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School Re-entry Protocols for Children with Acquired Brain Injury

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Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Education

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SCHOOL RE-ENTY PROTOCOLS FOR CHILDREN WITH ACQUIRED BRAIN INJURY

(Spine Title: School Re-entry Protocols for Children with Acquired Brain Injury)

(Thesis Format: Monograph)

By

Matthew W. White

Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Education

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THE UNIVERSITY OF WESTERN ONTARIO SCHOOL OF GRADUATE AND POSTDOCTORAL STUDIES

CERTIFICATE OF EXAMINATION

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ABSTRACT

Acquired brain injury (ABI) results from trauma that causes temporary or permanent brain damage. Once critical medical issues are resolved, rehabilitation mainly involves learning and relearning, thus, schools play a critical role. The primary problem facing educators is the lack of appropriate school re-entry protocols to facilitate the transition from medical to educational settings. Without proper protocols, appropriate information is omitted, inappropriate decisions are made, and inadequate IEPs are developed (Glang, 2008). This study first looked at identifying any pre-existing school re-entry protocols through a detailed literature review, conducting a review of ABI specific medical and educational legislation, and contacting each Ontario school board's special education learning consultant to determine whether any protocols existed. Based on these investigations the data revealed that there were no pre-existing protocols. Due to this gap in the literature and practice, the study's main focus became constructing and evaluating an original school re-entry protocol. The protocol was designed through adherence to policy theory practices and accepted standards of practice found in the literature. To validate the content and structure of the protocol an evaluation was conducted by 13 special education experts using a combination of one-to-one interview(s) and a focus group discussion. Each of these professionals was identified as having prior experience working with children with ABI throughout the school re-entry process. The evaluators were all in agreement regarding the changes and additions made to the protocol post-evaluation and they felt that it would be particularly useful for educators who do not have any experience with the school re-entry process for children with ABI. The designed protocol appears to help bridge the gap between healthcare and education in the school re-entry process. Its application will be able to provide optimal learning environments for children with ABI that are free of barriers that have been documented

to occur when protocols are not in place (Glang, 2008). The use of the designed protocol will also introduce more effective learning and/or behaviour management strategies that can maximize each student's learning potential.

Key words: Acquired brain injury, paediatric ABI, school re-entry, school transition.

TABLE OF CONTENTS

| | Page |
|---|------|
| CERTIFICATE OF EXAMINATION | ii |
| ABSTRACT | iii |
| ABLE OF CONTENTS | v |
| IST OF TABLES | viii |
| IST OF FIGURES | ix |
| IST OF APPENDICES | X |
| CHAPTER I - INTRODUCTION | 1 |
| .1 Overview of the Research Problem | 1 |
| 1.1.1 Medical Intervention Process | 2 |
| 1.1.2 Educational Intervention Process | 3 |
| .2 Thesis Organization | 5 |
| CHAPTER II – LITERATURE REVIEW | 8 |
| .1 Policy Theory | 8 |
| .2 Medical Perspective | 10 |
| .3 Educational Perspective | 12 |
| .4 Comparison of Medical and Educational Professional Involvement | 15 |
| 2.4.1 Phase One - Admission to the Hospital | 17 |
| 2.4.2 Phase Two - Throughout Hospital Admission | 18 |
| 2.4.3 Phase Three - Hospital Discharge | 19 |

| | 2.4.4 | Phase Four - Community Care | 21 |
|---------|-----------|--|----|
| | 2.4.5 | Phase Five - School Re-entry | 22 |
| 2.5 An | Exami | nation of Acquired Brain Injury Educational Resources Available to Educators | 23 |
| | 2.5.1 | ABI resources | 23 |
| | 2.5.2 | ABI and the Individualized Education Plan. | 25 |
| 2.6 An | Exami | nation of Canadian Provincial and Territorial Educational and Medical Policies | |
| for | Childre | en with Acquired Brain Injury | 34 |
| | 2.6.1 | ABI and Educational Policy | 34 |
| | 2.6.2 | ABI and Medical Policy | 36 |
| 2.7 Pro | blem S | tatement | 37 |
| | | | |
| СНАР | TER III | – METHOD | 40 |
| 3.1 An | alyses | | 46 |
| | | | |
| СНАР | TER IV | – RESULTS | 47 |
| 4.1 Pha | ase One | Findings: Canada wide examination of medical and educational policy's that | |
| rel | late to A | ABI | 47 |
| 4.2 Ph | ase Two | Findings: Are there any protocols within Ontario school boards? | 49 |
| 4.3 Ph | ase Thro | ee Findings: Analytic Framework | 50 |
| 4.4 Ph | ase Fou | r: Protocol Construction | 50 |
| 4.5 Pha | ase Five | e: Protocol Evaluation | 60 |
| | 4.5.1 | Phone Interview Evaluation | 60 |
| | 4.5.2 | Focus Group Evaluation | 63 |

| 4.6 Summary | 69 |
|---------------------------------|-----|
| | |
| CHAPTER V – CONCLUSIONS | 71 |
| 5.1 Adherence to Policy Theory | 71 |
| 5.2 Implications for the Future | 75 |
| 5.3 Limitations | 79 |
| | |
| APPENDICES | 81 |
| REFERENCES | 124 |
| KLI LIKLIVELS | 124 |
| CURRICULUM VITAE | 126 |

LIST OF TABLES

| Table | Description | Page |
|-------|---|------|
| 1 | Guidelines specific to ABI for each phase of the assessment/IEP model | |
| | by Edmunds and Edmunds (2008) | 30 |
| 2 | ABI recognitions and details of it by each of Canada's provinces | 47 |
| 3 | Educational case coordinator functions by Ylvisaker et al. (1995) | 52 |
| 4 | Tasks and timeline for the transition from rehabilitation to school by | |
| | Farmer et a. (1996) | 53 |
| 5 | Tasks and timeline for the transition from rehabilitation to school by | |
| | Clark (1996) | 54 |
| 6 | Tasks and timeline for the educational case coordinator throughout the | |
| | school re-entry process for children with ABI | 56 |
| 7 | Phone interview evaluation: evaluator one phone interview evaluation key points for | |
| | respective sections of the protocol | 61 |

LIST OF FIGURES

| Figure | Description | Page |
|--------|---|------|
| 1 | The six phases of the Assessment and IEP Process. | 27 |

LIST OF APPENDICES

| Figure | Description | Page |
|--------|---|------|
| A | School Re-entry Protocol for Children with Moderate to Severe | |
| | Acquired Brain Injury | 81 |
| В | Ethics Protocol | 97 |
| C | Ethics Approval. | 114 |
| D | Request for Research in School Board | 116 |
| E | Protocol Evaluation Questionnaire | 119 |
| F | Teacher Consent Form | 121 |

CHAPTER ONE: INTRODUCTION

Overview of the Research Problem

A child who has sustained trauma to his/her brain is said to have either an Acquired Brain Injury (ABI) or a Traumatic Brain Injury (TBI). ABI is the umbrella term which TBI is classified under and due to this they cannot be used interchangeably. ABI is any type of sudden injury that causes temporary or permanent damage to the normal structure and function of the brain. ABI can be classified as either traumatic or non-traumatic. TBI results from an external force applied to the head/brain and does not apply to brain injuries that are congenital or induced by birth trauma (Bennett, Good, & Kumpf, 2003). Examples of TBI include sustained trauma due to a fall or a motor vehicle accident (MVA). TBI can be further classified based on whether the injury is open or closed. An open injury is said to occur when there is an open/penetrating wound causing direct trauma to the brain such as with a gunshot. A closed injury occurs when the brain is jolted inside the skull causing a contusion which is often the case during whiplash. On the other hand, non-traumatic brain injury results from an internal force that causes injury to the brain such as suffocation, stroke, or infection. This study will address both traumatic and non-traumatic brain injuries so the umbrella term, ABI will be the term used throughout.

ABI severity is measured by assessing fluctuations in levels of consciousness following injury. The Glasgow Coma Scale (GCS), a neurological scale from 3 to 15, is the most widely used measure of consciousness and is administered within the first 24 hours following trauma (Jantz & Coulter, 2007). ABI severity has been shown to be correlated to the lowest post-resuscitation GSC score while in hospital and can range from mild (GSC 12-15) moderate (GCS 9-11) to severe (GCS 3-8) (Teasdale & Jennett, 1974). ABI can lead to virtually any ability or combination of abilities being impaired with each injury being different and producing a unique

pattern of damage and functional difficulties (Fogarty-Ellis, Kaseweter, Lavis, Littleford, McAllister, & McCallum, 2001). Despite these differences, impairments can be categorized within the following domains: health, cognition, sensory and perceptual, motor skills, and behavioural/social. Health deficits commonly present as fatigue, headaches, disturbed sleep, and/or seizures. Cognitive deficits can affect all areas of a child's function and development and include impairments of attention, concentration, memory, learning, and/or executive functioning. Communication impairments can include all aspects of speech, language skills, and/or the ability to use language effectively. Sensory deficits can include vision and/or hearing complications while perceptual impairments can lead to difficulties with recognizing and understanding sensory input. Motor skill difficulties vary greatly between children and can include both gross and fine motor problems. Lastly, behavioural/social impairments are often the most disabling effect of ABI causing the child to typically display more impulsive, irritable, aggressive, and/or inappropriate behaviour. Deficits in even one of these domains can lead to both short and long term academic difficulties. Yeates and Taylor (2002) examined the long-term difficulties of children with ABI and found that children with severe ABI experienced behaviour and academic problems that continued up to four years or more post-injury.

Medical Intervention Process

Recovery for a child with ABI can be a slow process and it is uncertain if full recovery will ever be achieved. When the child is first admitted to hospital, he/she works closely with allied health professionals composed of doctors and nurses as well as professionals from occupational therapy, physiotherapy, speech language pathology, audiology, social work, and dietetics. These professionals work within the jurisdiction of the hospital and follow specific protocols for diagnosis and rehabilitation as set forth by the institution. Protocols help to

organize allied health professionals and direct them towards completing critical tasks for the child as he/she progresses from hospital admission to discharge. The precise guidance these protocols provide allows for the child to receive comprehensive care which, allows quicker progression. Eventually, the child's medical status stabilizes and the allied health professionals involved in his/her care decrease in number. Once the child is discharged from hospital one of the major goals for him/her becomes re-entering school, therefore, the direct involvement of educational professionals is initiated and protocols to guide the child's education team throughout the school re-entry process would be beneficial. Based on a preliminary search of the literature no such protocols seem to exist nor does the re-entry process appear to be formalized within schools.

Educational Intervention Process

To address the needs of children with ABI, the ongoing educational assessment and implementation of specific interventions is required. Early planning on this process helps ensure the child receives continuous care and reduces the chance of school re-entry being delayed. Detailed planning must be completed for each child with ABI because the school re-entry process will look different for every child due to his/her unique impairments which will require individualized attention. This uniqueness leads to notable differences in the amount of time required to transition from hospital-to-school and the various professionals that assist along the way. Regardless of how different school re-entry may be for specific children the overall process requires the same involvement of key educational professionals throughout the transition who are required to complete specific tasks. If these professionals are not involved and/or the critical tasks are not completed, the re-entry process is likely to fail. To ensure that the right educational professionals are recruited and each critical task is completed and on time, a school re-entry

protocol is required. Similar to existing hospital protocols, such a protocol would outline the guidelines and procedures that detail the tasks each professional must complete throughout the school re-entry process and by which point in time. This document would have the potential to help educators resolve some of the current difficulties they face and/or avoid them completely when they would have to engage in the re-entry process for a child with ABI.

My professional physiotherapy experience and the existing research addressing the specialized area of school re-entry confirms the many difficulties that educational professionals face in this complicated process for a child with ABI. For example, during my professional consolidation placement as a Master of physiotherapy candidate, I was asked to work with a nine year old boy who had sustained a severe ABI after being struck by a car while riding his bike. When I started working with him he had successfully completed his transition out of the hospital and was continuing rehabilitation in the community. The rehabilitation was required to address his medical, physical, cognitive, and behavioural impairments that persisted after he left the hospital. To address each problem area, his rehabilitation was done by a physiotherapist, an occupational therapist, a speech language pathologist, and a psychiatrist. During my fifth week of working with him, I was asked by my supervisor to attend a team meeting to update his community medical team on his progress. The team was comprised of a case manager, physiotherapist, occupational therapist, speech language pathologist, psychiatrist, lawyer, support worker, and his parents. From the updates provided by each team member, he appeared to be progressing very well in all areas. Based on the evidence presented by the respective team members, it was determined that the next major step would be for him to return to school. The team began to brainstorm ideas about how to successfully achieve this and what his school reentry process would entail. I noticed that although this was an excellent goal, it required the

involvement of the educational professionals at his school who were not in attendance. Without the involvement of these professionals, I felt it was highly unlikely that the process would follow a systematized school re-entry protocol. From this experience, I am left to wonder whether educators, specifically Ontario educators, had access to clear protocols to assist a child with ABI re-enter school. And, if such protocols existed, I had wondered how effective they were and whether they were indeed used by educators in the school re-entry process.

Therefore, this research study will focus on determining the existence of ABI school reentry protocols that bridge the divide between medical experts and educational professionals. While this study is primarily theoretical in scope, I wish to emphasize its practical applications for educators. This academic inquiry into school re-entry was an attempt to identify and evaluate the existing protocols that educators use in Ontario for school re-entry for a child with ABI. It was felt that the results of this work may offer insights and assistance towards enhancing existing protocols or preparing a newly designed protocol that could provide educational professionals with sets of procedures to transition a child with ABI back to school.

Thesis Organization

Chapter One includes a discussion of the importance of understanding the school re-entry process for a child with ABI. It examines the challenges school re-entry presents to educators with a brief description of how a school re-entry protocol could help meet these challenges.

In Chapter Two, a detailed examination of the literature reviewed for this research study is discussed. The need for an examination into school re-entry protocols used by Ontario educators is explained. A summary is provided of Canadian provincial and territorial educational and medical policies that have been established for a child with ABI. The implications of each

policy towards assisting both allied health and educational professionals in the transition process is discussed. A review of the resources that have been made available to educators that each can access when assisting a child with ABI is also provided. How the IEP (Individualized Education Plan) relates to a child with ABI and the necessary adjustments that educators must take into consideration when designing are examined. As well, the need to couple a school re-entry protocol with these specific IEP adjustments is explained. Finally, the research problem and its significance are discussed and an outline for the thesis structure is provided.

Chapter Three provides the methodological overview of the study and the analytic framework that guides the research. Specifically, the analytic framework addresses the four main concerns that were studied: 1) whether ABI school re-entry protocols exist in Ontario school boards; 2) determining the theoretical and conceptual backgrounds upon which such protocols were designed; 3) whether such protocols are utilized by educators and if so, how are they utilized. Answers addressing these first three concerns were derived from official documents sourced from Ontario school boards and the theoretical and conceptual evidence found in the existing literature. Without attempting to presuppose the potential outcomes of this study, it appeared clear from preliminary research and readings, that no comprehensive protocol for educators outlining a school re-entry process for students with ABI existed. Therefore, 4) this research was prepared to attempt to resolve this concern by using the best available information to design, pilot, and refine a protocol to meet this need.

In Chapter Four the findings for each phase of the research study are provided. Through these findings the need for developing a school re-entry protocol was established and the key components that were included in the protocol are explained. Further, the results of the focus group that evaluated the content of the designed protocol are discussed.

Chapter Five provides a conclusion discussing the findings of the research as well as the key implications for the future including an example of how the protocol could be implemented in a school. The directions of future research involving the protocol are also outlined.

CHAPTER TWO: LITERATURE REVIEW

Policy Theory

Throughout our lives as we complete our day-to-day activities, although we may not realize it, policies are at work all around us. Policies can operate on a small scale such as, directing procedures for quality control at a small business to those on a large scale that help direct political officials and governments as a whole. Policies are implemented by different groups for different reasons. Regardless of what the overall goal of the policy may be, each must clearly outline in detail a plan of action that organizations and/or individuals must follow to help guide decisions and/or increase the likelihood of producing desired outcomes. The same holds true for educational policies that help govern the operation of education systems. These systems come in different sizes with the higher levels known as macrosystems, including federal and provincial systems and the lower levels known as microsystems, including board- and schoolspecific systems. It is commonplace for policies to be created by macrosystems and then implemented by education boards and/or schools to help drive student performance. However, in some cases, if macrosystem policies are absent, microsystems may identify the need for a specific policy and then design and implement it on their own in order to direct a specific process. Students with ABI are a low-incidence injury and ABI is not identified as an exceptionality in most provinces, however, they present numerous complications in the educational process. Therefore, policies are needed at both the macrosystem and microsystem levels in order to accommodate these children. These policies should direct the education of these students as they move through the school system. The aim of these policies, although specific for educating children with ABI, would also share the common goal of most other educational policies; improving education for the students for whom the policy is designed. To

accurately identify whether such policies exist for children with ABI, both the macro and microsystem levels need to be examined in detail.

Equally important to the process of policy development is the evaluation of each policy that is created. This evaluation process is important to ensure professional accountability, ensuring that a policy is appropriately designed and doing what it was created to do. Policy evaluation is a complicated process and one that cannot be done until an understanding of the four dimensions of policy theory is reached (Childers, 2007). These dimensions include 1) normative, 2) structural, 3) constituentive, and 4) technical. Evaluation of ABI policies under the normative dimension consider whether the outcome of the policy maintains the foundational principles established by researchers and educators. These principles would include both what has been established in the research as well as what has been proven. If the policy's outcomes do not match these principles the policy's data, process, and outcomes will be in question (Cooper, Fusarelli, & Randell, 2004) and revisions will be necessary. The structural dimension of policy evaluation reflects on the relationship between the organization of education at the federal, state, and local levels. The constituentive dimension focuses on persuasive interest group(s) concerned with specific programs that could be affected by an ABI policy being evaluated. The dimension includes the impact evaluation could have on both employment and resources related to the interest group(s).

Lastly, the technical dimension evaluates policies based on the influences each policy has on educational institutions and includes elements such as time, educators, resources, and instructions. Policies must be designed to take into account each of these elements otherwise they risk both short- and long-term failure. Any identified educational policy specific to children with ABI at either the micro or macrosystem level must be evaluated based on these dimensions.

If the evaluation process produces questions concerning the policy's effectiveness or appropriateness, the policy must be either discarded or modified.

The Medical Perspective

A detailed review of the literature on school re-entry revealed that, the majority of the research in this specialized area is found in the field of medicine. This body of research has identified key stages in the school re-entry process but, it has mainly focused on the three stages that involve medical professionals whose primary goal is to discharge the child from the hospital and not on how educational professionals are involved. Stage One is hospital admission and begins when the child is admitted. At this time, allied health professionals immediately begin working with him/her and their involvement is at its greatest. During this time the child needs to be assessed and monitored closely as his/her medical status could quickly change. Throughout this stage the child is in excellent care within the hospital setting. Each of the child's allied health professionals have a specific role and although these professionals work with the child independently, they also form a closely knit medical team that works together to make sure all the medical needs of the child are met. Team meetings are arranged on a frequent basis to keep all members current with the child's status. These meetings also allow for each member to provide input that could potentially assist other members in their delivery of care. The child's medical data collected by each professional is compiled into a common file that all team members can access. This file is usually in the form of a medical binder or an electronic healthcare record depending on what system the hospital has implemented. It is through the organized and coordinated care provided to the child by the allied health team that his/her medical status begins to improve.

Stage Two is reached when the child's medical status is stable and the amount and type of medical professional involvement starts to shift. Once the allied health team is confident that the child's status has stabilized, they begin to slowly decrease treatment frequencies and volume while still closely monitoring the child's status. As long as the child's status is improving, medical professional involvement continues to decrease as appropriate. It would be at this juncture that educational professionals may start to become involved in the child's situation.

Reintegration into school is a process that involves a great deal of planning. Therefore, ideally, educational professionals need to be recruited early in the process so they have the necessary time to become familiar with the child's status and prepare for his/her school re-entry.

Eventually, the child will progress to the point that he/she is ready to be discharged from the hospital.

At hospital discharge, Stage Three, a discharge team is formed. This team is responsible for making sure that pertinent information is passed onto the professionals that will continue to support the child in the community upon discharge. Given that returning to school is a large part of this phase of the child's life, the discharge team should be composed of health professionals from both the hospital and community as well as education professionals. Collaboration between all these professionals during discharge planning would allow for a more effective transition from hospital-to-community this increases the chances of successful school re-entry being achieved long term.

Once a child with ABI is cleared by the allied health team for discharge from the hospital, it does not mean that he/she has overcome all of his/her ABI impairments or is even close to pre-injury functional status. Discharge merely means that the child is stable enough that he/she no longer requires the ongoing monitoring and medical care that requires a hospital

setting. Upon discharge, children with ABI are only beginning down the road to recovery and carry with them a variety of impairments. These impairments can complicate and delay the school re-entry process and make educating them a particular challenge.

Just as hospital care is carefully planned and monitored, effective school re-entry requires extensive collaboration, planning, and problem-solving amongst all professionals involved and this process cannot be achieved in a short period of time. As a consequence, it is imperative that a school re-entry protocol provide educators with some guidance during the three stages discussed above and much more detailed guidance after the child is discharged. Unfortunately, the school re-entry stage that exists beyond hospital discharge that educators are predominately responsible for is not as clearly defined.

The Educational Perspective

It is evident that educators should have a protocol that could provide them with guidance and to help coordinate educational services for a child with ABI throughout the school re-entry process. The benefits and importance of providing such coordinated services to assist with the transition from hospital-to-school has been well documented. Children with ABI who started the hospital-to-school transition process immediately upon discharge from hospital were more likely to achieve functional independence (High, Roebuck-Spencer, Sander, Struchen, & Sherer, 2006). These results suggest that a formalized hospital-to-school transition process is a significant factor in assisting with recovery as students return to school (Dykeman, 2009). A formal hospital-to-school transition process requires detailed planning which should be guided by both medical and educational professionals who would follow specific, but different protocols. Each protocol would outline the specific tasks each group of professionals would be required to complete

throughout the school re-entry process and achieved within a designated timeframe. The guidance that a protocol provides professionals can allow the overall school re-entry process to be quick and successful.

