

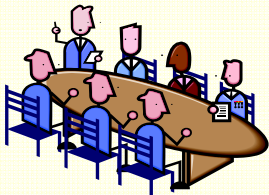
ABI Trajectories Study FINAL Newsletter



Trajectories and Consequences: Long-term follow-up of children and youth and their families after Acquired Brain Injury (ABI)

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WRAPPING UP THE ABI TRAJECTORIES STUDY:

The ABI Trajectories Study has come to an end, and we thank you very much for your participation over the years! All of you have provided us with lots of important and extremely useful information. The information will help us learn more about the long-term effects of ABI on children and youth, and their families. So far, we have found some interesting results. We would like to take this opportunity to share with you what we have learned.



THE JOURNEY OF ABI TRAJECTORIES STUDY:

Okay, before we get into the interesting findings, let's recap the background information of the ABI Trajectories Study first...

Why did we do this Study?

After an ABI, children and youth and their families may experience changes in many areas of their lives. These may include physical and mental health, ways of thinking, behaviour, social and family life, self-concept, and economic circumstances. Recovery from ABI varies a great deal among children and youth. Our understanding of the recovery process among young people is complicated because this recovery is happening at the same time as changes that occur naturally as part of typical development. We also know very little about the growing brain's ability to heal itself. Many doctors and researchers working in this area assume that children who seem to have mild injuries early on will have no problems later. In fact, we don't really know about the medium and long-term consequences of mild ABI. It is possible that some of these children and their families will have difficulties in the future, in spite of apparently complete recovery in the weeks immediately following the injury.

The main objectives of this study were:

- To find out how ABI affects the children and families in the long term (i.e., over 5 to 7 years). We are particularly interested in quality of life and neuropsychological functioning.
- To examine how these factors change as youth move from adolescence to being young adults.
- To learn how to identify which children and adolescents will require more intensive intervention and follow-up.

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ABI Trajectories Study is sponsored by:



How did we start?

It all started with the ABI Transitions Study (funded by the Ontario Neurotrauma Foundation). Yes, we are talking about the ABI Transitions Study that started way back in November 2001. Children and youth 5 to 18 years of age who were admitted to McMaster Children's Hospital with a diagnosis of ABI between November 2001 and December 2003 were invited to take part in our earlier ABI Transitions Study. By the end of the ABI Transitions Study, we were able to have continued participation of 175 families.

Since we would like to learn more about the long-term effects of ABI, our study team applied for another set of funding from the Canadian Institutes of Health Research. This new funding allowed us to follow the same group of families from the ABI Transitions Study for another 3 to 4 years – so the participating families would have 7 years at most and 5 years at least of follow-up after ABI by the end of this subsequent study. This is how we started the ABI Trajectories Study!



The ABI Trajectories Study began in December 2005 when we started to contact families who kindly participated in the ABI Transitions Study. We were unable to reach 24 families because their contact information was not up-to-date, and we decided not to contact the 14 children and youth with brain tumour (as the cause of ABI) due to the more complicated and different prognosis of brain tumour. Among the 137 families we contacted, 87 families (64%) consented to participate. By the end of the data collection phase of the ABI Trajectories Study, we had continued involvement of 78 families (90%)!

What was done?

Our study is a "prospective longitudinal cohort" study design, because it allowed the study team to observe and follow the same group of children and youth with ABI, and their families over an extended period of time. During the course of the study, we collected information on quality of life, participation, academic performance, self perception, behaviour issues, and parental and family environments through the use of standardized measures on a yearly basis. Since we would like to look at possible changes (if any) in these areas, it was very important for us to use these standardized measures over and over again throughout the years!



Based on the feedback we received from some of you, all of the study questions were available in both booklet and online formats. Twenty-four families (28%) had chosen to completed the annual assessment online, while 63 families (72%) preferred the booklet format.

A research-focused neuropsychological testing session was scheduled for participants when it was time for the 5th year post ABI assessment. Fifty-one children and youth (68%) took part in the testing. The main purpose of this testing was for the Study Team to learn more about the neuropsychological function post ABI, such as attention and memory.

WE HAVE OUR OWN ABI TRAJECTORIES STUDY PAGE ON *CANCHILD* WEBSITE!

Feel free to check out our website (www.trajectories.canchild.ca) for any further information and updates regarding the ABI Trajectories Study!

To learn more about other childhood disability research, please visit the *CanChild* website at www.canchild.ca!

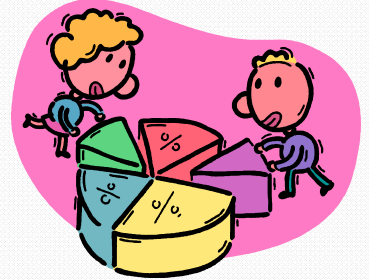


WHAT DID WE FIND?

The huge task of data analysis is not quite completed yet, but we are excited about what we have found so far! We have many more results, and here are some **brief summaries** on the key findings for your interest.

