



ABI Transitions Study Report

TRANSITIONS EXPERIENCED BY CHILDREN AND THEIR FAMILIES AFTER ACQUIRED BRAIN INJURY

THANK YOU!

The ABI Transitions Study Team would like to say a 'huge' thank you for your participation in this study! We would like to express our appreciation to the many teachers, parents, children and youth who took the time to provide us with invaluable and extremely useful information.

The information will help us to learn more about the effects of Acquired Brain Injury (ABI) on children, youth and their families.



Defining Terms for the ABI Study:

Acquired Brain Injury (ABI):

Damage to the brain at least 7 days after birth and caused by traumatic brain injury such as motor vehicle accident, falls, sport injury etc., or non-traumatic causes such as stroke, aneurysm, anoxia or infection and brain tumours.

Glasgow Coma Scale (GCS):

A common and widely used system for classifying the severity of head injuries or other neurological diseases. The scale includes numbers from 0-15 and classifies head injuries as Mild, Moderate and Severe.

Transitions:

Transitions, for the purpose of this study, were seen as times of significant change in a child's environment such as returning home from the hospital, returning to school and returning to activities in the community.

ABI Transitions Study Team

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Wrapping up the ABI Transitions Study:

The ABI Transitions Study has come to a conclusion and we are excited to inform you that it has been a **great success!** You provided us with a tremendous amount of important information and so far we have found some interesting results. We would like to take this opportunity to share with you what we have learned so far and what we plan to accomplish. This study could not have been possible without **your involvement** as well as the support from **McMaster University, the Hamilton Health Sciences McMaster Children's Hospital, CanChild Centre for Childhood Disability Research** as well as funding from the **Ontario Neurotrauma Foundation.**



Why did we do this Study?

Parents told us that times of transition were very difficult for them and their child with ABI. We wanted to look at the factors that influence transitions to home, school and community or recreational activities for school-aged children with acquired brain injury. The following is a list of main objectives of this study:

- to identify children at risk for difficult transitions and determine the conditions and factors that put them most at risk;
- to describe the stages and processes of transition for children with an ABI;
- to determine the needs of the children and their families at each stage of transition;
- to examine the evidence and present the information to families, service providers, as well as policy and program developers.

How did we start?

We have been following up children with head injuries for sometime now and you will see how this study compares to the older studies in some of the figures that follow.

The Transition study began in **November 2001** where we identified children and adolescents **5 to 18** years of age with a diagnosis of ABI who were admitted to McMaster Children's Hospital in Hamilton. Between November 2001 and December 2003, **435** children were admitted with an ABI. Of these 435 children and youth, 292 children were eligible to be a part of the study based on age and other study criteria. By the end of the study we were able to recruit and have continued involvement of **183** children and families. The study was successful because **73%** of the families who were contacted to be a part of the study agreed to participate!



What was done?

This study is called a 'longitudinal study design' because it allowed us to observe and follow children/youth for an extended period of time. We collected valuable medical information such as the severity and cause of the injury/illness on all of the 435 children and adolescents.

Booklets, containing important measures and questions, were completed by families, teachers and the child/youth. Thank you for completing these important booklets!!

The study team chose these questionnaires because they looked at functioning **at school**, at **home**, and a **child's health and well-being**. They are standardized tools which have been designed by researchers to measure child outcomes, particularly aspects of quality of life and participation in everyday life.

It was important to have the same booklets completed at various times throughout the study. The aim was to have questions completed at **4-weeks after discharge**, **4-weeks after returning to school**, **8-months after injury/illness**, **12-months after injury/illness**, and for some participants an assessment was completed at **one year** and **two years** after injury or illness. A **baseline** or initial questionnaire was also developed that many families completed which helped us look at some important information before the injury or illness.

What did we find?

The large task of analyzing and looking at the results from all of the data has really just started. We are excited about what we have found so far and have briefly summarized some of the interesting results that have been found to date.



- **Falls and Motor Vehicle Accidents** continue to account for most of the injuries (*Figure 1*)
- **School-aged children** continue to account for most of the injuries (*Figure 2*)
- Among children injured in motor vehicle accidents, **less than ½** were wearing **seatbelts**. (*Figure 3*)
- Even more striking is that of those injured in **bicycling accidents**, only about **20%** were wearing **helmets**. (*Figure 3*)

We also compared the different groups of children/youth based on their **Glasgow Coma Scale** classification (i.e. **mild, moderate and severe brain injuries**).

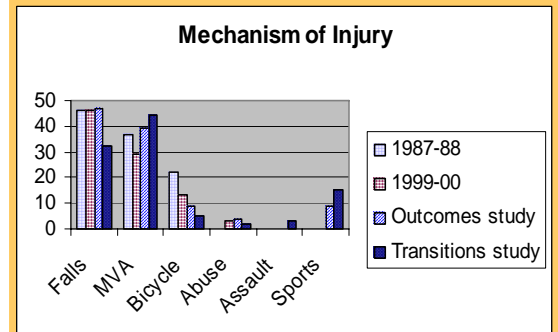


Figure 1- (showing results over 4 studies of which the ABI Transitions Study is the most recent).

