser and Strauss (2009) surmised, my hope would be to "'catch enough' that later will prove relevant", (p. 70). The specific data collection and data analysis procedures for this particular study will be described in the ensuing sections.

Role of the Researcher

I am a doctoral student with a master's degree in education in an educational administration program at an urban research and academic institution. I have been a school library media specialist for approximately seven years. In this position, I have taught research skills to students in kindergarten through twelfth grade, as well as to my colleagues. I am extremely organized and able to manage a flexible work schedule in my current position as a secondary school librarian. I work in a Pennsylvania public school, so I am held to strict confidentiality laws [such as the Family Educational Rights and Privacy Act (FERPA)] and school board policies. More specifically, as a librarian, I am one of the many people in the school building that teaches the students about the importance of academic integrity. My experience as a librarian has helped me to become a good communicator. In this position, I must be able to deal with multiple personalities, as this position is one of the very few in the school building that comes in contact with every student, staff and faculty member, and administrator in the building. I have also served in numerous leadership roles in various extra-curricular activities, both as a student and as a professional, which require good communication skills. One thing that I have learned is that everyone likes to be heard. It was important for me to listen to my subjects while I collected data through interviews and observations. As the webmaster of my building, I also need to be able to communicate to a large audience from various backgrounds, so that helps me learn to articulate clearly and understand others' perspectives. I did not anticipate any problems managing data, as I am skilled and experienced with technology and the use of tracking software such as creating spreadsheets in Microsoft Excel, and I am competent with data organization software, and I did not experience any difficulties with this. Lastly, I have the internal motivation and drive to learn and consider myself to be a lifelong learner.

One area where I thought I might struggle was removing my bias as I have sensitivity towards those who suffered a traumatic brain injury, after seeing my own mom go through this plight for approximately the past eighteen years of her life. On February 19, 1994, my mother was involved in an auto accident in which she suffered a traumatic brain injury that resulted in the loss of her long-term memory among other less significant consequences. This experience is the inspiration of this research topic. I feel as though I overcame this bias through the use of various methods of verification, as described below.

Population and Sample

BrainSTEPS is a child and adolescent brain injury school re-entry program in Pennsylvania created in 2007 by the Brain Injury Association of Pennsylvania, under contract from the PA Department of Health and partnered with the PA Department of Education. There is a BrainSTEPS team local to my residence, so for logistical reasons, I gathered my sample there through the help of the team leader for the county. The team leader stated in an e-mail that she thought she would have families that would be willing to share their experiences (S. Krusen, personal communication, October 5, 2009). I contacted the BrainSTEPS coordinator to reach out to the families that were part of its support group. The coordinator asked for participants directly and through the parent that runs their e-mail listserv. "The (county) team has a caseload of about 20 students, who run the spectrum in types of injury and help that's needed" (Bentman, 2009, p. A1). While the caseload had almost two dozen students, none responded to the team leader's initial call for participants. I then contacted Camp Cranium (2011), "a non-profit summer camp dedicated to providing a one-of-a-kind experience for children with brain injuries", to reach out to campers and their families that were from the same suburban county. This is how I obtained my first interview subject. When I was finally added to the BrainSTEPS listserv, I e-mailed the other members of the list that I had not already been in communication with to see if they were interested in participating. This is how I attained my second student interview subject. Lastly, contacts were made through school districts in the same county that utilized the services of the BrainSTEPS team. This is how I made the last connection. I did send follow up e-mails and make follow-up phone calls several times to certain schools, districts, and individuals that I believed would add to the study if interviewed, but not everyone responded and others were unavailable, so I used those individuals that agreed to participate or attended the meetings. I intended to select a sample from those willing to participate that ran the gamut of the spectrum from those recently discharged from the hospital or an in-patient rehabilitation program and beginning home schooling, to those that are going back to school on a part-time basis, to those that are returning to school full-time, but was unable to do so due to the difficulty in obtaining participants, so all of the students interviewed had returned to school on a full-time basis. I intended to include as many of those that were willing and able to participate in the caseload with the anticipation that some subjects would not be willing or able to participate in the study. I did not coerce the participation of any subjects that were unwilling to participate. Although I planned to allow participants to drop out at any time, none chose to do so, and all participated through the duration of the study. Permission was sought from the administration of each student's school and district prior to the action research phase of the study.

Data Collection

The results of this study arise from data collected through interviews, supporting documents such as Individualized Education Plans (IEPs) and 504 plans, and personal observations made at the schools, during the interviews, and at BrainSTEPS meetings. I attended monthly BrainSTEPS meetings held at the Intermediate Unit in the county of my participants from December 2010 to March 2011. The interviews, which lasted approximately thirty to forty five minutes each, were conducted with the participants from August 2011 through November 2011 at various places ranging from the subjects' home, place of work, or a public place. Although I did consider starting the interviews with a written survey to collect demographic data, I decided against this, so the interviews chiefly consisted of open-ended questions focused on the students with the brain injuries' transition back to school following the traumatic event. Although the interview protocols can be found in Appendices N through Y on pages 163 to 176, I feel that it is necessary to provide a sample of questions here since the interview protocols reflect the original longitudinal design of the study rather than the retrospective study that took place. For example, I would ask the students what their biggest fears about returning to school were, and then follow that up with a question about how that worry was going for them at the time of our interview. I personally transcribed the interviews, which were recorded on an Apple iPod Touch, and then reviewed the transcriptions for accuracy. The transcriptions were analyzed for reoccurring patterns that I first noticed at BrainSTEPS meetings that I attended. These common responses were highlighted in a bold font style, and then noted at the end of the transcription and also on a data analysis chart that I kept separately. I also collected data through direct observations of each school and participant before, during, and after the interviews. Documents including Individualized Education Plans (IEPs) and 504 Plans that were shared with me by the parents were also analyzed for commonalities; however, other than a general introduction to the student, I did not find that these documents provided any further insight into the students that was not revealed at the interviews. Please refer to appendices C through Z on pages 145 through 177 at the end of this document for the permission to study letters, informed consent forms, acknowledgement and consent forms, permission to audiotape forms, interview protocols, and data planning matrix.

Data Analysis Procedures

I used multiple data analysis procedures to analyze the data, which I began doing as soon as I started collecting it. I arranged the demographic data into multiple tables, as presented here, for organizational purposes.

Table 1: Student Interview Participant Demographics

Pseudonym*	**Gender**	**Age at Injury**	**Grade at Injury**	**Age at Interview**	**Grade at Interview**	**Cause of Brain Injury**	**Living situation/ conditions**
Heather	F	13	8th	17	12th	Brain Tumor followed by a Stroke	Home with parents and younger sister
Scott	M	9	4th	12	7th	Brain Tumor followed by a Stroke	Home with parents (dad has own medical issues)
Suzy	F	13	8th	14	9th	Kicked in the Head followed by a Fall (Concussions)	Home with twin brother

*Names have been changed to protect the confidentiality of the subjects.
Adapted from Table 1 in Wehman et al., 1990; Table 1 in Mealings & Douglas, 2010; and Table 1 in Sharp et al., 2006

Table 2: Adult Interview Participant Demographics

Gender (M/F)	Relationship to Student
F	Heather's Mom
M	Heather's MathTeacher
M	Scott's Principal
F	Scott's Reading Specialist
F	Scott's Counselor
F	Suzy's Mom
M	Suzy's Principal
M	Suzy's Asst. Principal
F	Suzy's Reading Teacher
M	Suzy's Science Teacher
M	Suzy's Social Studies Teacher
F	Suzy's Math Teacher
F	Suzy's EnglishTeacher
F	Suzy's Counselor

Table 3: Students attending BrainSTEPS Meetings

Student Subject No.	Gender (M/F)	Cause of Injury	Pseudonym*
1	F	Brain Tumor and Stroke	Heather**
2	M	Brain Tumor and Stroke	Scott**
3	F	Concussion and Fall	Suzy**
4	M	Stroke	Mike
5	F	Concussion	Nora
6	M	Concussion	Cameron
7	F	Motor Vehicle Accidents	Lynn
8	F	Stroke	Nancy
9	F	Concussion	Morgan
10	F	Motor Vehicle Accident (Passenger)	Brenna
11	F	Falls	Erica

*Names have been changed to protect the confidentiality of the subjects.
**Same as Table 1 above

Table 4: Adults attending BrainSTEPS Meetings

Adult Subject No.	Gender (M/F)	Relationship to Student
1a	F	Mom
3a	F	Mom
4a	F	Mom
5a	F	Mom
6a	M	Dad
7a	M	Dad
7b	F	Mom
10a	F	Mom
10b	M	Dad
22	F	BrainSTEPS county team coordinator
23	F	BrainSTEPS team member
24	F	BrainSTEPS team member
25	F	BrainSTEPS team member

Prior to commencing my study, I anticipated the use of only one client demographic profile, for the students with a brain injury; however, I quickly realized that I would need more than that to differentiate between the students and the adults and those that participated in interviews and/or attended BrainSTEPS meetings. These tables were referred to throughout the data analysis.

As you can see from the tables above, there were many participants in this study. Sixteen individuals were interviewed. Two of these individuals were students that had returned to school following a traumatic brain injury. A parent of each of these students was also interviewed. Three school administrators were interviewed. Two of these leaders are principals and one is an assistant principal. Seven teachers were interviewed ranging from classroom teachers to specialists. Two school counselors were also interviewed. All of the above were part of the K-12 education system in the suburbs of a major metropolis on the East Coast of the United States. While the number of attendees at the BrainSTEPS meetings I attended fluctuated, there were approximately an additional nine students and parents, including guest speakers, as well as members of the BrainSTEPS team, which included the countywide team coordinator, speech pathologists, occupational therapists, and physical therapists. The brain injuries of the students that were interviewed and/or attended the BrainSTEPS meetings were the result of the following: motor vehicle accidents, concussions, falls, brain tumors, and strokes. The individuals that were interviewed for this study were associated with the countywide BrainSTEPS program in some way. It was my hope to interview all of the students that attended the BrainSTEPS meetings, as well as a family member, and members of each individual's educational community, but not all of them could participate for a variety of reasons including that they already had too much on their plate, the school district not willing to participate, or they simply had no interest. I am grateful for those subjects that were willing and able to participate in the study.

I primarily used the constant comparative method of analysis developed by Glaser and Strauss in 1967 "as the means of developing grounded theory" (Merriam, 2001b). The use of the constant comparative method of "joint coding and analysis" allowed me to be flexible with my data as I accrued more and more of it. (Glaser and Strauss, 1999, p. 102). Since the constant comparative method is "dependent on the skills and sensitivities of the analyst" it does not "guarantee that two analysts working independently with the same data will achieve the same results" (p. 103). Instead, "it is designed to allow, with discipline, from some of the vagueness and flexibility that aid the creative generation of theory" (p. 103). I developed categories based on themes that exposed themselves in the data and linked them to the theories explored in Chapter One. I began developing these categories from the data that emerged through the field notes that I took at the BrainSTEPS meetings, and then confirmed their existence through the data that I collected at the interviews. When it was necessary, I developed additional categories by comparing data from one student with another student and from one student at a particular point in the re-entry process with that same student later in the re-entry process. I used these categories to identify which factors impeded and those that aided the re-entry process of students with a traumatic brain injury by seeing what all of the participants felt was helpful or lacking in individual cases.

Methods of Verification

As with any study, this study has several threats to its validity. First and foremost, I saw my own bias, as described above, as the major validity threat in this study. To combat this and the other threats to internal validity, I relied on rich data. I asked subjects to provide specific examples and to go into as much detail as possible in their responses to my interview questions. Recognizing that some subjects might not feel comfortable sharing specifics verbally or simply may not be able to, I used various collection methods. Through triangulation, both collecting data through various sources including IEPs and 504 plans, interviews, and observations, and from multiple perspectives including the student him- or herself, at least one family member, a school administrator, the school counselor, and at least one teacher, I was able to create a better whole picture. I also was able to confirm the validity of my data by searching for discrepant cases within my data and through comparison with similar studies. Threats to the validity of my study were not a problem with so many methods of verification.

Ethical Issues

Whereas threats to validity were not a problem in this study, the mere fact that the majority of the primary subjects in this study were be special education students under the age of eighteen means that ethics played a large role in this study. I minimized any potential harm to the subjects involved in the study by working closely with the adult subjects, my dissertation advisor and committee members, and the Temple University Institutional Review Board. A parent was present during each of my interviews with the students. Whereas my own experience with brain injured persons had the potential to create bias, my sensitivity to the subjects helped protect them, as I did not want anyone to suffer the slightest bit of harm, especially emotionally. As previously stated, I only conducted my study with those students that completed an informed consent form and all data collected will continue to remain anonymous and be stored in a secure location until it is destroyed.

Outcome of the Study and Its Relation to Theory and Literature

While there has been a plethora of studies on the effects of a traumatic brain injury on human beings, very little literature exists on TBI and its effects on students. In the literature review above, the reader is exposed to a large amount of research conducted by the Rehabilitation Research and Training Center on Supported Employment on the effects of supported employment on persons with developmental and other severe disabilities. This presents the case of support for work, but not for school. This study aimed to find out if a similar support system would help the students with brain injuries in the school re-entry process. While a job coach may help an employee, perhaps an aide might help a student. This study also looked at the effects of decreasing the involvement of the aide over time, both emotionally and academically.

The effects of traumatic brain injuries have been thoroughly studied. The literature review notes that medical professionals know what happens to people that suffer through TBIs and what their road to recovery looks like, but does not suggest the best factors to support the re-entry process to school. While some of the literature proposes strategies that may work, these approaches have not been widely tested. For example, we know that people that suffer TBI often have memory loss and a personality change as a result of the injury, but we do not know specific tactics to overcome these challenges and what support mechanisms need to be put in place for a successful re-entry. The study focused just as much on the process of re-entry as it did the effect of the TBI on the students. This study looked to find out what those factors are and how they can best be implemented, from a multitude of sources and perspectives, most saliently the students' own voice.

Federal legislation has included traumatic brain injury as a special education category for approximately twenty years. The legislation focuses on assessing the deficits that exist after a person suffers a TBI and how to accommodate for these deficits, since it is not always possible to completely ameliorate them. While there is no reported litigation in this arena, many governmental agencies have expressed the possibility that this could happen, so this study ultimately hoped to assist schools out in figuring out how to support students with disabilities associated with TBI.

Summary

Many children and adolescents suffer a traumatic brain injury each year in the United States, which affects how these individuals learn. Most students that suffer a TBI are unable to learn exactly how they did prior to the injury. Often times, the student is unable to return to school in the same capacity that he or she attended previously; however, a student with a brain injury will usually return as a special education student through a re-entry process. Organizations such as BrainSTEPS exist to support students and their families with this re-entry process, which this study looked to examine to find out what factors either impede or enhance this process.

This study focused on students who have suffered a traumatic brain injury in my locale for logistical purposes; however, I recognize that BrainSTEPS is a statewide organization based on successful models in other states. I intended to study students at various stages of the re-entry process from those just being released from the hospital or an in-patient rehabilitation program to those re-entering school on a full-time basis, but I ended up gaining a retrospective picture of students who had already re-entered back to school with a future outlook during one interview with each subject, other than the students that I saw at multiple BrainSTEPS meetings, students at various points in their education from elementary to secondary, and students who have suffered a variety of TBIs ranging from mild to severe.

I collected data through historical records that include medical records and academic records including IEPs and 504 plans, interviews, and observations, which I then analyzed using the constant comparative method. Through the analysis, I developed categories that spelled out the factors that impede or enhance the re-entry process. These themes will be discussed at length in Chapter Four below.

This study contributes to the already existing literature on traumatic brain injury and theoretical assumptions by narrowing its focus on several varied cases, which I looked at through an array of lenses including the student's own vantage point, a family member, and representatives from the students' school. I hope that the findings can be immediately applied to students recovering from a TBI and expanded to other students that are trying to overcome a prolonged absence from school for another reason.

Timeline

Activity	Dec 2009	Jan 2010	Feb 2010	Mar 2010	Apr 2010	May 2010	Jun 2010	Jul 2010	Aug 2010	Sep 2010	Oct 2010	Nov 2010	Dec 2010	Jan 2011	Feb 2011	Mar 2011	Apr 2011	May 2011
Establish contacts w/BrainSTEPS	■					■	■	■	■									
Preliminary Examination													■					
IRB Submission									■	■	■	■	■	■				
Literature Review	■						■	■	■									
Proposal Writing/Editing								■	■	■	■	■	■	■	■	■	■	■
Proposal Defense																		■

Activity	Jun 2011	Jul 2011	Aug 2011	Sep 2011	Oct 2011	Nov 2011	Dec 2011	Jan 2012	Feb 2012	Mar 2012	Apr 2012	May 2012
Gather demographic & historical data (medical & academic records)	■	■	■	■								
Data Analysis	■	■	■	■	■	■	■					
Round 1 of Interviews	■	■	■	■	■							
Round 2 of Interviews				■	■	■	■					
Findings								■	■			
Dissertation Defense									■	■		
Graduation												■

CHAPTER FOUR

RESULTS / FINDINGS

The findings are organized in two parts: (1) vignettes of six key actors in the re-entry process describing the transition in detail from various perspectives including: (a) students, (b) parents, and (c) educators; and (2) a discussion emergent themes including: (a) advocacy, (b) communication, (c) expectations, (d) support, and (e) awareness. Although each of the themes will be described in detail below, here is a graphical representation of them with a brief explanation of each:

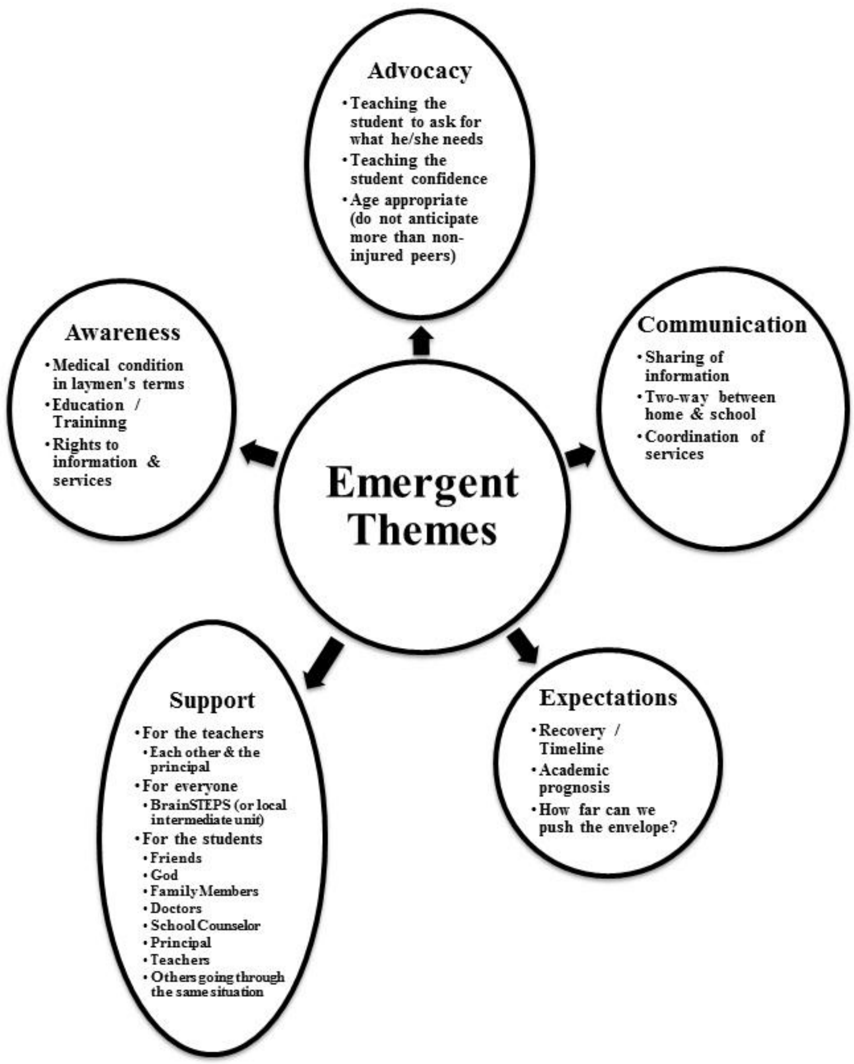

Figure 4: Emergent Themes © 2012 Rosenthal

Vignettes

The following stories are designed to give the reader an idea of what it is like to be a student with a brain injury, the parent or the educator of a student with a brain injury, or a member of the BrainSTEPS team. Although these stories are composed of small parts of the actual experiences of the subjects whom I have interviewed or observed for this study, they will give the reader an insight into their lives. The goal of these vignettes is to give the reader a feel for what I saw during my interviews and direct observations of these respondents, the information I gathered from supporting documents such as IEPs or 504 plans, or that I personally experienced as the family member of a brain-injured individual or as an educator.

Heather, A Student

Heather was a happy, go-lucky kid doing well in school; she had friends, and participated in extracurricular activities ranging from sports to theater. All that is lost one day and replaced by a constant headache and struggles to do simple tasks that were easy before. She still wants to be "normal" and go to school with peers, but instead getting better has become her new priority, which often means many trips to numerous doctors and trying various therapies. While Heather appeared to be more immature than her non-injured peers, she and her mom shared anecdotes such as preparing for the transition to college that show she still has plenty to live for. As I walked up to the front door of her house, I noticed two bumper stickers on a car in the driveway, one about equestrians and the other about dogs. I was greeted by Heather's service dog as soon as I stepped inside the house. She lit up when she was talking about the dog or about riding horses, which she has done occasionally for therapy. She was also really excited when she spoke about her school's soccer team. Even though she cannot play with them, and most likely will never be able to play with them or any other athletic team again, she was happy just to be a part of the team, even if that meant just sitting on the team bench on the sidelines. As Heather's high school years come to an end soon, she is hoping to be able to go to college, and then live on her own; however, she and her family describe plenty of obstacles in their way such as living independently. The following are some lingering questions that worry her mom.

> I think there's a lot of questions. Will she be able to hold down a full-time job with fatigue and her other issues? How will she manage to live independently? Where will she be able to live permanently? Will she be able to earn enough money to support herself? And, will she be able to manage household finances on her own and not forget things? And, I think there's a lot of questions. I think there's definitely a possibility that she could date and maybe get married someday, but I think it will be very different. She's somebody with visible, physical disabilities and some cognitive disabilities that affect social interaction, so, it's something that there's a lot of questions about.