Both medical and educational professionals are equally important members in the school re-entry process. If a systematic and proven reliable approach is only provided at one end of the process but not the other, it is likely to create gaps in the child's transition process and will impede delivery at the other end. Glang, Todis, Thomas, Hood, Bedell, and Cockrell (2008) demonstrated how service delivery could be affected in this manner. In their study they showed that children with ABI were less likely to receive proper special education services if the child's hospital did not communicate medical information to the child's school. Moreover, less than half of the students in the study with severe ABI were placed on IEPs despite their obvious needs. Based on these findings, it is highly likely that educators will not recognize the needs of children who have severe brain injuries unless these are specifically pointed out by medical personnel. It is also quite probable that teachers will adopt a wait-and-see approach if not provided with specific suggestions for educational programming by the child's medical team. This problem is compounded by the fact that educators and school psychologists frequently underestimate the need for support for a child with ABI in the early months or even years after injury. In some cases, this results in significant failure and a growing disability for the child (Ylvisaker, 1998). Schools must prevent having a child with ABI return to school without the proper supports so they do not jeopardize the child's future recovery. For schools to provide immediate and ongoing educational supports requires early planning, ongoing monitoring, and more intensive educational programming. Although these requirements are clear, the capability of schools to fulfill each of them is doubtful (Taylor, Yeates, Wade, Drotar, Klein, & Stancin, 2003).

However, the likelihood of fulfilling each of these important requirements can be increased if schools had an ABI school re-entry protocol. This protocol would include details on the professionals involved in the process and the tasks that each must complete. It would also guide educators on how to successfully take over the care of the child from the medical team.

Unfortunately, such a protocol does not appear to exist. It seems that the primary reason why such a protocol does not exist is because the incidence of ABI is very low, thus, the necessary processes and systems to take over from the medical team have not been procedurally delineated.

The allied health professionals who work with a child with ABI function solely within the jurisdiction of the hospital. These professionals work within specific protocols set forth by the hospital and know the tasks that he/she must complete. They also help to identify when the child is ready to leave the hospital, therefore, suitability for hospital discharge is their primary goal. As the medical team is busy progressing the child towards hospital discharge, the educational team should begin to mobilize. The team can only do this if processes and systems to take over from the medical team are procedurally delineated. Without a proper protocol, it would appear that educational professionals have to wait for the medical team to nearly finish their job and then relay information or make contact with them regarding the child's condition. Even if the medical team is quick to forward their information, this information may not deal with all of the issues that educators have to plan for and manage. Educators, therefore, should have specific processes in place that would allow them to take a more proactive approach towards gathering information that suits their needs and to prepare for the child's return. A well designed school re-entry protocol could guide educators towards accomplishing all of these. This guidance is particularly useful when assisting a new child with ABI as it allows for professionals to access resources quicker, implement intervention strategies faster, and understand the overall process better.

Based on this researchers' experiences, discussions with some Ontario educators, and supported by evidence throughout the literature in this area, it appears that there is a great deal of variation between the approaches that schools and educational districts take towards assisting a child with ABI to re-enter school. This is not surprising because as previously mentioned, a preliminary review of the literature did not yield a specific protocol that educators could follow. The literature does, however, seem to agree on most of the critical tasks that appear to be necessary for the re-entry process. While these tasks have been discussed in different parts of the literature it does not appear that they have been properly analyzed and assembled into a comprehensive protocol. Furthermore, it is quite likely that what is available for school re-entry is limited because it has been determined by educators' previously limited experiences in assisting children with ABI. Unfortunately, when a child with ABI returns to school, it is likely the very first time educators come together to assist him/her. When this occurs, previous experience and knowledge of ABI cannot be called upon and applied. Implementing a school reentry protocol would increase collaboration between all professionals, allowing for important information gathered by the child's health care team to be shared with his/her education team, and allowing the child's IEP to be developed accurately.

Comparison of Medical and Educational Professional Involvement

There are five stages of school re-entry that have been identified in the literature. These are initial hospital admission, hospital care, hospital discharge, community care, and school reentry. The length of time a child with ABI spends in each stage varies depending on his/her impairments and medical/educational needs. Medical and educational professional involvement differs at each stage based on the number of professionals of each discipline involved again

based on the child's needs. Regardless of the school re-entry stage the child is in, at each stage there are specific tasks identified in the literature that must be completed by both medical and educational professionals for successful school re-entry to occur, with each point building on what has been established in the previous one. Throughout the literature various frameworks have been discussed. Ylvisaker, Feeney, Maher-Maxwell, Meserve, Geary, and DeLorenzo (1995) discussed a framework that outlined tasks for an educational coordinator to complete at specific points throughout the school re-entry process. Farmer, Clippard, Luehr-Wiemann, Wright, and Owings (1996) expanded this framework into a general task list for school personnel to complete each of the specific phases throughout the process. A similar framework by Clark (1996) was developed into a reintegration checklist for professionals to complete at each phase to better guide the child with ABI towards school re-entry. These frameworks provide a general overview of the school re-entry process and outline the professionals that need to be involved in it. They further outline the tasks that each professional must complete at each phase. Due to the complexity of school re-entry for children with ABI, besides the professionals recruited along the way, specific representatives are needed to direct the process. Without these representatives it is unlikely that any school re-entry process will succeed. As well the specific roles and responsibilities of both the medical and educational professionals that guide the school re-entry process must be clearly outlined.

When the medical and educational professional involvement at each stage of school reentry is compared, the differences with regards to the protocols that each discipline follows to help facilitate school re-entry becomes apparent. The medical professionals work strictly within specific protocols set-forth by the hospital and use outcome measures (OM) such as muscle strength and/or range of motion testing to help direct decision making for the child. On the other

hand, although educational professionals use OM such as a reading level assessment of their own to direct decision making for the child, they do not appear to follow specific school board protocols that operate similar to those set forth by the hospital for medical professionals. Utilizing protocols specifically designed for both medical and educational professionals will increase the likelihood of avoiding service delivery gaps between the disciplines throughout school re-entry, thus, maintaining a continuum of care for the child. The medical and educational professional involvement will now be compared for each of the five points of school re-entry.

Phase One - Admission to the Hospital

As the child with ABI enters the hospital allied health professionals are recruited right away. One of these professionals is the designated medical representative (MR) who is likely an employee of the hospital. This professional has experience working with children with ABI and serves as the liaison responsible for gathering all medical information about the child during his/her time in the hospital. An education representative (ER) is also recruited who is likely an employee of the child's school or school board. This person also has experience working with children with ABI and serves as the liaison that is responsible for gathering all of the child's preinjury educational information. Both the MR and ER initiate contact with one another and begin sharing and compiling information. Between the child's education and medical information there is a lot that needs to be compiled. Ideally, this information should be compiled into a common file that both education and allied health professionals can easily access. This may be possible through utilizing an electronic database that can allow these professionals to easily organize, share, update, and retrieve information on the child. These professionals discuss the child's current medical status and couple it with his/her pre-injury educational status to determine his/her anticipated education needs. They also discuss the available education services that the

child would likely be able to access at his/her school. Lastly, the representatives identify the method by which they will communicate and set out specific dates to do so. At this point, the MR works within hospital protocols that help direct care for the child and progress him/her with the main goal of achieving hospital discharge. Although the ER's involvement is minimal at this stage, a protocol that could be used to help facilitate making contact with the MR and identify the tasks that the ER must complete at this stage would be beneficial.

Phase Two - Throughout Hospital Admission

After initial contact between the representatives, each returns to his/her respective disciplines to gather more information on the student. The MR will continue to speak to the medical professionals involved with the child. Usually, this is accomplished through sitting in on mandatory medical team rounds, identified in the hospital protocol, where the majority of the child's allied health professionals will be in attendance providing input on the child. At the same time, the ER begins updating personnel at the child's school that will likely be working with him/her upon his/her return. This usually includes the student's principal, teacher(s), and the school's special education coordinator. Further discussions will likely have to be made within the school board with professionals that can assist with accessing various resources for the child. Information from both disciplines continues to be compiled into the child's file. Both representatives should be in constant contact during this time and discuss in more detail the instructional and educational needs of the child based on his/her medical status now that it is stabilized. Appropriate placement options and community resources available to the child upon discharge are identified and matched to his/her needs. To assist in identifying these resources and assisting the child to access them upon discharge, a community representative (CR) is selected. Commonly, the MR is unable to transcend the hospital boundaries and act as the CR once the

child is discharged. In this sense, the CR is recruited to fill the void of the MR once the child is discharged and can be a consultant familiar with ABI or an employee of a public or private external agency depending on what is available within the child's geographic area. The CR is typically an allied health professional that should also understand school board processes. Similar to the MR, this representative works within protocols established through his/her agency or adapts a protocol that has been proven reliable and adheres to best practice. The CR will work closely with the child, ER, and his/her parents once the child is discharged and is therefore, a critical member that must be carefully selected. Once selected, the CR begins familiarizing themselves with the child and recruiting the appropriate community professionals that will likely be assisting the child upon discharge. The representatives also need to start to select professionals that will form the child's discharge planning team. These professionals are the ones who understand the child's impairments and can provide the best input into how to address his/her needs upon discharge. The team is usually composed of the MR, ER, CR, and the child's parents, as well as allied health and education professionals. Further, dates are set for a discharge team meeting that will occur before the hospitals proposed discharge date for the child. As with the hospital admission phase, the ER would be better guided at this stage by utilizing an educator-specific school re-entry protocol.

Phase Three – Hospital Discharge

As the child's discharge date approaches the designated discharge team meets. The discharge team meeting serves as an opportunity for each professional to discuss and summarize the child's current strengths and needs. The primary goal of the discharge team meeting is to make sure that the child's discharge plan is in place. This plan needs to clearly outline the details of discharge including where the child will be going, what further care the child will be

receiving, when he/she will receive the care, and the professionals who will provide the care. The discharge plan must also include an outline of the goals the child is expected to reach and a timeline of when he/she should be expected to reach these goals. These details are typically part of a pre-defined hospital and/or community discharge protocol utilized by the MR and CR to document proper discharge. The CR recruited in the last phase will discuss with the team the details of the resources the child will receive in the community and the professionals involved. It is critical that by the time hospital discharge is reached the CR has at very least contacted the community professionals who will be carrying on treatment with the child. Ideally, by hospital discharge these professionals will have already met with the CR to provide an overview of the child's status. The child's destination upon discharge will be partly dependent upon the healthcare structures in place within the child's hospital. In some hospitals, children with ABI have the option to transfer to a rehabilitation centre for further treatment. Usually, this option is contingent upon the child meeting various criteria as well as the facility being able to accommodate them. An alternative option is the child being discharged to his/her home and receiving at-home care. In Ontario, at-home care is commonly organized through the Community Care Access Centre or through a third-party insurance firm to recruit private medical professionals within the community. Discharge decision-making is also driven by specific medical protocols that assist both the MR and CR. Regardless of the discharge route taken by the child, he/she will still require the community care that has been organized by the CR to help overcome impairments. One of the most important tasks at this point is the successful transfer of information. The hospital team must properly debrief the CR, ER, and any other professionals who will work with the child after discharge. Debriefing includes answering any questions about the child's medical status or goals to be reached, ensuring all community professionals have the

necessary information, and identifying a hospital contact that will be available to answer any future questions and/or notified of any major developments in the child's status. For this stage to be successful, it is imperative that a breakdown in communication between the professionals of the discharge team does not occur. If hospital discharge is completed properly, the foundation will be set to allow for the child to return to the community, receive the required care he/she needs, and begin to prepare for school re-entry. This phase is heavily directed through established medical protocols and documentation by the MR, CR, and allied health professionals working in the hospital. This is needed to provide justification for why a specific discharge route was taken and to provide the necessary information for community medical professionals who will become involved with the child's care. To help the ER become more involved in this process, an educator-specific protocol would provide the necessary guidance to do this.

Phase Four – Community Care

Once the child has been discharged from the hospital he/she continues to work with medical professionals in the community to address his/her ongoing medical impairments. Similar to the medical professionals in the hospital, these community professionals work within specific protocols that guide treatment delivery and decision making. Once the child has successfully entered the community and is working with the appropriate professionals, school re-entry planning is initiated. There is just as much planning needed for school re-entry as there was for hospital discharge. As well, the success of school re-entry depends on the formation of a re-entry team, similar to the team formed for hospital discharge. This team is recruited by the ER and CR who begin recruitment, at the latest, once the child is discharged from hospital. This team is likely composed of the child's parents, ER, CR, the professionals currently working with the child, and professionals from the child's school and board. The education professionals will

likely be the same ones the ER had maintained contact with in Phase Two. The school re-entry team meets to identify educational goals and priorities for the child upon returning to school based on his/her current strengths and needs. During this meeting a school re-entry plan is developed. Based on input from each team member, an expected date for the child to return to school as well as the initial length of the school day is determined. Class structure, format, and teaching style that best suits the student's needs is also identified. The plan outlines the professionals that will be teaching the child and those providing support. The details of the school re-entry plan as well as the educational goals and priorities for the child are documented in the child's IEP. The IEP will be constantly updated throughout the child's time in school. For this reason, the re-entry team also establishes a timeline for reviewing it throughout the year. Utilizing an educator-specific re-entry protocol would greatly assist the ER and educational professionals at this point in school re-entry mainly towards creating a detailed school re-entry plan and understanding the main components that can be included in the child's IEP.

Phase Five - School Re-entry

Once the child re-enters school the educational team's involvement mirrors that of the allied health teams when the child was initially admitted to the hospital. Frequent intervention and close monitoring of the child is required as he/she becomes re-accustomed to the school environment. The education team also begins to initiate OM to further assist in identifying the educational difficulties the child has and the intervention strategies that may be of benefit to him/her. Data gathering is very important as it allows for the ongoing evaluation of current supports and allows educators to make decisions on when supports need to be added or withdrawn. It also allows for the identification of any modifications to the child's environment that could assist in meeting his/her needs. The child's IEP team, composed of educational

professionals and those still working with the child in the community, will plan to meet on an ongoing basis to re-assess the child's needs and update his/her IEP. Constant updating should be done on a monthly basis. As the child continues to progress and he/she overcomes impairments, community professionals will decrease frequency of care. This will continue until the child's care is completely transferred over to the education team. This team will look after the necessary future plans for the child and facilitate the child's transition between grades, schools, and/or work. It is during this phase that utilizing a detailed and educator-specific re-entry protocol would allow educators to best identify the child's needs and to implement appropriate education interventions specific to ABI.

An Examination of Acquired Brain Injury Resources Available to Educators

Based on the literature, it seems that the critical tasks and information for the school reentry process have been identified. Having said that, it does not appear that a comprehensive and
widely available school re-entry protocol has been designed. Teachers are able to access different
ABI resources depending on the school board's location that can be of great value when assisting
these children. However, a greater understanding of how the IEP relates to children with ABI is
required.

ABI Resources

Within Ontario, there is limited mention of ABI in any provincial special education guides/resource materials. When Ontario educators are faced with a child with ABI, the primary resource they have is the *Educating Educators about ABI* resource binder created by Bennett, et al. (2003). The binder is 160 pages divided into five chapters that address the following topics: 1) context of ABI and understanding it from a developmental perspective, 2) the challenges of working with ABI in the school setting and general techniques to do so, 3) IEP/Return to school,

4) utilizing a team approach to assessment and planning, and 5) the role of parents. The research team also created a website, www.abieducation.com, dedicated to educating educators about ABI and it includes an online version of the binder and video tutorials. A similar resource designed in British Columbia is the Teaching Students with Acquired Brain Injury a Resource Guide for Schools created by the province's Ministry of Education Special Program Branch. This resource manual is 132 pages divided into four different chapters that address the following topics: 1) the characteristics associated with ABI, 2) planning for students with ABI, 3) teaching students with severe and mild ABI, and 4) transition planning. The resource manual also provides specific forms that educators can use to guide the initial interview with the parent(s) of a child with ABI. Lastly, Ontario educators can also access manuals that are used by educators in the United States (US) and are state-specific. These include Educating Students with Traumatic Brain Injury: A Resource Planning Guide by the Wisconsin Department of Education created by Corbett and Ross-Thomson (1996) and Brain Injury: A Manual for Educators by the Colorado Department of Education created by Connor, Dettmer, Dise-Lewis, Murphy, Santistevan, and Seckinger (2001). Compared to the Canadian resource manuals, the US ones provide similar information on the context of ABI, working with ABI in the school setting and general techniques, the IEP/Return to school, and the role of parents. The main distinction of these is that the US manuals provide information on ABI legislation and how that relates to educators.

All of these ABI resources provide educators with details on how to transition a child with ABI back into the school system from the home, hospital, or rehabilitation centre. However, these transition details are mainly descriptions of the critical tasks, previously identified by researchers, which must be considered throughout the school re-entry process. These resources do not provide specific time frames/milestones for completion or specific guidance on how to

complete each critical task. Furthermore, these resources do not seem to have a systematized or step-by-step procedure that has been designed to meet all the needs of educators.

Cognitive Research Lab (CRL) at Brock University is the research group that created the *Educating Educators Resource Manual* and continues to work closely with Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). Their study looks at recruiting teachers across Ontario to gather information on each teacher's knowledge of ABI as well as to help disseminate the manual and receive feedback on the content. To date, 223 teachers out of the 2000 targeted teachers within Ontario that were originally contacted to participate in the study have returned completed surveys for a response rate of 11%. CRL is continuing to disseminate the manual through contact with Faculties of Education, Ontario School Boards, a support line, the Ontario Brain Injury Association, and conference presentations. It is very likely that through the ongoing work of CRL to raise awareness of the manual that in the near future more SELC's throughout Ontario will be able to identify the manual.

ABI and the Individualized Education Plan

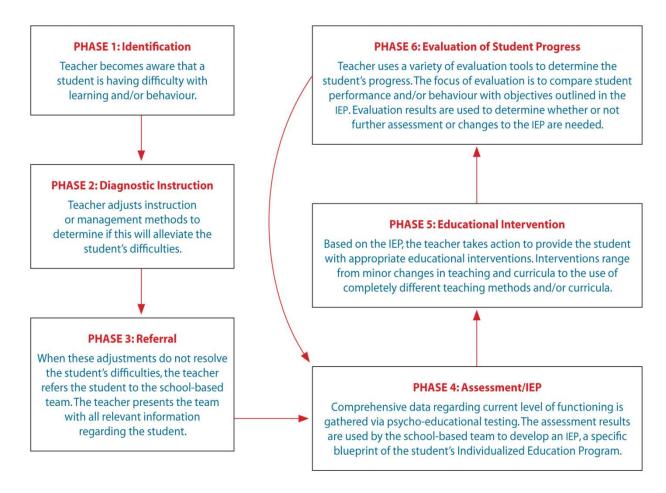
ABI resources and in-services can assist with educating educators on ABI but, may they not provide the ongoing guidance required to deal with the complexity of ABI and how quickly a child's status can change. Specific guidelines on how to assist a child with ABI that educators can use on an ongoing basis has the potential to assist them throughout a child's learning. These types of guidelines should assist educators from the time a child with ABI re-enters school until the time he/she leaves or transitions to another school. Further, coupling these guidelines with the IEP will provide educators with the tools they need to effectively work with a child with ABI and allow him/her to achieve academic success. The IEP process will now be explained in detail.

For many children with disabilities, school does not look like it does for most children. For these students to be able to attend school they require specific accommodations and professional assistance. To identify what needs these children have and the professionals required to assist them, the education system has developed the IEP. The IEP is a document that outlines the processes to be followed to assess the child and identify the interventions, accommodations, and/or modifications he/she requires. It also assists educators in setting specific educational goals for the child and to track his/her progress as he/she goes through school. Due to the complexity of ABI it becomes particularly challenging to both correctly identify and prescribe intervention strategies for a child with ABI. Even with the IEP in place, educators must fully understand ABI for the process to be successful. Further, educators must understand that strategies that are used for other students with exceptionalities may not work for a child with ABI. To correctly identify and provide appropriate intervention strategies, a trial and error approach needs to be taken that requires close monitoring by a number of educators. The status of a child with ABI can quickly change as his/her brain begins to heal. An intervention strategy that had shown to be effective one month commonly could no longer be appropriate the following month. For this reason, constant monitoring by the child's teachers and frequent updating of the child's IEP is mandatory. This frequency will be more than what educators are used to with other exceptionalities but it is one of the unique and critical features of ABI interventions. Guidelines that are coupled with the IEP provide educators with a more specific process to properly identify impairments, implement interventions, and direct services for the child. These guidelines must be specific to each phase of the assessment and IEP process. Edmunds and Edmunds (2008) outlined the six phases of the assessment and IEP process as 1)

Identification 2) Diagnostic Instruction 3) Referral 4) Assessment/IEP 5) Educational Intervention and 6) Evaluation of student progress (page 37).

Figure 1.

The Six Phases of the Assessment and IEP Process. The process flow is cyclical and frequent review and evaluation of the student is done at each phase in the process.



For many students who have learning difficulties, initial indicators of the existence of his/her disability is not always immediately apparent. For many students, it is usually the teacher who is the first person to become aware that he/she is not learning or behaving quite the same as his/her peers. This observation constitutes Phase One of the process and prompts the teacher to conduct further investigation into the problem. For children with ABI who are returning from

hospital, although his/her medical diagnosis of ABI maybe clear from medical professionals, the learning difficulties that he/she has may not be. His/her teacher will likely be the first person to become aware of these difficulties once the child begins to attempt academic tasks. At this point, the teacher should implement various classroom strategies such as preferential seating or specific teacher cueing to attempt to offset the difficulty the student is having. When a teacher knows that he/she has a child with ABI returning to the classroom, teaching interventions specific to ABI should be implemented as well as learning suggestions and/or recommendations made by the child's medical team. These attempts will also provide information on the degree of difficulty the child is having and if it is due to an isolated event and/or something specific. If it is more complicated, then further investigation is required. When the teachers' intervention strategies (Phase Two) do not assist the child, Phase Three is initiated through a referral process to the school-based team. Before addressing the remaining phases in the process, the school-based team will be described.