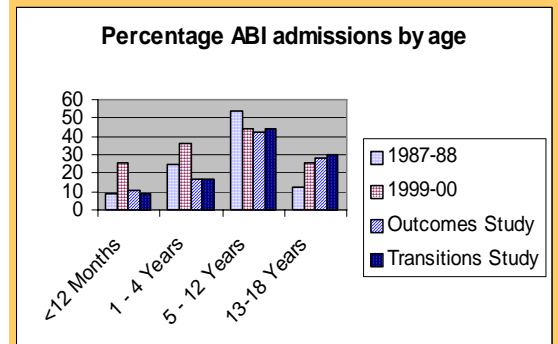


Figure 2

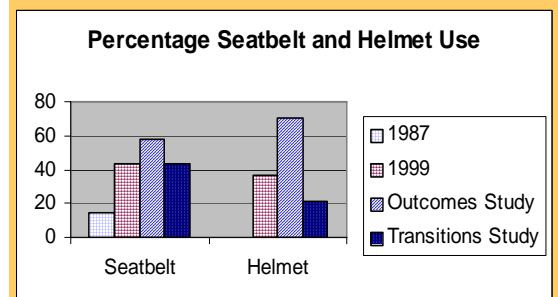


Figure 3

- There was a lot of **inconsistency** between the different groups of mild, moderate and severely injured children as to how long it took for them to **return to school** after their injury or illness. We found it interesting that children with mild injuries did not always return to school as quickly as might be expected. (Table 1)

- We were also able to collect a lot of information from the school records and questionnaires completed by the teachers. It appears that children who were classified as moderate and severe injuries had an increase in **school difficulties** after injury. It is clear that children who have severe injuries are more likely to have a problem in English or Math **prior** to the injury. It also appears that the chance of showing a problem in English or Math immediately after injury, when it was not evident before the injury, may be related to the severity of injury. (Table 2)

- When we looked at a **Child's Health Status**, we found that there is an **initial decline** in a Child's Health after the injury. What we hope to analyze further if we are funded for another study, is that there may be a possibility of another decline further down the road especially for moderately and severely injured children.

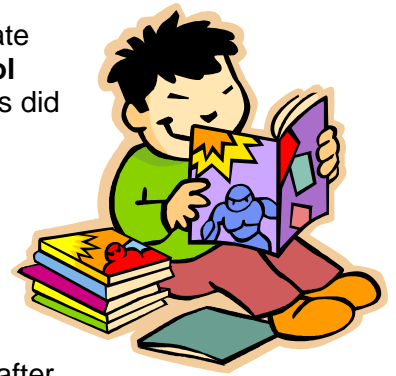


Table 1

Severity	Time to Return to School				Median Days to Return
	7 days	14 days	21 days	56 days	
Mild	18%	33%	47%	73%	24
Moderate	13%	47%	53%	73%	21
Severe	4%	8%	12%	44%	61



Table 2: Students with problems in English or Math before and after injury

Severity	% with pre-injury problems	% with post-injury problems	% having post-injury problems who did not have pre-injury problems
Mild n=72	39%	42%	11%
Moderate n=11	36%	55%	18%
Severe n=15	47%	67%	20%

What have we learned so far?

- After an ABI, we can see that the **effects of the severity of the head injury or illness** can be seen in **all areas** of the child and family functioning, including school function, health status, family function, and timing of key transitions.
- We have found that there is a lot of **variation** between the categories **mild, moderate and severe injuries**. At the present time just using the GCS for severity may be causing a disadvantage to children, particularly if it is used for making decisions about providing services and funding.
- Initial findings also suggest that there is **variability in longer term outcomes**. Ongoing analyses will help establish predictors of families' needs. Further results are likely to support the need for **longer term clinical follow-up** than is now routinely available in many regions of Ontario especially for children without insurance funding.

- Emerging results suggest that the **needs of children and families, will vary over the course of recovery.** For instance, analysis of longitudinal data for the functional, academic, psychosocial, and health outcomes suggests clearly that a period of crisis follows ABI, and that **length and severity of this crisis period may depend on GCS and other clinical variables, including pre-injury functioning.**
- Major transitions like change in school, change in grade, change in teacher, change in family situation, rehab centre back to community are all stressful events. We now know that **service delivery is probably best if it is delivered and focused at key times.** One example of a key time is within the first 20 weeks after injury. This seems to be when the family is having the most difficulty and the children show decreased participation in school. This supports our view that **these children and families should be prioritized** for entry into treatment centres and programs, not left at home without support while on a wait list.
- A very positive aspect of research studies such as this one is that it impacts services. Children and families in the ABI study were able to **receive longer follow-up than is normal in central south west Ontario.** We hope that in the future, services will be provided to families based on key times of expected difficulties during recovery.

Why are the results from this study important?

- We hope that the information we learn about child and family functioning and well being will help **clinicians and future children and families** know what to expect following ABI and to be able to help them make informed decisions during this stressful time.
- We hope that with further analysis we will be able to develop a **summary of other important factors** that may indicate the need for a child/youth to receive longer follow-up. Hopefully ensuring that future children and families will receive the opportunity for **longer term follow-up**



What is Next?

The ABI Transitions Study Team has applied for further funding to continue to follow children and their families and gain more insight into the long-term effects and impact of ABI.

We may be contacting you in the near future for your participation.

Please check out the *CanChild* website for any further information and updates regarding the ABI study. www.fhs.mcmaster.ca/canchild



We are very excited about the success of this study and again thank you for your valuable information and willingness to participate. It was very important to have information on all types and severity of injuries.