With college just around the corner for Heather, this will be the first step to seeing if Heather can live independently.

Heather attends a faith-based independent school that services students in grades kindergarten through twelve on two campuses. One campus houses all of the elementary grades while the other campus accommodates all of the secondary students in two buildings – one for grades six through eight and the other for grades nine through twelve. However, as a special education student, she is entitled to special education services through the school district in which she lives. Her mom felt that the school district was somewhat reluctant in providing these services since Heather did not attend one of their schools; however, as a middle-class school district located about thirty miles outside of a major metropolitan area, they are certainly capable of doing so.

Heather's re-entry process began during her three-month stay at the children's hospital in the major metropolitan city east coast city closest to where she lived. One of Heather's teachers drove a group of girls from her school to the hospital on several occasions for lunch or dinner so that she could interact socially with her peers. Upon being released from the hospital that spring, Heather finished up that school year at home. Each of her teachers sent home work that they felt was important for her not to miss. While Heather completed that year, it did not go on her transcript. About one week prior to the start of the next school year, Heather and her mom met with the principal of her school and each of her teachers, in a group setting, to prepare for the upcoming school year. Heather went back to school full-time; however, she really was not there a lot because she left for treatments, therapy, and doctors' appointments about three to four times per week. Sometimes those appointments would keep her out of school for an entire day, whereas other times she would just miss a portion of the day. Even when Heather was at school, she often went to the nurse for breaks when she was feeling fatigued. As Heather's health improved and she learned how to cope with the fatigue during the school day, she started attending classes more often and eventually became a true full-time student again.

According to the most recent Individualized Education Program (IEP) that I obtained about Heather, "neuropsychological testing indicated weaknesses in visual/spatial problem solving, visual memory, and math problem-solving, while language-related functions were preserved" when she sustained her brain injury. The IEP, along with feedback shared by Heather's math teacher and her mom, also indicate her inability "to focus and sustain attention" and control her impulses and hyperactivity. Heather's math teacher and mom also had concerns about Heather's social skills and maturity level.

Scott, A Student

Scott was an active elementary student, but he was used to medical problems, as his dad suffered several complications that resulted from his own accident that he was in. While the family was coping with Dad's issues, they lost everything when Scott was hospitalized. They lost their business as it took all of their money to pay for his medical bills and they lost their home. Aside from the medical effects of his injury, Scott's entire life changed, as the family had to move into a much smaller home in a different town. Thus, he was not only transitioning back to school after his injury, but he was also transitioning to a new school. Scott's parents told the school that they knew that he was different following his injury and that it was more difficult for him to learn, but they did not feel that his deficits amounted to much. When tested by the school, they found this fifth grader to be on a first grade level academically. Despite all of his challenges, Scott tried extremely hard in school following his injury. During my interviews with Scott's principal, reading specialist, and counselor it seemed as though his perseverance, persistence, and self-determination became a motivating factor for them to continue to try to help him. They wanted to see him succeed, as he had become an inspiration to his peers. He was able to increase his knowledge by one grade level during his first year back, just as his fifth grade peers did. However, Scott was treated as a life skills student when he transitioned to the middle school, which was unfortunate because his elementary education team did not even feel he was quite ready for that transition to middle school in the first place; however due to pressures of accountability and his parents not knowing much about the educational system, he was forced into middle school anyway. While Scott has been accepted by his peers, it remains to be seen where he belongs.

Scott's school district is a suburban school district experiencing growth along with neighboring districts in the county. The district is a fusion of the yesterday and today, but maintains a small-town feel that combines agriculture and industry together. The community is made up largely of single family homes and developments and provides easy access to several larger cities including one metropolis in the Northeast United States.

Scott's transition was very similar to Heather's re-entry process. Like Heather, he missed part of a school year while his medical condition was being addressed. However, unlike Heather, Scott did not begin his transition at the same time that he was receiving treatment. His transition did not begin until just prior to the next school year because he was switching schools. The principal of his new school met with the director of pupil services to find out about Scott. Then, the principal met with the team of individuals at the school that would be working with Scott including not only his classroom teacher, but also the learning support teacher, guidance counselor, instructional support teacher, and the reading specialist at the school. This meeting was very similar to the meeting that took place at Heather's school. While Scott and his parents did not attend that meeting, they did come in to tour the school over the summer and met with the principal. Also like Heather, Scott officially attended school full-time, but unofficially attended part-time due to therapy appointments. His transition to becoming an actual full-time student took a little bit longer than Heather's process.

Suzy, A Student

Suzy was just like Heather prior to suffering multiple concussions. She did well in school and had a lot of friends. However, when I looked into Suzy’s eyes when we met at a coffee shop, it was obvious that she was still healing. She was extremely timid even though we had previously met each other at a BrainSTEPS meeting; however, she still did her best to answer my questions. This was the only interview that I took a break from and asked her to think about some answers and to possibly write them down while I interviewed her Mom. I let her know that I would come back to her so that she did not feel the pressure to answer immediately. She did relax over time, especially when she heard her mom answering the same battery of questions. While Suzy suffered some physical and cognitive setbacks such as constant headaches (her pain never seemed to go below a six) and memory loss, the social changes that she experienced following her injury seem to bother her the most. Her relationship with her twin brother deteriorated because he resented that his life changed as a result of her injury. While some of her friends stuck by her side, others accused her of faking her injury so that she would have an excuse to get out of things at school and to draw attention to herself. Some of her peers that were asked to help her, and agreed at first, grew to resent the attention that she was getting too. Suzy was constantly worried about what others thought of her. She is still working to learn not to care what people think, but this has been a struggle for her.

Suzy's school district is located in the center of the county and is one of the largest in the state, but maintains a suburban atmosphere. The district's advanced planning for its growth has allowed it to maintain stability. The school district considers itself a pioneer in many educational endeavors. The school district is also located not too far away from an important urban area.

While Suzy's re-entry process looked similar to Heather's transition from a social standpoint, it was drastically different from an educational perspective. Suzy's traumatic brain injury occurred at the beginning of one school year, and even though it went undiagnosed for almost one full week, she was never hospitalized, so she attended school every day in the beginning, and then went to doctors' appointments from there. About two weeks after the injury, she was pulled out of school and since the doctor wanted her brain to rest, she was not receiving any kind of tutoring. When that rest did not improve her condition, she stayed home for another month without any schooling. Since there was still no change in her medical state, it was decided that it was time to start transitioning her back to school. She was on full homebound tutoring for approximately another month and a half, but was able to go to school for lunch to socialize with her peers. Then Suzy began attending school part-time. She would go into school halfway through the day and stay there for the remainder of the day; however, a break was scheduled into her day. When this became too much for Suzy, she was pulled out of school again for the rest of the school year. The goal for Suzy during the following school year, which is the current year, was to attend school full-time. She is doing that; however, she currently has breaks scheduled into her day when her peers are taking their electives. Since Suzy seems to be handling this schedule, the school administration is considering re-introducing those electives back into Suzy's schedule for the second half of the year, so it appears that her transition will end just like those of Heather and Scott.

According to the Assessment of Special Needs section of Suzy’s 504 Service Agreement, “she has had persistent headaches, cognitive impairment and heightened visual and auditory sensory awareness (sounds and background noise, bright lights)” since sustaining a concussion. “Over the course of her 8^{th} grade year, doctors prescribed varying levels of physical and cognitive rest. A Neuropsych evaluation documented average intellectual ability and academic skills, but significant impairment with learning, processing, and memory. Anxiety and persistent significant pain (caused by the headaches) is felt to be a major factor in her learning and memory issues. Suzy presents as quiet and withdrawn in unfamiliar social and certain classroom situations and has difficulty advocating for her needs.” While I agree with how the plan suggests that she presents herself, her mom indicated that she was always introverted, even prior to her injury.

Suzy’s Mom

Like most parents, Suzy’s mom had high hopes and dreams for her children. Although they are young teenagers, she envisioned them graduating from high school, going to college, getting a job, marrying, and having children of their own. Then, her daughter suffered a mild traumatic brain injury and life as they knew it, and as the family knew it had changed forever. While she still has the same hopes and dreams, she realizes that just getting through the next day will be a challenge, so she and her daughter focus on short term goals rather than long term ones. She spends hours researching treatments for her daughter because they are still searching for an answer. She also spends a large amount of time chauffeuring her to and from school and doctors' appointments. While her employer has been extremely flexible with her comings and goings, her life is dedicated to her daughter, which has changed her relationships with her friends and the family dynamics. Like any parent, Suzy's mom just wants the best for her daughter and is willing to go to the end of the Earth to get it.

Scott's School Principal

Scott's principal had been leading his school for five years, and was an assistant principal at another school in a neighboring school district for two years prior to that when he decided to leave the classroom behind and move into administration. Despite all of this experience, all he knew when he found out Scott was coming to his school was that it would take a team effort to help this student out, and that the team members would be relying on him for direction since they had just as little experience in working with students with brain injuries as he did. Scott's principal was up for the challenge. He immediately began gathering as much information about the student as possible, then began forming the team. He coordinated a meeting of the group prior to Scott's arrival, but they would soon learn that Scott was much further behind his peers than they thought. Therefore, Scott's principal had to continue coordinating services for the team, which he did with the help of the school guidance counselor. Scott's principal gladly accepted the challenges that Scott presented. He made himself available to the team members, to Scott himself, and to Scott's classmates whenever they had questions.

One challenge that seems to still bother Scott's principal is accommodating the needs of a student such as Scott with the demands of accountability. He definitely felt pressure from the central office administration to meet the standards published for all students in Scott's grade level and make sure that Scott was promoted on to the next grade with his peers, but he knew that Scott was not capable of learning on grade level. While Scott was capable of growth, he would have had to progress through four grade levels in one academic year to catch up with his peers. Scott's principal and the rest of the team knew that this was an impossible task for any student, let alone one who had suffered a traumatic brain injury like Scott. His principal guided the team to take Scott as far as they could during that school year. If that meant not meeting all of the requests made by central office administration, such as Scott completing the Pennsylvania System of School Assessment (PSSA) then Scott's principal was willing to take that risk rather than have Scott sit through hours of testing to prove what they already knew, that learning was difficult for him and he was not on par with his peers. This was just one of many of the duties that Scott's principal had, as he was not given an assistant nor was he relieved of his regular obligations as the school principal. However, Scott’s principal still seems committed to doing what is best for each and every student, regardless of what challenges that fight takes, even with the central office.

Heather's Math Teacher

Heather's math teacher had been going to work every day for ten years teaching students with all levels of intelligence and abilities. He found ways for each and every one of his students to succeed by getting to know them as individuals first, then as students second. Building relationships was, and still is, important to him. Then, a student arrives with a traumatic brain injury that will affect how she learns, but he knew little to nothing about that injury, so he did not even know where to begin teaching this student. Heather's teacher attended a meeting prior to the start of the school year with her other teachers, principal, mom, and her. He is willing to do whatever it will take to educate her. Heather's math teacher starts planning for this unique situation immediately, trying to figure out what strategies he should try to use with her. As the school year progressed, he found that meeting with her one-on-one seemed to work, so he did this, as often as she needed it. Having a family of his own and children that attended the same school, this often meant giving up the chance to see his sons play in a soccer game. However, as the school year wore on and he became used to having Heather in his class, he admits that he forgot the little things that had been recommended he do for her early on, so wishes, in hindsight that someone reminded him, whether that reminder came from Heather, or a member of her support team. Now having Heather for a second time with a couple of years in between now and when he taught her before, he is happy to see that she has grown and once again willing to do whatever it will take to help her succeed.

These vignettes provide insight into many of the themes that emerged in the interviews and during my observations and the following is a discussion of those themes that arose in the data that I collected. The themes often overlap and intertwine, which you will see evidence of throughout the ensuing discussion, especially in the quotes that I provided. While none of the quotes is repeated, they could easily have been placed in multiple locations throughout the discussion.

Discussion of the Findings

Theme 1: Advocacy

Our first common theme is advocacy, especially when the student is at the secondary level. Somebody needs to advocate, or plead, for what those in the transition process need from the student to the teacher to the administrator. Advocacy, or another form of the word, such as advocate, was mentioned at every BrainSTEPS meeting I attended and in almost all of the interviews. The more a student with a brain injury is able to advocate for him- or herself during the re-entry process, the more likely that process will go smoothly and with the least amount of frustration. Self-advocacy, then, is the first factor that enhances the re-entry process. On the other hand, if a parent is advocating on behalf of his/her own son/daughter, but the child is unable to advocate for him- or herself, this could impede the re-entry process.

One story that came up multiple times at the BrainSTEPS meetings and some of the interviews was that of Mike, a student with a brain injury that attended these meetings and that had grown to become a self-advocate in this process. Unfortunately, I did not have the chance to interview Mike due to his school district's unwillingness to participate in my study. Plans for Mike's re-entry to school following a stroke that caused a brain injury began without him when he was still in the hospital, therefore, he was not present. Even when Mike transitioned back to school, he still was not present at the meetings about his progress until a member of the BrainSTEPS team suggested that he attend. The BrainSTEPS county team coordinator suggested that Mike gradually become more involved in these meetings, letting the teachers know what he needed to learn. This BrainSTEPS team member as well as Mike's mom are proud to sit back and watch him, now a high school junior, lead the meetings about what supports he needs from the teachers. Each time the BrainSTEPS county team coordinator shared the story with the entire support group, his mom had a grin on her face that spanned from ear to ear. The leadership that Mike has shown in becoming a self-advocate inside the classroom has expanded to extra-curricular activities as well, where he has become active. Although Mike was not present at the initial meeting and did not take an active role in the first meetings that he did attend, just being present allowed his comfort level to increase around those adults present, which can be a difficult situation for children to be in even without a traumatic brain injury. The reverse is also true, as the adults were able to become more familiar and comfortable with Mike, which helped answer some of the questions they had about him and how he learns since they were not all that familiar with traumatic brain injuries. As previously stated, this story was repeated on numerous occasions and can be looked at as a success, especially since Mike is expected to graduate high school next year alongside his identical twin!!

Advocacy can be a difficult concept. Suzy's mom was disappointed at both the school and the doctors when they suggested that Suzy advocate for herself. She commented that when she was Suzy's age and there was nothing wrong with her brain, she would not have been comfortable going into a room full of adults, calling a meeting, or even going up to an individual teacher.

> When I was thirteen-years-old and there was nothing wrong with my brain, and I'm sure you were the same way, would you go into a room full of adults? Would you call a meeting? Would you go up to a teacher in the middle of a class and say, "I need help. I need this." No. I just thought that was a little bit unrealistic and on top of that, you're not dealing with a normal thirteen-year-old person. You're dealing with a person with a brain injury now – a thirteen-year-old middle school teenager with a brain injury. So, I just thought that that was really unrealistic to expect that from a student. So something that I would like to see change is lower that expectation and realize it's not going to happen.

However, after hearing about Mike's learned ability to advocate for himself at multiple BrainSTEPS meetings and knowing that Suzy's mom was present during one of these meetings, I asked her if this is something she thought could happen gradually, and she, without hesitation, responded, "Definitely." She followed that up with a story about how Suzy asked her if she could become more involved, wanting to make sure on her own that her teachers were following her special education plan. Suzy's mom felt that was "a step in the right direction" and confidently re-affirmed that advocacy can happen gradually. She then mentioned that she and Suzy had spoken with other students at the BrainSTEPS meeting who did go through the same process.

Ironically, when I met with Suzy's teachers, the only meeting that I completed collectively in the educational setting rather than one-on-one, they felt that she needed to be more of an advocate for herself now. When I asked them if they would say becoming a better self-advocate if they had to pick one thing that Suzy needed to work on, they unanimously answered “Yes!” Their response was resounding, quite powerful in fact. Five teachers looking me in the eye and confidently affirming my suggestion to me, then looking at each other and repeating that confirmation amongst one another. Suzy's teachers had sent a powerful message that they wanted, and needed, to hear from Suzy what it was that she needed from them.

A student with a brain injury needs to progress through these levels of advocacy from relying on others to discuss his/her needs to becoming a self-advocate as quickly as possible. When speaking to one teacher who taught a student with a brain injury, Heather, during the her first year back to school and who has her again now, in her senior year of high school, the teacher felt that the student needed to be a bigger self-advocate.

> The only thing I would say, her first year, I think she tried to be, she wanted to be normal as quickly as possible, so she wouldn't, she wasn't her own advocate as strongly as I think she should have been. In other words, [teacher], could you explain that again, just one more time. She wasn't asking those questions. And all of us were prepared, students as well, that she might need to ask a question or so forth. Here it is, three years later. And now I'm having her again. Today was a good example. She asked a question...and that's okay. It doesn't bother me. And, I don't want it to bother her. She was self-conscious about her disability [in the beginning] to the extent that I think sometimes she never, she didn't ask the question that she should have.

This example shows us, that while it may be difficult for students with a brain injury to advocate for themselves, they need to because another support, such as mom or dad, the principal, a counselor, the nurse, or a doctor, is not always going to be there and the teacher may not be able to figure out what the student needs. The sooner that the student learns to do this for him- or herself, the smoother his/her transition is likely to go. The teacher quoted above mentioned that "everyone has to be their own advocate in this busy world that we live in". As this teacher indicated, self-advocacy is not unique to students with traumatic brain injury, but will be beneficial to these students so that they can get the services that they need.

Then, there are some individuals that go beyond becoming a self-advocate and begin advocating for others. Morgan is one of these individuals. Now in her twenties when I had the opportunity to hear her speak at a BrainSTEPS meeting, she captivated the audience when she told her story.

> My life as a teenager was almost perfect. I was a starter on my high school varsity basketball team since my freshman year, I won a PIAA state medal in the long jump during my sophomore year [in track and field], and I was on the high honor list for my academics in school. I had many friends and I was set to achieve my goals for a scholarship, and nothing was going to stop me.

Sadly, Morgan suffered a concussion during one of her varsity basketball games. Although she felt the symptoms immediately and they continued to worsen as that game wore on, she continued to play, and then played in the next game two days later. After that game, she collapsed in the locker room and her "life of migraines, chronic pain, and depression had just begun." Just five and a half years later, Morgan, who had to leave the liberal arts college that she was attending in a small city about an hour away from her home during her first semester, spoke in support of Pennsylvania State Representative Tim Briggs' concussion management legislation known as the Safety in Youth Sports Act that was "designed to improve concussion management in youth sports and to increase awareness regarding the devastating, life-long effects they can cause when not handled properly." About four months later that bill was unanimously passed by the Pennsylvania state House of Representatives, then by the Senate less than one month later, and signed into law by Governor Corbett only two weeks after that. The law will take effect on July 1st.

Theme 2: Communication

Another idea that came up frequently during the research, especially during interviews, was that of communication. The multiplicity of key players in the transition process compelled me to expand the previous research from just the student with a brain injury and his or her family to include the school and supporting agencies. Obviously, the student is a key player, but he/she needs to be surrounded by a large support system that knows what he or she needs and this support system needs to grow throughout the transition process, and then shrink as the student's needs are met.

Ongoing communication can occur even when there are no formal meetings taking place. For example, Suzy's mom found it helpful when her teachers e-mailed home when they noticed a change in her or had concerns or questions, and when they spoke with each other.

> The teachers all seem to look out for her. They seem to watch if there's anything new or unusual. They'll e-mail me. I think they talk amongst each other. I'm sure that if one teacher has an idea, they might share information with the other teachers, so everybody wins.

Conversely, Suzy's teachers felt that it was helpful when her mom e-mailed them, and not just one of her teachers, but all of them, so that they were all on the same page.

If someone is coordinating these services, such as the counselor or principal, then communication could run through that person. Scott's counselor felt that was her role, along with the principal.

> I think I try to coordinate services for him and try to find out what was available and what we could do and just try to be that person. I always found my counseling role, a lot of times it is a coordination of services, whether it's outside services, whether it's inside services, whether it's teacher to parent to child to

> administrator whatever. So, I think coordination of services was probably the biggest thing that I thought I would probably do.

When asked about what role Scott's counselor expected the principal to play in his transition, she answered very similarly.

> [His role would be] to really help to coordinate all that too. I mean, he's the chief coordinator as far as I was concerned. Everything was going to have to go through him in terms of approval. Like, he was going to have to coordinate the services. Like, we, we would all come up w/the plan, but he was going to have to make sure that that plan worked.

Scott's counselor really summed up this communication and coordination well stating that "we need to coordinate quickly from day 1. As the counselor, I needed to take a lead role, as does the administrator, with the whole faculty including the lunch aides and recess aids because there is a trickle-down effect. Everyone needs to be made aware." Whether vertical or horizontal, communication must take place and everyone needs to remain aware, especially of changes in the student or to the student's services.

One very important piece of the communication puzzle is the dialogue that needs to take place between the educators and the injured student's peers so that they know why their classmate is different. I found varying suggestions on how and when to do this. First, and foremost, the school needs to get permission from the student with a brain injury's parents to discuss him or her with his/her peers. The parents should know that this request is being made to help make the student's transition back to school go as smoothly as possible. Some educators felt that they should wait until the peers start to ask questions; however, others felt that this difference needed to be addressed sooner in order to prevent problems from occurring, such as the peers ignoring the student with a brain injury or making fun of him or her. Everyone felt that the student with a brain injury should not be present when this discussion happens, so perhaps it could take place prior to the student's arrival back at school, when the student has to come in late or leave early for a doctor's appointment, or when the student is pulled out to see a specialist or therapist. Aside from the student's peers, several individuals ought be present including a school administrator, the students' teachers, a nurse, and a guidance counselor. The principal leads the meeting, introducing the topic to the students and setting the tone that the discussion they are about to have is extremely important. He or she can then turn the meeting over to the nurse who needs to explain what is medically wrong with the student, on a level that they would understand. The nurse covers the obvious physical troubles such as walking with a limp, but also touches on how this student learns differently. The counselor continues talking about the student with a brain injury's learning differences, but also addresses the student's peers with ways that they can include him or her. The principal wraps up the meeting by letting the students know that all of the individuals that spoke with them that day are available if they have any additional questions. If these core team members feel that a follow-up meeting is necessary, then they can be planned it as soon as the need arises. Often times, the initial meeting is held only with the student's classmates, but everyone the student interacts with should be made aware of his / her condition such as those he/she eats lunch with and/or rides the bus with (if they are able to). Scott's reading specialist, who was present at one of these meetings said, “Kids can go either way, but you give them enough knowledge so they can be empathetic. That was a powerful thing.” Someone needs to always be available to field questions as they arise after these meetings, whether on an individual or a group basis, to help the student's peers understand.