The school-based team has also been defined as the 'core team' throughout the literature. Kabler and Carlton (1982) defined the core team as a team comprised of at least three, and no more than six, professionals who are able to convene at predetermined points, understand the child's needs, and can determine the extent and direction of team intervention. They suggested that these professionals should be from at least three general categories: referring source, educational specialist, school psychologist, communication specialist, medical specialist, and/or school administrator. The majority of school board resource guides define the school-based team as the team that is involved in the development of the IEP. This team should be comprised of those who know the student best and those who will be working directly with the student. These members may include the student, student's parent(s), the student's teachers, the principal, and

appropriate special education staff and support personnel. Edmunds and Edmunds (2008) further recognized that the school-based team is usually comprised of the individual responsible for special education, the referring teacher, other teachers who work with the particular student, a school administrator, and often the guidance counselor in the case of junior and senior high schools. Further, parents are almost always included when their child's needs are very high, as with children with ABI, since they usually have a great deal of relevant information to contribute.

During the team referral process the referring teacher will present his/her findings, concerns, and questions about the child to other teachers who also work closely with the child, a school administrator, and any special education personnel in the school. These professionals work together to interpret the information provided by the teacher on the child and combine it with any other pertinent information found in the child's student file. For children with ABI his/her student file would contain additional medical information and/or progress notes that will be useful in developing learning strategies for the child. These professionals would also consult an ABI resource manual (if available) to further assist with specific interventions and how to troubleshoot specific learning barriers that the child may have. In doing so, these professionals then devise an educational plan for the child that may include implementing new intervention strategies in the classroom or may require further assessment by a professional either within the school or external to it. Looking back at the disability categories for the majority of these students, their impairments present many decision-making challenges for the school-based team and is often the case that further assessment is needed by professionals external to the school. From the results and interpretations of these assessments, the school-based team completes the IEP and finishes Phase Four of the process.

The assessment/IEP process also allows for the recruitment of new professionals onto the team. The specific assessments completed and their results may warrant the need for specific interventions that can only be provided by certain professionals. Provided concurrently with these specific interventions are those that are implemented by the teacher in the child's classroom and are suggested from the assessment process and documented on the IEP. As these new interventions are put into place, ongoing evaluations are also conducted by the child's teachers and professionals who work closely with him/her to determine whether the strategies being used are moving the child towards accomplishing the goals of the IEP. It is also at this point in the process that team members meet on a regular basis to discuss the student's progress. With ABI, these meetings will be required more frequently to update goals as the child's brain heals. This is a very different process than that typically used for students whose brain is not undergoing a dramatic healing process. The intervention and evaluation of student progress constitutes Phases Five and Six respectively. If changes to the IEP are needed or it is determined that further assessment or specific intervention strategies are needed, Phase Six reverts back to Phase Four and the process recurs. The overall process flow outlining the Six Phases of the Assessment and IEP Process can be seen in Figure 1 on page 32.

The Assessment/IEP Model provided by Edmunds and Edmunds (2008) can be used to assist a child with ABI. Based on the complexity of ABI and how quickly the status of a child with ABI changes, the model needs to be coupled with ABI specific guidelines. These guidelines are outlined for each phase of the model and shown below in Table 1.

Table 1.

Guidelines specific to ABI for each phase of the Assessment/IEP Model by Edmunds and Edmunds (2008)

| Phase | Guidelines |
|------------------------|---|
| Identification | Mild ABI: - this phase is the same for ABI as it is for identifying other children with difficulties with learning and/or behaviour |
| Diagnostic Instruction | Mild ABI: - teacher adjusted instructions and/or management methods may only alleviate the child's difficulties in a specific classroom and cannot be carried over to other classes - observation of the child must be across a variety of learning contexts |
| Referral | Mild ABI: - educators must be aware of the child's past history of head trauma, if documented, and understand that this could be a potential cause of his/her difficulties so as not to lead to incorrect identification |
| Assessment/IEP | Both mild and severe ABI: - psycho-educational testing alone will likely not produce the necessary information on current level of functioning - evaluation tools may not be the most appropriate due to the validity of standardized assessments lacking an ABI normative group to allow for appropriate comparisons - neuropsychological testing will likely be required to determine how the child learns - assessment must be done in a dynamic environment as formal testing can show how the child does only in isolation - cannot rely on the child's previous work before the injury to help with assessment as the ABI has changed how he/she now learns - need to be realistic with initial IEP goals and each must be carefully based on the nature of ABI |

| Educational Intervention | Both mild and severe ABI: - adjusted instructions and/or management methods need to be classroom specific - some interventions specific to ABI should be conducted/monitored by a therapist and the teacher should not be expected to carry them out - frequent communication between teacher(s) and administration staff is needed more often than it is for other students with exceptionalities |
|--------------------------------|---|
| Evaluation of Student Progress | Both mild and severe ABI: - Teacher and psychological evaluation needs to be conducted more frequently than it is with other exceptionalities considering the potential fast rate of recovery with ABI - IEP meetings need to be conducted in accordance to findings from teacher and psychological evaluations - Future IEP goals need to setting and subject specific |

By combining the Edmunds and Edmunds (2008) Assessment/IEP Model and the guidelines presented here, educators are provided with an Assessment/IEP Model that is specific to ABI. It is important to note that the severity of ABI will impact how the Assessment/IEP Model and ABI guidelines are utilized. A child with mild ABI will likely make a quick transition from hospital-to-school with little apparent changes in educational ability levels on his/her return to school. Also, certain cognitive impairments may not become apparent until the child reaches a specific stage of cognitive development that requires him/her to utilize the part of the brain that was initially injured. For this reason, a child with mild ABI will likely progress through the Assessment/IEP Model starting at Phase One: Identification. Educators must still take into account the guidelines specific to ABI at each of the remaining phases following identification in

order to properly assist the child. For a child with severe ABI, he/she will have a longer hospital stay and a more complicated hospital-to-school transition. The identification of cognitive impairments will likely be more immediate and apparent and educational intervention strategies will be needed immediately upon the child's return to school. Thus, a child with severe ABI will begin the process at Phase Four: Assessment/IEP, and it will likely be initiated <u>before</u> the child returns to school.

In summary it is critical for an ABI school re-entry protocol to work properly that it must provide detailed information on constructing an IEP for the child. The IEP assists educators in setting specific educational goals for the child and to track his/her progress as he/she goes through school. Due to the complexity of ABI, it becomes a particular challenge to both correctly identify and prescribe intervention strategies for a child with ABI. It is not as simple as merely creating an IEP. Even with the IEP in place, educators must fully understand ABI to allow for the process to be successful because strategies that are used for other students with exceptionalities may not work for a child with ABI. To correctly identify and provide appropriate intervention strategies, more of a trial and error approach is needed and it requires much closer monitoring by a number of educators. This is because the status and abilities of a child with ABI can quickly change as the brain begins to heal. It would not be uncommon for an intervention strategy that was effective during one month to no longer be appropriate in the month following. For this reason, constant monitoring by the child's teachers and frequent updating of the child's IEP are required. This frequency is likely to be much more invasive than what educators are used to with other children with exceptionalities. Based on the complexity of ABI and how quickly the status of a child with ABI can change, the IEP process needs to be coupled with ABI specific guidelines.

Based on these limited examples it is clear that a school re-entry protocol needs to contain these and other pertinent guidelines. When combined, educators would have a comprehensive process to properly identify impairments, design and implement interventions, and to coordinate and direct all services for a child with ABI. Overall, a school re-entry protocol that outlined the critical tasks that educators must complete, when these tasks need to be completed, and ABI-specific guidelines for the development and implementation of the IEP would guide educators to effectively working with a child with ABI and allowing him/her to achieve his/her academic potential. At this point in time, this type and scale of protocol does not exist. For all the above reasons, it is important that such a protocol is either identified or created.

An Examination of Canadian Provincial and Territorial Educational and Medical Policies

for Children with Acquired Brain Injury

One of the driving forces that could ensure proper protocols and/or guidelines for ABI school re-entry is legislation that specifically acknowledges ABI. When the provincial and/or federal government mandates a policy it has a top-down effect. That is it ensures that professionals, organizations, and boards are required to follow what the policy states. If policies are not in place these professionals, organizations, and boards have little guidance and are left to address the particular issue on their own. Therefore, both the educational and medical policies within Canada that relate to ABI will be reviewed.

ABI and Educational Policy

Education in Canada lacks any federal legislation to govern how education is provided other than the *Canadian Charter of Rights and Freedoms* (CCRF) that states that individuals have the right to equal treatment and discrimination based on disability or handicapping

condition is not allowed (Canadian Charter of Rights and Freedoms, 1982). To meet the conditions set forth in the CCRF, provinces have developed similar special education policies to support the inclusion of students with exceptionalities. However, each policy differs based on the degree to which each recognizes ABI. This was shown in Table 1.

Within Canada ABI is viewed differently by each of the provinces and it is only regarded as an exceptionality in any significant way by; Newfoundland and Labrador. The Ministry of this province recognizes ABI as a distinct exceptionality that requires accommodation (Zinga, Bennett, & Good, 2005). Within all of the other provinces ABI does not receive any regard as a unique exceptionality. Specifically within Ontario, the recognition of ABI is very limited. There is only a brief mention of it as a condition associated with learning disability in Policy/Program Memorandum No. 89. Limiting the recognition of ABI complicates how special education funding for a child with ABI is received and impacts the intervention strategies that are used to assist the child.

If a child with ABI has been injured in a MVA he/she will receive third party funding from an insurance provider. This provider is legally responsible for assisting the child with his/her recovery and paying for any supports that the child needs including those in special education. If a child did not suffer his/her injuries from a MVA, funding for special education accommodation can be received by placing him/her into a recognized funding category such as the behaviour category. This type of alternate placement is needed as without it, a child with ABI could be excluded. Researchers have argued that obtaining funding using this placement method can lead educators to implement strategies that are based on targeting the specific exceptionality of the category and not ABI directly. Bennett, Dworet and Diagle (2001) referred to this approach as fitting the square ABI peg into the round recognized exceptionality hole. In these

cases the strategies educators implement based on the exceptionality category will likely fail to address the unique impairments of the child with ABI.

ABI and Medical Policy

Healthcare in Canada provides medical care for all Canadians, similar to how education policy and practice is. Each is a universal policy primarily enacted by the province/territory with limited input from the federal government. At the federal level, medical responsibilities include health services for Indian and Inuit people, federal government employees, immigrants and civil aviation personnel. The federal government is also responsible for controlling the healthcare spending of each province which is tied to the *Canada Human Rights Act* (Canada Human Rights Act, 1985). This act establishes the criteria and conditions that must be met by each province before full payment is made for insured health services. The acts primary objected is:

"to protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers (p. 5)."

The act guarantees equal access to health services and care for Canadians but does not guarantee access to the conditions that lead to good health. In other words, it does not outline how healthcare is to be delivered or the type of healthcare programs that need to be made available to the residents of each province. This is done by the provinces who oversee health care delivery including the licensing of health professionals, medical insurance plans, and the delivery of certain public services. Many Canadian health reform reports have identified that there are issues other than medical care such as education, housing, employment, and the environment that need to be further addressed. The reports also argue for better regional management of services and human resources as well as expressing concern about the efficiency and effectiveness of the

current system and its delivery systems. One of the suggested solutions is to design and implement a *Canadian's with Disabilities Act* one that is modeled off of the *American's with Disabilities Act* (ADA) (Chenier, 2002). The ADA aims to reduce barriers to employment, transportation, public services, and telecommunications (American's with Disabilities Act, 1991).

In regards to health care legislation for children with ABI, there is no federal or provincial policy or procedure that makes specific reference to how a child with ABI should be managed. It appears that the management and identification of an appropriate way for assisting a child with ABI falls to each region and the hospitals within it. However, the treatment of ABI within most hospitals is, for the most part, standardized. Hospitals utilize similar protocols that outline specific OM and treatments that a child would need and at which point in his/her recovery. However, it is unclear whether hospitals utilize similar transition protocols to aid a child move to his/her next level of care that lies outside of the hospital. Within each province ABI organizations have been established to provide assistance to people with ABI and to work with other organizations within the area to provide better service for these individuals. Despite the work that these organizations do, identifying transition protocols that hospitals can use has the potential to greatly assist a student's medical team to help them in the transition process.

Implementing proper education policies that recognize fully the complexities of ABI would go far in assisting in the education of children with ABI. Even if ABI receives a high degree of recognition in the future, it does not guarantee that the child will be successfully educated. This success still will depend to a large extent on the child's school and how the professionals there approach educating children with ABI.

Problem Statement

It appears evident that one of the obvious problems that educators face is the lack of a clear protocol that could be used to direct the entire re-entry process. Without educators being guided by a detailed school re-entry protocol, it is very likely that inappropriate decision-making would occur, that appropriate information about the child would not be acquired, and that an incomplete IEP would likely be developed. Therefore, the goal of this study was to identify what school re-entry protocols exist within Ontario school boards. While the literature evidence appears obvious, it has not yet been clearly established that suitable protocols exist or do not exist in Ontario. Based on my preliminary assumption that school re-entry protocols were few and far between, and that if they exist they probably were not derived from a common body of research, this thesis also examined, compared, and amalgamated the conceptual similarities of the identified protocols into a comprehensive document. The specific questions this study attempted to answer were:

- 1) Do Ontario school boards have school re-entry protocols?
- 2) If so, do the identitied protocols specifically outline all the needed transitional elements/phases between the healthcare sector and education?
- 3) If protocols do exist, are they comprehensive and how are they used?
- 4) What conceptual and procedural elements need to be included in the design of a suitable protocol and would that protocol be considered effective by educators involved with students with exceptionalities at the school board level?

These procedures would take into consideration all the key tasks that must be completed throughout the process so that educators would confidently know what tasks must be completed throughout the process and the expected time frame for completion. This would increase the likelihood that a child with ABI would progress academically. This would help guide educators

towards making informed decisions and help to justify why certain choices were made throughout the re-entry process. Such a protocol would allow educators, who likely have very little experience working with a child with ABI, to fully recognize and understand the school reentry process. It would further allow educators to identify what information must be gathered and to assist them in developing an effective IEP that was specific to a child with ABI. The IEP is a document that outlines the processes to be followed to assess the child and identify the interventions, accommodations, and/or modifications he/she requires. The development of a proper IEP would help guide the delivery of learning interventions within appropriate learning environments. This would increase parent confidence and help to ensure them that there will not be any important tasks missed or gaps in service delivery for their child. Furthermore, this process of early and timely identification, assessment, and intervention would be beneficial to all educators working with that child.

CHAPTER THREE: METHOD

The study was conducted in five phases. Each phase was based on assumptions that this researcher had formed as a result of preliminary investigations of the literature.

Phase One was to conduct a Canada wide examination of medical and educational policies that relate specifically to ABI. This involved a preliminary investigation into ABI recognition in Canada. One of the driving forces that would help ensure that proper protocols were designed and utilized for school re-entry is legislation that specifically acknowledges ABI. When the provincial and/or federal government mandates a policy, it has a top-down effect. That is, it ensures that professionals, organizations, and boards are required to follow what the policy states. If policies are not in place these professionals, organizations, and boards have little guidance and are left to address the particular issue on their own. In the absence of specific legislation, professionals and organizations will be forced to design their own policies or procedures to properly manage certain issues. These policies are usually designed to handle specific issues/incidents that occur fairly infrequently but are not covered by existing policies or procedures.

Phase Two was to determine whether Ontario school boards had protocols that educators could use to assist a child with ABI re-enter school – the assumption here was that there were currently no protocols available. It also appeared that such a protocol was not required under the Education Act nor any Ministry of Education special education guidelines or procedures. This assumption was verified/confirmed. In the case of school re-entry for students with ABI, it is highly likely that the extremely low incidence rate of the condition has not forced educators to design timely and suitable policies/procedures. The researcher contacted each Ontario school board's Special Education Learning Consultant (SELC). Each SELC contacted was asked to

provide information on the procedures that the board provides to educators when assisting a child with ABI for the first time. The SELC at each Ontario school board was the primary contact to determine whether protocols existed for each board. It is likely that if a school board does have a school re-entry protocol, its existence will be known to the SELC. The contact information for each Ontario school board was gathered using the government of Canada's website, http://www.edu.gov.on.ca/eng/sbinfo/boardList.html. Using the contact information that this website provides, each board was contacted to identify its SELC. Once each SELC had been identified, each was contacted by email and/or phone and asked to complete a brief questionnaire. The questionnaire was initiated with the following five questions:

- 1) What is your personal experience with assisting children with ABI?
- 2) What is your school board's experience with assisting children with ABI?
- 3) What assistance do you provide to schools when they are going to receive a child with ABI?
- 4) To the best of your knowledge do you have a protocol to facilitate ABI school re-entry?
- 5) What do other school boards do when they are going to receive a child with ABI? The direction of further questions was based off the answers to these first five. The goal of the questions was to identify how each SELC and his/her school board handled transitioning a child with ABI back into school. This served to help identify what resources the board used when doing so. If a protocol was identified through the questionnaire, a hard copy of it and any other resources that were used were obtained for examination. Even if a board did not have a designated protocol, each SELC was asked to provide information on whatever procedures the board provided to educators when assisting a child with ABI. This data provided valuable

information on the knowledge base of each board about ABI resources and how each board

approached assisting a child with ABI. This information, in turn, also revealed the need each school board had for a comprehensive re-entry protocol.

Phase Three was to determine the comprehensiveness of any protocols that resulted from Phase Two – the assumption here was that while some boards may have protocols, these are probably not as comprehensive as they need to be. The comprehensiveness of any discovered protocols would be determined by comparing the elements and features of said protocols with the best practices reported by the literature. To determine each protocol's comprehensiveness, the responsible professionals involved, the tasks required, and the procedures and timelines that were outlined were to be compared to recommended standards of practice found in the research literature as described below. To accomplish this, a threefold analytic framework was applied to identify and compare similarities and differences. An analytic framework poses specific questions that explicitly examine the conceptual and application components that appear to be required in order for a policy or protocol to be effective. Therefore, each element of this framework identified a fundamental issue that must be addressed in order to properly carry out school re-entry for students with ABI. These elements were expressed as questions about three fundamental and interrelated issues:

Question #1: What are the roles of the educational professionals identified in the protocol?

In a review of the medical literature on the professionals involved in the school re-entry process, it appears that there is an emphasis on the importance of having a designated ECC (Educational Case Coordinator) throughout the process. For example, the ECC could be a special education teacher at the child's school or an itinerant professional that has been designated by the school board. In either case, the general role of the ECC would be to coordinate educational services for the returning child and communicate with his/her medical team. Researchers agree

that due to the number of critical tasks requiring completion in this process, an ECC is needed to quarterback the process. PABICOP is a program that resides within a healthcare facility that effectively utilizes an ECC in the school re-entry process to assist educators in the school reentry process. The program is specific to Southwestern Ontario and aims to be holistic, parent/family centered, and to incorporate the community in the ongoing care and management of a child with ABI. It recognizes schools as rehabilitation partners and the school as the primary site of vital skill development and an important factor in determining the long-term success of the child. The PABICOP team consists of a pediatric neurologist that acts as the medical case coordinator, a community outreach coordinator, and an ECC that work together to assist children in the transition process. The primary role of the ECC is to make sure that the child is able to successfully transition back into school. From the beginning of the school re-entry process, which is typically identified as hospital admission, the ECC is actively involved. While the inclusion of an ECC is a step in the right direction, it does not seem sufficient that this individual would be the sole educational professional involved in the school re-entry process. Successful school re-entry requires coordination amongst multiple educational professionals.

Question #2: Are these roles well delineated/defined? and

Question #3: Is the timeframe logically sequential?

For a protocol to be effective it must clearly outline the tasks that each professional must complete throughout the school re-entry process. It must also identify the time frame that each professional has to complete each of his/her task(s) and these must be logical and sequential based on the identified critical stages of school re-entry. Each protocol was to be examined for its adherence to the tasks deemed critical to the process and the general timelines of when each should commence and be completed (as appropriate) as outlined by Ylvisaker, et al. (1995),

Farmer et al. (1996) and Clarke (1996). The school re-entry protocol(s) gathered in this study (if any) were to be evaluated based on inclusion of the critical tasks that are emphasized in the above literature and the depth of description provided for each. It was quite possible that Ontario school boards would not have school re-entry protocols. It was also possible that any protocols identified would not be comprehensive enough to properly guide educators throughout the process.

Phase Four was the construction of a comprehensive protocol that educators could use because school re-entry protocol(s) were not identified through Phase Two. The protocol was designed based on accepted standards of practice found in the literature – these practices were sporadically described throughout the literature, but they had not been assembled into a logical and systematized protocol that educators could easily use. Phase Four of this research was to construct a comprehensive school re-entry protocol that educators could use. This protocol's aim was to outline the critical tasks identified by researchers as key to the school re-entry process and to couple these with the effective procedural elements found in programs such as PABICOP (mentioned previously). The newly designed protocol would take into account the different stages of the school re-entry process, each of the critical tasks of the process, the professionals assigned to each task, and a logical timeline/milestones for the commencement and completion of the entire process.

