# Validation of the Pediatric Family Needs Questionnaire (FNQ-P) across Three Countries

## **Project Summary**

Centre for Leadership in Acquired Brain Injury

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Holland Bloorview

Kids Rehabilitation Hospital

# Blcorview RESEARCH INSTITUTE

#### SHARING OUR WORK

- First
  International
  Conference on
  Paediatric
  Acquired Brain
  Injury UK
- BRI symposium
- OACRS Conference
- 40<sup>th</sup> Annual Brain Injury Conference, Williamsburg, VA, USA
- ABI Network conference abstract submission
- Gained new collaborators in the United Kingdom, Lithuania, and British Columbia

## WHAT WAS THIS STUDY ABOUT?

In this study, we tested a new questionnaire that tells us about the needs of family members after a child or youth has had an acquired brain injury (ABI).

The author (Kreutzer) of the adult Family Needs Questionnaire (FNQ) gave us permission to adapt it so that it would be a good fit for families of children with ABI. The adapted measure has been named the Family Needs Questionnaire – Pediatric Version (FNQ-P), and is designed to be completed by a primary caregiver of a child or youth with an ABI. Clinical researchers in Sweden and Australia joined in this study in which we tested the FNQ-P to see how well it works as a measure of family needs post-ABI.

#### WHAT DID WE DO?

- Developed a plan to compare the two completions of the FNQ-P by each participant to see if it holds up over time (*reliability testing*).
- Developed a plan to compare the FNQ-P to two other questionnaires to see if it measures what it is supposed to measure (*construct validity evaluation*).
- Twenty-one Canadian caregivers of children with an ABI completed the FNQ-P twice (one week apart) (*reliability*). Two related questionnaires were completed once (*construct validity*).
- Partnered with researchers in Sweden and Australia and finalized contracts to extend FNQ-P testing to these two countries (including translation into Swedish). This allows us to take a first look at expanded use of the measure beyond Canada (*cross-cultural validation*).

## IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE

Testing of the FNQ-P will allow clinicians to be confident about the measure when they go to use it. We anticipate that:

- Clinicians will be able to use this questionnaire to learn how well they are doing at meeting families' needs and how they can improve.
- This tool can be used for long-term monitoring of family needs, evaluation of services, and program planning.

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#### WHAT DID WE LEARN?

- Family participants in the Holland Bloorview reliability/validity sample told us they thought the FNQ-P was a valuable tool that could help them and other caregivers of children and youth with ABI.
- > Our international research partners in phases 2 and 3 of this study have expressed an interest in using the FNQ-P once we finish testing the measure.
- > Two-year timelines are recommended for research involving international partners to allow enough time for developing research contracts and translation agreements.

#### **NEXT STEPS:**

Phase 3 of the research, titled "Validation of the Pediatric Family Needs Questionnaire (FNQ-P) Across Five Countries" has been extended to include 2 other international partners. We are awaiting the data from all our partners at other sites before we conduct our reliability and validity analyses in order to meet sample size requirements. We will do cross-cultural validity testing of the FNQ-P (and translated versions as applicable) with up to 100 family caregivers of children and youth with ABI in Australia, Lithuania, the United Kingdom, and Sweden.

#### TO LEARN MORE ABOUT THIS STUDY, PLEASE CONTACT:

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#### WHO ARE WE?

#### **Holland Bloorview Team:**

- Caron Gan, Principal Investigator
- Virginia Wright, Principal Investigator
- Sarah Sheffe, Research Coordinator
- Kathy Gravel, Clinician Collaborator
- Sharon St. Jean, Family Collaborator
- Marilyn Ballantyne, Collaborator

#### **International Collaborators:**

- Ingrid van't Hooft, Astrid Lindgren Children's Hospital
- Naomi Brookes, Sydney Children's Hospital

#### **THANK YOU!**

We would like to extend our sincere thanks to the participants in this study, and to the health care providers that helped us to find participants!

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The Centre for Leadership in Acquired Brain Injury

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