Theme 3: Expectations

While I named our third theme “expectations”, it could appropriately be named, “questions left unanswered”, “goal setting”, or “pushing the envelope”. While the levels of preparedness felt by the schools varied, most educators from administrators to counselors to classroom teachers knew very little, if anything at all, about how to work with students with a traumatic brain injury. Therefore, they did not know if they could expect the same out of the student with a brain injury as they could their other students. Even after the transition, many of the educators still had questions (sometimes expressed as a statement).

When leading the transition efforts for Scott's re-entry at school with no prior experience working with students with a brain injury, his principal was one of the educators that had questions. His biggest concern was "how to determine his abilities." He and his team tried to answer this anxiety in the beginning by testing him as they did other students; however, Scott needed to be tested cognitively and emotionally whereas other students are usually only tested in only one of the above areas when the need arises, not both. So, they never felt like they ever got a true assessment. Their feelings were confirmed when they felt Scott could follow the regular education curriculum in middle school, but the middle school moved him to a Life Skills class because they felt he was more like those students and did not have potential to learn like higher-functioning special education students.

Although Scott's principal expressed his concerns for himself and his team; those educators that were not administrators empathized with his point of view. Heather's math teacher, after just beginning to work with her for a second non-consecutive school year, expressed similar concerns.

> I'd like to know what recovery, what we as teachers can expect in terms of recovery time. I don't think there was ever a discussion, like, is she going to return to normal? … I guess recovery and maybe a timeline as to maybe what we should expect to see. Like her first year, what should we expect to see? Like every year, I think we should have gotten an update, a more detailed update as to what our expectations should be on her abilities…What are our expectations of her? We don't want to coddle her if that in fact is going to prevent progress…Is there a way we could push the envelope with her memory, class participation, etcetera? … I've got to remember that (to call on her). And, not to coddle her, but to, again, push the envelope of recovery if that's even an appropriate phrase.

Heather's math teacher wanted to know specific ways that he could help her without harming her, but felt that he could not do this until he knew what was best for her.

Like Heather's math teacher and Scott's principal, specialists felt the same way. Scott's reading specialist confirmed that the classroom teachers were not alone.

> We had some information, but it would have been nice to know a little bit more of like 'How far can we push?' … I didn't know how quickly we could expect him to regain things or not…[I would like to know more about] the academic prognosis. How much do we expect? How much can we expect? Maybe it's an unknown…Never having dealt with a brain injury kind of thing, it would have been nice to know don't expect this too much.

Other types of specialists felt the same way. Scott's counselor asked, "How much time do you give us?" Knowing that Scott was only going to be in their school for one school year, she and the rest of the team seemed to feel that was not enough. His elementary team really wanted to hold him back because they felt that were just beginning to figure out what he needed and what they could give him. Unfortunately, due to a strong-willed central office administration and uninformed parents, they were not given this opportunity to continue educating him at their school for another school year.

Suzy's teachers collectively echoed the same sentiment; however, they expressed their concerns through their own emotions and how the situation made them feel. They stated that they were "a little fearful, apprehensive due to not knowing what to expect. The fear of the unknown." The first of Suzy's teachers to express this concern looked at her peers before responding and a sense of relief came over her face when her colleagues agreed with her and expressed the same feelings. Many of the educators that I spoke with expressed frustration due to the not knowing, so perhaps if these questions could be answered, there would be less disappointment and feelings of defeat.

Similar questions about expectations were also heard from the other end of the spectrum. Some parents lowered their expectations, even without knowing the long-term effects that this could have, such as pushing back their high school graduation. Suzy's mom said, "I don't have great expectations for her this year because I understand that she is brain-injured. The goal for 9th grade for [child] should be just to eventually return to school full-time. I don't care what the grades are." I got the feeling that those worries would come over time, as each milestone was reached. Not surprisingly, all of the parents interviewed still hoped to see their children graduate high school, go on to college, get a job, get married, and have children, so the big picture goals did not change.

Theme 4: Support

The next theme that emerged from the data is support. Much like communication, all parties involved, especially the student, the teachers, and the family members, expressed a need to feel supported, particularly by each other. The teachers talked about needing to feel supported by the principal of their school, as well as the other members of the core team such as the guidance counselor. The school administration, counselors, and teachers also needed to feel supported by the family of the student with a brain injury.

Scott's principal spoke of many varieties of support, but focused on the team approach. In fact, he mentioned the idea of the team approach eight different times during our thirty-five minute interview!!! In this case, the team referred to the learning support teacher, guidance counselor, instructional support teacher, reading specialist. He said, "I felt confident with the support of the rest of the team that he was going to be successful." Although he was one of the leaders for Scott's transition, he recognized that he was not the focus, stating "The classroom teacher, of course, is a very big part, but I had a lot of people going in there to support her for him." Scott's principal not only talked about the support that he and his team needed, but that assistance that Scott needed as well, "We knew he needed a lot of support." He also knew that they would need support in order to provide it to Scott. The following are his comments about the support he and his staff, and Scott, received from the intermediate unit, "Fantastic. The resources. The support. Being able to assist the teacher with everything that needed to happen." Whereas some leaders want to be heroes and do everything on their own, Scott's principal did not mind sharing the resources and obtaining help from wherever it was available.

BrainSTEPS played a very supportive role in the re-entry process for both the families and the schools. Heather's mom felt, "It's such a great thing for us to have the BrainSTEPS support." Scott's reading specialist felt, "I think we needed all hands on deck. And the more support that came from BrainSTEPS when they got involved and the OT, and the PT, like the speech...never had too much." Whether the members of the BrainSTEPS team were offering moral support or somatic support, their help was greatly appreciated by many of the subjects in this study.

Scott's guidance counselor recognized the team approach like his principal, but felt that the role of each individual was also important and that everyone needed to know their role. She stated, "I expected there to be a lot of support from the school, but I knew that we were going to need to figure out what we needed to do…Here's what we need to do to support him."
She realized that while she played a role in coordinating his transition, like her administrator, she hoped that his classroom teacher would be able to say, "What do I need? How can everyone support me without, with him being part of this classroom and not being pulled out all the time or not being outside the classroom all the time?" She also felt that the role of the family was a supporting one, "I was hoping that there would be a lot of support and follow-through." Again,

she made it clear that everyone needed to offer support to everyone else and that this would be easier if they knew how they could from their perspective.

Often times, the family members did not feel that they got enough support. While Heather's Mom appreciated the help of BrainSTEPS as mentioned earlier, she also felt that it would have been helpful to have the support of another family that had been through exactly what they were going through from an oncology and a brain injury perspective, rather than only one or the other. Even a few years out of the hospital, she still seemed to be searching for this support. Similarly, Suzy's mom wanted to know, "What can you do to expand the support network?" She felt that she and her family, as well as Suzy herself, needed more support. She thought, "The more support they have, the sooner they're going to feel better about things." As you can see from the above remarks, everyone involved knew that a smooth transition was dependent upon a team effort. They were continuously looking for more support from whomever they could receive it.

For the students with the brain injury, support came from a number of different sources including friends, faith in God, family members, doctors, school counselors, the principal, the teachers, and from other students going through a similar situation that they met in their brain injury support groups. It seemed as though the personal relationships that were strong prior to the brain injury were the ones that prevailed and provided the most support after the brain injury occurred. Heather said that her friends "were extremely supportive." Suzy's mother felt that the friends her daughter had for the previous five years were supportive and "that they stood by her throughout this whole twelve months". She felt that these true friends never resented having to help her daughter, and were not hanging around just for some extra attention. At school, these friends helped Suzy socialize and stay on task in class. Suzy also went to her friends for emotional support, “emotionally I go to my friends for the most support”. Unfortunately, due to the effects of the brain injuries, it appeared to me that the students did not know how or when to ask for more support and from whom. Instead, they seemed to accept the amount they were getting as appropriate, especially from the school. That being said, both students and their parents were quick to point out that they felt the personnel at the schools they attended went above and beyond what they needed to do in order to help with the transition.

Some of the parents felt frustrated because they were not getting the right kind of support. With so many challenges surrounding brain injuries, beginning with their causes, it was hard for some of the families to find another family that knew exactly what they were going through. For example, one student had a brain tumor and suffered a stroke during surgery. During the student's hospital stay, they attended both the oncology support group and the brain injury support group, but this led to further frustration because they did not feel as though they belonged to either group. Suzy’s mom felt frustrated with the doctors when they seemed to giving up on her daughter and seemed to be testing remedies out rather than knowing, but she realized that a lot of this angst was unintentional because the doctors really did not know.

> Unfortunately some of the doctors that we turned to for help ended up hurting us. We've hooked up with some bizarre doctors. Unintentionally. They came highly recommended. That has cost us time and it has done mental damage to her. Looking back, I wonder if I did more harm than good.

In some cases, they had never seen anything like what they were seeing before. Unlike the students, the parents showed their frustration levels.

Theme 5: Awareness

Our final theme is awareness about concussions and brain injuries, from many standpoints. All of the educators that I interviewed for this project from administrators to classroom teachers, knew very little, if anything at all, about traumatic brain injuries prior to a student with a brain injury showing up in their schools and classrooms. The same is true for the parents of the students with a brain injury, and the students themselves. I found evidence that if more people from students to parents to educators knew more about brain injuries, then they would know more about how to handle them when they occur, from initial treatment to the student's education.

While the educators interviewed were willing to learn about traumatic brain injury to help their students, they would have liked to know more prior to the students' arrival, and they still have questions, even for those educators whose students have moved on. I was able to confirm the findings of Mohr and Bullock (2005) and Stahl (2008) that the teachers, and administrators, wanted to enhance their knowledge about TBI. From learning the medical jargon to supporting the family to general information, the educators seemed willing to go above and beyond to learn, if someone was willing to teach them. Scott's reading specialist was one educator that felt this way.

> The only thing that I think could have been better is having a doctor there who could have said, who could have like explained in lay terms, non-medical terms this is what's going on, not a paper where I couldn't... I guess knowing a little bit more about the medical.

After his experiences with Heather, her math teacher was willing to have another student with a brain injury, but wanted more information specific to that student since every student is different.

> Everyone's different. Heather, it was, it seemed to me, Heather, and still now is just a matter of just reminding. I mean, she's got the intelligence. She's got the motor skills to the degree that is adequate. So, that part hasn't been difficult, but if I'm going to have, be given a student that has really hard, or, noticeable, cognitive abilities that would be a challenge because I don't have that training.

Despite the lack of training, he was fine with having another student with a brain injury in his class in the future. Most educators prior experiences with students with needs similar to those in the study that had suffered a brain injury were with special needs students, such as those with multiple disabilities and those placed in life skills classes; however, they all recognized that while there were many similarities between those students and the students with brain injuries, there were also many differences and in some cases, the two groups were not essentially similar. In some cases the student the brain injury had more needs, but in most cases the needs were just different than what the educators were used to. Due to not knowing, Scott's principal was concerned about how to determine the student's abilities and how to ensure progress. There were also concerns about how to adapt the curriculum for the student with the brain injury's needs rather than trying to fit the student into the existing curriculum. It was not just differentiation that was the question, but how and how much were as well. Also, while recognizing that no two brain injuries are alike, the educators wanted to know all of the different learning challenges that they should look for in these students. They wanted to know more specifically what the brain injury did in terms of learning and what they could do to support the student's learning.

Although Heather's math teacher knew two people with brain injuries, one of whom was a distant relative, he still was not that familiar with what to expect in his student with a brain injury. Even after having a student with a brain injury in his class for a year, he said that although he was fine with having another one in his class, he realized that the experience could be vastly difficult and felt that it would be a challenge since he does not have the training. His comments are a testament to the need for training on teaching students with brain injuries. They wished this training could, and should, take place during pre-service teacher training and during in-service trainings.

"Nothing." "Virtually nothing." "I really knew very little about brain injuries." These were some of the responses I received when she asked some of the educators what they knew about traumatic brain injury prior to the student walking in. The report that the school received from the hospital did not make the situation any better because there was a lot of language that the teacher could not decode, especially without any background knowledge. She felt that it would have been extremely helpful to have a doctor attend one of their planning meetings so that they could ask questions and receive immediate answers. The educators at this school, particularly this specialist, the counselor, and the principal, had to research brain injuries and medical jargon to make some sense of the report, which boiled down to “an illness, surgeries, reduced brain capacity, loss of things he had before” for them until they got to know the student. They felt that had they been given this information up front, that time could have been better spent preparing to help the student.

One encouraging point to make is the educators' willingness to continue to learn more about traumatic brain injuries. Every educator that participated in the study was willing to have another student with a brain injury in their classroom or school and already had ideas on how to make the experience a more positive one based on information that they had learned from the experienced that they discussed with me. For example, one teacher met with the student face-to-face on numerous occasions, almost daily, and while he felt that these meetings were very valuable, he also concluded that the time would have been better spent if he had the notes written out for the student ahead of time, either partially or completely. While noting that putting these handouts together would take more time, he was willing to do it if it meant that the student's transition would go even better. Another educator was amazed to learn how the brain can recoup things. Unfortunately, these realizations only came to the teachers as they reflected back on their experiences and there was a general feeling that they wished there could have been many more of them.

Both parents and educators felt that the parents did not know about what services were available to them, so making them aware of what they are entitled to by law and by their school district's board policy is important. For example, the educators at Scott's school would have liked to keep him for one more year prior to seeing him transition to the next level and they pushed for that, but without the parental support, their central office did not agree with them.

> It's such a shame that we have to move kids on sometimes where a child would have benefited. It's almost like the, I don't think the parents knew that they could have pushed more. Sometimes in public education, parents have much more power. Some parents are overzealous about things and then there are other parents who really should demand more and they don't. I think it's a lot of they don't even know. They're not sure what's available to them. They don't realize how much power they have.

One parent admitted that while she was happy with the services being provided by the school, such as allowing her child to come to school for lunch when she was on full homebound tutoring, she was unaware of what school officials were required to do and what they were doing just because they felt it would help her daughter.

> I've never been through anything like this before, so I wasn't too sure of what the role of the school would be. I still don't know what they're obligated to do and what they're doing on a voluntary basis. And, it doesn't really matter as far as I'm concerned. But, I feel, honestly, what they did for (my child), and I don't think they were obligated to do this, they were all very compassionate. They all said that the first thing that has to happen is that she needs to get better, that that gets priority.

Even though parents have a right to know this information about the services that should legally be provided to them and their families, especially their children, by law, since traumatic brain injury was added as a category of Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA), previously known as Education for All Handicapped Children Act of 1975 (Public Law 94-142), they are not aware of it. I found it very humbling that even without knowing this information, the parents felt that the educators went above and beyond.

Parents were opinionated regarding their feelings about the teachers, and everyone in general including themselves, not knowing enough about traumatic brain injuries. Suzy's mom expressed a desire for more individuals from teenagers to adults to know about concussions, like the ones her daughter suffered.

> One of the things I would like to see come from all this research is I would love to see, some day, every school have an assembly in the beginning of the year when they talk about concussions, they seem to want to limit it to sports players. And I think it needs to be realized that you can suffer a concussion in a car accident, in a slip and fall, just playing around. There are so many ways to suffer a concussion or brain injury, not just by playing sports and so I think the schools need to address...everybody needs to be educated and I would love to see at the beginning of every school year, somebody give, educate these kids, and teachers, some kind of an assembly on concussions. Not only so that more people are aware that God forbid anybody in the audience were to hit their head at a future date that might lead to them to think, 'Maybe I have a concussion. I better have it ruled out. Let somebody know that, that I hit my head. I need to make sure that I don't have a concussion.' Just to raise the general awareness throughout the entire population, not just the sports population.

Suzy's mom felt that had her daughter or one of her peers that witnessed Suzy getting injured known to tell someone immediately, then maybe they would not be going through the ordeal that they are currently experiencing. Even if Suzy did not tell someone, she felt that perhaps one of her teachers might have questioned her headache and sent her to the nurse.

Nancy is also suffering because her parents did not recognize the sings of a head injury. When Nancy was complaining that she could not see right and had a mild headache, her father told her that nothing was wrong and she would be okay. At first, her mother agreed with her father, and then she finally insisted that they take their daughter to the hospital where Nancy was diagnosed as suffering a stroke that caused a traumatic injury. While Nancy's parents did not attend a BrainSTEPS meeting, Lynn's mom shared Nancy's story with me, then echoed the same sentiments as Suzy's mom that she wished they knew. Education and awareness will be discussed further in Chapter Five.

Summary

Now that we have met some of the subjects that took part in the study including the students with a brain injury that I interviewed as well as some of the principal actors in the re-entry process and taken a look at the themes (advocacy, communication, expectations, support, and awareness) that emerged from the data, I will offer recommendations about how the above can be translated into practice. Although we saw many similarities between the subjects in my study, since each brain injury is different, the treatment of each student with a brain injury should be handled separately in practice. Since my study was based off a small sample from a relatively homogenous background, the suggestions offered in the ensuing chapter are simply ideas that may need to be tested on a case by case basis before being fully implemented. It is important to remember that generalization was not my goal.

CHAPTER FIVE

DISCUSSION

Summary of the Purpose and Results

The purpose of this study was to investigate the specific factors that both impede and enhance the re-entry process to school on a full-time basis by students who have suffered a traumatic brain injury. This study came to fruition after a thorough review of current literature showed that very little research exists on students with brain injuries learning and even less on these students' re-entry following the traumatic brain injury. The study includes an examination of the whole school community but also specifically focuses on the role of school leaders. For example, I was only able to find two studies, both performed in the past decade in Australia, on the student and family perspectives of the school re-entry process. Yet the National Institute of Neurological Disorders and Stroke in the United States (NINDS, 2009) recognizes traumatic brain injury as a major public health problem. However, while there is an abundance of research on the effects of supported employment on persons with developmental and other severe disabilities, including brain injury, the researchers of the two Australian studies, mentioned above, urged more research on the effects of such disabilities on adolescents and their school re-entry process.

In order to better understand the transition process that students with a brain injury experience after their injury, this study was created employing a multiple-perspective retrospective design that surveyed students in elementary through high school. I followed students whose parents, teachers, counselors, nurses, and principals participated in the study so that a complete picture could be captured.

This study addressed the following primary research question: What factors impede or enhance the re-entry to school of students with a brain injury? In order for this larger question to be answered, the following secondary questions were also explored: (1) What does the re-entry process look like and how does that process unfold? (2) Who are the principal actors in the re-entry process? Each will be answered below.

First, although there were similarities amongst the re-entry process for some of the students, in general, this process unfolded individually and differently for each student as described in the vignettes in Chapter Four above. For some, the transition began while they were still receiving treatment in the hospital or rehabilitation setting, while for others it began once they were released. Some of the students started with homebound tutoring, either partial or full-time, while others went directly back to school. Those that began their transition with homebound tutoring gradually built up to going back to school on a full-time basis. In almost every case, it was realized that the student needed scheduled breaks when they were initially going back to school on a full-time basis. The ideal transition process that emerged in this research will be discussed in more detail in the recommendations for practice section that appears later in this chapter.

My second question asked who the principal actors are. The principal actors in the re-entry process are the students themselves, their parents and siblings, their school administrator, counselor, teachers (both classroom teachers and specialists), school nurse, doctors, and friends. For counties that have a child and adolescent brain injury school re-entry program such as BrainSTEPS, members of that team can be added to this list as well. Since the goal of the re-entry process is to have the student transition back to school, the student would obviously be the most important actor in the process. Those directly involved with the student in the transition process, such as family members and those individuals at the school that will have an influence on the student's education, are extremely crucial in the process as well. The other principal actors, perhaps not part of the core group, such as friends, are also play an important role in the re-entry process. As you can see from the participant demographic tables in Chapter Three on pages 46 through 48, I directly included many of these actors in the study either through interviews, observations, or both; however, I did not realize how important all of these actors would be in the process or I would have interviewed them as well. When the importance of siblings came out in the interviews and observations of students that had siblings, I did ask if I could interview them, but my request was not looked upon favorably by the parents. It seemed as though they felt that enough attention was already being given to the child with a brain injury and they did not want to draw any more attention to that injured family member. Nonetheless, each of these actors from family to school to medical is vital to the re-entry process.

Relationship to Theory

All of the theories that I hypothesized would be relevant to this study did come to fruition. They are presented here in the order that I felt they related. The students that I interviewed, as well as those I encountered at BrainSTEPS meetings, partially followed the Kübler-Ross Grief Cycle (1969). They all seemed to skip the initial shock stage because they were so traumatized immediately after suffering their setback. Once they began to realize what had happened, they did become immobilized, which is when they began needing support. They needed others to work through the rehabilitation process for them and figure out when their transitions would take place. When they became aware of their surroundings, most of the students were in denial about how grave their situation really was. As previously stated, most still thought they could go to college, get married, and have children. Those students that were up to that point or beyond in their education during the duration of this study, realized that they would have to look at higher education institutions that had programs that would offer some of the same supports that they were getting at the high school level. Some realized, even with those supports, that they could not complete college. Some became angry and depressed when they realized that not only would they not be able to live out some of their dreams, such as going away for college, but they could not complete simple tasks that were so easy before, that so many of us take for granted. The students needed support to deal with these emotions they encountered as they went through the Kübler-Ross Grief Cycle. They especially needed support to help them look for rational solutions. Unfortunately, as stated above, most of the students did not know when to ask for the support, so their support team would just have to monitor them and provide it accordingly. Sometimes this is obvious. For example, one student said, "I let it (what other people were thinking about her) ruin my day." When asked what the brain injury meant to this student from her own perspective, she said, "Really annoying 'cause it ruined my 8th grad year, and it's like changed life." Unfortunately, figuring out the cause of the student's feelings and where she, or any student in her situation, needs support can be difficult. Although her mom noticed that her daughter's self-confidence had plummeted, she did not know what was causing that to happen for a couple of months. On the other hand, a student may not go through these cycles. For example, one student even commented "I think that I'm even happier now then I was before." However, my observations of this student, as well as those commented on by one of her teachers, clearly showed the need for support, just not as much in the emotional realm as in the physical or cognitive arenas.