Phase Five was an evaluation of the protocol designed in Phase Four. The evaluation focused on validating the content and structure and was conducted by 13 special education experts. These special education experts have experience in the school re-entry process for children with ABI and have an extensive understanding of how special education operates within Ontario school boards evaluated the protocol. Evaluation was done through combination of one-

to-one interview(s) and a focus group discussion. The focus group evaluation was critical as it allowed all involved to explore and clarify their views in ways that would be less easily accessible in a one-to-one interview alone (Kitzinger, 1995). The main purpose of this evaluation was to determine whether the components of the protocol were consistent with what each expert had experienced in practice during the school re-entry process and to make recommendations for changes to the protocol if needed. This intensive process was conducted to create a final version of the protocol that would have the potential to assist educators who have had limited or no experience with children with ABI to understand the protocol and to allow each to feel comfortable using it in the event they received such a child at their school.

The website indentified a total of 83 school boards within Ontario with accompanying contact information. Through using this contact information each school board was contacted to identify the SELC within it from September 2010 through to December 2010. An SELC was able to be identified and contacted either directly or through leaving a message for 36 of these school boards. Out of the messages left for each SELC, direct contact was made with 12 to discuss directly his/her school boards approach to school re-entry and if a school re-entry protocol was used. Each SELC directly contacted did not make any reference or direct mention to a specific ABI re-entry protocol and identified the IEP as the main process used to assist these children.

The low rate of SELC contact for this part of the study was largely due to once the SELC was contacted he/she referred to another educational professional that would better be able to discuss the school board's experience working with children with ABI. For the majority of the SELC's contacted a message had to be left before he/she called back or preferred to be contacted through email. The majority required secondary follow-up both by phone and email before contact was made. After a third follow-up by both phone and email the SELC was not contacted

again for that specific board. In this case, an alternate contact was identified and contacted. In the majority of the cases this alternate contact referred to the original SELC as the boards contact for identifying ABI school re-entry protocols. For those SELC's contacted not all had personal experience assisting children with ABI within his/her educational career. This could be due to the low occurrence of ABI or actually having worked with a child with ABI and not being aware of it.

To further evaluate if school re-entry protocols exist within Ontario, PAIBCOP was contacted and a meeting with one of the programs school re-entry liaisons was organized. This meeting served to provide more in-depth information on the role of the program in the school reentry process and how the liaisons help to facilitate this process. The liaisons will help facilitate the school re-entry process after permission to do so is received from the school board that the child will be returning to. The liaisons provide assistance through distributing ABI specific resources to the board's educators along with in-services if required. The liaison was also not aware of any specific school re-entry protocols that exist that can be provided to educators to better assist with the school re-entry process.

Analyses

Based on these analyses, this study makes suggestions toward a more effective school reentry protocol that could be used to assist children with ABI. This suggested protocol may be of use to provincial educators when faced with having to assist a child with ABI. The protocol provides educators with clear tasks and timelines throughout the re-entry process. Educators will be confident that through using the protocol, they will be able to recognize and complete the critical tasks in the process that could potentially impede transition if missed for a child with ABI.

CHAPTER FOUR: RESULTS

Phase One of this research study attempted to determine whether any medical and/or educational policies exist regarding ABI recognition in Canada. The findings of this investigation are summarized below in Table 2

Table 2.

ABI Recognition and details of it by each of Canada's provinces

| Province | ABI Recognition Level | Details of Recognition |
|-----------------------------|-----------------------|--------------------------------|
| | | - ABI recognized by the |
| Newfoundland and Labrador | Education: High | Minister of Education as a |
| Trewfoundfund und Eustrador | | distinct exceptionality |
| | | requiring accommodation |
| | | - Provincial government |
| | | created resource manual for |
| British Columbia | Education: Moderate | educators to assist with |
| Brush Columbia | | accommodating students with |
| | | ABI |
| | | |
| | | - Very brief mention of ABI as |
| Ontario | Education: Low | being a condition associated |
| | | with learning disability in |
| | | Policy/Program Memorandum |
| | | No. 89 |
| | | - Some mention of ABI in |

| | | special education |
|-----------------------------|--------------------|--------------------------------|
| | | guides/resources materials |
| Manitoba, Prince Edward | | - Very brief mention of ABI in |
| Island, Quebec, and | Education: Minimal | special education |
| Saskatchewan | | guides/resource materials |
| | | - No reference to ABI in |
| Alberta, New Brunswick, | | provincial legislation and no |
| Northwest Territories, Nova | Education: None | mention of ABI in special |
| Scotia, Nunavut, and Yukon | | education guides/resource |
| | | material |

Based on these findings it is clear that ABI receives little to no recognition in the provinces and territories with the exception of Newfoundland and Labrador. Despite this province identifying ABI as a distinct exceptionality that requires accommodation, there were no ABI resources and/or school re-entry protocols identified in the literature specific to this province. If a re-entry protocol exists it should be readily available to educators to assist with accommodating these children and easily obtained. This is particularly true when ABI is a recognized exceptionality within a province. Based on this, it is likely that a school re-entry protocol does not exist for Newfoundland and Labrador and it is doubtful that one would exist within the other provinces that do not recognize ABI as an exceptionality. This point is further confirmed through the findings in Phase Two that looked specifically at Ontario school boards.

Phase Two of this research took a close look at Ontario school boards to determine whether any boards had school re-entry protocols that educators could use to assist a child with ABI re-enter school. Each SELC confirmed that his/her board had in the past been faced with the task of educating a child with ABI. Each also identified that the primary mechanism that schools use to assist these children is the IEP process, if needed. Any other preparation was done through external organizations and/or material that can be easily accessed online. No SELC provided direct mention of a school re-entry protocol and was not aware of one that the school board had on hand. Even more so, each did not make mention of any ABI resource material that could be provided to educators and were not aware of any that other school boards may have had that could be utilized if their own board received a child with ABI.

Some of the SELC's contacted in this phase of the study had heard of the *Educating Educators* resource manual. These SELC's were all located in London, the same location that PABICOP is located and the main program that has and continues to assist with distributing the resource manual to educators. The London SELCs were likely made aware of the resource manual through the regular in-servicing and assistance that PABICOP provides to the London and surrounding area school boards. This would also help explain why SELCs external to these areas did not mention the resource manual. The low identification rate of the *Educating Educators* manual is consistent with why there is currently an ongoing study by CRL at Brock University that looks at increasing teacher awareness of ABI and introducing the manual to teachers across Ontario as previously discussed.

The lack of a school re-entry protocol could also potentially be due to a lack of policies specific to school re-entry. Those policies would drive a school re-entry protocol to be defined and used by educators in the school re-entry process for these children. Another possibility is that

although there is an identified need for a school re-entry protocol to assist with accommodating these children, such a protocol has yet to be developed.

Phase Three Findings: Analytic Framework

Because none of the contacted school boards reported the use or existence of a school reentry protocol for students with ABI, there was no analyses for Phase Three.

Phase Four Findings: Protocol Construction

The absence of identified school re-entry protocols within Ontario school boards justified the need for a school re-entry protocol to be developed. Phase Four of the study was to construct a comprehensive school re-entry protocol that educators could use. The protocol was designed to include the critical tasks outlined in the literature and identified by researchers as being the key elements of the school re-entry process with the purpose of coupling these with the effective elements found in resource materials available through organizations such as PABICOP. Based on all the above, the newly designed protocol had to include information on the following five elements 1) age specific symptoms of ABI, 2) key implications for moderate to severe ABI school re-entry, 3) school re-entry key points and requirements, 4) an explanation of neurological assessments for children and, 5) an explanation of the teams involved in the school re-entry process. The protocol had to also provide an overview of the school re-entry process through a flow diagram that summarized the phases of the process and served as a visual aid for educators to better understand the process.

1) Age specific symptoms of ABI, 2) key implications for moderate to severe ABI school re-entry, and 4) an explanation of neurological assessments for children. These sections are all described

in detail in the *Educating Educators Resource Manual*. For this reason, the main details of each of these topics were included in the protocol.

3) School re-entry key points and requirements

The school re-entry key points and requirements as well as the responsibilities of the SELC and SBLT (school based team lead) were identified through both the literature and information from PABICOP. The literature that identifies the key points and requirements discusses the SELC and SBLT as one title: the Educational Case Coordinator. The split of the ECC role into the SELC and SBLT was incorporated into the protocol to allow for a division of responsibilities. It was also done to foster collaboration between medical and educational professionals through the guidance of these two professionals that would better assist the child re-enter school. The SELC was described as a community representative while the SBLT described as an educational representative. The split was confirmed through information obtained by PABICOP and the Special Education Experts. Further, the key phases of school reentry were expanded to seven key phases through including two new phases beyond the school re-entry phase. Phase Six was called Assessment and Individualized Education Program (IEP) and Phase Seven was called Introduction of ABI Educational Resource. Both of these phases were added directly after the school re-entry phase to allow for more detail as to the processes that should occur once the child is at school. This is a key piece that is not identified in the literature but, is needed to better direct educational professionals in the overall school re-entry process. The critical tasks that needed to be completed by the ECC at each phase were identified through an amalgamation of those outlined in the research which will now be explained.

Ylvisaker et al. (1995) outlined tasks that were organized into categories based on the overall function of the ECC and is shown below in Table 3.

Table 3.

Educational Case Coordinator Functions by Ylvisaker et al. (1995)

| Category | Functions |
|---|---|
| Direct Service In Schools | Problem solving; helping school staff test hypotheses about what type of instruction and intervention will be most successful Staff training, including providing information about the unique characteristics of students of ABI Translating medical information into school language Supporting school staff Facilitating the development of school based teams Supporting peers |
| Case Management | Finding needed services, supports, and expertise in the community Coordinating school and community providers |
| Team Training | - Training teachers and clinicians to be local resources for each other |
| Information Dissemination | Providing general information about ABI Developing a library of resources |
| Transition from Hospital to School Case Management | - Facilitating the transfer of function from hospital case managers to individuals in schools who play the role of case manager |
| Family Support | Helping family members understand medical and educational issues Supporting family members through their grieving process Providing information about ABI and community resources Helping school personnel recognize and understand family issues |

The functions included direct service in school, case management, team training, information dissemination, transitioning from hospital to school case management, and family support. These functions are ones that the ECC must continuously do throughout the school re-entry process.

Although these functions are important, they do not provide the detail required to guide an ECC throughout the process.

Farmer et al. (1996) discussed tasks that school personnel need to complete at key points in the school re-entry process. They outlined a task timeline for these professionals shown below in Table 4.

Table 4.

Tasks and Timeline for the Transition from Rehabilitation to School by Farmer et al. (1996)

| Time | Tasks |
|--|--|
| Immediately Following Injury | Contact parent(s) to inquire about their child's condition and to obtain release for hospital contact Contact the child's case manager at the hospital Meet with the child's classroom teacher(s) to inform them of child's condition and review current educational records |
| After Student's Condition Has Stabilized | - Arrange a meeting with the hospital case manager to obtain information regarding the child's condition |
| Prior to Discharge | Visit with the student and rehabilitation staff Obtain copies of hospital evaluations Conduct in-service in school |
| Immediately After Hospital Discharge | Contact parent(s) to determine if the child will be getting post-acute rehab care Set a tentative date for return to school |

| | Follow-up with hospital case manager Establish an ABI school re-entry team and designate a case manager Develop a tentative plan for school re entry |
|-----------------------------|--|
| Arrival at School | Assign personnel to conduct initial evaluation and give feedback to teachers and parents Further modify classroom environment to meet student's needs |
| After First Weeks at School | Reassess the student's needs and modify educational planMaintain contact with parents and teachers |

They also acknowledged the importance of identifying the ECC immediately in the school reentry process. This timeline only includes tasks for the ECC to complete up to hospital discharge in the school re-entry process. Identifying tasks for the ECC after hospital discharge is very important as the child is no longer in the hospital and under complete allied health professional care. To accomplish successful school re-entry, the ECC must be actively involved and ensure a number of tasks are successfully completed after hospital discharge. The failure to complete even one task can cause a delay in school re-entry. For this reason, the ECC must clearly understand his/her involvement after hospital discharge and the tasks that must be completed.

Clark (1996) discussed a task timeline that provided tasks for the ECC to complete throughout the entire school re-entry process and is shown below in Table 5.

Table 5.

Tasks and Timeline for the Transition from Rehabilitation to School by Clark (1996)

| Time | Tasks |
|------|-------|
| | |

Upon Hospital Admission

- Send all school records to hospital staff
- Indicate school's knowledge of ABI and training needs
- Send school materials for use in therapy
- Share information regarding district special services

Throughout Admission

- Maintain contact with rehabilitation staff through visits and/or teleconferences
- Visit the student and attend therapies if Possible
- Begin considering student's needs for return to school
- Share information with any personnel that may be working with the student in school
- Request specific written material for educating students with ABI to provide to school staff
- Schedule training for staff regarding ABI

At Hospital Discharge

- Set date for discharge planning meeting and identify personnel who should attend
- Prepare a list of questions remaining for parent(s) and/or rehabilitation staff
- Develop list of possible schedules, instructors, and services to discuss during discharge meeting (including homebound services)
- Identify other agencies that may be necessary to provide services
- Identify hospital contact person to answer any further medical related questions and/or notify of child's progress

This timeline refers to the ECC as the school representative and outlines what tasks he/she must complete immediately following injury to after hospital discharge for the child. From this point, the ECC becomes a part of the school based team but, is still responsible for completing the tasks for arrival at school and after the first weeks there on this task timeline.

By combining both task timelines and the general functions of the ECC, an ECC is provided with a timeline that assists in identifying his/her function and the tasks that need to be completed at all major points in the school re-entry process. This new ECC task time line is shown below in Table 6.

Table 6.

Tasks and Timeline for the Educational Case Coordinator Throughout the School Re-entry

Process for Children with ABI

| Time | Tasks |
|----------------------|--|
| Hospital Admission | Inquire about the child's status through his/her parent(s) and obtain consent for release of hospital contact Indicate school's knowledge of ABI and training needs Send school materials (books, tapes, etc.) for use in therapy Inform child's teachers of his/her condition Obtain/review current educational records Send student records to the hospital |
| Throughout Admission | Maintain contact with rehabilitation staff through visits and/or teleconferences Visit the student and attend therapies if possible Obtain copies of hospital evaluations (psychological, PT/OT, speech) Begin considering student's needs for return to school (physical, educational, emotional, etc.) and share options available based on knowledge of district resources and schedules Share information with any personnel that may be working with the student in school Request specific written material for educating students with ABI to disseminate to staff |

| | Schedule training for staff regarding ABI through in-services at the child's school Facilitate peer contact by sending audiotapes or videotapes of brief messages or good wishes |
|----------------------------------|--|
| At Hospital Discharge | Set date for discharge planning meeting and identify personnel who should attend Prepare a list of questions remaining for parent(s) and/or rehabilitation staff Develop list of possible schedules, instructors, and services to discuss during discharge meeting (including homebound services) Identify other agencies that may be necessary to provide services Identify hospital contact person to answer any further medical related questions and/or notify of child's progress |
| In the Community | If required, determine who will provide the child with post-acute rehab care Follow-up with hospital case manager and those providing post-acute rehab care to get update on child's condition/special needs Establish a school transition team Set a tentative date for return to school Develop a plan for school re-entry |
| School Re-entry | Assign personnel to conduct initial evaluation and give feedback to teachers and parent(s) Modify classroom environment to meet student's needs Reassess the student's needs and modify educational plan accordingly |
| Functions Throughout the Process | Assisting school staff by answering any questions they may have regarding the child and/or ABI Providing peer support and educating them about ABI Finding needed services, supports, and expertise in the community to assist the child |

- Helping family members understand medical and educational issues
- Supporting family members through their grieving process
- Helping school personnel recognize and understand family issues

By utilizing this type of task timeline, an ECC can check to be sure that these tasks are completed within the given time period. This has the potential to increase the likelihood of a quick and successful school re-entry process for a child with ABI. Even if successful school re-entry occurs, it does not guarantee long term success for the child. This success is dependent upon how the professionals within a school function when educating a child with ABI.

The critical points were further expanded with an emphasis on Phase Six and Seven of the protocol as each of these Phases were education specific and needed to be built up in order to provide more guidance for the ECC and educational professionals. These critical tasks were identified through PABICOP and the tasks that the organization's ECC typically completes at these stages as well as the main tasks that need to be completed by educational professionals for special education.

5) Explanation of the teams involved in the school re-entry process
Hospital and Community Based Teams

The allied health professionals working with a child with ABI in the hospital or community work within specific guidelines and know the tasks that he/she must complete to progress the child. If these professionals reside within the hospital they form the child's hospital based team and are responsible for progressing the child towards discharge. Due to the ongoing medical needs that persist beyond hospital discharge for children with moderate to severe ABI, community allied health professionals are commonly needed. These professionals comprise the

community based team for the child and are responsible for progressing the child further. Both the hospital and community based teams were incorporated into the protocol.

The School Based Team

The school-based team is usually comprised of educational professionals who are able to convene at predetermined points, understand the child's needs, and can determine the extent and direction of team intervention. Within the child's school, these professionals are often the child's teacher(s), special education coordinator, learning support teacher, school psychologist, and/or a school administrator. One of the team members usually a special education coordinator or learning support teacher at the child's school assumes the role as the SBTL. The team lead is responsible for communicating with the hospital and community based teams with the assistance of the SELC. The school based team was incorporated into the protocol with the emphasis on the SELC.

The SELC coordinates educational services for a child with ABI and communicates with both medical professionals from the hospital and community as well as educational professionals who work with the child. The SELC is a member of both the hospital and community based teams as well as the school based team and acts as a liaison between each. The main function of the SELC is to allow for the child to transition back into school into the care of the school based team. Once this occurs, the education professionals that comprise the school based team for the child who usually work within the child's school, must begin to take on a more active role in assisting the child on a regular basis. Once the child is back in school, the SELC can still act as an educational consultant when needed. The child's school may request routine check-ups by the SELC on the child to ensure that he/she is progressing and/or require advice on appropriate intervention strategies to help overcome any problems encountered while educating him/her.

Phase Five Findings: Protocol Evaluation

To evaluate the protocol, 13 special education experts were recruited. Each of these professionals was identified as having prior experience working with children with ABI throughout the school re-entry process despite the fact that no formal protocols exist. More so, each had extensive knowledge of special education and were regarded as the lead professional for his/her discipline in special education for the school board. For example, each of these professionals had helped to facilitate special education services for children within his/her district through working collaboratively with educational and medical professionals and as a member of the school board's primary special education team. Further, there was excellent representation of different professional groups as the group contained special education leads, a guidance counselor, a psychologist, and a speech-language pathologist. The collective experience of these professionals was critical to effectively evaluate and validate the content of the protocol. The group's combined experiences and familiarity with special education increased the likelihood that the changes and suggestions made to the protocol would strengthen its validity.

The recruitment of participants was done through a southwestern Ontario school board. Once the University of Western Ontario's ethics approval was obtained, the research ethics approval form and all supporting documentation was submitted and approval was received from the board to begin recruitment. The school board provided initial contact with a key expert (Evaluator One) within their special education department. This expert agreed to be the first person to evaluate the protocol and to provide feedback through a phone interview, as well as to assist with organizing a focus group to allow for other special education experts to evaluate the protocol. Before the phone interview evaluation commenced Evaluator One was provided with a

draft of the school re-entry protocol and was given the necessary time to evaluate its content thoroughly. The results of the phone interview evaluation are summarized in Table 7.

Table 7.

Phone Interview Evaluation: Evaluator One phone interview evaluation key point(s) for respective sections of the protocol

| Protocol Section | Protocol Page Number(s) | Key Evaluation Point(s) |
|------------------------------|-------------------------|---------------------------------|
| | 1-2 | More recent data needs to be |
| Introduction | | provided if it exists. Majority |
| introduction | 1-2 | of cited references are greater |
| | | than 10 years old. |
| | | Protocol should state |
| | | throughout it "if/as warranted" |
| Multiple Sections | Throughout Protocol | or "as necessary" instead of |
| | | "must" as well as "may |
| | | require" not "will require." |
| Multiple Sections | Throughout Protocol | ABI is not an exceptionality |
| whitiple sections | | cannot mention this directly. |
| | | Make point of home |
| School Re-entry Protocol Key | 5 | instruction through school |
| Points and Requirements | | board and how it can be |
| (Community Care) | | applied for through school |
| (Community Care) | | board as a community |
| | | intervention. |

| | | Neuropsychological testing |
|--|------|--------------------------------|
| | | may be needed and would be |
| School Re-entry Protocol Key | | initiated by school board |
| Points and Requirements | 6 | Psychologist if deemed |
| (Assessment and | | appropriate and necessary by |
| Individualized Education Plan) | | them. Minimum testing of this |
| | | type is actually done. |
| | | SELC not necessarily involved |
| School Re-entry Protocol Key | | in IEP process and expertise |
| Points and Requirements (Assessment and | | maybe requested by school but |
| | 6 | maybe requested by school but |
| | | may not necessarily need to |
| Individualized Education Plan) | | come in directly to create the |
| | | IEP. |
| | | At times it could be that the |
| | | SELC is the SBTL depending |
| | | on the situation. Need to |
| Teams Involved in the School Re-entry Process | 9-11 | mention this as this situation |
| | | could happen particularly if |
| | | the SBTL has experience with |
| | | ABI school re-entry. |

In summary, the preliminary evaluation of the protocol by Evaluator One showed the protocol was structurally sound based on what is observed in practice. However, it would not be required

within Evaluator One's school board due to the school re-entry process already working well due to the extensive involvement of community support groups.