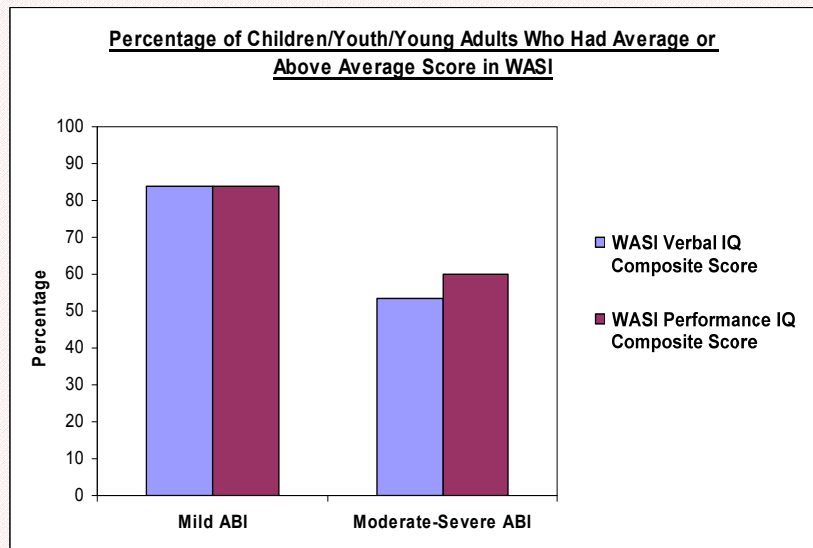
Results on Study Participation

- We started as the ABI Transitions Study (back in November 2001), and then we asked for your continued participation in this subsequent ABI Trajectories Study. To help us better plan for future studies, we are interested in finding out what are the differences between your family and those who did not continue.
- We looked into the demographics (i.e., child's gender), and other ABI related factors (i.e., age at the time of ABI, cause of ABI, and severity). Surprisingly, we found that none of these mattered!
- The only difference between your family who had continued participation in the ABI Trajectories Study and those who did not is — the questionnaire completion rate in the ABI Transitions Study! That is, those of you who had a good track record of completing the study questionnaires in the ABI Transitions Study are also the ones who continued to participate in the ABI Trajectories Study! KUDOS TO YOU!



Results on Neuropsychological Functioning

- Fifty-one participants completed the 2-3 hour long neuropsychological testing session at the 5th year post ABI follow-up. Fifteen had moderate-severe ABI, and the other 36 had mild ABI. This neuropsychological testing session is an evaluation of brain functions and how they have been affected by ABI. We administered a wide range of tests to evaluate areas such as attention, memory, and language abilities, etc.
- Overall, we found that the majority of children, youth, and young adults did well in their neuropsychological testing session. BUT, some neuropsychological problems were still detectable even at 5 years post ABI.
- For example, we used the Wechsler Abbreviated Scale of Intelligence (WASI) to get IQ estimates in verbal and non-verbal/performance domains. Compared to children, youth, and young adults with moderate-severe ABI, those with mild ABI did better in both verbal and non-verbal/performance IQ domains. Although some children with moderate-severe ABI still had neuropsychological problems, about 75% of the study cohort had average or above average IQ scores.

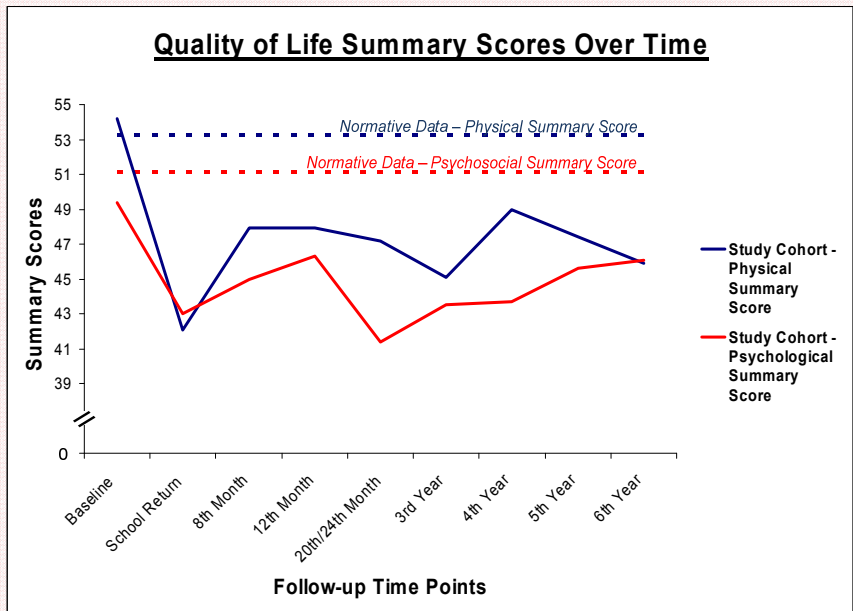


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WHAT DID WE FIND?

Results on Quality of Life

- We were also able to collect a lot of information on quality of life over the years, from baseline (when families were asked to recall things about child's health and well-being *before* the injury/illness) to 5-7 years *after* the ABI.
- We found that quality of life had a sharp decrease right after the injury/illness. There was a gradual partial recovery as time went by, but quality of life was definitely affected for children and youth of all severities for a number of years after their injury/illness. Even at the 5th and 6th year follow-ups, many domains of quality of life were still significantly lower than children without ABI.
- We also found similar results for other measures used in the study.



WHY ARE THE RESULTS FROM THIS STUDY IMPORTANT?

We can see that ABI impacts children, youth and young adults of all severities in many different areas, such as their neuropsychological functioning and quality of life. For some children with mild ABI, in spite of apparently complete recovery in the weeks immediately following the injury/illness, impacts of ABI can still be detectable even when many years have gone by. There is also variability in the long-term outcomes — issues faced by the child and family might change at different points in time.

We hope the increased knowledge provided here about long-term recovery trajectories will...

- help service providers plan for better long-term follow-up for children with ABI of all severities. Follow-up should be provided soon after discharge and for as long as symptoms persist!
- help future children and their family know what to expect following ABI and allow them to make informed decisions during difficult times.
- increase awareness of ABI among families, educators, and service providers. Multidisciplinary resources should be provided through support, education, and services to address problems in different domains.

Thank you!

We are very excited about the success of this study, and once again, thank you for your long-term participation and your willingness to share valuable information with us! We would not be able to complete this study successfully without your help!

**Please Stay Safe!
Wear Your Helmet!**