Similar to the students, the parents and family members went through various emotional stages; however, the parents were more direct about expressing these feelings. Therefore it was more obvious to see where the family members were in the six-stage model developed by Lezak (1986). One mother, whose child was injured a little over one year ago, seems to still be in stage one, maintaining a positive outlook.

> I honestly haven't thought about it (what areas she thought her child would excel in with the brain injury) yet because I haven't given up to, I haven't reached the point where I'm going to realize that she may be stuck like this. I haven't reached that point yet. There are still stones that I haven't unturned yet. I still think there's an answer out there. I'm not ready to give up and say that she may be stuck like this. I think that there's still a lot of hope. I think that we just haven't talked to the right people yet, gotten the right answers yet.

I did see glimmers of some of the other stages during the interview. For example, when talking about taking her child to numerous therapy and doctor appointments, this mother definitely blamed herself and shared her guilty feelings about not giving her child enough rest, especially in the early stages of the recovery process.

> Oh my G-d, we would, that was hard too because looking back, I wonder if I did more harm than good. Because in my quest to make her better, to get her back where she was, if I didn't like the answer I got from one doctor, I would take her to another. Often times, I would pick her up and we would go right to an appointment, whether it was physical therapy or a medical appointment or something else to try to help her get better. Now I wonder if maybe I should've just left her alone to heal. Maybe that's what she needed. I don't know what it would've looked like if I hadn't taken her to the appointments and pushed the physical therapy and certain things. Maybe she would've been worse off, maybe she would've been better off, we'll never know.

I feel that the above remarks also show a little bit of the reality starting to set in, even though the parent does not want to admit this. This particular parent is experiencing a sense of Lezak’s third stage.

This same mother also spoke about how the brain injury affected the rest of the family, including her relationship with her husband and how her son's behavior changed.

> I also have a son and a husband who this has impacted because it's been thirteen months and so a lot of things within the family unit have changed because of this. It's a lot harder for a rambunctious fourteen and a half year old boy to understand

> that his sister has a constant headache and he can't jump around and he can't act like a boy because it'll spike her head pain. So that's a battle that we've been fighting for thirteen months that I wish I didn't have to fight. Not too much time for the husband because she has issues that need to be dealt with from the time she gets home from school to the time she finally goes to bed at night....The other two members of the family suffered – my husband and my son. I feel that he has been acting out more so than usual over the past thirteen months. There were actually two altercations that he had at school. One was the result of two kids tapping on his head. He's terrified of concussions now. He turned around and punched someone in the face because he was, it was a knee-jerk reaction. He did not want a concussion and the only way that he knew to stop it, to get this kid off his head, was to turn around and punch him. Recently, another student made a comment and my son retaliated verbally and the kid physically attacked him and put him in a headlock. He was being choked. He grabbed a pencil and stabbed the kid with it and punctured his skin. He reacted the way he did out of fear of brain injury for himself. He sees what she goes through; he doesn't care to go through it himself. The other thing is he doesn't like to be told that he needs to lower the volume, he needs, he can't run through the house... It's very hard for him and I guess it would be very hard for anybody. Imagine having a brain-injured person in your house that has a constant headache and you have to be quiet for thirteen months. You can't live a normal life. You have to walk on eggshells near this person. You can only take so much because you're not the one with the problem. And so that's what happens. He resents...he's just tired of it. He's tired of dealing with this. He's tired of being told to be quiet. He's tired of being punished for not being quiet. He's tired of being yelled at for yelling.

While the young boy does not necessarily go through the stages in Lezak's model, his acting out shows that he is going through emotions due to his sister's brain injury. He is obviously upset about what happened to her, but he is also angry about it since it has affected his life. He seems to be in the third stage where he is disappointed that his sister is not the person that she used to be. His sister, the student with a brain injury, has noticed that there is more tension between the two of them than is normal for siblings and that her brother takes out his frustrations on her. I left this interview feeling that not only did the student need support in this case, but the entire family needed it as well.

Ironically, although the family dynamics changed with some of our other subjects, the opposite reactions occurred. Heather felt that she got along better with her sister since the brain injury. Her mother saw it differently.

> I think when the tumor diagnosis and the stroke first happened, (my uninjured daughter) was extremely nice and compassionate and almost afraid to do anything negative around (my injured daughter), and then after about 6 months that wore off and then she was quite nasty for a while because of some jealousy issues. The fact that I had to live in the hospital for three months with (my injured daughter) was hurtful. But I would say after about a year and a half she got passed that and now this past year they've gotten along better than ever.

Although Heather’s mother spent so much time away from her husband when she was at the hospital with her daughter with a brain injury, she felt that this experience made them stronger because they were both in it together to provide her whatever she needed. She only remembers one time where they did not agree with a medical decision that a doctor was suggesting for their daughter, but they were able to work through this on the same day. As you can see, the adults in these situations both reacted with the first instinct to do what needed to be done for their children, but one couple let this interfere with their relationship, while the other used it to grow. It would appear that the first relationship between the siblings presented above will develop as the second one did through pendulums of positive and negative reactions towards each other. Again, the family needs therapy and counseling just as much as the student with a brain injury does.

One student, Scott, displayed more self-determination than any other student that I interviewed, and some of the others that attended the BrainSTEPS meetings, but I was not able to interview, including Mike and Lynn, also displayed self-determination. For example, when Scott’s principal was speaking about all of the help that he had coming in to assist his classroom teacher, I asked how Scott felt about that and it did not seem to bother him since he knew he needed it to get better. His principal said, “He was open to, with some prodding, because he wanted to do it himself. ‘Nope, I can do it.’” Similarly, his reading teacher and guidance counselor noticed the same determination. His teacher said, “He wanted to learn how to read, and he didn’t care how much time and energy he used. The poor little boy was exhausted every day that he went home because physically and mentally, he was just like plugging away every single day.” Scott was giving everything he had. As I stated in the vignette about Scott earlier, not only was his self-determination noticed by the adults at school, but it was also recognized by his peers.

Driver’s theory of self-efficacy was also important to this study. While Driver felt that past performance accomplishments would have the greatest impact on the student with a brain injury’s recovery followed by vicarious experiences, social persuasion, and physiological arousal, I found the reverse to true with the population that I studied. As seen in the data presented in the previous chapter and the explanation of how the Kübler-Ross Grief Cycle was associated with my study, how the students felt physiologically and emotionally played a major role in their recovery. Also, even though many of the students with a brain injury presented as less mature than their non-injured peers, they wanted to fit in with their peers and tried to act accordingly. I felt that past performance had the least impact because they all seemed focus on the present and future rather than the past. Self-efficacy was definitely an underlying factor in the re-entry process for the students with a brain injury.

Relationship to Literature

The current study closely related to the existing literature on traumatic brain injury. First, and foremost, this study agrees with previous ones that found that each brain injury is unique and that it is important to gather as much information as possible. The current study went beyond the existing literature, in that I found that those on the educational side of the transition such as principals, counselors, and teachers, want specific information about the student's injury rather than general information about traumatic brain injury. Many of the factors that Bowen (2005) found to be helpful in the re-entry process are still valuable today including advance communication and coordination of services prior to the students arrival back at school, ongoing communication throughout the transition process, specific classroom interventions, the realization that a student's physical and mental endurances may be limited during their initial return to school, but should steadily improve over time, that different schooling options may be necessary, the student's schedule needs to be flexible and customized to fit their changing needs as noticed through ongoing observations and assessment. I also agree with Deidrick and Farmer (2005) that a team approach and including the students' peers are also important factors based on the data I found. Sharp, Bye, Llewellyn, and Cusick (2006) were also on target when they focused on family needs. The findings about what the educational leader means to the re-entry process were also similar. The current study found that many of the roles that Janus (1994) mentioned for the administrators are still important; however, the school principal does delegate many of his/her responsibilities to his/her supporting staff, especially the counselor, as Bohmann (2007) suggested. As anticipated, based on the findings in previous studies, teachers are unaware about traumatic brain injuries and how to educate students with such a disability until they appear on their roster. Much of the information found in the literature on assessments was similar as well. Lastly, the students in the current study "highlighted the importance of personal relationships and helping styles of those supporting them" as did those in the study performed by Mealings and Douglas (2010, p. 14). While the findings in this study were found to relate closely to those mentioned in Chapter Two, this study was able to integrate them and makes some important recommendations for practice below based on the newest findings.

Recommendations for Practice

The results of this research supported my beginning premise that students who have suffered a traumatic brain injury need a lot of support during the re-entry process. Typically, their family members and educators are often unable to provide all of the necessary support because of their inability and lack of knowledge about the injury itself. The following ideas emerged from the interviews and other data sources, as factors that respondents described as helpful during the transition process: general education about brain injuries for all to create and awareness prior to a specific injury occurring, the scheduling of frequent breaks during the school day, a gradual transition, providing each student with a brain injury with a non-injured study buddy in the classroom, teaching the student to become an advocate for him- or herself, constant communication between all of the key players that begins as early as possible, and support provided by the administration and therapists for the classroom teachers in the form of periodic check-ups. Each will be described in more detail below.

Education and awareness was a theme covered in detail in Chapter Four above. Previous studies described in Chapter Two found that most educators were almost completely uninformed about traumatic brain injury despite the relative frequency of injured students in their schools. Educators and parents expressed an interest in having this topic covered in teacher preparation curricular programs and in-service programs. This will also help educators be able to better identify when a student has suffered a traumatic brain injury and what the effects of that injury are on their learning. Once that identification piece has taken place, then the educator will be able to recognize what supports need to be in place in order for the students to be able to transition back to school on a full-time basis without as much uncertainty, difficulty and disruption.

Awareness and education about traumatic brain injuries needs to begin now. Those in the medical field should start with prevention techniques. From there, the education should move to how to recognize the signs of a brain injury, regardless of how minor, because if an injury goes undiagnosed, it can become worse over time. Once a brain injury has been recognized, then treatment should begin right away, as should the transition back to school, especially for the traumatic brain injuries that are considered minor. The more that people know, the sooner that the students will receive appropriate care. Fortunately many schools are now beginning concussion training and ImPact evaluations (Immediate Post-Concussion Assessment and Cognitive Testing), testing for athletes; however, the training should be for everyone, not just athletes, as many of the subjects involved in this study were not injured on an athletic field. Athletes seem open to the testing due to the attention and publicity being given to concussions suffered by professional athletes, such as Major League Baseball (MLB) second baseman Chase Utley, National Football League (NFL) quarterback Michael Vick and National Hockey League (NHL) player Jeremy Roenick. "ImPACT provides computerized neurocognitive assessment tools and services that are used by medical doctors, psychologists, athletic trainers, and other licensed healthcare professionals to assist them in determining an athlete's ability to return to play after suffering a concussion" (ImPACT Applications). In Pennsylvania, Governor Corbett recently signed the Safety in Youth Sports Act, which requires schools to have an athletic trainer on staff, requires all coaches to go through concussion training, and mandates that all athletes that have shown signs of a concussion be immediately pulled out of an athletic contest until they are no longer showing such signs. These signs are sometimes difficult to see since brain injuries are often considered “an invisible injury” as one parent interviewed described them. This same parent, whose child was not playing a sport when she suffered a minor traumatic brain injury that was diagnosed as a concussion, urges that this awareness spread beyond athletics.

Brain injury awareness is growing. Hopefully it will spread from athletics to everyone. Coaches, teachers, medical staff from school nurses to athletic trainers, and parents need to be educated about brain injuries. Teenagers are old enough to be able to understand that they need notify someone know when they hit their head, especially if the adults, that they tell, are properly trained to handle such events. As awareness increases then perhaps the severity of the consequences suffered will decrease. This information could be incorporated into in-service trainings, meetings, and parent education classes. Administrators could facilitate the awareness training.

It became evident during this research that the students with brain injuries often tired easily and their brains needed rest. Building frequent breaks into the student’s schedule often helped. Perhaps the student could be exempt from attending elective courses at the secondary level or specials at the elementary level, such as art and physical education, and spend this time relaxing in the nurse’s office or just in a quiet, dark room such as an office that is not being used. Below is an example of how such a break has helped one student in this study.

> Another good thing that came of this too is what the school has done with (my child) at the suggestion of the neuropsych doctor and myself is (my child) doesn't have an elective this year. And she doesn't have gym class this year. She has breaks instead. So she attends three academic classes each morning and then fourth period she goes to the nurse's office and lays down in a dark bay in the nurse's office and by the end of third period, her headache is about an eight. So just her laying down for forty-five minutes in a dark area will bring the head pain back down to what's normal for her. Then she goes to lunch and that's enjoyment time for her. It's not a stressful time, and then fifth period she goes into the library where it's quiet. She can just work quietly or put her head down if she needs to, but it's quiet there. Then she goes to her last couple of classes of the day and that's the only reason she's able to be there full-time and get through the day.

> If she didn't have those breaks, I don't think there's any way she'd be getting through the school day. So it's important for the schools to realize that while the school as a school is so focused on the number of credits that each kid earns because you need X amount of credits to graduate, you're dealing with a problem. You have a kid here that the credits are secondary. And so you can't be worried about the half of a credit that you'll get from taking this elective or the credit, the 1 credit, that you're going to get from gym class.

Perhaps the student could make up the credits by completing research projects during times when they are feeling up to it, or during summer school when they are not taking their core academic classes.

Another parent found that similar breaks in her child's day also had the same positive effects, and had permission to go to the nurse's office in her IEP at one point.

> It was in her IEP, but we took it out because I think she does have the fatigue from the brain injury, but she kind of can just push herself. And then I've tried to teach her to understand that about herself and place naps in her day when it fits better rather than just crashing at some point.

For both of the above students, these breaks helped them make it through the day without having a major meltdown at some point, especially at the end of the day. The further into the re-entry process that the students were, the fewer breaks they seemed to need. They also seemed able to recognize which activities caused them to tire creating fatigue.

The discussion about breaks brought up another important point, that the students with a brain injury should probably not attend physical education class, due to the risk of suffering another brain injury if they are hit in the head with a ball, bang into a classmate or pole, or fall and hit their head. Successive concussions increase the negative effects of the original brain injury each time they occur, so they should be avoided as much as possible. Often times when students are unable to participate in their physical education class due to an injury such as a broken arm or leg, they go to the library to complete a webquest created by the gym teacher or a research paper and presentation on a health topic of their choice.

Early on in the transition process, when the student is just beginning to recover and needs a lot of support, a gradual transition back to school can help instead of a full day at school with the breaks. Most of the students in this study began their transition back with full-time tutoring at home; however, many of the schools still wanted the students to come to school for lunch or to participate in extra-curricular activities to help with the social transition.

> She was on full homebound tutoring. She was just going for lunch. That was it and I would sit out in the parking lot and wait for her. That was so that she could still, her friends could see her and that she wouldn't be forgotten because out of sight, out of mind. So, actually that was a great service that the school did for us was say, 'At least bring her in for lunch.'

One student could hardly contain herself when she talked about still being able to be a part of the soccer team at her school that she once played for. At first, this was a painful experience for her, but now she looks at it in a positive light.

> I really miss playing sports. For the first two years, I think it was, I couldn't even go to the girls' soccer games because I felt like it was just a constant reminder that I couldn't play. Before, I was really into soccer and basketball and tennis. I can't play them now, but like I go to the events to watch them. I can't run and I only have the one hand and my vision. Especially for soccer, I was the goalie, so there's no way. The coach did tell me I'm their back-up goalie. And they let me go and sit on the bench. They let me be a part of the team. Honorary team member.

The smile on this Heather's face as she talked about being a part of the team shone so brightly. She looked me in the eye and inflection in her voice radiated excitement. During other parts of the interview, this student often looked at the floor or seemed distracted, but during this part, she was attentive and happy to share her story. She looked so proud to be able to be a part of something that "normal" kids were also a part of.

From full-time homebound tutoring, the next step was part-time homebound tutoring and attending school part-time. Some students attended school in the morning after a long night's rest, then came to rest for a little while before beginning tutoring while others slept in in the morning, had some tutoring, then went to school, or slept in late until they went to school, and had their tutoring when they came home. Often times this schedule was dictated by the student and when he or she was at his or her best, but the schedule was sometimes predicated upon when doctors and therapy appointments could be scheduled, when the student had transportation to and from school, or when the tutor was available. Creating this schedule with the student as the priority would be best, but any time of partial attendance is better than none at all where the student is simply thrown back into school full-time.

When the student is ready, he or she will eventually need to go back to school on a full-time basis. This is where they should be at the school during the entire regular school day, but having breaks scheduled into their day. Eventually those scheduled breaks should be removed and the student should be allowed to take breaks as needed. Finally, those breaks should be eliminated altogether and the student should attend a full day of classes. When this happens, the student's courses should be chosen carefully so that their course load is not too strenuous. The figure below illustrates what this transition process looks like.

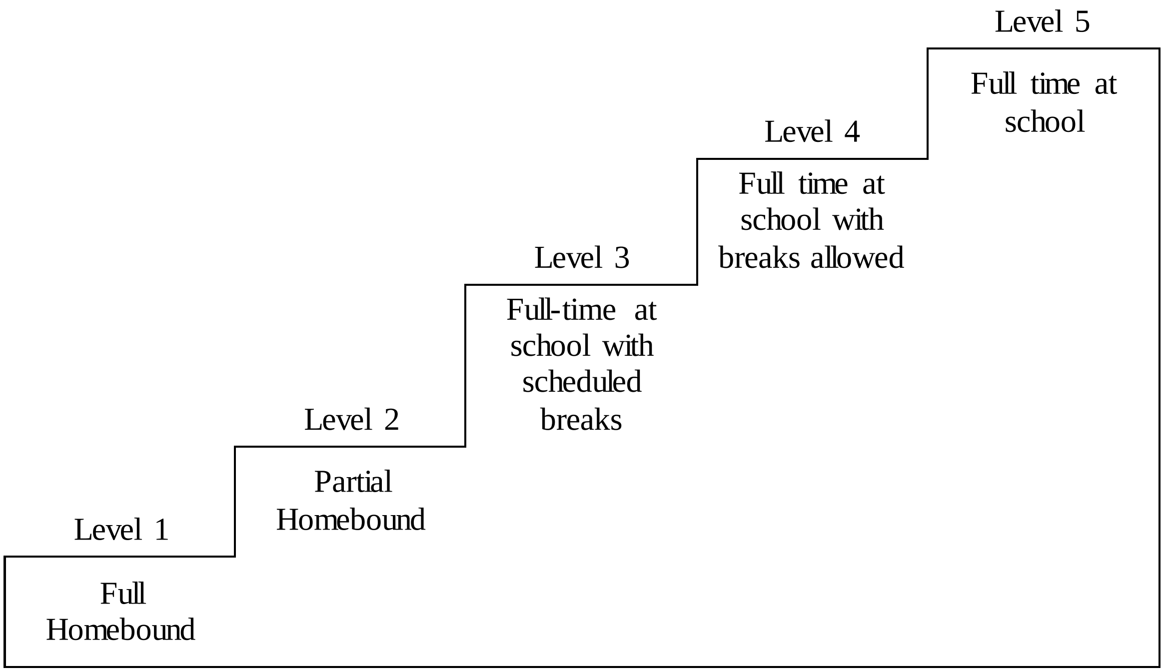

Figure 5: Suggested Transition Process © 2012 Rosenthal

The student should graduate to the next step in this re-entry process as needed, but it is suggested that most go through it in a minimum of two to three years. The student, his/her parents, the principal, the tutor(s) and classroom teacher(s) should all determine when the student is ready to move to the next step in the re-entry process, making sure to provide for the best least restrictive environment as possible, as required by IDEA.

Another factor that enhanced the transition process of students with a brain injury going back to school is the institution of study buddies. Traditionally, study buddies have been thought of as a support to be utilized outside of school that will help students do well in school. Usually students gather on their own time to do homework together, compare the notes that they took in class to make sure they recorded all of the important ideas and supporting details that they need to understand those ideas, and study for quizzes and tests. The concept of study buddies presented here is a twist on that idea; however, instead of the study buddy only working with one of his/her peers outside of school, it is being suggested the study buddy act as a student leader for the student with a brain injury during the school day, an idea that aligns itself with Driver's self-efficacy theory. The first priority of the study buddy would be to make sure that his/her peer with a brain injury is focused and staying on task, which is important since the students with a brain injury seem to be easily distracted and get tired quickly, thus their attention wanes.

> (My child) needed to have somebody in each classroom that could help keep her on task because there were times when she would stare at her nail polish, anything shiny would seem to attract her. And she couldn't look away from it and it would be hard for the teacher to re-direct her away from it. So if she was sitting next to a student that could say, 'Hey, this is what page we're on' and maybe pound her finger on the page or something. So (my child) needed that in the few classes that she was able to attend.

The study buddies should be carefully chosen by the student, his/her parents, teachers, and the principal so that the student with a brain injury feels comfortable with whomever is working with them and the study knows, understands, and supports the purpose of this position. Otherwise, this support that is meant to enhance the transition process will really be an impediment.

> The problem was, the kids who were chosen by the teachers, came to resent having to help her. So when (my child) would ask these girls for help, they would (give her) an eye roll. They would comment under one's breath. She would get the huffing of the breath, all signs that said to (my child), you're so annoying. Why did they stick me with you (for)? And her self-confidence plummeted and she began to say things like 'Nobody likes me, everybody thinks I'm stupid. I'm so stupid. I hate myself.'

Unfortunately, the cause of this student's plummeting self-confidence was unknown at the time because she did not share the negative behaviors and attitudes that she was receiving from her teacher-assigned study buddies with anyone until close to the end of that school year. However, the student selected her own study buddies the following year and the school "stepped up" by ensuring that at least one of these study buddies was placed in each one of the student with a brain injury's classes. These new study buddies had been long-time friends of the student with the brain injury, prior to the student experiencing her injury, so they have been really supportive of the student.

The in-school study buddy could still provide the same outside tasks that traditional study buddies have always offered. Since the student with a brain injury often processes external stimuli much more slowly, the study buddy could compare notes with the student with a brain injury to make sure that he/she was able to record everything of importance. The two could also work together on homework to keep the frustration level of the student with a brain injury down when he/she does not understand something and is struggling to complete an assignment. Lastly, the study buddy could really "study" with the student with a brain injury as both prepare for upcoming quizzes and tests. Again, the concept of study buddies is not a new one, simply adding some new dimensions.