Focus Group Evaluation

The focus group evaluation date was set approximately one month after the phone interview evaluation occurred with Evaluator One. The group evaluation was organized as part of the school board's quarterly special education meeting and it was placed first on the agenda to allow enough time for detailed group discussion/evaluation to occur. Evaluator One felt that building the protocol evaluation into the quarterly meeting would increase the likelihood of having enough evaluators present as each is required by the board to be present. The meeting was scheduled well in advance to allow each evaluator the necessary time to review the protocol. Before the meeting occurred, each professional attending was provided with an electronic copy of the protocol and the consent form explaining the purpose of the study (by Evaluator One). The purpose of the study was again explained at the meeting and it was made clear to each professional in attendance that participation was voluntary. Written consent was obtained for the 13 professionals who participated in the group evaluation. One participant opted to not be part of the evaluation and therefore was excluded from the group evaluation. The protocol was presented by Evaluator One on a large overhead projector and each table of participants had access to a hard copy or was able to view it on a laptop. Evaluator One walked the group through each page of the protocol, but was very careful to not mention any of her own previously suggested changes while the evaluation of the protocol was performed by the group. This allowed all the other evaluators to make their own suggestions and to generate their own opinion of the protocol without being influenced by Evaluator One. This was particularly important to prevent a potential hierarchy bias which can be common in focus group evaluations.

The results of the focus group evaluation was discussed by a) each key point identified by the group, b) whether the point led to a change in the final version of the protocol, and c) what the evaluators' perspectives of the final version of the protocol were once their suggested changes were be made. A total of 14 suggestions were presented by the group. Each point that was made and the discussion and results of the discussion are outlined below.

Point One

The protocol should state throughout "if/as warranted" or "as necessary" instead of "must" as well as "may require" not "will require." Point One was incorporated into the final protocol and all the suggested statements were changed. All evaluators felt more comfortable with the final protocol using these new statements as they now suggest that some variation can occur between children even when an educator is using the protocol.

Point Two

It is important to make sure that ABI is not stated as an exceptionality in the protocol specifically for Ontario. Point Two was incorporated into the final protocol. Although this was a small change, all evaluators felt that this was a very important one because if ABI is mistakenly mentioned as an exceptionality in Ontario (which it is not) it would take away from the credibility of the protocol.

Point Three

The protocol needs to continue to emphasize providing information to parents and possibly to be done by more than just by the School Based Team Lead. Point Three was incorporated into the final protocol by emphasizing this point in the section: Teams Involved in the School Re-entry Process. The section: school Re-entry Protocol Key Points and Requirements already included

parental contact throughout. All evaluators felt that parental involvement could be emphasized enough in the protocol.

Point Four

Initiating the IEP process is only necessary based on the child's needs. Point Four was not included in the final protocol. Although children with ABI can vary greatly based on their educational programming required, the literature has clearly established that for children with moderate or severe ABI, there is a serious risk in not establishing an IEP for them once they have returned to school even if initially they do not present with serious needs. Also based on the literature, Point Four is certainly the case for children with mild ABI who can progress through school with little difficulty until particular learning demands are reached.

Point Five

The Guidance department should be mentioned in the protocol to become involved in the reentry process if necessary to help assist with the child's and/or parent's emotional issues. Point
Five was included in the final protocol. The experience guidance departments can provide is
deemed critical in the school re-entry process with regards to not only assisting the child's and/or
parent's emotional issues related to the ABI but, also with regards to helping with establishing
the re-entry plan and creating the IEP for the child. As this point was made by the lead guidance
counselor, the group felt confident that by adding this professional to the school and, if
necessary, community based teams, the protocol would be strengthened.

Point Six

Daily evaluation/monitoring by teachers, both formal/informal, do not all need to be done through a formal written assessment and can be done as required. Point Six was partially added into the final protocol as the required documentation depends on what type of intervention is

being implemented by a teacher. In the case that the child's teacher is evaluating/monitoring the outcome of a specific classroom intervention strategy that is specific to children with ABI based on best practice, the outcome of this should be documented. This documentation allows for other professionals to understand the outcome and to either adapt it or provide feedback on it.

Point Seven

Community medical professionals and the SELC should assist with IEP development through providing input as required but, do not necessarily fully assist in the entire process. Point Seven was included into the protocol as the involvement of these professionals is case specific depending on the re-entry plan, the child's needs, as well as the comfort level in dealing with ABI of the educational professionals receiving the child, even with the protocol being used. If the re-entry plan has been well established before the child re-enters school and the IEP started the expertise of the SELC may not be needed at that time would follow-up at a later date. It is important to note that the child's parent(s) may request that the SELC and medical professionals be involved in the IEP planning.

Point Eight

Neuropsychology testing is only ever reviewed by a school team but, not initiated by it. In the majority of cases the neuropsychology testing is not completed. Point Eight was included into the final protocol. Based on each evaluator's experience, this point was consistent for everyone. Based on the complexity of moderate to severe ABI this type of testing would likely be initiated by medical professionals either in the hospital or in the community and used as medical information. The results of this testing can provide educators with valuable information on how the child may learn when he/she returns to school. If neuropsychology testing is completed prior

to school re-entry it is very important that this information is transferred to the school based team likely with the assistance of the SELC.

Point Nine

A guidance counselor and/or a speech language pathologist should become a part of the community based team and mentioned as such in the protocol. Point Nine was already included in the protocol and therefore, did not need to be included in the final version. The involvement of a guidance counselor was addressed in the final protocol in Point Five. The involvement of a speech language pathologist was incorporated under the title: Allied Health Professionals already outlined in the protocol.

Point Ten

Hospital, community, and school based teams maybe composed of six or more individuals.

Usually due to the complexity of ABI, the school based team is comprised of more than six members and should be reflected in the protocol. Point Ten was included into the protocol through changing the wording from no more than six professionals to maybe composed of six or more professionals. This is an important change because, based on the complexity of moderate to severe ABI, it would not be beneficial to restrict the members of the school based team especially when more than six could be warranted. All evaluators felt that making this change would allow the protocol to closer reflect what is commonly seen in practice with the school based team.

Point Eleven

The protocol needs to make mention that the child's parent(s) should be encouraged to be an active member of all teams. Point Eleven was not included in the final protocol as it was addressed already through Point Three.

Point Twelve

The protocol needs to mention that the SBTL could be a LST or possibly a guidance counselor. Point Twelve was included in the final protocol. This point is a very important one as it helps to establish what types of educational professionals can act as the SBTL. By emphasizing that the role can be taken on by different educational professionals, the protocol does not corner a school into allowing just one professional to be the designated SBTL. All evaluators were pleased with this change particularly as each felt that what may work for one school with whom they designate as the SBTL, there could be a more suitable candidate for the role at another school.

Assessments for school should be emphasized in the protocol as a part of community care, not just initiated at the assessment and IEP stage. Instead these assessments should be mentioned as a continuation at the assessment and IEP stage. Point Thirteen was added into the final protocol. The evaluators felt that making this point was very important because if assessment can take place before a child's enters school, especially if his/her community involvement is prolonged, it should. This would allow educators to be more proactive in planning the educational strategies that are going to be used with the child before he/she enters school.

Point Fourteen

Point Thirteen

Need to switch Phase 6 and 7 to have ABI resource manual introduced first in the protocol to help identify possible intervention strategies for the classroom even before the IEP is initiated. Point Fourteen was added to the final protocol. All evaluators felt that using an ABI resource manual to identify possible intervention strategies that can be used for the child with ABI should be utilized right away. If the IEP development is not complete this will allow the child's teachers to still have interventions in place and for evaluation of these to occur immediately.

Summary

During both the phone and focus group evaluations, each professional was asked about his/her experience working with children with ABI during the school re-entry process. Although the overall experience levels varied working with these children, each professional identified that he/she has worked with a child with ABI in the past and has been a part of the school re-entry process. The key evaluation points made were based on each evaluator's experience. Each key evaluation point recorded for the focus group was eventually agreed upon by all attending evaluators.

There are similar evaluation issues between the focus group evaluators and Evaluator One that are important to note. All evaluators, both focus group evaluators and Evaluator One, thought that it is necessary to avoid using "must" or "will require" due to the varying degree of injury with these children and how the tasks completed by each professional in the process may vary because of this. Evaluators also noted that due to this protocol probably being used in Ontario school boards, ABI cannot be mentioned as an exceptionality. Evaluators also outlined that during the Assessment and IEP stage of school re-entry, it is not always necessary for community medical professionals along with the SELC to be directly involved with the IEP although their input maybe requested. The largest agreed upon points by the evaluators was with regards to the need for neuropsychological testing. Evaluators stated that this type of evaluation is only ever reviewed by the school based team. It is not necessarily initiated by the team as it likely would have already been done so while the child is working with medical professionals during the earlier stages of the school re-entry process. Even more so, based on the experience of the evaluators this type of testing does not usually occur and therefore, it is questionable if it needs to be included in the protocol. Evaluator One identified that the re-entry tasks outlined in

the protocol and the key members identified are consistent with what is completed in the majority of cases in practice during school re-entry for children with ABI. The focus group evaluators were in agreement as each did not comment on any tasks, professionals, and/or timelines outlined in the re-entry protocol that deviated from what each has observed in practice during school re-entry for children with ABI.

At the end of this process, it would appear that a comprehensive protocol, based on the best information available, had been produced.

CHAPTER FIVE: CONCLUSIONS

The original goal of this thesis was to identify an effective school re-entry protocol that could be used to assist children with ABI re-enter school. School re-entry has been shown to be a pivotal point in the child's recovery with educators playing a significant part in facilitating this recovery. If school re-entry is delayed for a child with ABI, the child is at increased risk for having his/her recovery delayed or not recovering to his/her fullest potential. Due to the complexity of school re-entry and the educational needs of these children, educators would greatly benefit from using a school re-entry protocol. Such a protocol would increase the likelihood of the educational professionals involved with the child to allow him/her to transition quicker and more efficiently. The protocol would assist educators in realizing the importance of successful school re-entry and would provide parents with the confidence that there is a structured plan in place that is being followed.

Adherence to Policy Theory

Since a school re-entry protocol was not identified as being available for educators, an original one was created and evaluated through best practices and by following the principles of policy theory. The educational policies specific to the designed ABI school re-entry protocol focused on the normative and technical dimensions. These dimensions look at how the policy maintains the foundational principles established by researchers and educators as well as, the influence the policy has on educational institutions. Both the structural and constituentive domains were excluded as they focus on the relationship between government and private organizations and how each relates to and is affected by a protocol. As this was the first school

re-entry protocol to be developed, there were no organizational or governmental agency relationships that pertained to the protocol that needed to be evaluated.

To adhere to the technical dimension of policy theory, the opinions of the 13 special education experts regarding the potential effectiveness of the protocol was obtained. Each evaluator felt that the protocol was easy to follow and if used in a real-time school re-entry situation, it would be useful for educators who do not have experience with the school re-entry process for children with ABI. Although they did not feel that the protocol would add anything to the current overall process within their own school board, each felt that other boards would potentially benefit from the protocol. The evaluators did not have any concerns regarding the protocol potentially limiting board resources and/or educators' time that would serve as significant barriers in its use as an effective protocol and/or decrease its strength in the technical dimension.

To adhere to the normative dimension, the final version of the school re-entry protocol was designed by identifying the foundational principles of school re-entry established by both researchers and educators. The initial protocol was primarily designed directly based on best practices for school re-entry identified in the literature. To strengthen the foundational principles of the protocol, this content of the protocol then underwent extensive evaluation by special education experts who were able to evaluate its content and criteria to fine-tune it. These experts were a relatively homogeneous group based on their areas of practice however, the process also allowed the diversity of members to maximize their different special education perspectives on the protocol. Regardless of the perspective offered, the evaluators were in agreement on all the changes and additions made to the protocol. This demonstrated that the group as a whole was confident in what needed to be included in the protocol for it to be effective in practice. In

addition, the excellent representation of different professional groups and the combined experiences and familiarity with special education amongst the evaluators strengthened the protocols validity thus, satisfying the requirement of the normative dimension of policy theory.

Besides the direct protocol changes that were suggested by both Evaluator One during the phone interview and all other evaluators during the focus group evaluation, conversation around the potential use and effectiveness of the protocol in practice occurred. Focus group evaluators commented on the extensive community organizational support that the school board receives from organizations external to the board that is invaluable to assisting with the overall re-entry process for children with ABI. Evaluator One also felt that community support is very strong allowing for the overall process to run smoothly and effectively for children with ABI returning to school in the school board. Due to this extensive support, Evaluator One explained that a reentry protocol would likely not need to be adopted by the school board as the boards processes for school re-entry were already very sound. Although, the protocol would not be needed to adjust the current re-entry process for the school board, Evaluator One did state that other school boards in Ontario may not be as strong in the re-entry process for children with ABI. These boards may not have direct support from community partners and/or organizations that can provide assistance in the re-entry process if needed. In this case, the protocol could be of great value towards educating the professionals at the child's school on the overall re-entry process and the key tasks that will have to be completed throughout it. This could increase the likelihood that school re-entry would be successful for a child with ABI. The focus group evaluators also agreed that the protocol would potentially be beneficial to other Ontario school boards that do not have a high level of community support and do not receive regular in-servicing and

education on ABI from external organizations. These evaluators agreed that the protocol could help raise awareness towards the importance of medical information being transferred successfully to educational professionals, something that does not always occur in the process. Medical information can play a large role in assisting educators to develop a more effective learning environment for the child when he/she returns to school. Both Evaluator One and the focus group evaluators felt that it was excellent that the protocol puts emphasis on transition planning, particularly if the child is in the community for an extended period of time. They acknowledged that it was very important for the child's school to be on board with this planning to help with accessing possible learning in the community, if needed, and to help facilitate the transition process back to school. This would allow the educational professionals at the child's school to be proactive in planning for the child's learning well in advance of when the child reenters school. All evaluators felt that the protocol was easy to follow and likely would be userfriendly for educators to use in real-time school re-entry situations. Furthermore, they felt that it would be particularly useful for educators who do not have any experience with the school reentry process for children with ABI.

The designed protocol appears to bridge the gap between healthcare and education professionals in the school re-entry process for children with ABI. The protocol does not make any suggestions or recommendations about the processes and protocols currently in place at the hospital level as these are already well developed. The hospital procedures and protocols in place for medical professionals do what they are suppose to do; allow the child to be discharged from the hospital. However, it is the responsibility of the community and educational teams at the time of hospital discharge to be proactive in the process to prepare and facilitate the child's school reentry. This protocol will provide educators with an understanding of the overall school re-entry

process and the key points that need to be completed at each stage of process. More so, the protocol will help educators understand how important it is that an educational team is established, having well defined roles, and that collaboration between the child's community team and educational team occurs. Further, the protocol appears to be able to provide special education teachers with direct guidance on how to assist a child with ABI once he/she returns to school. This is accomplished because the protocol emphasizes how important setting up an IEP is for the child and how ABI specific classroom strategies must be considered and documented. With these steps being completed, the child's ability to realize his/her full potential will be in maximized.

Implications for the Future

The immediate implication for the future use of the protocol will be with regards to fully satisfying the technical domain of policy theory whereby the protocol would be used and evaluated during a real-time school re-entry situation. This will be done through future research that will be aimed at identifying a child that has suffered a recent ABI and is looking to re-entry school. The evaluation could be done in coordination with an external organization to the child's school board that has a member who is familiar with ABI and could serve as the SELC and facilitate the school re-entry process using the protocol. If an external organization does not exist or if no one can serve as the SELC, a private consultant familiar with ABI could be selected to serve as the SELC and use the protocol. This consultant could be the case coordinator for the child if he/she has suffered injury through a MVA.

Through the application of the school re-entry protocol, schools will be able to provide optimal learning environments for children with ABI that are free of barriers. This will decrease

the frustration that the child could have trying to learn. It also has the capability of introducing effective learning and/or behaviour management strategies for the child before problems arise between the child and his/her teachers and/or peers (which could be written into the child's IEP). For example, many children with ABI who re-enter school experience cognitive fatigue. To assist with this challenge, the child's IEP could outline the need for allowing him/her to rest for an appropriate identified amount of time between educational tasks. Each teacher would be required to follow this procedure which would prevent the student from becoming overwhelmed and fatigued to the point that he/she could become further engaged in additional educational tasks.

To assist in understanding how the protocol could be implemented, here is an example of its potential use in practice. Where appropriate, the benefits of particular elements of the protocol have been highlighted. These benefits will be contrasted against what would likely happen if the protocol was not available. The practical application of the protocol will be explained drawing on initial experience of working with a child with ABI, outlined previously. This experience initiated the pursuit of this thesis.

To re-iterate, the child with ABI that I was working with at the time was in the Community Phase of school re-entry and he was working towards school re-entry. He had an excellent representation of medical professionals that were discussing school re-entry. In fact, since initial injury and admission to hospital up until the community phase, he had been involved predominately with medical professionals. All of the community medical professionals were aware that school was the next step that he needed to take to further facilitate recovery. Up to this point, the protocol would not change treatment delivery or the approach taken by the medical team, however it would allow educational professionals to understand that their involvement is

now critical and the specific tasks needed to be completed in collaboration with the medical team.

By having a much better understanding regarding the literature's predominant focus on the medical side of school re-entry, it is no surprise that there was an emphasis on medical professionals for the child up to the Community Phase in the process while educational professionals were under-represented. The literature emphasizes medical involvement and the majority of the critical tasks that need to be completed fall within the medical phases of school re-entry. It is also not a surprise that although the medical team was aware of school re-entry, they were still having a difficult time achieving this due to the educational team being absent.

It is clear now how important it was at this point in the child's care that educational professionals needed to be included in the school re-entry team and the difference this involvement could have made for him. They needed to work with the medical team to receive him properly thereby, ensuring the required continuum of care between both disciplines. To do this effectively would have required the educational professionals to understand the phases of school re-entry, the critical tasks that must be completed at each stage, and the overall educational team role in the process. Implementing the protocol would have helped to achieve this understanding which in turn would have had a large impact on the child's overall care.

With the protocol being available, it would first be reviewed by the child's case manager and distributed as soon as possible to all key team members. This would have included both community medical and educational professionals that were currently or would be at a later time involved with the child's care. The early introduction of the protocol, as early as hospital admission, would have allowed educational professionals to become involved earlier in the process and to identify what educational resources the child would have been of benefit to him.

This could have included at-home teaching provided for early identification of learning strategies that may have been useful when he returned to school. Unfortunately, he was left without educational assistance from the school board and guidance from educational professionals once in the community.

Through the protocol emphasizing that the case manager remains in close contact with each professional once the child was at the Community Phase, the school re-entry team would have been brought together and planning commenced. This team would be represented by both medical and educational professionals that all would now have a better understand school reentry through previously reviewing the protocol. This understanding would have allowed for a timely school re-entry plan to be developed with input from both disciplines. Such a plan would have outlined how and when medical services would continue to be provided when the child is at school as well as, how the child's first day of school would look and when it would occur. At the same time, the educational professionals would have begun looking at specific classroom strategies to be used when the child arrives in class for the first time. This identification of strategies would have been done in collaboration with the medical team alongside the utilization of an ABI educational resource manual such as, *Educating Educators about ABI*.

I am not aware of how and when the child I was working with returned to school nor am I aware of the route taken by the educational professionals to assist him. However, I am skeptical as to whether these professionals were implementing ABI specific learning strategies that were outlined on his IEP, as well as providing the necessary follow-up to ensure that they were effective and changing them as needed. The protocol would have continued to assist these professionals after the community phase of school re-entry through allowing them to understand

the importance of establishing a proper IEP for the child and the need for ongoing learning strategy implementation specific to ABI.

It is the goal that through this final evaluation, school boards will have at their disposal a tool that can be provided to any educator and school within the board when faced with assisting a child with ABI re-enter school. The protocol will have the advantage of not being school or educator specific and will be adaptable within different educational environments. This flexibility will allow a school board to provide the protocol to any school and the educators within it who are receiving a child with ABI for the first time. The protocol also has the capability of allowing boards to identify if and where gaps in service delivery for these children exist. For example, this could be a specific position within the board that needs to be created within the special education department or it may identify another supportive process that should be put in place. These types of adjustments have the potential to not only benefit children with ABI but other students as well. The protocol will be made readily available to Ontario school boards to have on file if and when a child with ABI requires reintegration into school. As the protocol relies on the Educating Educators about ABI resource manual to provide extensive detail on ABI and classroom intervention strategies, its dissemination to Ontario school boards will help CRL with increasing awareness of the manual. More importantly, the dissemination of the protocol will help increase awareness of the educational needs of children with ABI to the policy and decision-makers that operate at a macrosystem level. This has the ability to one day help drive implementation of policy that recognizes these children as an exceptionality of their own.

Limitations

It is important to note that this study is not without limitations and it is within the technical dimension of policy theory that the main limitation of this study resides. To fully satisfy this dimension it would be necessary for the protocol to be evaluated in a real-time school re-entry situation with a child with ABI. This is needed as it is not until this type of evaluation occurs can the protocol's true effectiveness be determined. It is also through this further evaluation that changes and/or additions to the protocol could be made that would be sensitive to successful practice. Until this type of evaluation occurs the technical domain of policy theory cannot be fully satisfied. It was the original plan of this study to evaluate the protocol in a real-time school re-entry scenario with a child who had recently suffered an ABI. Fortunately, within the time-frame allocated for this study to commence and complete this type of evaluation there was not a child that suffered this type of injury and was at the stage that protocol implementation would have been appropriate.

APPENDIX A: School Re-entry Protocol

by

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January 2011

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TABLE OF CONTENTS

INTRODUCTION

AGE SPECIFIC SYMPTOMS OF ABI

KEY IMPLICATIONS FOR MODERATE TO SEVERE ABI SCHOOL RE-ENTRY

SCHOOL RE-ENTRY KEY POINTS AND REQUIREMENTS

NEUROLOGICAL ASSESSMENTS FOR CHILDREN WITH ABI

Why Neuropsychological Assessments are Required

TEAMS INVOLVED IN THE SCHOOL RE-ENTRY PROCESS

Hospital and Community Based Teams

The School Based Team

OVERVIEW OF THE SCHOOL RE-ENTRY PROTOCOL PHASES

Introduction

There are approximately 27,000 school-aged individuals in Ontario who have an Acquired Brain Injury (ABI) with twice as many boys sustaining an injury than girls (Bennett, Good, and Kumpf 2003). ABI severity is measured by assessing fluctuations in the level of consciousness following injury. The Glasgow Coma Scale (GCS), a neurological scale from 3 to 15, is the most widely used measure of consciousness and is administered within the first 24 hours following trauma (Jantz & Coulter, 2007). ABI severity has been shown to be correlated to the lowest post-resuscitation GSC score while in hospital and can range from being mild (GSC 12-15) moderate (GCS 9-11) or severe (GCS 3-8) (Teasdale & Jennett, 1974). ABI can lead to virtually any ability or combination of abilities being impaired with each injury being different and producing a unique pattern of damage and functional difficulties (Fogarty-Ellis, 2001). Despite these differences, impairments can be categorized within the following domains: health, cognition, sensory and perceptual, motor skills, and behavioural/social. It is important to note, the size of the injury does not always predict the level of dysfunction. Factors such as age at injury, cause of injury, and most of all, site of injury determine functional outcome and disability in each domain. Deficits in even one of these domains can lead to both short and long term academic difficulties. Yeates and Taylor (2002) examined the long-term difficulties that children with ABI can have and found that children with severe ABI experienced behaviour and academic problems that continued up to 4 years or more post-injury. Further, due to the unparalleled complexity of the brain it is very difficult to determine the prognosis for recovery. There are many factors influencing the recovery process including the characteristic of the injury, physical recovery of the brain, the individual child, and the environment. The speed and extent of recovery is variable. The greatest recovery and functional improvement is expected within the

first two years post-injury and typically there is no long-term prognosis given until that time (Bennett, Good, and Kumpf 2003). Most of the spontaneous physical recovery of the brain is expected to occur within one year post-injury and generally gains occur more slowly after that time. Within this time frame the child will likely return to school making education a significant factor in the child's recovery process.

School re-integration is no easy task which is why this protocol has been developed. It has been designed to assist educators throughout the school re-entry process for children with moderate to severe ABI. This is due to the amount of time that these children will miss from school and the need for medical interventions within a hospital setting carried out by a medical team. It is with these two severity levels that deficits are immediately apparent and the greatest transition period between healthcare and education exists. This protocol aims to help educators bridge that gap.

Mild ABI is hard to identify as it can occur from as little as a concussion. It does not have any implications for school re-entry due to the lack of a significant absence from school and has therefore, been excluded from this protocol. These children who suffer head injury likely return to school after, at most, a short stay in the emergency department. Based on this short stay there is no transition period between hospital and school. How educators deal with mild ABI is different than that of moderate and severe ABI. Mild ABI is an issue that warrants a protocol of its own, designed to help educators identify mild ABI in children. This falls outside the scope of the protocol discussed here.

Age Specific Symptoms of ABI (Bennett, Good, and Kumpf 2003) Symptoms of Moderate and Severe ABI

| Symptoms of Moderate and Severe ABI | | |
|---|--|--|
| Symptoms of a Moderate Brain Injury (one or | Symptoms of a Severe Brain Injury (one or | |
| more of the following) | more of the following) | |
| - Loss of consciousness | - Coma/loss of consciousness exceeding 24 | |
| - Seizures may occur | hours | |
| - Frequent headaches | - May often be accompanied by multiple | |
| - Motor coordination difficulties | injuries | |
| - Limited attention span, concentration and/or | - Frequent concern of seizures | |
| ability to attend to multiple aspects of the | - Frequent headaches | |
| environment | - Decreased ability or an inability to control | |
| - Memory retrieval and/or encoding | spontaneous movement | |
| complications | - Limited attention span, concentration and/or | |
| - Slowed information processing speed | inconsistent ability to attend to a stimuli | |
| - Problems with "working' memory (conscious, | - Limited ability or inability to voluntarily | |
| on-line thinking) | swallow | |
| - Inability to organize | -Decrease level of consciousness | |
| - Inconsistent communication skills, including | - Slowed information processing speed | |
| word finding problems and poor pragmatics | - Decreased ability to an inability to | |
| - Inappropriate social behaviour | communicate | |
| - Central sensorial complications | - Inappropriate social behaviour | |
| - Poor transfer of information between | | |
| modalities | | |
| - Limited generalization of learned information | | |
| or skills | | |
| - Concrete thinking, inflexible thinking and | | |
| reasoning, contextually based behaviour. | | |
| Note: 33% of all people with a moderate | Note: 90% of all people with a severe brain | |
| brain injury experience lifetime problems | injury experience lifetime problems with | |
| with living and learning | living and learning | |

Key Implications for Moderate and Severe ABI School Re-entry (Bennett, Good, and Kumpf 2003)

| Good, and Kumpi 2005) | | | |
|--|--|--|--|
| Implications for school | Moderate | Severe | |
| setting | | | |
| School's awareness of injury and whether or not the school would be notified | School would most likely be notified and aware of the injury | School would be notified and aware of injury | |
| Absence from school | A couple to a few weeks, student should theoretically be able to catch up on missed work | A couple to a few months or more, making the amount of worked missed difficult to get caught up on | |
| Communication between hospital and school | May be some liaison with the hospital while the child is recovering, generally handled through the parent(s) | Liaison with the hospital during the child's recovery and after discharge generally through case managers and special ed. staff | |
| Information and training for school staff in ABI | Focus needs to be on cognitive issues as well as how to aid the student in socialization and integration issues. May include information on how to overcome physical barriers in the environment. | Teachers will need information on cognitive issues pertaining to varying modalities for learning along with the physical socialization needs of the student | |
| Assessment considerations | May be based on performance and would consist of a more formal assessment performed by a psychologist | A full neuro-psychological assessment may be performed, assessment of student's physical needs within the school may be necessary | |
| Goals and IEP | As much as possible, curriculum should be followed, allowing modifications to time schedule, and additional support from external sources (e.g. physical therapist, speech and language therapist, etc.) | Program should be modified so that the focus is on the child's strengths and capabilities. Major shift in curriculum Academic, social, physical, and cognitive goals will need to be generated | |

School Re-entry Protocol Key Points and Requirements

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|----------------------------|---|---|--|
| Initial Hospital Admission | Child's condition is unstable Medical professional involvement is at its greatest Goal is to stabilize child's condition Medical neuropsychological | School based team lead (SBTL) selected School lead with special education learning consultant (SELC) inquires about child's absence from school through child's parent(s) and/or are contacted by parent(s) | |
| | assessments initiated Special education learning consultant recruited | about child's injury Obtain additional knowledge on ABI not covered in protocol from different sources i.e. ABI resource manual and medical team | |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|-----------------------|--|---|
| Hospital Care | Child's condition stable and he/she continues to work with medical professionals in hospital but number of those involved is decreasing Medical neuropsychological assessments continue Professionals work within protocols set forth by the hospital that outline child's needs/goals to meet requirements for hospital discharge | SBTL communicates with the child's parents, hospital staff, and/or SELC to identify severity of injury and child's progress Match of child's age and severity with potential symptoms and consequences from ABI resource manual |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|-----------------------|---|--|
| Hospital Discharge | Discharge team formation composed of: medical professionals from both the hospital and the community SBTL SELC child's parent(s) Discuss when the child will be discharged and how his/her care in the community will continue Begin forming school re-entry team | SBTL attends the meeting Ask questions and gather information on the child including therapy outcome and details on impairments Establish contacts of those that will be working with the child upon D/C Set a follow-up date with community medical members and SELC Identify impairments in cognitive, behavioural/emotional, and/or physical domains and match with potential classroom challenges SELC requests neuropsychological testing results from medical team to be discussed with education team |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|---------------------------------------|---|---|--|
| School Re-entry Phase Community Care | Transition back to home Medical care continues in the community with medical professionals that comprise the community based team Ongoing communication between the SELC and SBTL as well as with the | SBTL corresponds with community medical professionals and SELC Update school professionals that will be involved with the child upon his/her return to school Initiate IEP process Continue to identify impairments that will | |
| | community and school based teams Develop school re-entry plan Initiation of home education if available through the child's school board | likely be present upon return to school through education specific assessments - Identify educational intervention strategies and implement through home education if available - Team meeting with school personnel that | |

| | | will be involved with the child |
|-----------------------|---|---|
| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
| School Re-entry | School re-entry is attempted based on preliminary school re-entry plan Community medical involvement continues if necessary | Implementation of initial interventions based on identified impairments matched with interventions and results of the neuropsychological testing if completed Evaluation of the effectiveness of each intervention done both formal and informal by school based team Daily evaluation of the child's ability in school environment by his/her teachers Weekly meetings organized by the child's school based team Guidance department involved to help assist with the child's or parent(s) emotional issues |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|---|---|--|--|
| Introduction of ABI Educational Resource | School based team primarily responsible for child's progress SELC assumes a consultant role when needed by educational professionals at the child's school ABI resource manual consulted for further assistance and problem solving | School based team continues with IEP process and selecting appropriate interventions from those initially implemented in the last phase Consults ABI resource manual for further assistance and implementation of new interventions specific to ABI Ongoing education assessment is completed both formal and informal and pertinent parts documented on the IEP SELC contacted for further assistance and/or follow up if deemed necessary by the school based team | |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|--|---|--|--|
| | | | |
| Assessment and Individualized Education Plan (IEP) | IEP development is initiated Community medical professionals and SELC assist with initial IEP development | IEP process is completed through the school based team with at times the involvement of the SELC and community medical professionals School based team includes educational neuropsychological testing if available Education specific assessments continue from community phase School based team meets frequently to update the child's IEP based on new findings and child's progress If the team deems that the school re-entry process is unsuccessful on first attempt the child can be moved back to the Community Care Phase and school re-entry adjusted and re-attempted | |

Neuropsychological Assessments for Children with ABI

From hospital admission to school re-entry, professionals are gathering a great deal of information on the child's medical, physical, cognitive, behavioural, and social impairments. Professionals will usually implement various outcome measures (OM) that provide data on the child's progress in each domain. Commonly, medical data is conducted by allied health professionals at the hospital while educational data is conducted by education professionals at school. Both types of data are equally important in properly tracking progress. OM allows for professionals in both disciplines to identify the need for different intervention strategies that are geared toward improving what the OM is measuring. OM information is not isolated to one discipline. Medical information is very important for educators and allows them to foresee potential problems that the child could have upon returning to school. For example, upon admission to the hospital the allied health team may identify that the child's ABI severity is significant. The education team can use this information to foresee that the child is going to have a slower recovery and likely need greater assistance when he/she returns to school. This information can prepare the education team well in advance for what to expect when they receive the child. The flow of information and the sharing of it between professionals must be continuous throughout the child's recovery and if it is, the likelihood of both short and long term recovery is increased. Neuropsychological Assessment (NA) is one such OM used by both allied health and educational professionals.

Why Neuropsychological Assessments are Required

Utilizing NA is very important for children with ABI more so than it is for other exceptionalities. The main reason for this is, due to the nature of injury with ABI that is multi-

faceted and commonly affects multiple domains. With NA information is provided on the extent of injury in each domain and how each may affect the child's academic performance. This information is particularly important for educators to design an appropriate individualized education program for the child once he/she re-enters school. Traditional achievement and intelligence tests that are commonly implemented for children with exceptionalities do not play as large of a role with ABI. This is due to these tests measuring pre-injury learning and not the post-injury ability to learn. An assessment which focuses solely on an examination of their academic and social achievement in comparison to their peers or curriculum expectations alone will not provide the necessary information to develop an effective program. (Bennett, Good, and Kumpf 2003).

When assessment fails to take into account "how the student thinks" there can be a continued decline in the student's performance post-injury. This decline may appear to be a continued effect of the student's injury, while in reality, continued decline presents in a very small percentage of individuals who have sustained an ABI. It is far more likely that a student with an ABI, who is failing to learn, may be doing so as a result of a mismatch between factors such as the learning environment, pace of instruction, mode of delivery, and the underlying cognitive limitations and strengths of the student (Bennett, Good, Kumpf 2003). Coupling the results from the neurological assessments completed with ongoing observations made by the school based team will allow the team to effectively design and update the child's IEP. Frequent re-evaluation and IEP revision is a necessity to ensure both short and long term academic success for the child due to the periods of rapid recovery that are common for children with ABI that can last for up to 2 years.

Teams Involved in the School Re-entry Process

Hospital and Community Based Teams

School re-entry looks different for every child with ABI due to his/her unique impairments that require individualized attention. This uniqueness leads to differences in the amount of time required to transition from hospital-to-school and the various professionals that assist along the way. Regardless of how different school re-entry looks, the overall process requires the involvement of key professionals that ensure it is successfully completed.

The allied health professionals working with a child with ABI in the hospital or community work within specific guidelines and know the tasks that he/she must complete to progress the child. If these professionals reside within the hospital they form the child's hospital based team and are responsible for progressing the child towards discharge. Due to the ongoing medical needs that persist beyond hospital discharge for children with moderate to severe ABI, community allied health professionals are commonly needed. These professionals comprise the community based team for the child and are responsible for progressing the child further.

Similar to these allied health professionals working with the child, educational professionals within the child's school form the school based team. They are responsible for academically progressing the child once he/she returns to school. Reintegration into school for children with ABI is a very challenging process, one that requires detailed planning and coordination in and between both community and school based teams. For this reason, the process often requires a Special Education Learning Consultant (SELC) to facilitate this.

The SELC coordinates educational services for a child with ABI and communicates with both medical professionals from the hospital and community as well as educational professionals who work with the child. The SELC is a member of both the hospital and community based

teams as well as the school based team and acts as a liaison between each. The main function of the SELC is to allow for the child to transition back into school into the care of the school based team. Once this occurs, the education professionals that comprise the school based team for the child who usually work within the child's school, must begin to take on a more active role in assisting the child on a regular basis. Once the child is back in school, the SELC can still act as an educational consultant when needed. The child's school may request routine check-ups by the SELC on the child to ensure that he/she is progressing and/or require advice on appropriate intervention strategies to help overcome any problems encountered while educating him/her.

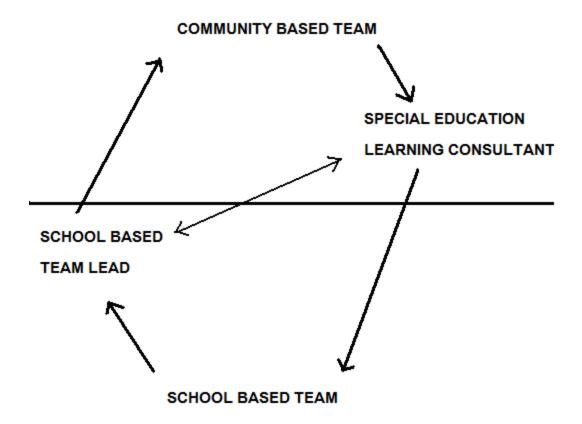
The School Based Team

The school-based team is usually comprised of at least three but usually more than six professionals who are able to convene at predetermined points, understand the child's needs, and can determine the extent and direction of team intervention. Within the child's school, these professionals are often the child's teacher(s), special education coordinator, learning support teacher, school psychologist, and/or a school administrator. One of the team members usually a special education coordinator, learning support teacher, or guidance counselor at the child's school assumes the role as the school based team lead (SBTL). The team lead is responsible for communicating with the hospital and community based teams with the assistance of the SELC (figure one). The SBTL must gather as much information as possible from these teams and to properly communicate it to the other members of the school based team. This often includes sitting in on team meetings and/or contacting team members on a frequent basis. Using the information compiled from the hospital and community based teams the school based team begins to work closely through the assessment/IEP process for the child. Specific assessments

must be completed and based on their results specific interventions implemented by those educational professionals working with the child. These interventions are often implemented directly by the teacher in the child's classroom and are suggested from the assessment process and documented on the IEP. As these new interventions are put into place, evaluation of each is measured by the child's teacher(s) and professionals who work closely with him/her to determine if the strategies being used are moving the child towards accomplishing the goals on the IEP. The members of the school based team must meet on a regular basis often more than they would with other exceptionalities to discuss student progress, make the necessary changes to the IEP, and/or determine if further assessment or specific intervention strategies are needed.

It is important to emphasize that all members of both the hospital and school based teams need to include the child's parent(s) at all stages of the process and to be involved in decision making at all times. Medical and educational information on the child should be relayed to the child's parent(s) promptly and how this information will direct decision making.

Community environment



School environment

Figure 1: Flow of communication between the school based team lead and the special education learning consultant as well as how each relates to the school and community based teams.

PHASE 1

Initial Hospital Admission

The child enters the hospital to receive extensive medical care to stablize his/her condition.

Medical neuropsychological assessments initiated.



Hospital Care

Child's condition stable.
He/she continues to
work with medical
professionals to progress
towards discharge.

IF NEEDED

PHASE 3

Hospital Discharge

Discharge team is formed and meets to discuss plans for the child upon his/her return into the community.

PHASE 4

Community Care

Medical care for the child continues in the community. School re-entry planning between community and school based teams is lead by the SELC.

PHASE 7

Assessment and IEP

School based team initiates further assessments as needed and the IEP is developed.

PHASE 6

Introduction of ABI Resource Manual

School based team consults SELC and/or ABI resource manual to help problem solve and for educational intervention strategies.



PHASE 5

School Re-entry

Child returns to school for the first time based on school re-entry plan and into the care of the school based team.

REFERENCES

- Bennett, S., Good, D., & Kumpf, J. (2003). *Educating Educators about ABI: Resource Manual*. Ontario Brain Injury Association.
- Fogarty-Ellis, E., Kaseweter, C., Lavis, H., Littleford, R., McAllister, M., McCallum A., et al. (2001). *Teaching Students with Acquired Brain Injury: A Resource Manual for Schools*. Ministry of Education British Columbia.
- Jantz, P., & Coulter, G. (2007). Child and adolescent traumatic brain injury: academic, behavioural, and social consequences in the classroom. *Support for Learning*, 22, 84-89.
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: A practical scale. *Lancet*, 2, 81-84
- Yeates, K. O., & Taylor, H. G. (2002). Behavior problems in school and their educational correlates among children with traumatic brain injury. *Exceptionality*, 14, 141-154.

APPENDIX B: Ethics Protocol

SECTION 1 PROJECT REGISTRATION

| 1.1 | Project Title |
|------|---|
| A SC | CHOOL RE-ENRTY PROTOCOL FOR CHILDREN WITH ACQUIRED BRAIN INJURY |

| 1.2a | Anticipated Project dates | Start Date | September 1, 2011 |
|------|---|------------------------|-------------------|
| | | Completion Date | December 31, 2011 |
| 1.2b | While all protocols are dealt with as quickly as possible it is helpful to know in advance about pending agency deadlines. Indicate if there is a specific funding agency deadline by which approval is required. | Pending deadline date | |

| 1.3 | Principal or Lead Investigator, or Sponsor of Student's/Visiting Scholar's project at this site. (PI must be a faculty or staff member in the Faculty of Education. If this is a student project, the faculty advisor is the Principal Investigator. Sponsors of Visiting Scholars should be the Dean of the unit where the visitor is primarily located.) | |
|--|--|---------------------|
| PI Name | | Dr. Alan Edmunds |
| Title & Position | | Associate Professor |
| Email | | |
| (Please complete this section if this is a student project or thesis.) | | |
| Student Name | | Matt White |
| Course / thesis / project | | Thesis |
| Address | | |
| Telephone | | |
| Email | | |

1.4 Signature of Principal Investigator attesting that:

- a) all co-investigators have reviewed the protocol contents and are in agreement with the protocol as submitted;
- b) all investigators have read the <u>Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans</u> (TCPS 2; 2010) and the <u>UWO Guidelines on Non-Medical Research Involving Human Subjects</u> and agree to abide by the guidelines therein;
- c) the investigator(s) will adhere to the Protocol and Consent Form as approved; and
- d) the Principal Investigator will notify the Faculty Research Ethics Board of any changes or adverse events/experiences in a timely manner;
- e) the study, if funded by an external sponsor, will not start until the contract/ agreement has been approved by the appropriate university, hospital or research institute official.