Another support that needs to be put in place is helping the student to become a self-advocate, as they are the best people to let others know what they need once they know how to express their needs. The figure below represents the suggested level of advocacy recommended for the transition process. Level 1, where the student is not present at any meetings about him/her should be avoided if at all possible. I recommend that the student always be present at planning and follow-up meetings, which is Level 2 in the figure below, even if he/she does not feel comfortable participating or is unable to participate. The goal should be to move as quickly as possible from Level 2 to Level 5. In Level 3, the student does not initiate any of the conversation, but answers questions when asked by another attendee. In Level 4, the student not only answers questions as he/she did in Level 3, but now he/she asks questions and makes statements on his/her own behalf. In Level 5, the student is fully able to self-advocate. He/she may not only lead the meeting when it takes place, but might also call the meeting when he/she feels the need to have one. While some may feel that self-advocacy is a paradox for students with a traumatic brain injury since this is often a difficult skill for their uninjured peers, I feel that the student will obtain the most appropriate assistance if he/she is able to advocate for what he/she needs.

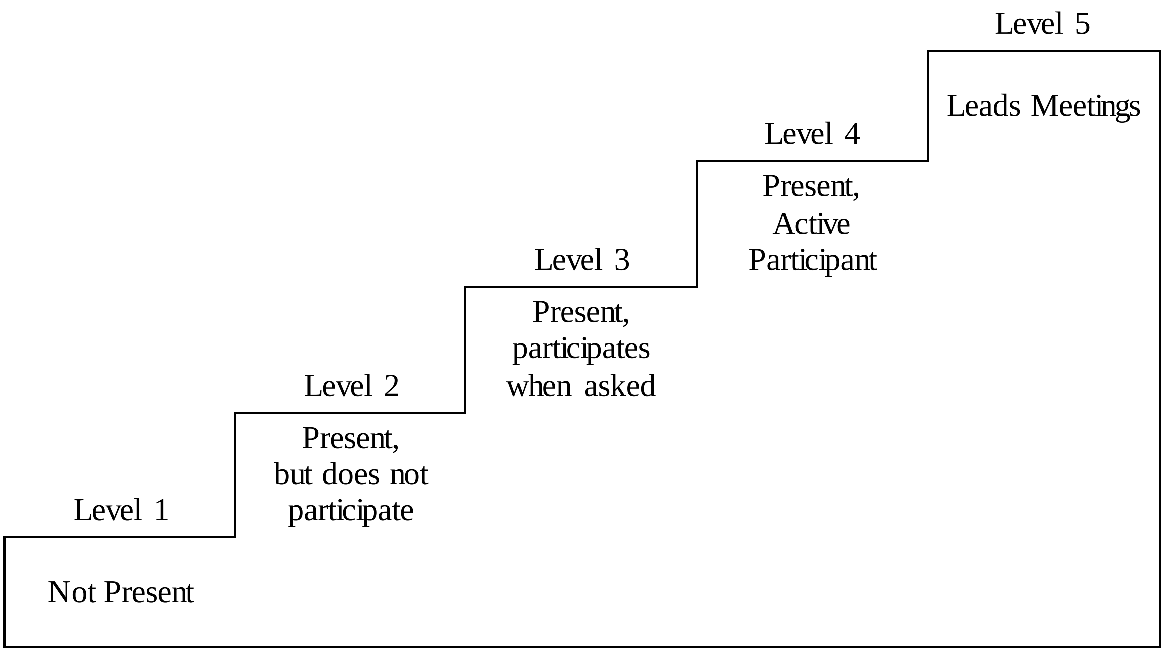

Figure 6: Suggested Levels of Student Advocacy © 2012 Rosenthal

Obviously, if a student is not present, then he/she will be unable to advocate for him- or herself. Even when the student begins to attend the meetings, facing a room full of adults can be intimidating, but it is important for the student to at least listen. While Level 3 in the above table suggests that the student begin answering questions when asked and Level 4 proposes that the student participate equally with the other attendees, an in-between stage might be needed where the student approaches these individuals on a one-on-one basis, and although this contact might be made verbally, the student could have his/her needs written down. This “Passport” idea was initiated at a BrainSTEPS meeting. It gave the student a chance to sit down and write out what he/she needed as a support. Even if the student was unable to write him- or herself, the student could dictate his/her needs to someone that he/she was comfortable with and to who was willing to transcribe the student's needs. The student could then show his/her passport to his/her classroom teachers, which would, in effect, say, "This is what I need to learn." Again, the best form of advocacy is the one that includes I need, a statement in the first person rather than so-and-so needs, a statement in the third person.

The next support that was found to enhance the re-entry process is constant communication. The table below demonstrates the suggested meetings that should take place before and during the transition process. A planning meeting should occur prior to the student ever stepping foot back in school as soon as the doctors and the parents have an estimated time that the student will return to school. If the student is able to attend, then he or she should be present. If not, then perhaps another planning meeting should be help. The other attendees at the planning meeting should include a doctor that can explain in laymen's terms what happened to the student medically and how this might effect his/her learning. If possible, all of the doctors that have contributed to the medical reports sent to the school should attend. Aside from explaining the medical jargon in these reports, the doctors should be able to tell the educators what the student is capable of doing – cognitively and physically. Both of the student's parents should attend the meeting if possible. While they may not have the medical knowledge or the educational pedagogy that some of the other attendees will have, they will most likely be the student's biggest advocate at this stage of the transition process. At a time when the student may not be able to self-advocate, the parent is probably the next best person because he/she has watched the student grow up and will recognize strengths and weaknesses, and how these have changed since the injury. The core team at the school, which is usually made up of administrators, counselors, and nurses should be present. While they most likely will not work directly with the student on a daily basis upon his/her return to school, these personnel will most likely coordinate services and provide support for the teachers. If the principal knows who the student's teacher(s) will be, then those individuals should be present. If not, then a follow-up planning meeting should be held prior to the student's arrival at school. These planning meetings should occur with as much time as possible before the student's arrival at school so that the school has time to plan for the accommodations that the student will need.

	Planning Meeting	Check-Up Meeting	2nd Check-Up Meeting	Transition Meeting	Follow-meetings
When	Prior to arrival	1 month	Halfway*	End of School Year	As Needed
Who	Counselor Doctor Parents Principal School Nurse Student Teachers	Counselor I.U. Staff Nurse Parents Principal Student Support Staff Teachers	Counselor Nurse Parents Principal Student Teachers Therapists	Counselor Nurse Parents Principal Student Teachers	Counselor Nurse Parents Principal Student Teachers Therapists

*The second check-up meeting may occur at the end of the first marking period, in which case this would become the third check-up meeting. Another check-up meeting may occur at the end of the third marking period.

Figure 7: Recommended Meeting Schedule © 2012 Rosenthal

After the student comes back to school, a series of meetings must take place to ensure that the transition is going as smoothly as possible for everyone. The doctor(s) should not be needed as he/she/they should have explained everything that the school needs to know at the initial meeting. If questions arise, the doctor(s) could be invited to the future meetings, or could simply be contacted as needed. The teacher(s) should definitely be present at the follow-up meetings, as they will be the ones spending the most time with the student during the school day. By the first check-up meeting, the school should know what services they are unable to provide that perhaps could be better fulfilled by the intermediate unit. Also, any aides that work with the student, whether it is on a one-on-one basis or in a larger setting such as the cafeteria, library, or playground during recess for elementary students, should be present. Once the intermediate unit begins providing services, then those individuals helping with the student, such as therapists should be present at future meetings. The first of these meetings should take place only a short while after the student's return, such as one month into the transition. This is because, as one principal stated, “you never really know [what they need] until they're here”. The next definite meeting should take place halfway through the school year. A meeting can occur before this if any of the above individuals feels it is necessary. Natural breaks in the school year, such as the end of a marking period, would be good times to meet and make changes. A transition meeting should be held at the end of the school year to determine what needs the student will require in the next grade level. If the student is changing schools (moving from the elementary school to the middle level, middle level to high school, or high school to college), then the core team from the next level should attend the meeting if possible. While these meetings may appear to be time-consuming, the hope is that they will prevent more problems from occurring in the future.

Communication should not just take place at these meetings. School personnel should constantly talk to one another as needed, especially at the secondary level where the student may switch classes. When Suzy's teachers began sharing what was working for her in their individual classrooms, and they went back and tried those ideas out, they found that the ideas worked for them too. Suzy's teachers, principal, and counselor were also in constant two-way communication with her mother, usually via e-mail. For example, they all knew when she had a really bad headache and adapted accordingly. Nobody can ever have too much information, so communication is a must. Everyone involved needed to work together towards the common goal of re-entry.

The final support that can be implemented to enhance the transition process is primarily for the educators. In an ideal situation, the teachers of the student with a brain injury would be able to dedicate their time and efforts to that student; however, we know that that cannot happen in reality. While the teachers can ask for assistance as needed and can be told how to help the student with a brain injury in an initial planning meeting, check-up meetings, and follow-up meetings, it is possible that they may forget the little things once they get stuck in their day to day routines, so periodic check-ups or reminders would be extremely helpful. These reminders could come from the student themselves, the parents, or from a therapist or an administrator.

> She asked me for a copy of her 504 plan. They (the teachers) hadn't obviously had a chance to read through this in great detail and memorized certain things or whatever. Now they have, but so she came to me and said, "I don't think the 504 plan is being followed. Can I have a copy of it?" So that she stood up and said, 'I want to carry this around with me and I want to be able to check it.'

Now, when this student notices that she is not receiving a service that she should be receiving, she can remind the teacher that she needs it, or, if the student is not at that point, could tell a parent that could tell the teacher. Also, when the student realizes that she needs a service that is not listed in her 504 plan, she can suggest that it be added at her next meeting. After such services are put into the 504 plan or IEP, then the therapists or principal could follow-up with the teachers to make sure that they are happening.

> I've got really deep relationships with a lot of students so as much as our focus was on (this student) for the first month or two, the real world is I'm focusing on a hundred people. I guess it would have been helpful to have, I mentioned the halfway meeting, with those experts in the room, I guess maybe some accountability on the teachers' part, because let's be honest, if, if no one's asking me a question, I'm not going to...in other words, our natural instinct is really not to be proactive, it's to be reactive. So, I guess in order to make a me a better teacher for students like this, it would be nice to have maybe a periodical questionnaire or a quick e-mail. I mean it could be the same e-mail every 3 weeks or, just something to keep me in mind, like, wait a minute, have I done that for her lately because, quite frankly, I'll forget. Because in her particular case, she, she didn't want to be thought of as different. She likes the attention like anybody else. But,

> in terms of the attention that comes with 'Hey, you have a disability.' Yea, I think she didn't really want that. So, again, she didn't ask enough questions in my mind during class and also a reminder from her case worker, therapist, whatever, to keep us, to keep in the forefront of our minds, are we looking for these things? Are you doing what we discussed in the beginning of the year meeting? Not expecting an answer, but just as a reminder. What would help me is the experts reminding me what it is that we should be doing. So, I don't mind being held accountable. Are you doing what we agreed that (the student) needs?

While the teacher quoted above did not mind being held accountable, that accountability was to the student and his or her family, not to the administration. This teacher saw this check-up as more of a reminder than an evaluative piece from the administration. Again, if we put a lot of support in place and introduce the factors that have been suggested to enhance the transition process, but do not follow-through with them, then they will not be any good.

Recommendations for Future Research

While many studies have been completed about the return to work of brain-injured adults, this is the first known comprehensive study concerning the return to school of students with brain injuries. Similar studies have included only one spoke of the wheel - the students [Mealings and Douglas (2010)], their families [Sharp, Bye, Llewellyn, & Cusick (2006)], the administrators, the counselors, the nurses, or the teachers [Mohr and Bullock (2005) and Stahl (2008)], but not all of the above. Now that this study has been completed, there are many directions that other researchers can take it. Although, I attempted to be as comprehensive as possible, I still missed some principal actors as mentioned in Chapter Four, so the value of siblings and friends in the re-entry process of students with a brain injury could be studied. Perhaps including some individuals from the medical profession could strengthen the results as well. Future research could evaluate the effectiveness of a re-entry program such as BrainSTEPS by comparing the transition process of students in schools with this support with those without such assistance. Not only do students miss school due to brain injuries, but there are also other medical reasons, such as surgeries and diseases such as cancer. They might also miss for drug and/or alcohol rehabilitation. Some further reasons are a short-term family move due to a parent's temporary job transfer or military assignment. Some of the factors that enhance the transition back to school for the students with brain injuries might help the students that are missing school for other reasons. My colleagues may branch off of my study to find out. Another area of research is to find out how well these students are prepared for their transition to college, since that is still the goal for many of them!! That could even be expanded to see how these students transition to the workforce after graduating from college. Perhaps the study could also be strengthened with the use of a survey. Lastly, quantitative data could be utilized in a follow-up study to reinforce the results achieved using the qualitative approach that this researcher chose. Each of these recommendations is discussed below.

While the current study included students with brain injuries, their parents, school administrators, teachers, and counselors, it did not include the siblings or friends of the students with brain injuries nor the doctors, nurses, and therapists that treated the students. Each of these groups was mentioned in all of the interviews with the students and the parents, as well as most of the interviews with the teachers and administrators, and they were also brought up at the BrainSTEPS meetings. Whether they provided support for the student, information for the schools, or caused tension for the students, they each played an important role, so hearing about the re-entry process from their perspective could add even more insight than what was gathered in this and other similar studies.

BrainSTEPS was highly regarded by most of the subjects interviewed for this study, which makes me ponder about how difficult the transition process would be for students, schools, and families that do not have their support. Perhaps someone could compare the experience of students and schools that are not associated with a re-entry program like BrainSTEPS with the experience of those in my study that did have this support. They could do this in a neighboring county, or across the nation where various re-entry programs similar to BrainSTEPS exist.

I believe that the concept of transitioning back to school after a long-term absence (more than a few days) should be explored further. As stated above, there are a number of reasons that a student might be absent for an extended period of time from medical to familial. Perhaps these students need some or all of the same supports put in place for their transition to go well.

Obviously, if the purpose of this research was fulfilled, then the factors that enhance the transition process will be implemented for students returning to a K-12 school after a traumatic brain injury and those that impede this process will be eliminated; however, we do not know if the factors that enhance the process will remain effective at the collegiate level, especially if the student is not living at home. Therefore, another recommendation in regard to future research would be to follow the student subjects in my study, or students with similar experiences, to see if the same factors that enhance their transition back to school at the K-12 level also enhance their transition to higher education and the workforce.

Next, similar research in the future could implement the use of a survey as a type of data collection. Perhaps the data gathered through the use of a survey would yield more information than some of the participants were willing to share in the interview due to such personality traits as embarrassment, bashfulness, or nervousness around others. Maybe some of the participants would have been more relaxed and found writing easier than speaking. The survey may also help to gather quantitative data, my last recommendation, which is discussed in the next paragraph.

My final recommendation would be to collect quantitative data to substantiate the results obtained qualitatively in this study. This data could help highlight specific advantages and disadvantages of supports put in place to help the transition of students with a brain injury. For example, future researchers could have one group that does not have any of the factors, or supports, mentioned above that have been found to enhance the students with a brain injuries' re-entry process in place compared with another group that does have these elements in place to see if the latter are able to spend more time receiving academic instruction and higher grades. Researchers could also compare the grades received by the students with a brain injury with or without the supports mentioned above with their non-injured peers. However, the other recommendations mentioned for future research above are probably the more viable ones because withholding support may have legal ramifications and it certainly would be unethical.

The Qualitative Approach

I chose a qualitative approach to this study in order to interview a number of individuals that have a stake in the transition process students with a brain injury going back to school following their injury. The qualitative case study method enabled me to collect evidence from multiple-perspectives in a variety of formats. I gathered the detailed, first person accounts from the students with brain injuries themselves, their parents, their teachers, their counselors, their principals, and their therapists that included emotion and revelations that may not have been revealed in a quantitative study. Since many of the interviews of the educators took place at the schools where these students attend, I was also able to gather field notes on personal observations. The last pieces of data collected were IEPs and 504 plans. Perhaps similar qualitative research undertaken in the future can continue to address any lingering questions that may have not been answered in this study, such as the impact of the supporting factors meant to enhance the transition process being implemented, whether or not the same supports are helpful at the collegiate level or at the students' place of employment, and whether these supports can also help students that are going through a transition back to school for a reason other than a traumatic brain injury. The qualitative design is necessary to give a voice to the students with brain injuries, as well as those that are also affected by the students' injury.

Implications for the Field

This research attempted to highlight factors that both enhance and those that impede the transition of students with brain injuries. Obviously, we now need to promote the factors that enhance the transition and discontinue those that impede it. A strength of this study is that it took in all perspectives of those involved in the transition process, something that had not previously been done. The results of this study revealed that everyone needs to communicate to each other, especially about what they need from the other. The outcome of this study could be used to identify general goals for the transition, such as to have the child attend school for the whole day to having them graduate from high school. Finally, this study helped define the role of a school administrator in the transition process. The school administrator needs to be a leader in this process, especially in the organization of the transition, from coordinating meetings and services between the medical staff, school, parents, and the student, to arranging the student's schedule. The educational leader needs to consider the student's schedule carefully, choosing teachers that will best suit the needs of the student with the brain injury, ensuring that there will be at least one study buddy in each of the student's classes, and picking classes that will not tax the student's brain too quickly. The principal also needs to prepare the student body for this transition, as well as staff members that are not present at planning meetings. An application of this research would suggest that the school administrator needs to set the example by learning as much as possible about traumatic brain injuries and sharing this information with his or her staff. In addition, the principal should set up in-service training regarding everything from recognizing a brain injury, especially concussions, to how to help support a student that has experienced one. All staff should receive professional development during in-service days or faculty meetings concerning general awareness about brain injuries. This training should cover how to detect a brain injury by looking into the student's eyes, listening to the student's speech, consider changes in the student's attention span, and asking about the cause of a headache when the student makes such a complaint. Head injuries should be taken seriously until otherwise directed by medical personnel such as the school nurse. Professional development should be more focused for staff members that will be directly working with an individual who has suffered a traumatic brain injury as soon as they find out they have such a case. This training should occur prior to the student's re-entry back to school, and then should be followed-up once staff members have had a chance to work with the student and learn about specific troubles the student is having or recognizing difficulties that they are having teaching the student. This training could take place before or after school with the affected staff members being offered flex time to trade in or other compensation if the training occurs outside of the contractual day. This training could also take place during a common time arranged during the school day as long as the principal can provide substitute coverage for the affected staff members. The principal also needs to balance everyone's perspective, from the parent that only wants the best for his or her child to the teacher that needs support in dealing with the student on a daily basis to the student that needs to learn to become his or her own advocate to the central administration that is putting pressure on the school to meet demands such as annual yearly progress (AYP) and graduation rates. If the principal makes sure that everyone is on the same page and reasonable goals are set, then the transition process should run smoothly. It is important to note that the principal can delegate some of his or her tasks, as the counselor can accomplish many of them as demonstrated in the data collected through interviews in this research study. Collectively, the results of this study can be used to better understand the re-entry process and the results will help school personnel guide their students to a full transition, one that will most likely happen gradually and with some bumps in the road.

Limitations of the Study

The results from this research add to the experimental knowledge base of understanding the transition process of students with brain injuries and the role of the school administrator in this process. Despite this research's significant gains to the field of educational administration as noted above, there are some limitations to the study including the use of the qualitative approach, the reliability of the participants' memories for historical data and the honesty with which they shared their thoughts and feelings, and the diminutive size of the population studied and the similarity of the subjects. These limitations will be discussed below.

As with any research that utilizes a qualitative case study approach, I must accept the information shared during the interviews with the subjects as truthful, accurate, and meant to be taken at face value without hidden agendas. Even though participants were assured that their responses to interview questions would remain confidential, it is possible that the participants, many of whom did not know me prior to their meeting other than through correspondence to set up the meeting or their attendance at the same BrainSTEPS meetings, felt uncomfortable in divulging as much information regarding the transition process as might have been helpful to me. It is also possible, especially during the latter interviews when I had already begun recognizing the common themes mentioned above, that I unintentionally introduced a bias towards those themes in the interviews. I feel that by utilizing the multiple-perspective approach and pre-determined interview protocols that yielded similar answers that varied only by perspective, and that respondents often commented when their memory was unclear about a particular topic, that the results are accurate and were not coerced in any way either my potential bias or outside pressures.

A second limitation to this study is the accuracy of the participants' responses due to memory lapses. Memory problems are well-documented in persons with brain injuries, so it would be natural for some of the student participants to give inaccurate answers because their memories are incomplete. Similarly, the human body has a natural instinct to eliminate memories that are associated with negative emotions (Reinhold and Markowitsch, 2009), so the parents of the students with the brain injury may also have inaccurate memories of their child's injury, recovery process, and early transition back to school. However, it is possible that all of the participants gave inaccurate responses due to the retrospective design used in the study. This approach was chosen to see if various supports could be withdrawn as the transition progresses; however, the further that we got from the initial point of re-entry, the harder it seemed to be to remember some of the details for the participants. Many of the participants divulged their memory lapses when they were unsure of the clarity with which they spoke, so I feel that the results are accurate to best of the participants' knowledge and any conflicting responses given by the participants are unimportant pieces of data.

Lastly, another limitation to this research is the participant population itself. Due to geographic and other logistical limitations such as me working full-time while collecting the data and conducting the research and the confidential nature of the topic, I was unable to immerse myself completely in the study with a voluminous sample. I struggled to find students and families willing to participate because she could not easily get their contact information to communicate about her research directly to them. Therefore, I was unable to differentiate my results based on the type and severity of brain injury suffered since there were only two types involved in the interview process. Furthermore, the observations and information revealed during the interviews showed that participants were relatively homogenous in regards to their ethnicity and socioeconomic status. However, I feel that the information gathered during the interviews agrees with the information collected during my attendance at BrainSTEPS meetings, which provided a much larger and varied sample, thus is accurate and sufficient. The students utilized in this study were all enrolled in schools across school districts throughout the same county. Therefore, as stated in the introductory chapter above, the results of the study are not intended to be generalized and caution should be exercised when the results are applied to students outside of the population studied. Also, expanding the student population to a larger, more diverse group could be an area of further research.