0

| Signatu | re | | Date |) | | |
|---------|--|--|--|-------------------|-------------|----------|
| 1.5 | List all local co-investigators and collaborator significant role in the conduct of the study. | | | personnel only i | f they have | a |
| | Name | Title/Position | Degrees | Role | } | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| 1.6a | le this a multi con | torod study? | | | YES | |
| 1.0a | Is this a multi-cen | iereu siudy? | | | NO | Х |
| 1.6b | If YES, who is the | Principal Investigator | or Project Leader for the | entire study? Pro | | |
| | contact information | n. | | | | |
| | | | | | | |
| | | | | | | |
| 1.7a | | | on of this project an acade | emic | YES | Χ |
| 1 7h | | course or degree? | area (a a nama af agura | no Honouro DA | NO Noot | oro or |
| 1.7b | - | | egree. (e.g. name of cours n the research (e.g. quest | | | |
| | interviews, data a | | 1 and 1000aron (o.g. quoot | ormano acoign, | data conco | |
| | | | Master of Education degre | | | |
| Psycho | Psychology. The role of the student is with protocol design, data collection, interviews, and data analyses. | | | | | |
| | | | | | | |
| | | | | | | |
| 1.7c | | of Student attesting th | | | | |
| | | ncil Policy Statement a agree to abide by the c | and the UWO Guidelines | on Non-Medical | Research II | nvolving |
| | • | , , | • | B: and | | |
| | / | | | manner; | | |
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| Signat | Signature Date | | | | | |
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| 1 7 4 | le this a Visitina C | abalar'a project? | | | VEC | |
| 1.7d | Is this a Visiting S | undar s project? | | | YES NO | X |
| 1.7e | If YES, Signature | of Visiting Scholar atte | esting that they: | | .,,, | |
| | | | | | | |

| , | and the UWO Guidelines on Non-Medical Research Involving | | |
|---|--|--|--|
| Human Subjects and agree to abide by the | guidelines therein; | | |
| b) will adhere to the Protocol and Consent For | m as approved by the REB; and | | |
| c) will notify their Sponsor and the REB of any | | | |
| , , , , | | | |
| | | | |
| Signature | Date | | |
| , s | | | |
| SECTION 2 FUNDING | | | |
| <u></u> | | | |

| 2.1 | What is the status of the funding or support for thi project? Since preparing and reviewing a protoco | FUNDING DOLLADIUMAD | X |
|-----|--|-----------------------------|---|
| | takes a significant amount of time, we strongly recommend waiting to apply for ethics approval until after a project submitted for funding has | Application Pending | |
| | received notification that the funding has been approved. | Funded | |
| | | In-Kind contribution only | |
| | If Application Pending; Funded; or In-Kind Contrib | oution fill in chart below. | |
| 2.2 | Name of funding agency(s) or | | |
| | sponsor(s) | | |
| 2.3 | Name of investigator | | |
| | receiving/applying for funding | | |
| 2.4 | Date submitted for funding. | | |
| 2.5 | Agency/sponsor reference | | |
| | number if known | | |
| 2.6 | Title as submitted to funding | | |
| | agency(s) if different than title of | | |
| | this ethics submission | | |

SECTION 3 PROJECT DESCRIPTION

Complete each section under the appropriate heading. Be succinct and adhere to the page limitations. DO NOT DIRECT THE COMMITTEE TO 'SEE ATTACHED'. DO NOT USE TEXT COPIED FROM FUNDING APPLICATIONS OR STUDY PROTOCOLS UNLESS IT PROVIDES A SUCCINCT SUMMARY OF THE METHODOLOGY APPROPRIATE FOR ETHICAL REVIEW AND DEALS WITH ETHICAL ISSUES. Copies of detailed proposals submitted to a funding agency or sponsoring agency protocols will not be reviewed as the ethical issues are not often adequately addressed in such documents and they frequently do not provide a succinct summary as noted above. Your protocol will be RETURNED UNREVIEWED if the project description information is incomplete, illegible or improperly filled out.

| 3.1a | Is this a sequel to previously approved research? | YES | |
|------|--|-----|---|
| | | NO | Χ |
| 3.1b | If YES, indicate the previous ethics review number(s): | · | |
| | | | |
| 3.1c | If YES, describe differences from the previously approved protocol(s): | | |

- Provide a <u>brief</u> one or two sentence overview of the proposed research describing the population, intervention and outcome. *E.g. Children 5 to 8 years of age will view a video about animal mothers and their babies then be asked if they think there are any similarities between an animal mother's behaviour and a human mother's behaviour. The research will take place in the children's classroom.*
- A child with moderate to severe ABI aged 5-19 years of age who is attempting to re-enter school will be recruited for the study. Also to be recruited are the special education professionals at the child's school that he/she will be transitioning to and a special education learning consultant (SELC) external to the school but, employed by the school's board. Amongst other things, these personnel are responsible for conducting a psycheducational assessment, designing the student's IEP, and designing and monitoring all educational interventions. In this study, these education professionals will utilize the school re-entry protocol designed by this writer specifically to assist them in the re-entry process. Based on this trial, the protocol will be evaluated for its effectiveness. In the event that a child cannot be recruited by the completion date 12-20 special education professionals within Ontario will be recruited to evaluate the protocol's format and content. This will be used to gain further insight into both the protocol's strengths and weaknesses to better construct it to be used in a real-time school re-entry situation at a later time.
- 3.4 Background & Justification Summarize the scholarly and scientific validity of the study. (1 page maximum)

From a detailed review of the literature on school re-entry, it is clear that most of the research in this specialized area comes from the field of medicine. While this research has identified key stages in the school re-entry process, it exclusively focuses on the stages that involve medical professionals up to the point when the child is discharged from the hospital. For example, when the child is first admitted to hospital he/she works closely with allied health professionals who work within the jurisdiction of the hospital and follow specific protocols set forth by the institution (Clark, 1996). These protocols allow the child to receive comprehensive care which allows for quicker rehabilitation and they play a crucial role in organizing all allied health professionals and directing them towards completing critical tasks for the child as he/she progresses from hospital admission to discharge.

Once the child is discharged from hospital, his/her major goal is to re-enter school. Therefore, the involvement of educational professionals needs to increase and protocols are needed to guide the child's education team throughout the school re-entry process. Unfortunately, such protocols do not exist. Just as hospital care is carefully planned and monitored, effective school re-entry requires extensive collaboration, planning, and problem-solving amongst all involved educational professionals. This process cannot be achieved in a short period of time. Detailed planning must be completed for each child with ABI. The school re-entry process looks different for every child with ABI due to his/her unique impairments requiring individualized attention. This uniqueness means there are differences in the amount of time required to transition from hospital-to-school and the various professionals that assist along the way. Regardless of how different school re-entry appears, the process does involve key educational professionals to complete specific tasks throughout the transition (Farmer, 1996). If these key professionals are not involved and/or the critical tasks are not completed, the re-entry process is likely to fail. To ensure that the right educational professionals are recruited and each critical task is completed, I designed a school re-entry protocol. This series of guidelines and procedures provides an outline of what tasks each professional must complete during the school re-entry process and by which point in time. Similar to existing hospital protocols, this

school re-entry protocol will organize educators and direct them in the tasks that must be completed during the re-entry process. This document has the potential to help educators avoid the current difficulties they face when they engage in the re-entry process.

Objectives and Hypotheses: Provide a clear statement of the purpose and objectives of the project. (1 page maximum)

To my knowledge, this study is the first of its kind to design a school re-entry protocol specifically for children with ABI that educators can use throughout the process. The purpose of this study is to evaluate the designed school re-entry protocol in its ability to assist educators in the school re-entry process for a child with ABI as he/she attempts to make the transition back to school. This study attempts to address the gap that exists in the continuum of care between healthcare and education professionals and provide children with ABI better overall care through a quicker and more complete school re-entry process.

3.6 Methodology – Describe the study design and what participants will be asked to do at each stage of the research. Investigators are encouraged to use flow charts or diagrams in their descriptions. (2 page maximum)

The use of the school re-entry protocol will not interfere in any way with the normal functioning of the school-based team. In fact, the protocol will enhance and facilitate the re-entry process for the schoolbased team because it is guite likely that the team does not know what to do or when as they transition a child with ABI. The protocol will be tested and evaluated via its pilot use by a school-based team that helps a child with ABI re-enter school. This will be done in coordination with the child's school board and a SELC external to the school but, employed by the school's board. The SELC will be a special education professional from the child's school board that would normally be involved in the transition process and to act as a resource for the child, parent(s), and teachers during the transition process. The school board will inform this writer of a child's expected return date. Once student, parent, teacher, SELC, school and school board consents and ethical approvals have been obtained, each member of the school-based team involved in the school re-entry process along with the SELC will be provided with the school re-entry protocol. The team will use the protocol to complete the outlined requirements at each phase of the school re-entry process. This procedure will allow the school-based team and the researcher to measure and evaluate the effectiveness of the protocol in a real-time school re-entry situation. The effectiveness of the protocol will be measured through the researcher providing questionnaires and conducting interviews with each school based team member. Each of these professionals will be asked to describe his/her experience using the protocol, how it assisted him/her as well as, if there are any questions and/or concerns regarding it. This evaluation will be used to revise the protocol as needed into its final version. In the event that this writer is not contacted by the school board about a child with ABI returning to school within the studies time period, 12-20 special education professionals will be recruited to evaluate the protocol's format and content. This will be used to further gain more insight into both the protocol's strengths and weaknesses to better construct it to be used in a real-time school re-entry situation at a later time. The school re-entry protocol requirements at the identified key phases of the re-entry process are outlined below.

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|-----------------------|--|---|--|
| | | | |
| | Child's condition is unstable | School based team lead (SBTL) selected | |
| Initial Hospital | Medical professional involvement is | School lead with special education | |
| Admission | at its greatest | learning consultant (SELC) inquires about | |
| | Goal is to stabilize child's condition | child's absence from school through child's | |
| | Medical neurological assessments | parent(s) and/or are contacted by parent(s) | |
| | initiated | about child's injury | |
| | Special education learning consultant | Obtain knowledge on ABI from ABI | |
| | recruited | resource manual | |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|-----------------------|--|---|--|
| | | | |
| Hospital Care | Child's condition stable and he/she continues to work with medical professionals in hospital but number of those involved is decreasing Medical neurological assessments continue Professionals work within protocols set forth by the hospital that outline child's needs/goals to meet requirements for hospital discharge | SBTL communicates with the child's parents, hospital staff, and/or SELC to identify severity of injury and child's progress Match of child's age and severity with potential symptoms and consequences from ABI resource manual | |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|-----------------------|---|---|
| | Discharge team formation composed | SBTL attends the meeting |
| Hospital Discharge | of: - medical professionals from both the hospital and the community - SBTL - SELC - child's parent(s) - Discuss when the child will be discharged and how his/her care in the community will continue - Begin forming school re-entry team | - Ask questions and gather information on the child including therapy outcome and details on impairments - Establish contacts of those that will be working with the child upon D/C - Set a follow-up date with community medical members and SELC • Identify impairments in cognitive, behavioural/emotional, and/or physical domains and match with potential classroom challenges |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|-----------------------|---|---|
| | | |
| Community Care | Transition back to home Medical care continues in the community with medical professionals that comprise the community based team Ongoing communication between the SELC and SBTL as well as with the community and school based teams Develop school re-entry plan | SBTL corresponds with community medical professionals and SELC Update school professionals that will be involved with the child upon his/her return to school Initiate IEP process Continue to identify impairments that will likely be present upon return to school Identify educational intervention strategies based on ABI resource manual Team meeting with school personnel that will be involved with the child |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals | |
|-----------------------|---|---|--|
| | | | |
| | School re-entry is attempted based on | Implementation of initial interventions | |
| School Re-entry | preliminary school re-entry plan | based on identified impairments matched | |

| Community medical involvement continues if necessary | with interventions • Evaluation of the effectiveness of each |
|---|---|
| | intervention Daily evaluation of the child's ability in school environment by his/her teachers |
| | Weekly meetings organized by the child's school based team |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|---|---|--|
| Assessment and Individualized Education Program (IEP) | Key Points IEP development is initiated Community medical professionals and SELC assist with initial IEP development | IEP process begins through the school based team, SELC, and community medical professionals School based team initiates educational neuropsychological testing |
| | | School based team meets frequently to update the child's IEP based on new findings and child's progress |

| School Re-entry Phase | Key Points | Requirements for Educational Professionals |
|---|---|--|
| Introduction of ABI Educational Resource | School based team primarily responsible for child's progress SELC assumes a consultant role when needed by educational professionals at the child's school ABI resource manual consulted for further assistance and problem solving | School based team continues with IEP process Consults ABI resource manual for further assistance SELC contacted for further assistance and/or follow up if deemed necessary by the school based team |

3.7 Address the strengths and weaknesses of the selected design. Specifically indicate why a particular design was selected. (1 page maximum)

⇒ This study aims to evaluate the ability of the designed school re-entry protocol to facilitate school re-entry for educational professionals who have to assist a child with ABI. The main strength of this study is that to our knowledge this is the first study of its kind that has attempted to design, implement, and measure a school re-entry protocol that is specifically designed to assist educators in the school re-entry process. An extensive review of the literature revealed that educators need, but do not have, a protocol specifically designed for this purpose.

The only possible minor weakness of this study is that in its one-time use with a single child and his/her medical and educational teams during re-entry, the protocol may not be consistent with what other teams might feel about its effectiveness. Nonetheless, a single case design is unavoidable because of the extremely low and unpredictable occurrence of ABI within the study's time frame. It is not anticipated that multiple tests of the protocol are needed to produce an exemplary final working protocol.

3.8 References – If possible please restrict the list to ten of the most relevant references. References must contain the author, title of article, journal and page number(s).

Clark, E. (1996). Children and adolescents with traumatic brain injury: Reintegration challenges in educational settings. *Journal of Learning Disabilities*, 29, 549-560.

Farmer, E., Clippard, D., Luehr-Wiemann, Y., Wright, E., & Owings, S. (1996). Assessing children with traumatic brain injury during rehabilitation: Promoting school and community reentry. *Journal of Learning Disabilities*, 29, 532-548.

| 3.9 | Analysis – Discuss how the data will be analyzed. | (1 page maximum) |
|-----|---|------------------|

Data gathered from questionnaires and interviews completed with the educational professionals directly involved with the child's school re-entry will be analyzed. The analysis will be conducted to assess each educator's opinion of the protocol's functionality. The analysis will include how user-friendly the protocol was, each education professional's ability to understand what was required at each phase of the school reentry as outlined by the protocol, and overall how comfortable each professional was with using the protocol for assisting a child with ABI re-enter school for the first time. This last evaluation will not be applicable to the 12-20 professionals evaluating the protocol as they will not be working directly with a child using the protocol and instead, will only be evaluating the format and content of it. Revisions will be completed as needed to make the final version of the protocol as functional and precise as possible.

| 3.10 | CONTINUING REVIEW | | | |
|---------------|---|----------------|---|--|
| 3.10a | Are the risks associated with this project sufficiently low that the | YES | Χ | |
| | project requires only an annual review? | NO | | |
| 3.10b | If NO, please note that the proposal cannot be reviewed by the Faculty of Education REB. You must submit your ethics review to the UWO Non-Medical Research Ethics Board. Please indicate why you feel a more frequent review is required. | | | |
| \Rightarrow | | | | |
| 3.10a | If NO, please indicate your recommendation as to the | EVERY 6 MONTHS | | |
| | appropriate frequency of the continuing review. | EVERY 3 MONTHS | | |
| | | EVERY MONTH | | |

SECTION 4 RESEARCH PARTICIPANTS

| Sample | Sample Size: | | | | |
|--------|---|--|--|--|--|
| 4.1a | Number of subjects in entire study | 1 Child, Up to 6 Educators, 1 special education learning consultant, 12-20 special education professionals | | | |
| 4.1b | Number of subjects at this centre (if a multi-centered study) | NA | | | |
| 4.1c | Number of centres participating | 1 School | | | |

4.2 What is the rationale for using the intended number of subjects?

Due to the occurrence of ABI being impossible to predict, it is unlikely that given the short period of time for this study that multiple children with moderate - severe ABI will be processed through their hospital rehabilitation and will be attempting to re-enter school. Nonetheless, it is not anticipated that multiple tests of the draft protocol will be needed to produce an exemplary final working protocol. In the event that a child cannot be recruited a minimum of 12 and a maximum of 20 special education professionals have been selected to evaluate the format and content of the protocol. The minimum has been selected as 12 to prevent only the viewpoints of a few professionals being received on the protocol and potentially biasing the recommended changes and/or suggestions made to the protocol. The maximum has been selected as 20 due to the time frame outlined for this study. Recruiting more than 20 professionals for this study makes it unlikely that questionnaires can be distributed, interviews conducted, and data collected within the given time frame.

| 4.3a | Was a formal sample size calculation used? | YES | |
|------|--|-----|-------------|
| | | NO | Χ |
| 4.3b | If YES – give the actual calculation and a reference for the formula used. If, instead of a calculation table in a published source was used, provide the reference(s) and table reference numbers. If a sample size calculator was used, provide a description of the software package used and/or the life for internet-based calculators. | | nbers. If a |

 \Rightarrow

| 4.4 The study will involve: (check all that apply) | √ |
|--|---|
| Incompetent or unconscious participants | |
| Minors (under 18) | √ |
| Institutionalized persons (e.g. prison, extended care facility) | |
| UWO Psychology Pool | |
| Participants with language barriers (e.g. illiterate, non-English speaking, dysphasic) | |
| Employees or students of UWO or the institution where the study is being carried out | |
| Patients | |
| Pregnant women | |
| Participants recruited in emergency or life-threatening situations | |
| Others whose participation may be problematic for some reason (describe) | |



| 4.5a | Will the study involve males AND females? | YES | Χ |
|------|---|--------------|---------|
| | | NO | |
| 4.5b | If NO, explain why only one gender is being selected. (e.g. condition under study | is gender sp | ecific) |
| | | | |
| | | | |

| 4.6 | What is the age range of the participants? | LOWER AGE LIMIT | 5 Child |
|-----|--|-----------------|------------------------|
| | | UPPER AGE LIMIT | 60 Teachers/Consultant |

| 4.7 | Participant Inclusion and Exclusion Criteria: List all inclusion/exclusion criteria and indicate with an |
|-----|--|
| | asterisk (*) those criteria which will be included in the Letter of Information. |
| | |

4.7a Inclusion Criteria

The child must have been diagnosed as having a moderate to severe ABI by his/her medical team; must be 5-19 years of age; must be stable and ready to be discharged from hospital; and must be attempting to re-enter school. Each special education professional must have at least 10 years experience working in the field of special education in Canada.

4.7b Exclusion Criteria and rationale for exclusion

⇒ *The child has been diagnosed with a mild ABI. *The child is younger than 5 years of age or older than 19 years of age. The child is not attempting to re-enter school. The professional has less than 10 years of experience in special education within Canada.

| 4.8a | Are there any risks for these participants if they are also taking part in | YES | |
|---------------|---|-----|---|
| | other research? | NO | Χ |
| 4.8b | If YES, explain any risks associated with participation in multiple studies | | |
| \Rightarrow | | | |

| 4.9 | What (if any) is the relationship between the researcher(s) and the subjects? |
|--|---|
| ⇒ The researcher will not have any relationship with the child or educator subjects or the SELC. | |

SECTION 5 PARTICIPANT RECRUITMENT

- 5.1 Describe the method of selecting, sampling and recruiting participants.
- ⇒The subject for this study will be identified by the child's school board when notification is received that he/she will be re-entering school. The board is notified by the child's parent(s) and/or medical professionals as he/she enters hospital and is transitioned to community care.
- 5.2 Identify who will be contacting them.

On behalf of the researcher, the school board will make initial contact with the child and his/her parents and inquire about their potential interest in being part of this study. If interest is indicated, the board representative will refer the student/parents to the researcher and provide appropriate contact information. Once the researcher is contacted by student/parents the researcher will contact the child's school board and the principal of the school that the child will be returning to. Contact with each individual will be done over the phone.

| 5.3 | Indicate where the research will be conducted. |
|--------|---|
| ⇒The r | research will be conducted within the child's school. |

| | 5.4 | Will announcements or advertisements be used? | YES | |
|---|-----|--|-----|---|
| | | | NO | Χ |
| Ī | | If YES (Provide copies of all advertisements /announcements that will be used) | | |

SECTION 6 RESEARCH PROCEDURES

| 6.1 | , | | | ıman |
|-------------------------------------|--|--|--|------|
| | participants as part of this research study. (Check as many as needed) | | | |
| Interview/survey/questionnaire | | | Evaluation of program or services | Χ |
| Experiment | | | Non-invasive physical measurements (e.g. BP, | |
| Observation of public behaviour | | | temperature) | |
| Observation of laboratory behaviour | | | Collection of biological materials | |
| Observation of classroom behaviour | | | Retrospective chart or file review | |
| Analysis of existing data | | | Other (specify) | |
| Audio recording | | | | |
| Video recording | | | | |

SECTION 7 INSTRUMENTS TO BE USED IN STUDY

Instruments (forms) = questionnaires, assessment forms, scales, interviews, surveys and diaries etc. Please provide a full copy of all instruments with each of the copies of the protocol (i.e. four copies in all).

| 7.1 | In the chart below list all instruments that will be used in the study. Expand chart as required. | | | | |
|-----------|---|---|-----------------------------|--|--|
| | If you are conducting open-ended or unstructured interviews or focus groups provide an outline of the topics to be discussed. | | | | |
| | To assist the REB indicate clearly on this chart, who will be cor administered, subject-interviewed, caregiver, teacher etc) | npleting the form (e.g. sub | ject – self | | |
| INSTRU | IMENT | Who will be completing the form? | STATUS Standard New Adapted | | |
| Question | nnaire | Education Professionals working with the child or those evaluating the protocol | New | | |
| Interviev | V | Education Professionals working with the child or those evaluating the protocol | New | | |
| | | | | | |

SECTION 8 DECEPTION OR PARTIAL DISCLOSURE TO BE USED IN THE STUDY

| 8.1a | This section refers to instances of deliberate deception or the withholding of key YES | | | |
|------|---|----|---|--|
| | information that may influence a participant's performance or responses. Do any of the procedures in this study include the use of this type of deception or partial disclosure of information to participants? | NO | X | |
| 8.1b | If YES, provide a rationale for the planned deception or partial disclosure. | | 1 | |

 \Rightarrow

8.1c If YES, describe the procedures for a) debriefing the participants and b) giving them a second opportunity to consent to participate after debriefing. If debriefing and reconsent are not viable options please explain.

 \Rightarrow

SECTION 9 RISKS AND BENEFITS OF THE RESEARCH

- RISKS & DISCOMFORTS: Discuss the overall risks of the proposed research, and specify the particular risks and discomforts associated with each aspect of the protocol. Consider physical, psychological, emotional, social, economic etc. risks and stressors.
- ⇒There will be no risk or discomfort to any of the participants. This study focuses on evaluating the school reentry protocol that will be used by educational professionals. The child and his/her parents will be provided with information about the study and the use of the protocol.
- 9.2 **BENEFITS:** Discuss benefits to the research participants, to groups or to society at large or the population being studied. Please note that monetary compensation is not considered a benefit.
- The school re-entry protocol to be used in this study has been designed from the best evidence in the literature and from the scant but excellent evidence available about best educational practices. Through the utilization of this protocol, it is expected that the child will receive more coordinated services and a quicker and more effective school re-entry.

SECTION 10 COMPENSATION AND COSTS

| 10.1a | Will the participants be compensated or reimbursed for their time and YES | | | | |
|---------------|--|----|---|--|--|
| | expenses? | NO | Χ | | |
| 10.1b | If YES, provide details. Specify the amount, what the compensation or reimbursement is for, and how payment will be determined for participants who do not complete the study. | | | | |
| \Rightarrow | | | | | |

| 10.2a | Are the participants likely to incur any additional expenses or inconveniences as | YES | |
|---------------|---|-----|---|
| | a result of their participation in this study? | NO | Χ |
| 10.2b | If YES, describe | | |
| \Rightarrow | | | |

SECTION 11 PROTECTION OF HEALTH AND SAFETY OF PARTICIPANTS

Describe facilities and procedures to protect the physical and mental health, comfort and safety of the participants.