The internal validity of this study is strengthened by the rich data collected from multiple perspectives and through various sources. The responses received were usually consistent with each other and those that participated in the study were willing to do so without any coercion. While many of the participants were interested in my story, they participated because of their own experiences and the desire to improve the transition process for themselves, their children, these students, and those that may have to go through this experience in the future. They were able to provide specific examples and the researcher asked for clarification where needed, therefore any threats to the validity of the study were overcome.

Despite the above discussed limitations, this research design yielded many advantages. First, the design nearly eliminated experimental bias. Interview protocols were followed that asked all of the participants the same questions, simply from the perspective with which they were involved. The data were then systematically analyzed so that each BrainSTEPS meeting and each interview was treated with equal weight. As stated above, I took the valuable information shared with me at face value.

Another advantage of this research design is the longitudinal approach used. For example, supports that were put in place to enhance the transition process may have been seen as negative when they did not work immediately; however, as they were refined over time, such as the study buddy concept discussed above, the net results were positive. Another illustration of this concept is shown here.

> The first thing (the principal) did was pull her out of Spanish and said, 'She can't, it's hard enough for her English right now...', so for her to have back-to-back language, intensive language programs, so he changed her entire schedule is what he did, in one fell swoop, he changed her schedule mid-year. Looking back, it was probably necessary, but as far as your concerned with doing your research, was that a good idea for her with what she was dealing with (because that's a transition in and of itself) and that caused a certain amount of stress. One of the issues that we ran into with that was (my child) needed to have (it) and this is something we learned as we went along.

While it appeared to the parent that the principal made a rash decision that caused a lot of stress initially, it was a decision that the parent agreed with in the end. Therefore, it is believed that the factors mentioned above as ones that will enhance the transition process have proven to work over a time, often a period of at least one year.

Epilogue

While I officially chose the topic of traumatic brain injury and its effect on students during a case study course that I took in the fall of 2009, the idea came to me in the mid-1990s when I was a student dealing with a family member that had suffered a traumatic brain injury. It was then that I decided that I would someday complete research associated with TBI so that others would hopefully not have to go through all of what my family and I were experiencing. At the time, I thought that I would focus on ways to regain memory, since that was the biggest concern we had to deal with. I decided that I would pursue a degree from Temple University in the late-1990s because both of my parents earned degrees from the school, but I also knew that attending Temple as an undergraduate was not right for me since I am not accustomed to city life, having grown up in suburban Philadelphia; however, I felt that Temple was the right place for me when I decided to pursue my doctorate and the preceding research, so I did not look anywhere else. Unfortunately, I did not do my homework. As the first member of my immediate family to earn a doctorate degree, I decided to do this without fully knowing what it entailed. I knew that there would be coursework and research, but I assumed that this research consisted of an exceptionally substantial literature review or empirical research, not both. I also did not realize how much others would influence my research, from multiple perspectives. First, from shortly after the time when I defined my topic of study until now, I felt that the research became what others wanted it to be and not what I originally intended; therefore, while I was, and still am, passionate about the topic, I lost my passion for the research, so it became grueling at times. When I expressed this feeling to others that had been through the process or knew someone that had been, they agreed that that is what doctoral research was like, so I learned to accept it; however, I cannot recall ever putting more time into a project than I did this one. I feel that it is a collaborative piece of work at this point, and not just my own, but I am pleased with the outcome. Secondly, my topic made me dependent upon other people, as I needed my subjects to be available for interviews, and I usually had to obtain permission from the subject as well as at least one other person, such as a school superintendent, to complete these interviews. Also, due to confidentiality, it was much harder for me to gain access to these subjects than I anticipated. Lastly, not all of these subjects shared my passion for the topic, so they were not as eager to participate in the study as I was for their involvement. I also feel that I probably made this study harder on myself by choosing to research the effects of TBI from various perspectives rather than just one perspective. Since other researchers had already studied teacher awareness of TBI, the student perspective (Mealings and Douglas), and the family perspective (Sharp), perhaps I could have focused solely on the leadership perspective, but I still feel that even to do that thoroughly, I needed to see the whole picture. While others that have completed quantitative research may disagree, I feel that choosing quantitative project would have been less of a hassle to complete than my project was, especially since there are many topics that lend themselves to data that is already public. Despite the discontent that I am feeling towards myself, I still feel that my research has brought heightened awareness to TBI and will have a positive impact on families going through such an ordeal. Completing my research also makes me feel that I was able to share the burden of some of the suffering that my mom went through. I am also proud to be the first doctor in my family, and to have earned this degree from Temple University, which means so much to my family. I hope that prospective doctoral students and current doctoral students at any stage of the research process from topic selection to defense will consult me for advice so that they can have a better experience than the one I had and learn from my mistakes.

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APPENDIX A: BACKGROUND INFORMATION ON TRAUMATIC BRAIN INJURY

As noted above, traumatic brain injury was defined in the field of education through the Individuals with Disabilities Education Act of 1990. Prior to that definition, most explanations came from medical organizations and were similar to the definition provided above by the National Institute of Neurological Disorders and Stroke. "Every 21 seconds, a person sustains TBI in this country, resulting in 1.4 million new TBIs each year. TBI is the leading cause of disability and death among children and adolescents, with over 1 million children sustaining brain injuries each year. Nationwide each year, 30,000 children end up with severe disability as the result of brain injury" (BIAPA, n.d.a). Therefore, this problem cannot be ignored. Below is a discussion of various facets of TBI that are provided to help the reader fully understand this medical puzzle.

Causes of and Risk Factors of TBI – To help the reader understand traumatic brain injuries, knowing the causes and risk factors is extremely important. "The most common causes of TBI are falls, motor vehicle crashes, bicycle accidents, sports and recreation injuries, shaken baby syndrome, gunshot wounds and assaults" (BIAPA, n.d.a). "Half of all TBIs are due to transportation accidents involving automobiles, motorcycles, bicycles, and pedestrians. These accidents are the major cause of TBI in people under age 75" (NINDS, 2009). According to Langlois, Rutland-Brown, and Thomas (2006) "the rate of motor vehicle-traffic-related TBI is highest among adolescents ages 15 to 19 years (273.1 per 100,000)" (p. 10). "Approximately 20 percent of TBIs are due to violence, such as firearm assaults and child abuse, and about 3 percent are due to sports injuries" (NINDS, 2009). According to Langlois, Rutland-Brown, and Wald (2006) "sports and recreation activities are also a major cause of TBI. An accurate approximation may be that 1.6

million to 3.8 million sports-related TBIs occur each year, including those for which no medical care is sought" (p. 375-376). According to the Defense and Veterans Brain Injury Center ([DVBIC], 2005), "America's armed forces in Iraq and Afghanistan have sustained numerous attacks from weapons such as rocket-propelled grenades, improvised explosive devices and land mines. Sixty-four percent of soldiers recently wounded in action in Operation Iraqi Freedom sustained blast injuries, according to the Office of the Surgeon General of the Army. Soldiers suffering injuries from these devices require specialized care from providers experienced in treating TBI." "Half of TBI incidents involve alcohol use" (NINDS, 2009). I suspect that alcohol is an underlying factor that contributes to each of the frequent causes shown in Figure 6 below.

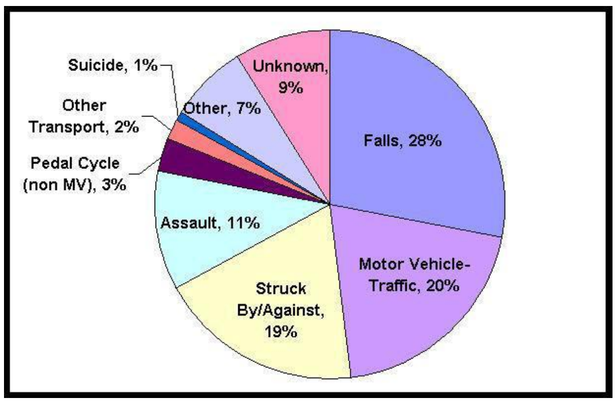

Figure 8: Causes of TBI © 2007 National Center for Injury Prevention and Control

If we reduce the causes, then perhaps we could reduce the incidence of traumatic brain injury.

The proximity and severity of the cause to the brain can effect how the individual reacts to the injury. "The cause of the TBI plays a role in determining the patient's outcome. For example, approximately 91 percent of firearm TBIs (two-thirds of which may be suicidal in intent) result in death, while only 11 percent of TBIs from falls result in death" (National Center for Injury Prevention and Control [NCIPC], 2007; NINDS, 2009). "Firearm use is the leading cause of death related to TBI" (NCIPC, 2007). Unfortunately, many TBIs go undetected until problems begin to occur later in a person's life. Many people that suffer from a TBI think that they are okay if they maintained consciousness and do not have any physical signs of an injury.

The reader should be able to begin piecing together the groups that are most risk for suffering a TBI now that he/she knows the major causes. According to Langlois, Rutland-Brown, and Thomas (2006), "In almost every age group, TBI rates are higher for males than for females. Approximately 1.5 times as many TBIs occurred among males as among females" (p. 1 & 9). Faul, Xu, Wald, and Coronado (2010) proclaim males are more likely to die from a TBI than females (p. 38) and that "children aged 0 to 4 years, older adolescents aged 15 to 19 years, and adults aged 65 years and older are most likely to sustain a TBI. Almost half a million (473,947) emergency department visits for TBI are made annually by children aged 0 to 14 years." (p. 7). "The estimated average annual rate of TBI-related hospitalizations is highest among blacks" according to Langlois, Rutland-Brown, and Thomas (2006, p. 29) and Faul, Xu, Wald, and Coronado (2010, p. 34). While following recommended safety tips can probably prevent most traumatic brain injuries, everyone should know some of the visible signs and symptoms of traumatic brain injury in case these injuries do occur. The signs and symptoms will be discussed in detail in the next section.

<u>*Signs and Symptoms of TBI*</u> – As stated above, those that suffer a TBI may not always have signs and symptoms that are outwardly visible, so each individual that suspects that he/she may have suffered a head injury should seek medical attention. "Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain.

Some symptoms are evident immediately, while others do not surface until several days or weeks after the injury. A person with a mild TBI may remain conscious or may experience a loss of consciousness for a few seconds or minutes. The person may also feel dazed or not like himself for several days or weeks after the initial injury. Other symptoms of mild TBI include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, bad taste in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking" (NINDS, 2009). According to Brown et al. (1981), children that display problems such as hyperactivity prior to their brain injury are more likely to incur a mild but not severe head injury (p. 67-69). As you can see, some of these symptoms are similar to those experienced when a person has had trouble sleeping or is coming down with the common cold for flu. Therefore, if the person experiencing these symptoms knows that they may be related to a head injury, they should seek medical attention.

Those who suffer a more serious TBI may show some of the above symptoms, but to a higher degree and will most likely suffer additional symptoms as well. "A person with a moderate or severe TBI may show these same symptoms, but may also have a headache that gets worse or does not go away, repeated vomiting or nausea, convulsions or seizures, inability to awaken from sleep, dilation of one or both pupils of the eyes, slurred speech, weakness or numbness in the extremities, loss of coordination, and/or increased confusion, restlessness, or agitation. Small children with moderate to severe TBI may show some of these signs as well as signs specific to young children, such as persistent crying, inability to be consoled, and/or refusal to nurse or eat" (NINDS, 2009).

"Children with a brain injury can have the same symptoms as adults, but it is often harder for them to let others know how they feel" (BIAPA, n.d.c). Anyone with signs of moderate or severe TBI should receive medical attention as soon as possible" (NINDS, 2009). These injuries should not be taken lightly, as they may result in further complications. The literature review will continue immediately below with short-term complications, and then will go into long-term problems associated with a TBI.

Complications that Occur from a TBI – The following information is provided by National Institute of Neurological Disorders and Stroke (2009). "Disabilities resulting from a TBI depend upon the severity of the injury, the location of the injury, and the age and general health of the patient. Some common disabilities include problems with cognition (thinking, memory, and reasoning), sensory processing (sight, hearing, touch, taste, and smell), communication (expression and understanding), and behavior or mental health (depression, anxiety, personality changes, aggression, acting out, and social inappropriateness).

Within days to weeks of the head injury approximately 40 percent of TBI patients develop a host of troubling symptoms collectively called post concussion syndrome (PCS). A patient need not have suffered a concussion or loss of consciousness to develop the syndrome and many patients with mild TBI suffer from PCS. Symptoms include headache, dizziness, vertigo (a sensation of spinning around or of objects spinning around the patient), memory problems, trouble concentrating, sleeping problems, restlessness, irritability, apathy, depression, and anxiety. These symptoms may last for a few weeks after the head injury. The syndrome is more prevalent in patients who had psychiatric symptoms, such as depression or anxiety, before the injury. Treatment for PCS may include medicines for pain and psychiatric conditions, and psychotherapy and occupational therapy to develop coping skills.

Cognition is a term used to describe the processes of thinking, reasoning, problem solving, information processing, and memory. Most patients with severe TBI, if they recover consciousness, suffer from cognitive disabilities, including the loss of many higher level mental skills. The most common cognitive impairment among severely head-injured patients is memory loss, characterized by some loss of specific memories and the partial inability to form or store new ones. Some of these patients may experience post-traumatic amnesia (PTA), either anterograde or retrograde. Anterograde PTA is impaired memory of events that happened after the TBI, while retrograde PTA is impaired memory of events that happened before the TBI.

Many patients with mild to moderate head injuries who experience cognitive deficits become easily confused or distracted and have problems with concentration and attention. They also have problems with higher level, so-called executive functions, such as planning, organizing, abstract reasoning, problem solving, and making judgments, which may make it difficult to resume pre-injury work-related activities. Recovery from cognitive deficits is greatest within the first 6 months after the injury and more gradual after that. Patients with moderate to severe TBI have more problems with cognitive deficits than patients with mild TBI, but a history of several mild TBIs may have an additive effect, causing cognitive deficits equal to a moderate or severe injury.

Many TBI patients have sensory problems, especially problems with vision. Patients may not be able to register what they are seeing or may be slow to recognize objects. Also, TBI patients often have difficulty with hand-eye coordination. Because of this, TBI patients may be prone to bumping into or dropping objects, or may seem generally unsteady. TBI patients may have difficulty driving a car, working complex machinery, or playing sports. Other sensory deficits may include problems with hearing, smell, taste, or touch. Some TBI patients develop tinnitus, a ringing or roaring in the ears. A person with damage to the part of the brain that processes taste or smell may develop a persistent bitter taste in the mouth or perceive a persistent noxious smell. Damage to the part of the brain that controls the sense of touch may cause a TBI patient to develop persistent skin tingling, itching, or pain. Although rare, these conditions are hard to treat.

Language and communication problems are common disabilities in TBI patients. Some may experience aphasia, defined as difficulty with understanding and producing spoken and written language; others may have difficulty with the more subtle aspects of communication, such as body language and emotional, non-verbal signals.

In non-fluent aphasia, also called Broca's aphasia or motor aphasia, TBI patients often have trouble recalling words and speaking in complete sentences. They may speak in broken phrases and pause frequently. Most patients are aware of these deficits and may become extremely frustrated. Patients with fluent aphasia, also called Wernicke's aphasia or sensory aphasia, display little meaning in their speech, even though they speak in complete sentences and use correct grammar. Instead, they speak in flowing gibberish, drawing out their sentences with non-essential and invented words. Many patients with fluent aphasia are unaware that they make little sense and become angry with others for not understanding them. Patients with global aphasia have extensive damage to the portions of the brain responsible for language and often suffer severe communication disabilities.

TBI patients may have problems with spoken language if the part of the brain that controls speech muscles is damaged. In this disorder, called dysarthria, the patient can think of the appropriate language, but cannot easily speak the words because they are unable to use the muscles needed to form the words and produce the sounds. Speech is often slow, slurred, and garbled. Some may have problems with intonation or inflection, called prosodic dysfunction. An important aspect of speech, inflection conveys emotional meaning and is necessary for certain aspects of language, such as irony. These language deficits can lead to miscommunication, confusion, and frustration for the patient as well as those interacting with him or her.

Most TBI patients have emotional or behavioral problems that fit under the broad category of psychiatric health. Family members of TBI patients often find that personality changes and behavioral problems are the most difficult disabilities to handle. Psychiatric problems that may surface include depression, apathy, anxiety, irritability, anger, paranoia, confusion, frustration, agitation, insomnia or other sleep problems, and mood swings. Problem behaviors may include aggression and violence, impulsivity, disinhibition, acting out, noncompliance, social inappropriateness, emotional outbursts, childish behavior, impaired self-control, impaired self awareness, inability to take responsibility or accept criticism, egocentrism, inappropriate sexual activity, and alcohol or drug abuse/addiction. Some patients' personality problems may be so severe that they are diagnosed with borderline personality disorder, a psychiatric condition characterized by many of the problems mentioned above. Sometimes TBI patients suffer from developmental stagnation, meaning that they fail to mature emotionally, socially, or psychologically after the trauma. This is a serious problem for children and young adults who suffer from a TBI. Attitudes and behaviors that are appropriate for a child or teenager become inappropriate in adulthood. Many TBI patients who show psychiatric or behavioral problems can be helped with medication and psychotherapy.

In addition to the post-injury complications discussed above, other long-term problems can develop after a TBI. These include Parkinson's disease and other motor problems, Alzheimer's disease, dementia pugilistica, and post-traumatic dementia. Alzheimer's disease (AD) is a progressive, neurodegenerative disease characterized by dementia, memory loss, and deteriorating cognitive abilities. Recent research suggests an association between head injury in early adulthood and the development of AD later in life; the more severe the head injury, the greater the risk of developing AD. Some evidence indicates that a head injury may interact with other factors to trigger the disease and may hasten the onset of the disease in individuals already at risk. For example, people who have a particular form of the protein apolipoprotein E (apoE4) and suffer a head injury fall into this increased risk category. (ApoE4 is a naturally occurring protein that helps transport cholesterol through the bloodstream.)

Movement disorders as a result of TBI, such as Parkinson's disease and other motor problems, are rare but can occur. Parkinson's disease may develop years after TBI as a result of damage to the basal ganglia. Symptoms of Parkinson's disease include tremor or trembling, rigidity or stiffness, slow movement (bradykinesia), inability to move (akinesia), shuffling walk, and stooped posture. Despite many scientific advances in recent years, Parkinson's disease remains a chronic and progressive disorder, meaning that it is incurable and will progress in severity until the end of life. Other movement disorders that may develop after TBI include tremor, ataxia (uncoordinated muscle movements), and myoclonus (shock-like contractions of muscles).

Dementia pugilistica, also called chronic traumatic encephalopathy primarily affects career boxers. The most common symptoms of the condition are dementia and parkinsonism caused by repetitive blows to the head over a long period of time. Symptoms begin anywhere between 6 and 40 years after the start of a boxing career, with an average onset of about 16 years.

The symptoms of post-traumatic dementia are very similar to those of dementia pugilistica, except that post-traumatic dementia is also characterized by long-term memory problems and is caused by a single, severe TBI that results in a coma."

Rehabilitation for a TBI Patient – Despite the myriad of complications mentioned above, there is hope for TBI patients to make some form of a recovery. The following information on rehabilitation for TBI patients is also provided by National Institute of Neurological Disorders and Stroke (2009). "Rehabilitation is an important part of the recovery process for a TBI patient. During the acute stage, moderately to severely injured patients may receive treatment and care in an intensive care unit of a hospital. Once stable, the patient may be transferred to a subacute unit of the medical center or to an independent rehabilitation hospital. At this point, patients follow many diverse paths toward recovery because there are a wide variety of options for rehabilitation.

Testing by a trained neuropsychologist can assess the individual's cognitive, language, behavioral, motor, and executive functions and provide information regarding the need for rehabilitative services. In 1998, the NIH held a Consensus Development Conference on Rehabilitation of Persons with Traumatic Brain Injury. The Consensus Development Panel recommended that TBI patients receive an individualized rehabilitation program based upon the patient's strengths and capacities and that rehabilitation services should be modified over time to adapt to the patient's changing needs. The panel also recommended that moderately to severely injured patients receive rehabilitation treatment that draws on the skills of many specialists. This involves individually tailored treatment programs in the areas of physical therapy, occupational therapy, speech/language therapy, physical medicine, psychology/psychiatry, and social support. Medical personnel who provide this care include rehabilitation specialists, such as rehabilitation nurses, psychologists, speech/language pathologists, physical and occupational therapists, physical medicine specialists, social workers, and a team coordinator or administrator.

Rehabilitation therapy is an important part of the recovery process of TBI patients. The overall goal of rehabilitation after a TBI is to improve the patient's ability to function at home and in society. Therapists help the patient adapt to disabilities or change the patient's living space, called environmental modification, to make everyday activities easier.

Some patients may need medication for psychiatric and physical problems resulting from the TBI. Great care must be taken in prescribing medications because TBI patients are more susceptible to side effects and may react adversely to some pharmacological agents. It is important for the family to provide social support for the patient by being involved in the rehabilitation program. Family members may also benefit from psychotherapy.

It is important for TBI patients and their families to select the most appropriate setting for rehabilitation. There are several options, including home-based rehabilitation, hospital outpatient rehabilitation, inpatient rehabilitation centers, comprehensive day programs at rehabilitation centers, supportive living programs, independent living centers, club-house programs, school based programs for children, and others. The TBI patient, the family, and the rehabilitation team members should work together to find the best place for the patient to recover." This study focuses on school based programs for students in grades kindergarten through twelfth grade.

APPENDIX B: BACKGROUND INFORMATION ON ASSESSMENTS FOR THE EVALUATION OF TBI STUDENTS

The following is a description of a multitude of assessments as referenced in Farmer et al. (1996). Each assessment will be described briefly by the "major area of functioning important to school re-entry following TBI including the medical/health domain, intellectual/cognitive domain, speech/language domain, academic arena, sensorimotor skills, and behavioral domain". Many of the assessments listed are norm-referenced, standardized tests. "The advantages of norm-referenced testing include the fact that the student is being compared with his or her peers, the uniformity of procedure, and, with careful test selection, the high degree of reliability and validity. Alternative, informal assessment techniques are (also) crucial for obtaining a full picture of a child's abilities following TBI. The Rancho Los Amigos Levels of Cognitive Functioning Scale (Hagen, Malkmus, & Durham, 1981) outlines eight stages of cognitive and behavioral recovery. The Children's Orientation and Amnesia Test (COAT; Ewing-Cobbs, Levin, Fletcher, Miner, & Eisenberg, 1990; Iverson, Iverson, Barton, & Farmer, 1994) can be used to measure orientation to person, place, and time, as well as attention/concentration and post-traumatic amnesia (PTA; the length of time until new memories are stored and recalled). The same information can be obtained using the Galveston Orientation and Amnesia Test (GOAT; Levin, Benton, & Grossman, 1982). The Mini-Mental State Examination can be used as a brief screening measure of cognition early in recovery. The Wechsler Intelligence Scale for Children-Third Edition (WISC-III; Wechsler, 1991) provides a baseline measure of global cognitive functioning following injury in school-aged children. Several specific cognitive tests have demonstrated sensitivity to the effects of brain injury in children. For example, more severely injured children have shown changes on measures of attention, such as continuous performance testes (Kaufman, Fletcher, Levin, Miner & Ewing-Cobbs, 1993; Murphy-Berman & Wright, 1987); memory and new-learning measures, such as the California Verbal Learning Test-Children's Version (Delis, Kramer, Kaplan, & Ober, 1989; Fay et al., 1994; Levin et al., 1993); concept formation and problem-solving measures, such as the Wisconsin Card Sorting Test (Heaton, 1981; Levin et al., 1993) and the 20 Questions Test (Denney & Denney, 1973; Levin et al., 1993); planning measures such as the Tower of London (Levin et al., 1994; Shallice, 1982); and measures of cognitive productivity, such as the Controlled Oral Word Test (Benton, 1968; Levin et al. 1993) and the Invention of Designs Test (Jones-Gotman & Milner, 1977; Levin et al., 1993). Neuropsychologists might use these tests in a flexible battery approach designed to clarify a child's cognitive strengths and weaknesses. A fixed battery, such as the Halstead-Reitan Neuropsychological Test Battery for Older Children (Reitan & Wolfson, 1992) is not recommended, as this approach is primarily useful in diagnosing brain damage rather than suggesting practical interventions; however, selected subtests, such as the Trail Making Test, the Category Test, and the Tactual Performance Test, can provide additional information about specific cognitive abilities (Fay et al., 1994). These tests can be supplemented by new measures of children's memory functioning such as the Wide Range Assessment of Memory and Learning (Sheslow & Adams, 1990) or the Test of Memory and Learning (TOMAL; Reynolds & Bigler)." The above is a list of the cognitive tests. The tests that fit in the other domains will continue below.

Just as there were specific tests to evaluate cognitive abilities, the other areas of possible damage also have specific tests. For speech and language functioning, "the Clinical Evaluation of Language Fundamentals-Revised (CELF-R; Semel, Wiig, & Secord, 1987) assesses phonology, semantics, morphology, syntax, word retrieval, and verbal memory across a variety of receptive and expressive contexts. The Word Test (Jorgenson, Barrett, Huisingh, & Zachman, 1981) and the Test of Language Competence (Wiig & Secord, 1988) evaluate ability to understand and use increasingly complex and abstract language, such as semantic absurdities, inferences, and figurative language. The Kaufman Test of Educational Achievement (K-TEA; Kaufman & Kaufman, 1985) and the Woodcock-Johnson Psycho-Educational Battery-Revise (Tests of Achievement) (WJ-R; Woodcock & Johnson, 1989) are two widely used achievement measures that are reliable and highly correlated with academic achievement in noninjured children. Performance-based assessment is more likely to identify the effect of TBI on skills necessary for academic progress, and to clarify important areas to target for intervention (Ylvisaker et al., 1990). To assess the child's visual-perceptual and visual-motor skills, tests such as the Motor Free Visual Perception Test (Colarusso & Hammill, 1972) and the Developmental Test of Visual Motor Integration (Beery & Buktenica, 1982) are brief and easy to administer. Gross and fine motor skills can be documented with a measure such as the Bruininks-Oseretsky Test of Motor Proficiency (Bruininks, 1978). Measures of sensory and motor abilities in younger children include the Peabody Developmental Scales (Folio & Fewell, 1983.) Several tools have been developed to examine functional behaviors in young children (Haley, Coster, & Ludlow, 1991). These include the Wee-Functional Independence Measure (Wee-FIM; Braun & Granger, 1991) and the Pediatric Evaluation of Disability Inventory (Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992), both designed for children (up) to 7 years. The Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) is also a useful measure of behavioral competence after TBI. Knights et al. (1991) found decreased attention span and increased disruptive behaviors among severely injured children using the Conners Parent and Teacher Rating Scales (Goyette, Conners, Ulrich, 1978)." While the above list is by no means complete, it can be considered comprehensive for TBI students. I will not conduct any of this testing during my study, but I am expecting to see the results of some of this testing in both medical and academic records of my student subjects. I will rely mainly on informal, anecdotal evidence in my study.

APPENDIX C: BRAINSTEPS PERMISSION TO STUDY

Dear Ms. Krusen,

My name is Stacy Rosenthal and I am doctoral student in Temple University's educational administration program. I am conducting a study entitled, "Traumatic Brain Injury and Its Effect on Students". As you know from our previous contact in October 2009, this study will examine what factors impede or support the re-entry to school of brain-injured students.

At this time, I would like proceed working with you and your BrainSTEPS team to identify students in Bucks County that are transitioning back to school, and who, along with their families, are willing and able to participate in this study by sharing their experiences with me over the next calendar year. Participation in this study is completely voluntary and anyone participating may pull out from the study at any time without penalty to anyone involved. Each participant will be asked to fill out and return a signed consent form to participate. Participants under the age of 18 must also secure the signature of a parent or guardian. In order to see the entire picture, I would like to know if you and your team members would be interested in participating in this study as well.

The study is qualitative in nature, and will require audio taped interviews with each of the students and their parents several times during the transition process. Each interview is expected to last between 45 minutes and one hour. The interview is the only requirement for participants, should they choose to participate in the study. I will also ask each student and his/her family members to keep a journal about his/her feelings throughout the transition process if they want to and I would like to observe the student at school if they are okay with that.

All information collected will remain confidential and anonymous except as may be required by federal, state, or local law. Confidentiality will be assured through the use of pseudonyms and coded number system so the educational leader's identity will be protected. Additionally, all information collected will be retained on file for three years.

I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacts at (215) 822-0360 or tub07463@temple.edu. You may also direct your concerns to Richard C. Throm, Director, Office for Human Subjects Protection, Temple University at (215) 707-8757 or richard.throm@temple.edu. Thank you for your time!

Sincerely,

Stacy B. Rosenthal
Student Investigator (SI)
Ed.D. Candidate
Temple University

Date _______________

____ Yes, I give permission for BrainSTEPS team members to participate in interview sessions with Stacy B. Rosenthal as part of her dissertation research for Temple University.

____ No, I do not give my permission to allow BrainSTEPS team members to participate in interview sessions with Stacy B. Rosenthal as part of her dissertation research for Temple University.

________________________________ ________________________________

Signature of Person Approving Request Title of Person Approving Request

APPENDIX D: SUPERINTENDENT'S PERMISSION TO STUDY

Dear School Superintendent,

My name is Stacy Rosenthal and I am doctoral student in Temple University's educational administration program and I have been an educator in public schools almost six years. I am conducting a study entitled, "Traumatic Brain Injury and Its Effect on Students". This study will examine what factors impede or support the re-entry to school of brain-injured students.

I have been working with BrainSTEPS to identify students in Bucks County that are transitioning back to school, and who, along with their families, are willing and able to participate in this study over the next calendar year. Participation in this study is completely voluntary and anyone participating may pull out from the study at any time without penalty to yourself or your school district. Each participant will be asked to fill out and return a signed consent form to participate. Participants under the age of 18 must also secure the signature of a parent or guardian.

In order to see the entire picture, I would like to know if your school district would be interested in participating in this study as well. It is qualitative in nature, and will require audio taped interviews with the school principal, school psychologist, counselor and teachers of each student. Each interview is expected to last between 45 minutes and one hour, and it is expected that each of the above-mentioned individuals would participate in a maximum of three interviews. The interview is the only requirement for these individuals, should your district choose to participate in the study. I will also ask each teacher to keep a journal about his/her feelings throughout the transition process if they want to and I would like to observe the student at school if all parties are okay with that.

All information collected will remain confidential and anonymous except as may be required by federal, state, or local law. Confidentiality will be assured through the use of pseudonyms and coded number system so the educational leader's identity will be protected. Additionally, all information collected will be retained on file for three years.

I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacts at (215) 822-0360 or tub07463@temple.edu. You may also direct your concerns to Richard C. Throm, Director, Office for Human Subjects Protection, Temple University at (215) 707-8757 or richard.throm@temple.edu. Thank you for your time!

Sincerely,

Stacy B. Rosenthal
Student Investigator (SI)
Ed.D. Candidate
Temple University

Date ______________

____ Yes, I give permission for educational leaders (school principals, school psychologists, counselors and teachers) in my school district to participate in interview sessions with Stacy B. Rosenthal as part of her dissertation research for Temple University.

____ No, I do not give my permission to allow educational leaders (school principals, school psychologists, counselors and teachers) in my school district to participate in interview sessions with Stacy B. Rosenthal as part of her dissertation research for Temple University.

______________________________ ______________________________
Signature of Person Approving Request Title of Person Approving Request

____
School District

APPENDIX E: INFORMED CONSENT FORM – ASSENT FOR STUDENTS

Study Title: Traumatic Brain Injury and Its Effect on Students

Principal Investigator: Corrinne A. Caldwell, PhD, Professor, Educational Leadership and Policy Studies, (610) 353-0633
Student Investigator: Ms. Stacy B. Rosenthal, Doctoral Student, Educational Administration Program, (215) 822-0360

Dear Student Participant,

I am doing a study entitled, "Traumatic Brain Injury and Its Effect on Students". This study will examine what factors impede or support your transition back to school following your injury.

My research is a graduation requirement for a Doctorate Degree in Educational Administration at Temple University in Philadelphia, Pennsylvania. You were selected as a student participant in this study by your BrainSTEPS team leader. Participation in this study is completely voluntary and you may pull out from it at any time without any consequences. You and one of your parents/guardians must sign the acknowledgement and consent form, which may be turned in directly to me or through your BrainSTEPS coordinator. If you plan to participate, please fill out and return this survey within two weeks.

The study is qualitative in nature, and will require audio taped interviews with you several times during the transition process, up to a maximum of one year. Each interview is expected to include 8-14 questions and last approximately 45 minutes. The interview is the primary requirement for participants, should you choose to join the study. I will also ask you and your family members to keep a journal about your feelings throughout the transition process if you want to and I would like to observe you at school and attend IEP meetings. It is not expected that your routine activities will be disrupted in any way because I will schedule interviews with you at a time and place that is mutually agreeable and convenient for both of us.

Although I do not anticipate any risks at this point in time, if you become uncomfortable during any interview or observation, you may skip a question, end that session, and/or drop out of the study completely. I will also do my best to lessen any possible discomfort for you before, during, and after the study.

I feel that you, and society in general, will benefit tremendously from your participation in this research. First, you will benefit by being given a voice, which may help everyone involved celebrate many more successes than frustrations, and open the door for future conversations. Due to the frequency of traumatic brain injury to school-aged children, the study has the potential to help brain injured students, their family members, teachers, counselors, school psychologists,

Initials_____Date____

and educational leaders better understand the effects of a traumatic brain injury and what factors enhance or impede the re-entry process. Perhaps this study will conclude that accommodations thought to be helpful in the past are still useful, but it is my hope that the study will illuminate new ideas that can and should be implemented to help the student make a successful transition back to school. This transition process cannot be made without the cooperation of the student, his/her family, individuals from the medical field, and educators including teachers, counselors, school psychologists, and administrators. This study will help educators carry out the guidelines posed to them in special education laws such as Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA) since traumatic brain injury is recognized as a disability.

CONFIDENTIALITY
The purpose of the confidentiality statement is to inform you about the agencies and organizations that will have access to your study data.

All documents and information pertaining to this research study will be kept confidential, unless required by applicable federal, state, and local laws and regulations to be disclosed. I understand that records and data generated by the study may be reviewed by Temple University and its agents, the study sponsor or the sponsor's agents (if applicable), and/or governmental agencies to assure proper conduct of the study and compliance with regulations. [Occasionally data will also be sent to regulatory agencies of foreign governments seeking approval of a medical intervention in that country.] I understand that the results of this study may be published. If any data is published, I will not be identified by name.

QUESTIONS
I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacted at (215) 822-0360 or tub07463@temple.edu. If you have any questions about your rights as a research subject, you may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
Institutional Review Board Coordinator
Temple University Research Administration
Student Faculty Conference Center
3340 North Board Street – Suite 304
Philadelphia, PA 19140

Initials_____Date_____

APPENDIX F: ACKNOWLEDGEMENT AND CONSENT FORM – ASSENT FOR STUDENTS

Study Title: Traumatic Brain Injury and Its Effect on Students

I, ____________________________________, hereby state that:
(Print Full Legal Name)

1. I have read all information provided on the consent form as it relates to the research study entitled, "Traumatic Brain Injury and Its Effect on Students" conducted by Stacy B. Rosenthal, Ed.D. candidate of Temple University, Philadelphia, Pennsylvania.
2. I have been given the opportunity to ask questions that I may have and have received responses that meet my satisfaction.
3. I have been given a cover letter explaining the research objective and instructions and a copy of this "Acknowledgement and Consent" form.
4. If I have any questions about my rights as a research subject, I may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:

   Institutional Review Board Coordinator
   Temple University Research Administration
   Student Faculty Conference Center
   3340 North Board Street – Suite 304
   Philadelphia, PA 19140.
5. By signing this "Acknowledgement and Consent" form, I consent to being a participant in the aforementioned study.
6. I understand that I need the signature of a parent or guardian if I am below the age of 18 and/or have suffered a traumatic brain injury.

____________________________________ ____________
Print Participant's Full Legal Name Date

____________________________________ ____________
Signature of Participant Date

____________________________________ ____________
Print Parent/Guardian's Full Legal Name Date
(if participant is under the age of 18 and/or brain injured)

____________________________________ ____________
Signature of Parent/Guardian Date
(if participant is under the age of 18 and/or brain injured)

Study Title: Traumatic Brain Injury and Its Effect on Students

As the investigator in this study, I hereby state to the best of my knowledge and belief, that all statements made in the documents listed are true. Any participants involved in this study may withdraw or discontinue participation at any time without penalty.

______________________________________ ____________
Print Full Legal Name of Investigator Date

______________________________________ ____________
Signature of Investigator Date

Initials_____Date_____

APPENDIX G: INFORMED CONSENT FORM FOR PARENTS/GUARDIANS

Study Title: Traumatic Brain Injury and Its Effect on Students

Principal Investigator: Corrinne A. Caldwell, PhD, Professor, Educational Leadership and Policy Studies, (610) 353-0633
Student Investigator: Ms. Stacy B. Rosenthal, Doctoral Student, Educational Administration Program, (215) 822-0360

Dear Parent/Guardian,

I am conducting a study entitled, "Traumatic Brain Injury and Its Effect on Students". This study will examine what factors impede or support the re-entry to school of brain-injured students.

My research is a graduation requirement for a Doctorate Degree in Educational Administration at Temple University in Philadelphia, Pennsylvania. You were identified as a participant in this study by your BrainSTEPS team leader or your association with a traumatic brain injured student that is a part of the BrainSTEPS program. Participation in this study is completely voluntary and you may withdraw from the study at any time without penalty to yourself or your family. Each participant will be asked to fill out and return a signed consent form to participate. Participants under the age of 18 and/or brain injured must also secure the signature of a parent or guardian. Completed consent forms may be turned in directly to me or through your BrainSTEPS coordinator. If you intend to participate, please fill out and return this survey within two weeks.

The study is qualitative in nature, and will require audio taped interviews with each subject several times during the transition process, up to a maximum of one year. Each interview is expected to include 8-14 questions and last approximately 45 minutes. The interview is the primary requirement for participants, should they choose to participate in the study. I will also ask each student and his/her family members to keep a journal about his/her feelings throughout the transition process if they want to and I would like to observe the student at school and attend IEP meetings if all parties are okay with that. It is not expected that your routine activities will be disrupted in any way because I will schedule interviews with you at a time and place that is mutually agreeable and convenient for both of us.

Although I do not anticipate any risks at this juncture, should you become uncomfortable during any interview or observation, you may skip a question, end that session, and/or drop out of the study completely at any time. I will also do my best to minimize any possible discomfort for you before, during, and after the study.

I feel that you, and society in general, will benefit tremendously from your participation in this research. First, you will benefit by being given a voice, which may help everyone involved celebrate many more successes than frustrations, and open the door for future conversations.

Initials_____Date_____

Due to the incidence in traumatic brain injury to school-aged children, the study has the potential to help brain injured students, their family members, teachers, counselors, school psychologists, and educational leaders better understand the effects of a traumatic brain injury and what factors enhance or impede the re-entry process. Perhaps this study will conclude that accommodations thought to be helpful in the past are still useful, but it is my hope that the study will illuminate new ideas that can and should be implemented to help the student make a successful transition back to school. This transition process cannot be made without the cooperation of the student, his/her family, individuals from the medical field, and educators including teachers, counselors, school psychologists, and administrators. This study will help educators carry out the guidelines posed to them in special education laws such as Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA) since traumatic brain injury is recognized as a disability.

CONFIDENTIALITY

The purpose of the confidentiality statement is to inform you about the agencies and organizations that will have access to your study data.

All documents and information pertaining to this research study will be kept confidential, unless required by applicable federal, state, and local laws and regulations to be disclosed. I understand that records and data generated by the study may be reviewed by Temple University and its agents, the study sponsor or the sponsor's agents (if applicable), and/or governmental agencies to assure proper conduct of the study and compliance with regulations. [Occasionally data will also be sent to regulatory agencies of foreign governments seeking approval of a medical intervention in that country.] I understand that the results of this study may be published. If any data is published, I will not be identified by name.

QUESTIONS

I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacted at (215) 822-0360 or tub07463@temple.edu. If you have any questions about your rights as a research subject, you may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
Institutional Review Board Coordinator
Temple University Research Administration
Student Faculty Conference Center
3340 North Board Street – Suite 304
Philadelphia, PA 19140

APPENDIX H: ACKNOWLEDGEMENT AND CONSENT FORM FOR PARENTS/GUARDIANS

Study Title: Traumatic Brain Injury and Its Effect on Students

I, ___________________________________, hereby state that:
(Print Full Legal Name)

1. I have read all information provided on the consent form as it relates to the research study entitled, "Traumatic Brain Injury and Its Effect on Students" conducted by Stacy B. Rosenthal, Ed.D. candidate of Temple University, Philadelphia, Pennsylvania.
2. I have been given the opportunity to ask questions that I may have and have received responses that meet my satisfaction.
3. I have been given a cover letter explaining the research objective and instructions and a copy of this "Acknowledgement and Consent" form.
4. If I have any questions about my rights as a research subject, I may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
   Institutional Review Board Coordinator
   Temple University Research Administration
   Student Faculty Conference Center
   3340 North Board Street – Suite 304
   Philadelphia, PA 19140.
5. By signing this "Acknowledgement and Consent" form, I consent to being a participant in the aforementioned study.
6. I understand that I need the signature of a parent or guardian if I am below the age of 18 and/or have suffered a traumatic brain injury.

___________________________________ ____________
Print Participant's Full Legal Name Date

___________________________________ ____________
Signature of Participant Date

§

As the investigator in this study, I hereby state to the best of my knowledge and belief, that all statements made in the documents listed are true. Any participants involved in this study may withdraw or discontinue participation at any time without penalty.

___________________________________ ____________
Print Full Legal Name of Investigator Date

___________________________________ ____________
Signature of Investigator Date

APPENDIX I: INFORMED CONSENT FORM FOR TEACHERS, COUNSELORS, PSYCHOLOGISTS

Study Title: Traumatic Brain Injury and Its Effect on Students

Principal Investigator: Corrinne A. Caldwell, PhD, Professor, Educational Leadership and Policy Studies, (610) 353-0633
Student Investigator: Ms. Stacy B. Rosenthal, Doctoral Student, Educational Administration Program, (215) 822-0360

Dear Teacher, Counselor, Psychologist,

I am conducting a study entitled, "Traumatic Brain Injury and Its Effect on Students". This study will examine what factors impede or support the re-entry to school of brain-injured students.

My research is a graduation requirement for a Doctorate Degree in Educational Administration at Temple University in Philadelphia, Pennsylvania. You were identified as a participant in this study by your association with a traumatic brain injured student that is a part of the BrainSTEPS program. Participation in this study is completely voluntary and you may withdraw from the study at any time without penalty to yourself or your school. Each participant will be asked to fill out and return a signed consent form to participate. Completed consent forms may be turned in directly to me or through the student's BrainSTEPS coordinator. If you intend to participate, please fill out and return this survey within two weeks.

The study is qualitative in nature, and will require audio taped interviews with each subject several times during the transition process, up to a maximum of one year. Each interview is expected to include 8-14 questions and last approximately 45 minutes. The interview is the primary requirement for participants, should they choose to participate in the study. I will also ask you to keep a journal about your feelings throughout the transition process if you want to and I would like to observe the student at school and attend IEP meetings if all parties are okay with that. It is not expected that your routine activities will be disrupted in any way because I will schedule interviews with you at a time and place that is mutually agreeable and convenient for both of us.

Although I do not anticipate any risks at this juncture, should you become uncomfortable during any interview or observation, you may skip a question, end that session, and/or drop out of the study completely at any time. I will also do my best to minimize any possible discomfort for you before, during, and after the study.