⇒The child will be working with his/her medical and educational based teams during the school re-entry process. The education professionals comprising his/her school based team will be working through the school re-entry protocol to help assist with the child's school re-entry. Based on this, the child will be within his/her regular school setting and under the supervision/care of the school personnel. It is not anticipated that anything will occur that would compromise the child's physical or mental health or his/her comfort and safety.

| 11.2a | Will the study be likely to induce high levels of stress, fear, anxiety in some or all YES | | | | | |
|---------------|--|----|---|--|--|--|
| | participants or require them to discuss painful memories of past events? | NO | Χ | | | |
| 11.2b | If YES, please note that the proposal cannot be reviewed by the Faculty of Education REB. You must | | | | | |
| | submit your ethics review to the UWO Non-Medical Research Ethics Board. | | | | | |
| | If YES, explain what resources you will make available to subjects to cope with such stress. | | | | | |
| \Rightarrow | | | | | | |

SECTION 12 CONFIDENTIALITY & PROTECTION OF PRIVACY

- Describe the procedures to be used to ensure anonymity of participants and for preserving the confidentiality of data both during the research and in the release of the findings. This would include procedures such as removing identifiable information, collecting anonymous data and ensuring that highly visible subjects in small communities or groups will be protected from inadvertent identification. Describe any condition in which confidentiality or anonymity cannot be guaranteed or must be breached.
- ⇒ All data obtained for this study will be kept confidential by the primary researcher. The researcher will only be informed of the name of the child with ABI. The researcher will not directly interact with the child. Only the child's educators and the SELC will have access to any/all of the child's other personal information. In the thesis, the student will simply be referred to as a child with ABI in southwestern Ontario. There will be no identification of the participant, parents, educators, SELC, or the child's school or school board.

| 122a | 22a Is identifiable participant data being sent off-site to a sponsor, co-investigator or central data collection site or registry? | | YES | |
|------|--|---|---------------|-----|
| | | | NO | Х |
| 122b | If YES, indicate which, if | Surname Nar | ne &/or Initi | als |
| | any, of these participant identifiers will be included | Contact info: addre | ess, phone | etc |
| | | Date of | Birth or De | ath |
| | with the data? | Personal Numbers: e.g. SIN, employee or stu | udent numb | er, |
| | | Institutional / Hospital Cha | rt or Recor | d # |
| 122c | If any of the above identifiers will be included, provide a rationale why it is necessary to include this | | | |
| | information and why a unique, de-identified code cannot be used instead. | | | |
| ⇒ | | | | |

| • | 12.3 | Describe the procedures for securing and storing written records, videotapes, computer discs, |
|---|------|--|
| | | recordings and questionnaires etc. Indicate if the material will be retained indefinitely or the length of |
| | | time the material will be retained and describe the method of disposal if it is to be destroyed. |

All information/data gathered will be stored in a locked cabinet with access only to the researchers. The information will be retained until the completion of the thesis, two years, and then it will be destroyed. Recorded information will not include the name of the participant; only an identification code will be used. Transcribed data will not include participant names or any other identifying information. Participant names or contact information will not be stored in the same location, on the same computer, CD, or any other electronic devices as the transcribed data or audio recordings. All electronic data will be stored on password protected devices.

12.4 Identify all agencies or individuals other than the research team you know will have access to confidential data collected for this study.

⇒Access by the school-based team and the SELC to the child's confidential data is a normal requirement for both groups. However, no one other than the researcher will be able to access the research data for this study.

SECTION 13 INFORMED CONSENT

Disclaimer: The REB does not assess the legal validity of the consent form nor does it provide any other legal advice.

13.1 Briefly describe any plans for provision of feedback to participants.

⇒The child's school, school board, the SELC, and if needed, the child's parent(s), will be provided with general feedback about the effectiveness of the protocol. Once the thesis is completed, it is expected that all Ontario school boards and schools will receive a copy of the final protocol.

13.2 If written consent cannot be obtained from potential participants prior to intervention or written consent is not appropriate, provide a justification. (E.g. completion of a questionnaire in a survey study is evidence of compliance.)

13.3a Will minors or persons not able to consent for themselves be included in the study?

13.3b If YES, describe the consent process and indicate who will be asked to consent on their behalf and discuss what safeguards will be employed to ensure the rights of the research participant are protected. Whether or not a separate assent form is used, investigators and parents or guardians should discuss the study with the person (when appropriate) and explain exactly what will happen and what the person's rights are. In certain circumstances, the REB may find it acceptable for mature or emancipated minors to give consent without also requiring consent from parents or guardians.

⇒Consent will be obtained for the participation of the child in the study from his/her parent(s) and from the child if age appropriate. The parent(s) will be provided with a letter that will provide a detailed description of the study.

Attach a copy of the documentation that will be used to inform and obtain consent from the potential participants about the research. Separate Information/consent documents or a combined Information/Consent document may be used. Wording regarding the participant's consent must comply with the UWO policies and procedures and participants must be given a copy of the Letter of Information or combined Information/consent document to keep for reference if they wish.

Some requests for interviews with competent persons who hold or have held positions of responsibility and who are primarily relating their experiences in public or private office (e.g. politicians, government officials, senior executives) need not follow such a structured outline. (See Section 10.0 in the NMREB Guidelines.)

PLEASE COMPLETE THE CHECKLIST ON NEXT PAGE

| 13.5 | СНЕС | KLIST – INFORMATI | ION & CONSENT DOCUMENTATION | | | |
|------|---|----------------------------------|---|--|--|--|
| HAV | HAVE YOU INCLUDED OR ADDRESSED THE FOLLOWING ISSUES IN YOUR | | | | | |
| LET | TER O | F INFORMATIO | N AND CONSENT FORM? | | | |
| YES | Not | | nt documentation guidelines Appendix 1 NMREB Guidelines for detailed | | | |
| | Appl | | nts of each category) | | | |
| X | | Title of the research | | | | |
| X | | Identity of research | | | | |
| X | | Invitation to particip | | | | |
| | | | documents addressed to research participant | | | |
| X | | Summary explanation | | | | |
| X | | Number of participa | | | | |
| X | | | n & exclusion criteria | | | |
| X | | | esearch and any experimental procedures | | | |
| X | | Explained specific r | ' | | | |
| | X | | ant's time commitment | | | |
| X | | Location of the rese | arch | | | |
| X | | Described Risks / H | | | | |
| X | | Explained voluntary | participation and freedom to refuse to participate/withdraw at any time. | | | |
| X | | Participation in cond | current or future studies | | | |
| X | | Anonymity | | | | |
| X | | Confidentiality | | | | |
| | X | Alternative options | to participating in the research if appropriate | | | |
| | | Told they may keep | the Letter of Information | | | |
| X | | Contact person(s) for | Contact person(s) for participants a) regarding the study & b) subject rights | | | |
| X | | Compensation & Costs to Subjects | | | | |
| X | | No waiver of rights | | | | |
| X | | No indication of inst | itutional or REB approval | | | |
| X | | Publication of result | S | | | |
| | X | Conflict of Interest declared | | | | |
| | X | Measures taken to | deal with stress, anxiety, or fear induced by study, if any | | | |
| X | | Language Level - la | ay language, grade 8 level | | | |
| X | | Formatting – pages | numbered, type size, page layout, header/footer, headings | | | |
| X | | Consent Statement | as per UWO standard or written consent not required | | | |
| X | | Signatures – partici | pant, person obtaining consent | | | |
| | | Assent form for | what the study is about | | | |
| | | children 7+ | why the child is eligible to participate for the study | | | |
| | | (Optional) | procedures, what will happen | | | |
| | | | voluntary participation, withdrawal | | | |
| | | | risks, discomforts | | | |
| | | | benefits | | | |
| | | | contacts | | | |
| | | | an invitation to ask questions | | | |
| | | | signature | | | |
| | 1 | 1 | 1 0.0 | | | |

NOTIFICATION OF REVISIONS, AMENDMENTS, REVISED BROCHURES TO AN APPROVED PROTOCOL

FORM 3-F-004 UWO Non-Medical Research Ethics Board (NMREB) Revised 04-06-01

| UW | O ETHICS NUMBER | 1106-1 | |
|---------------------------------|---|------------------|-------|
| LOCAL PRINCIPAL INVESTIGATOR | | Dr. Alan Edmunds | |
| PROJECT TITLE | School Re-entry Protocols for Children with Acquired Brain Injury | | |
| Signature of P | rincipal Investigator: | | Date: |
| | | | |

| 1 | Do the proposed changes alter the information contained in the UWO protocol submission, Letters of | YES | YES V |
|----|--|-----|-------|
| 1. | Information and Consent documentation or affect local participants? | NO | |

| 2 | SUMMARY OF CHANGES IN THIS REQUEST FOR A REVISION | √ IF YES | IF YES TO ANY ITEM IN THIS CHART, PROVIDE ADDITIONAL INFORMATION ON A SEPARATE SHEET AND/OR DOCUMENTATION AS NOTED BELOW. (Put Ethics # on each additional page) | |
|--|---|----------------|--|--|
| Stud | Study design or methods? | | Provide detailed explanation/rationale for changes. Revising the UWO protocol form as appropriate. | |
| Information/Consent documentation? | | √ | Provide copy of revised documentation with changes <u>underlined</u> , <i>italicized</i> or <u>grey-shaded</u> . Do not use coloured marker unless you are prepared to highlight each copy. | |
| Study instruments, questionnaires etc? | | V | Provide copy of revised or additional questionnaires, instruments etc. | |
| Number of study participants? | | 1 | | |
| Part | Participant recruitment? | | Provide detailed explanation/rationale for changes. Address statistical issues i appropriate. | |
| Elig | ible subjects? | √ | | |
| Stud | ly end date? | √ | Provide revised date and detailed explanation/rationale for change. | |
| Adn | Administrative changes? | | Summarize changes and revise UWO documentation as appropriate. | |
| | Principal and/or Co-Investigators? | | If PI changing, include letter signed by both PI who is stepping down and the new PI indicating they both agree to the change and that the new PI is prepared to take over all responsibility for the study. | |
| Other | | No | Provide a complete description. | |

LEAVE THIS SPACE BLANKO

APPENDIX C: Ethics Approval Forms



THE UNIVERSITY OF WESTERN ONTARIO FACULTY OF EDUCATION

COTTI USE OF HUMAN SUBJECTS - ETHICS APPROVAL NOTICE

Review Number: 1101-6 Principal Investigator: Alan Edmunds Student Name: Matt White

Title: School Re-entry Protocols for Children with Acquired Brain Injury

Expiry Date: June 30, 2011 Type: M. Ed. Thesis

Ethics Approval Date: February 22, 2011

Revision #:

Documents Reviewed &

Approved: UWO Protocol, Letters of Information & Consent

This is to notify you that the Faculty of Education Sub-Research Ethics Board (REB), which operates under the authority of The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects, according to the Tri-Council Policy Statement and the applicable laws and regulations of Ontario has granted approval to the above named research study on the date noted above. The approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the REB's periodic requests for surveillance and monitoring information.

During the course of the research, no deviations from, or changes to, the study or information/consent documents may be initiated without prior written approval from the REB, except for minor administrative aspects. Participants must receive a copy of the signed information/consent documentation. Investigators must promptly report to the Chair of the Faculty Sub-REB any adverse or unexpected experiences or events that are both serious and unexpected, and any new information which may adversely affect the safety of the subjects or the conduct of the study. In the event that any changes require a change in the information/consent documentation and/or recruitment advertisement, newly revised documents must be submitted to the Sub-REB for approval.

Dr. Alan Edmunds (Chair)

2010-2011 Faculty of Education Sub-Research Ethics Board

Dr. Alan Edmunds Faculty of Education (Chair)
Dr. John Barnett Faculty of Education
Dr. Jacqueline Specht Faculty of Education
Dr. Farahnaz Faez
Dr. Wayne Martino
Dr. George Gadanidis Faculty of Education

Dr. Immaculate Namukasa Faculty of Education
Dr. Kari Veblen Faculty of Music
Dr. Ruth Wright Faculty of Music

Dr. Robert Macmillan Faculty of Education, Associate Dean, Graduate Programs & Research (ex officio)
Dr. Susan Rodger Faculty of Education, UWO Non-Medical Research Ethics Board (ex officio)

The Faculty of Education 1137 Western Rd. London, ON N6G 1G7

Karen Kueneman, Research Officer Faculty of Education Building

Copy: Office of Research Ethics



THE UNIVERSITY OF WESTERN ONTARIO FACULTY OF EDUCATION

Western use of human subjects - ethics approval notice

Review Number: 1101-6 Principal Investigator: Alan Edmunds Student Name: Matt White

Title: School Re-entry Protocols for Children with Acquired Brain Injury

Expiry Date: December 31, 2011 Type: M. Ed. Thesis Ethics Approval Date: June 23, 2011

Revision #: 1

Documents Reviewed & Revised Research Method, Questionnaire & Interview for Special Educators, Letter Approved: of Information & Consent for Special Educators, Revised Study End Date

This is to notify you that the Faculty of Education Sub-Research Ethics Board (REB), which operates under the authority of The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects, according to the Tri-Council Policy Statement and the applicable laws and regulations of Ontario has granted approval to the above named research study on the date noted above. The approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the REB's periodic requests for surveillance and monitoring information.

During the course of the research, no deviations from, or changes to, the study or information/consent documents may be initiated without prior written approval from the REB, except for minor administrative aspects. Participants must receive a copy of the signed information/consent documentation. Investigators must promptly report to the Chair of the Faculty Sub-REB any adverse or unexpected experiences or events that are both serious and unexpected, and any new information which may adversely affect the safety of the subjects or the conduct of the study. In the event that any changes require a change in the information/consent documentation and/or recruitment advertisement, newly revised documents must be submitted to the Sub-REB for approval.

Dr. Alan Edmunds (Chair)

2010-2011 Faculty of Education Sub-Research Ethics Board

Dr. Alan Edmunds
Dr. John Barnett
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Dr. Farahnaz Faez
Dr. Wayne Martino
Dr. George Gadanidis
Dr. Immaculate Namukasa
Dr. Land State Speckt
Dr. Land Education
Faculty of Education

Dr. Kari Veblen Faculty of Music
Dr. Ruth Wright Faculty of Music

Dr. Robert Macmillan
Dr. Susan Rodger
Faculty of Education, Associate Dean, Graduate Programs & Research (ex officio)
Faculty of Education, UWO Non-Medical Research Ethics Board (ex officio)

The Faculty of Education 1137 Western Rd. London, ON N6G 1G7 Karen Kueneman, Research Officer Faculty of Education Building

Copy: Office of Research Ethics

APPENDIX D: School Board Request for Research

SUMMARY FORM OF RESEARCH REQUEST

To be completed and attached to your Ethical Review Protocol. Please keep your answers to the following questions to 2 pages. Longer answers may delay your approval. **After you have received ethical approval from the Faculty of Education,** you will turn into the Board the following three things: (1) this form, (2) your Ethical Review Protocol, and (3) your ethical approval sheet.

| 1. | Title of Study: |
|----|---|
| | A SCHOOL RE-ENRTY PROTOCOL FOR CHILDREN WITH ACQUIRED BRAIN INJURY |
| 2. | Name of Researcher: |
| | Matt White - currently enrolled in the Master of Education program Special Education and Educational Psychology stream at the University of Western Ontario. This research study is a part of my Master thesis. |
| | Name of Supervisor: |
| | Dr. Alan Edmunds |
| 3. | Telephone Contact Number: |
| 4 | |
| 4. | E-mail Address of Researcher: |
| 5. | Abstract for Study (one paragraph giving the study's rationale, research questions or hypotheses, and basic methodology with participants using plain language that could be used for recruitment) |
| | A child with moderate to severe ABI aged 5-19 years of age who is attempting to re-enter school will be recruited for the study. Also to be recruited will be all school personnel who will help transition the student back into school. This will likely be the School Based Team personnel who typically handle students with exceptionalities. Amongst other things, these personnel are responsible for conducting a psych-educational assessment, designing the student's IEP, and designing and monitoring all educational interventions. In this study, these education professionals will utilize the school re-entry protocol designed by this writer specifically to assist them in the re-entry process. Based on this trial, the protocol will be evaluated for its effectiveness. |
| 6. | Needed start date for data collection: |

| Immediately |
|---|
| 7. Anticipated end date for data collection: |
| June 1, 2011 |
| |
| 8. If you are using students as participants, what is their grade level? |
| The grade level of the student does not matter as long as the student is within 5-19 years of age and attempting to re-enter school after suffering an ABI. |
| 9. How many participants are you requesting? |
| Students 1 |
| Teachers 2-5 (mainly those involved directly with the students and responsible for assisting with his/her transition back into school and IEP development. |
| Principals 1 |
| 10. Are you an employee of the Thames Valley District School Board? |
| No 🗆 |
| 11. Are you an employee of the London District Catholic School Board? |
| No |
| |
| 12. Number of sites needed: |
| one |
| 13. What site(s) are you considering? |
| The site does not matter for this study. |
| 14. Have you obtained informal approval for this site(s)? |
| No as the site is not known at this time as to what school the child will be returning to. The Pediatric Acquired Brain Injury Community Outreach Program has been contacted by the researcher and input provided on the protocol. As well, PABICOP will be involved as the team normally would within Southwestern Ontario for the child who is returning to school. |

15. What will be the workload/time commitment

Students: none (the student will not be in involved with the researcher).

Teachers: 15 minutes for an interview with the researcher. Each teacher will also be using the protocol throughout the re-entry process which will involve reading through the protocol, becoming familiar with it, and taking the time to ask any questions throughout the process.

Principals: none

16. What will be the benefit of your study to the school, parents, teachers, students?

The school re-entry protocol to be used in this study has been designed from the best evidence in the literature and from the scant but excellent evidence available about best educational practices. Through the utilization of this protocol, it is expected that the child will receive more coordinated services and a quicker and more effective school re-entry.

17. What are your plans for feedback to the school(s) and participants used in your study?

The child's school, school board, the PABICOP team, and if needed, the child's parent(s), will be provided with general feedback about the effectiveness of the protocol. Once the thesis is completed, it is expected that all Ontario school boards and schools as well as the PABICOP group will receive a copy of the final protocol.

APPENDIX E: Protocol Evaluation Questionnaire

School Re-entry Questionnaire for Educational Professionals

Based on your experience working with a child with Acquired Brain Injury (ABI) during the school re-entry process, please use the questions below to comment on the protocol and how it could have assisted you throughout the process. If you have not worked with a child with ABI during the school re-entry process please comment on the protocol and how you feel it could assist you in the future if you were to work with such a child. The main purpose of the questionnaire is to gain more insight into both the protocol's strengths and weaknesses if it were to be used in a real-time school re-entry situation. The information collected from the questionnaire will be used to make any further modifications to the school re-entry protocol.

| What did you find most useful about the school re-entry protocol? | | |
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| Were there any area(s) of the protocol that were not clear? | | |
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| Based on your experience do you feel that the protocol could assist you with the re-entry process? | | |
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| What recommendations and/or suggestions do you have for the protocol? | | | |
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| Additional Comments: | | | |
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APPENDIX F: Teacher Consent Form

School Re-entry Protocol for Children with Acquired Brain Injury

LETTER OF INFORMATION

Introduction

My name is Matt White and I am a masters student at the Faculty of Education at The University of Western Ontario. I am currently conducting research into examining a school re-entry protocol for children with Acquired Brain Injury and would like to invite you to participate in this study.

Purpose of the study

The aims of this study are to evaluate the designed school re-entry protocol in its ability to assist educators in the school re-entry process for a child with ABI as he/she attempts to make the transition back to school. This study attempts to address the gap that exists in the continuum of care between healthcare and education professionals and provide children with ABI better overall care through a quicker and more complete school re-entry process.

If you agree to participate

If you agree to participate in this study you along with each member of the school-based team involved in the school re-entry process for this child will be provided with the school re-entry protocol. The team will use the protocol to complete the outlined requirements at each phase of the school re-entry process to facilitate reintegration. At the final phase of the re-entry protocol you will be asked to complete a questionnaire that asks questions based on the overall re-entry process and using the protocol. After the questionnaire is complete and received by the researcher, you will be asked to participate in a 15 minute interview at your facility with the researcher during a time that is most convenient for you. The researcher will ask further questions based on answers to the questionnaire with answers being recorded in written format.

Confidentiality

The information collected will be used for research purposes only, and neither your name, nor information which could identify you will be used in any publication or presentation of the study results. All information collected for the study will be kept confidential. The researcher will only be informed of the name of the child with ABI and will not have access to any/all of the child's other personal information. In the thesis, you will simply be referred to as an educational professional in southwestern Ontario. The identify of you, the child, the educators, PABICOP personnel, or the child's school or school board will not be disclosed. All information/data gathered will be stored confidentially with access only to the

researchers. The information will be retained until the completion of the thesis and then it will be destroyed.

Risks & Benefits

There are no known risks to participating in this study.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your employment status.

Questions

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, The University of Western Ontario. If you have any questions about this study, please contact Matt White or my supervisor, Dr. Alan Edmunds.

This letter is yours to keep for future reference.

A School Re-entry Protocol for Children with Acquired Brain Injury

Matt White and Dr. Alan Edmunds

CONSENT FORM

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

| Name (please print): | | | | |
|---|-------|--|--|--|
| Signature: | Date: | | | |
| Name of Person Obtaining Informed Consent: | | | | |
| Signature of Person Obtaining Informed Consent: | | | | |
| Date: | | | | |

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VITA

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