I feel that you, and society in general, will benefit tremendously from your participation in this research. First, you will benefit by being given a voice, which may help everyone involved celebrate many more successes than frustrations, and open the door for future conversations. Due to the incidence in traumatic brain injury to school-aged children, the study has the potential to help brain injured students, their family members, teachers, counselors, school psychologists, and educational leaders better understand the effects of a traumatic brain injury and what factors enhance or impede the re-entry process. Perhaps this study will conclude that accommodations thought to be helpful in the past are still useful, but it is my hope that the study will illuminate new ideas that can and should be implemented to help the student make a successful transition back to school. This transition process cannot be made without the cooperation of the student, his/her family, individuals from the medical field, and educators including teachers, counselors, school psychologists, and administrators. This study will help educators carry out the guidelines posed to them in special education laws such as Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA) since traumatic brain injury is recognized as a disability.

CONFIDENTIALITY

The purpose of the confidentiality statement is to inform you about the agencies and organizations that will have access to your study data.

All documents and information pertaining to this research study will be kept confidential, unless required by applicable federal, state, and local laws and regulations to be disclosed. I understand that records and data generated by the study may be reviewed by Temple University and its agents, the study sponsor or the sponsor's agents (if applicable), and/or governmental agencies to assure proper conduct of the study and compliance with regulations. [Occasionally data will also be sent to regulatory agencies of foreign governments seeking approval of a medical intervention in that country.] I understand that the results of this study may be published. If any data is published, I will not be identified by name.

QUESTIONS

I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacted at (215) 822-0360 or tub07463@temple.edu. If you have any questions about your rights as a research subject, you may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
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Student Faculty Conference Center
3340 North Board Street – Suite 304
Philadelphia, PA 19140

Initials_____Date____

APPENDIX J: ACKNOWLEDGEMENT AND CONSENT FORM FOR TEACHERS, COUNSELORS, AND PSYCHOLOGISTS

Study Title: Traumatic Brain Injury and Its Effect on Students

I, ___________________________________, hereby state that:
(Print Full Legal Name)

1. I have read all information provided on the consent form as it relates to the research study entitled, "Traumatic Brain Injury and Its Effect on Students" conducted by Stacy B. Rosenthal, Ed.D. candidate of Temple University, Philadelphia, Pennsylvania.
2. I have been given the opportunity to ask questions that I may have and have received responses that meet my satisfaction.
3. I have been given a cover letter explaining the research objective and instructions and a copy of this "Acknowledgement and Consent" form.
4. If I have any questions about my rights as a research subject, I may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
   Institutional Review Board Coordinator
   Temple University Research Administration
   Student Faculty Conference Center
   3340 North Board Street – Suite 304
   Philadelphia, PA 19140.
5. By signing this "Acknowledgement and Consent" form, I consent to being a participant in the aforementioned study.
6. I understand that I need the signature of a parent or guardian if I am below the age of 18 and/or have suffered a traumatic brain injury.

___________________________________ ____________
Print Participant's Full Legal Name Date

___________________________________ ____________
Signature of Participant Date

§

As the investigator in this study, I hereby state to the best of my knowledge and belief, that all statements made in the documents listed are true. Any participants involved in this study may withdraw or discontinue participation at any time without penalty.

___________________________________ ____________
Print Full Legal Name of Investigator Date

___________________________________ ____________
Signature of Investigator Date

APPENDIX K: INFORMED CONSENT FORM FOR SCHOOL ADMINISTRATORS

Study Title: Traumatic Brain Injury and Its Effect on Students

Principal Investigator: Corrinne A. Caldwell, PhD, Professor, Educational Leadership and Policy Studies, (610) 353-0633
Student Investigator: Ms. Stacy B. Rosenthal, Doctoral Student, Educational Administration Program, (215) 822-0360

Dear School Administrator,

I am conducting a study entitled, "Traumatic Brain Injury and Its Effect on Students". This study will examine what factors impede or support the re-entry to school of brain-injured students.

My research is a graduation requirement for a Doctorate Degree in Educational Administration at Temple University in Philadelphia, Pennsylvania. You were identified as a participant in this study by your association with a traumatic brain injured student that is a part of the BrainSTEPS program. Participation in this study is completely voluntary and you may withdraw from the study at any time without penalty to yourself or your school. Each participant will be asked to fill out and return a signed consent form to participate. Completed consent forms may be turned in directly to me or through the student's BrainSTEPS coordinator. If you intend to participate, please fill out and return this survey within two weeks.

The study is qualitative in nature, and will require audio taped interviews with each subject several times during the transition process, up to a maximum of one year. Each interview is expected to include 8-14 questions and last approximately 45 minutes. The interview is the primary requirement for participants, should they choose to participate in the study. I will also ask each student and his/her family members and teachers to keep a journal about his/her feelings throughout the transition process if they want to and I would like to observe the student at school and attend IEP meetings if all parties are okay with that. It is not expected that your routine activities will be disrupted in any way because I will schedule interviews with you at a time and place that is mutually agreeable and convenient for both of us.

Although I do not anticipate any risks at this juncture, should you become uncomfortable during any interview or observation, you may skip a question, end that session, and/or drop out of the study completely at any time. I will also do my best to minimize any possible discomfort for you before, during, and after the study.

I feel that you, and society in general, will benefit tremendously from your participation in this research. First, you will benefit by being given a voice, which may help everyone involved celebrate many more successes than frustrations, and open the door for future conversations. Due to the incidence in traumatic brain injury to school-aged children, the study has the potential

Initials_____Date____

to help brain injured students, their family members, teachers, counselors, school psychologists, and educational leaders better understand the effects of a traumatic brain injury and what factors enhance or impede the re-entry process. Perhaps this study will conclude that accommodations thought to be helpful in the past are still useful, but it is my hope that the study will illuminate new ideas that can and should be implemented to help the student make a successful transition back to school. This transition process cannot be made without the cooperation of the student, his/her family, individuals from the medical field, and educators including teachers, counselors, school psychologists, and administrators. This study will help educators carry out the guidelines posed to them in special education laws such as Public Law 101-476, the Individuals with Disabilities Education Act of 1990 (IDEA) since traumatic brain injury is recognized as a disability.

CONFIDENTIALITY

The purpose of the confidentiality statement is to inform you about the agencies and organizations that will have access to your study data.

All documents and information pertaining to this research study will be kept confidential, unless required by applicable federal, state, and local laws and regulations to be disclosed. I understand that records and data generated by the study may be reviewed by Temple University and its agents, the study sponsor or the sponsor's agents (if applicable), and/or governmental agencies to assure proper conduct of the study and compliance with regulations. [Occasionally data will also be sent to regulatory agencies of foreign governments seeking approval of a medical intervention in that country.] I understand that the results of this study may be published. If any data is published, I will not be identified by name.

QUESTIONS

I appreciate your consideration of my request to participate in this study. If you have any questions or concerns, I may be contacted at (215) 822-0360 or tub07463@temple.edu. If you have any questions about your rights as a research subject, you may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
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Temple University Research Administration
Student Faculty Conference Center
3340 North Board Street – Suite 304
Philadelphia, PA 19140

APPENDIX L: ACKNOWLEDGEMENT AND CONSENT FORM FOR SCHOOL ADMINISTRATORS

Study Title: Traumatic Brain Injury and Its Effect on Students

I, ____________________________________, hereby state that:
(Print Full Legal Name)

1. I have read all information provided on the consent form as it relates to the research study entitled, "Traumatic Brain Injury and Its Effect on Students" conducted by Stacy B. Rosenthal, Ed.D. candidate of Temple University, Philadelphia, Pennsylvania.
2. I have been given the opportunity to ask questions that I may have and have received responses that meet my satisfaction.
3. I have been given a cover letter explaining the research objective and instructions and a copy of this "Acknowledgement and Consent" form.
4. If I have any questions about my rights as a research subject, I may contact the Institutional Review Board Coordinator at (215) 707-3390. The IRB Coordinator may also be reached by email: IRB@temple.edu or regular mail:
   Institutional Review Board Coordinator
   Temple University Research Administration
   Student Faculty Conference Center
   3340 North Board Street – Suite 304
   Philadelphia, PA 19140.
5. By signing this "Acknowledgement and Consent" form, I consent to being a participant in the aforementioned study.
6. I understand that I need the signature of a parent or guardian if I am below the age of 18 and/or have suffered a traumatic brain injury.

____________________________________ ____________
Print Participant's Full Legal Name Date

____________________________________ ____________
Signature of Participant Date

§

As the investigator in this study, I hereby state to the best of my knowledge and belief, that all statements made in the documents listed are true. Any participants involved in this study may withdraw or discontinue participation at any time without penalty.

____________________________________ ____________
Print Full Legal Name of Investigator Date

____________________________________ ____________
Signature of Investigator Date

APPENDIX M: PERMISSION TO AUDIOTAPE

Study Title: Traumatic Brain Injury and Its Effect on Students

Principal Investigator: Corrinne A. Caldwell, PhD, Professor, Educational Leadership and Policy Studies, (610) 353-0633
Student Investigator: Ms. Stacy B. Rosenthal, Doctoral Student, Educational Administration Program, (215) 822-0360

______________________________ ____________
Print Participant's Full Legal Name Date

I give Stacy Rosenthal permission to audiotape me for research purposes as part of her dissertation research project at Temple University in Philadelphia, Pennsylvania. I have already given written consent for my participation in this research project. At no time will my name be used.

I agree to be audio taped during the time period beginning January 2011 through January 2012.

I give my permission for these tapes to be used during this time period and beyond until the completion of Ms. Rosenthal's research. (Data will be stored for 3 years after completion of this study.)

I understand that I can withdraw my permission at any time. Upon my request, the audiotape(s) will no longer be used. This will not affect my care or relationship with Ms. Rosenthal in any way.

I understand that I will not be paid for being audio taped or for the use of the audiotapes.

If I want more information about the audiotape(s), or if I have a question or concerns at any time, I can contact Stacy Rosenthal at (215) 822-0360 or tub07463@temple.edu.

This form will be placed in my records and Ms. Rosenthal will keep a copy. A copy will also be given to me.

______________________________ ____________
Signature of Participant Date

______________________________ ____________
Signature of Parent/Guardian Date
(if participant is under the age of 18 and/or brain injured)

APPENDIX N: INTERVIEW PROTOCOL FOR BRAINSTEPS EMPLOYEES

1. Could you tell me a little about why you became involved in BrainSTEPS?
2. I am interested in knowing a little more about your career and how BrainSteps fits in. Please tell me about your career path (leading to BrainSTEPS)?
3. BrainSTEPS is a very interesting agency; I would really like to know more about it. Can you tell me how and why it was founded and perhaps how it has grown or changed over the years?
4. How do the students become part of BrainSTEPS? / Is every student accepted or are there some injuries too severe? / What criteria are used to determine acceptance?
5. What does the transition process look like for …
   a. the students that are part of BrainSTEPS?
   b. for their families?
6. What role …
   a. does the school play in the transition process?
   b. do administrators play in the transition process?
   c. do teachers play in the transition process?
   d. do school counselors play in the transition process?
7. Who determines / how is it determined that the student is ready for the next stage in the transition process? (ex. home school --> part-time --> full-time)
8. What are your criteria to measure success?
9. What factors do you see as being most important in enhancing or impeding success?
   a. The student's prior academic record (before the injury)
   b. Family situation (only child versus siblings / two parents versus one)

c. Type and severity of brain injury

d. Years of experience of teacher

e. Prior experience of the teacher

f. School's achievement level (ex. meets AYP on a regular basis)

10. How do you measure the success rate of your program? / Can you tell me a little about how BrainSTEPS "graduates" or discontinues involvement with the student? How and when does this occur?
11. What proportion of your students return to school full-time until the completion of their high school diploma?
12. How long does the transition usually take from start (discharge from hospital or in-patient rehabilitation facility) to finish (return to school full-time)?
13. How does this program compare to students re-entry into school after an extended absence for another reason (ex. drug rehabilitation or non-cerebral medical issue)?
14. Is there anything else that I might have missed that is important for me to know?

APPENDIX O: FIRST INTERVIEW PROTOCOL FOR BRAIN INJURED STUDENTS

1. Could you tell me a little bit about yourself? / Who are you in your family, school, community? / Have these relationships changed since your brain injury?
2. It would be very helpful for me to hear about your injury in your own words. Would you please share your thoughts about your TBI with me?
3. Could you tell me about yourself as a student prior to your brain injury?
4. I am interested in knowing a little more about how your injury affects you as a student. I really want to know about the areas in life that you feel you are really good at and you would consider yourself strong and also some of those areas where you think you are struggling?
5. What were/are your biggest fears about returning to school? / What areas do you feel you are struggling with and need the most help? / What do you think is dragging you down the most right now? (Feelings)
6. Who do you think will provide you with the most support in your return to school? (i.e. principals, teachers, counselors, peers, parents, etc.)
7. Let’s talk about your goals. What is your goal as you return to school?
   a. Consider academic goals, vocational goals, social goals
8. Is there anything else that I might have missed that is important for me to know?

APPENDIX P: INTERVIEW PROTOCOL FOR BRAIN INJURED STUDENTS DURING SCHOOL YEAR

1. How do you feel that your transition back to school is going?
2. When we met back in [month of first interview], you felt that an area that you would excel in was [answer from first interview]. Has this been a skill that you have been able to rely on?
3. The last time we met, you were worried about [answer from first interview]. How is this going for you?
4. What has been the biggest change for you between being a student now and from what you remember before the injury?
5. Who has provided you with the most support in your return to school? (i.e. principals, teachers, counselors, peers, etc.)
6. Who could provide you with more support during the second half of the school year?
7. Have you modified your goals at all? If so, how?
8. Is there anything else that I might have missed that is important for me to know?

APPENDIX Q: INTERVIEW PROTOCOL FOR BRAIN INJURED STUDENTS AFTER SCHOOL YEAR

1. How do you feel that your transition back to school went this year?
2. Did you continue to rely on [strength answer from mid-year interview]?
3. Is [weakness answer from second interview] going any better for you?
4. Who provided you with the most support in your return to school this year? (i.e. principals, teachers, counselors, peers, etc.)
5. Are you planning to return to school again in the fall?
6. Who could provide you with more support next school year?
7. Will you modify your goals over the summer at all?
8. What will you do over the summer to maintain or improve upon the progress that you made this school year?
9. Is there anything else that I might have missed that is important for me to know?

APPENDIX R: FIRST INTERVIEW PROTOCOL FOR FAMILIES OF BRAIN INJURED STUDENTS

1. Tell me what you think is important for me to know about your family and you as a parent?
2. Could you tell me a little bit about your child's brain injury?
3. Did s/he suffer any other setbacks aside from the TBI?
4. How do you think the injury will affect your son/daughter as a student? What areas do you think your son/daughter will excel in and what areas do you think that s/he will struggle with?
5. What were/are your biggest concerns about your son/daughter in the return to school?
6. Who do you think will provide you with the most support as your child returns to school? (i.e. principals, teachers, counselors, peers, etc.)
7. What are your goals for your son/daughter? When will you consider his/her return to school to be a successful one? (i.e. can attend school full-time, completion of their high school diploma, etc.)
    a. Consider academic goals, vocational goals, social goals
8. Was your child a good student prior to his/her brain injury?
9. Is there anything else that I might have missed that is important for me to know?

APPENDIX S: INTERVIEW PROTOCOL FOR FAMILIES OF BRAIN INJURED STUDENTS DURING SCHOOL YEAR

1. How do you feel that your child's transition back to school is going?
2. When we met back in August, you felt that an area that s/he would excel in was [answer from late summer]. Has s/he relied on this skill?
3. The last time we met, you were worried about [answer from late summer]. How is this going for your child?
4. What has been the biggest change for your child between being a student now and from before the injury?
5. Who has provided you with the most support in his/her return to school? (i.e. principals, teachers, counselors, peers, etc.)
6. Who could provide you with more support during the second half of the school year?
7. Have you modified your goals for your child at all? If so, how?
8. Is there anything else that I might have missed that is important for me to know?

APPENDIX T: INTERVIEW PROTOCOL FOR FAMILIES OF BRAIN INJURED STUDENTS AFTER SCHOOL YEAR

1. How do you feel that your child's transition back to school went this year?
2. Did s/he continue to rely on [strength answer from mid-year interview]?
3. Is [weakness answer from mid-year] going any better for him/her?
4. Who provided you with the most support in his/her return to school this year? (i.e. principals, teachers, counselors, peers, etc.)
5. Is your son/daughter planning to return to school again in the fall?
6. Who could provide you with more support next school year?
7. Will you modify your goals for your son/daughter over the summer at all?
8. What will you do with your son/daughter over the summer to maintain or improve upon the progress that s/he made this school year?
9. Is there anything else that I might have missed that is important for me to know?

APPENDIX U: FIRST INTERVIEW PROTOCOL FOR TEACHERS OF BRAIN INJURED STUDENTS

1. Tell me what you think is important for me to know about you as a teacher?
2. Could you tell me a little about why you became a teacher?
3. I am interested in knowing a little more about your teaching career. How long have you been teaching? / What are your areas of certification?
4. Are you aware that one of the students in your classroom this school year is returning to school after suffering a traumatic brain injury?
5. What do you know about TBI?
6. What role do you expect …
   a. to play in the transition process?
   b. the school to play in the transition process?
   c. your administrators to play in the transition process?
   d. the school counselors to play in the transition process?
   e. the family to play in the transition process?
7. What are your biggest fears about having a brain injured student in your classroom and how do you plan to overcome them?
8. What would you like to know more about as you prepare to help the student with this transition?
9. Is there anything else that I might have missed that is important for me to know?

APPENDIX V: INTERVIEW PROTOCOL FOR TEACHERS OF BRAIN INJURED STUDENTS DURING SCHOOL YEAR

1. How is your school year going?
2. How do you feel [student's name]'s transition is going?
3. What have you learned about traumatic brain injury?
4. Have you overcome your biggest fears?
5. Do you feel that you were well prepared for this transition?
6. Is there anything that you would still like to know more about regarding TBI as the school year continues?
7. Is there anything else that I might have missed that is important for me to know?

APPENDIX W: INTERVIEW PROTOCOL FOR TEACHERS OF BRAIN INJURED STUDENTS AFTER SCHOOL YEAR

1. How did your school year go?
2. How do you feel [student's name]'s transition went?
3. What have you learned about traumatic brain injury?
4. Do you think [student's name]'s will be able to continue school in the fall?
5. What recommendations will you make to [student's name]'s to do over the summer to maintain or improve upon the progress that s/he made this school year?
6. Do you feel that you were well prepared for this transition?
7. Would you be willing to have another brain-injured student in your classroom in the future?
8. How did this student compare to other students with special needs in your classroom?
9. Is there anything else that I might have missed that is important for me to know?

APPENDIX X: FIRST INTERVIEW PROTOCOL FOR ADMINISTRATORS, COUNSELORS, AND PSYCHOLOGISTS OF BRAIN INJURED STUDENTS

1. Are you aware that one of the students in your school is returning or has returned after suffering a traumatic brain injury?
2. Could you tell me a little about your experience with inclusion, especially children recovering from trauma?
3. What do you know specifically about TBI?
4. What role do you expect …
   f. to play in the transition process?
   g. the school to play in the transition process?
   h. the student's teacher(s) to play in the transition process?
   i. the school counselors to play in the transition process?
   j. the family to play in the transition process?
   k. BrainSTEPS to play in the transition process?
4. What are your biggest concerns about having a brain injured student in your school and how do you plan to overcome them?
5. What would you like to know more about as you prepare to help the student, his/her family, and your staff with this transition?
6. How do you think that the other students in the school will react?
   a. Do you think that the other students will be prepared to handle the changes in their peer?
   b. Do you expect the other students to treat this individual as they would any other special needs peer?

7. I would say that a successful transition is when a student is able to return to school full-time until the completion of their high school diploma. How would you measure success?
8. Is there anything else that I might have missed that is important for me to know?

APPENDIX Y: INTERVIEW PROTOCOL FOR ADMINISTRATORS, COUNSELORS, AND PSYCHOLOGISTS OF BRAIN INJURED STUDENTS AFTER SCHOOL YEAR

1. How did your school year go?
2. How do you feel [student's name]'s transition went?
3. What have you learned about traumatic brain injury?
4. Do you think [student's name]'s will be able to continue school in the fall?
5. What recommendations will you make to [student's name]'s and his/her family to do over the summer to maintain or improve upon the progress that s/he made this school year?
6. Do you feel that you were well prepared for this transition?
    a. …your teachers…
    b. …the student body…
7. How would you prepare differently for another brain-injured student in your school in the future?
9. How did this student compare to other students with special needs in your classroom?
10. Is there anything else that I might have missed that is important for me to know?

APPENDIX Z: DATA PLANNING MATRIX

Category	What do I need to know?	Why do I need to know this?	What kind of data will answer the questions?	Where can I find the data?
Demographics	How old was each student when he/she suffered the traumatic brain injury?	To see if age impacts the re-entry process	Birth records & interviews	Schools & BrainSTEPS
	What grade was each student in when he/she suffered the traumatic brain injury?	To see if grade level impacts the re-entry process	School records & interviews	Schools & BrainSTEPS
	What type of traumatic brain injury (TBI) did the student suffer?	To see if type of injury impacts the re-entry process	Medical records & interviews	Hospitals, Rehabilitation Centers, BrainSTEPS
	What is the level of academic achievement before the brain injury?	To determine whether or not prior academic achievement has an impact on the re-entry process	School records & interviews	Schools; BrainSTEPS
	What is the level of academic achievement after the brain injury?	To determine whether or not prior academic achievement has an impact on the re-entry process	School records & interviews	Schools; BrainSTEPS

Category	What do I need to know?	Why do I need to know this?	What kind of data will answer the questions?	Where can I find the data?
Re-Entry Process	What level of support do the injured students receive from their parents?	To determine if parental involvement impacts the re-entry process	Interviews	BrainSteps
	What level of support do the injured students receive from BrainSteps?	To determine if the level of involvement provided by BrainSteps impacts the re-entry process	Interviews	BrainSteps
	What level of support do the injured students receive from their schools? (Principals, Counselors, & Teachers)	To determine if the level of involvement provided by the school impacts the re-entry process	Interviews	Schools & BrainSTEPS
	What does the transition process look like for the students? Their families?	To understand the steps involved	Interviews	BrainSteps
	What preparation occurs at school prior to re-entry?	To understand the steps involved	Interviews	Schools & BrainSTEPS
	What are the goals of the re-entry process? (e.g. to earn h.s. diploma or to get into college)	To see if internal motivation impacts the re-entry process	Interviews	BrainSteps

Adapted from Figure 5.1 in Maxwell, 2005