

**Methods**

- **Study sample:** ~100 caregivers of children with disabilities, 2-19 years of age inclusive receiving care from one of the five hospital clinical areas:
  - Inpatient Complex Continuing Care and Specialized Orthopedic and Developmental Rehab
  - Outpatient Spina Bifida Transition, Neuromotor, and Autism clinics.
- **Reliability:** Test-retest reliability evaluation of the FNQ-PR.
- **Construct validity:** Evaluation of associations with *Impact on Family Scale-15* (IFS-15) and *Measure of Processes of Care-20* (MPOC-20).
- **Data Analysis:** Test-retest reliability evaluated via intra-class correlation coefficients (ICCs). Pearson correlations (r) for validity evaluations.

**Reliability and Evaluation Methods:**

- The FNQ-PR will be completed at two time points (baseline and retest) – 7-10 days retest interval
- The IFS-15 and MPOC-20 will be completed after the FNQ-PR at the baseline assessment.

**Measure Platform:**



**Anticipated Impact on Clients and Families**

The project aims to **lead and model social change** by enabling:

1. Caregivers to become more knowledgeable about and **empowered** to identify and advocate for their needs.
2. Clinicians to **personalize pathways** for families of children and disabilities through clinical adoption of the FNQ-PR.
3. **Mobilization of people and clinical teams** around center-wide FNQ-PR implementation using guidelines from the *FNQ-P Implementation Roadmap*
4. Long-term monitoring of family needs for **program planning and quality improvement**
5. **System connection** through multi-center use in pediatric rehabilitation research
6. **Discovery for action** by leveraging existing FNQ-P international links to enhance capacity and supports for families of children with disabilities

**Project Collaborators**

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**Funding**

- Centre for Leadership

# How are you doing at addressing the needs that are important to families of children with disabilities?



**Validation of the Pediatric Family Needs Questionnaire for Pediatric Rehab [FNQ-PR]**

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**Background**

- Families of children with disabilities experience a large variety of needs over and above those of families with typically developing children.
- Lack of validated tools to assess family needs makes it challenging for clinicians to know what is important to families in the rehabilitation process.
- The Family Needs Questionnaire – Pediatric Version (FNQ-P) was developed to enable a family whose child has sustained an ABI to identify their needs and the extent to which each need is currently met.
- In collaboration with 12 family leaders and 9 clinicians, we adapted the well-validated FNQ-P to make it suitable for children across a wider range of disabilities (**Family Needs Questionnaire – Pediatric Rehabilitation Version [FNQ-PR]**).

**Objectives**

1. To conduct **reliability and validity** testing of the new co-created FNQ-PR
2. Prepare for **solution implementation** of this newly validated tool with families and into clinical care.

**Family Needs Questionnaire – Pediatric Rehabilitation Version**

How much has each need been met?	Not Needed	1 (Not at all met)	2 (Met a little)	3 (Somewhat met)	4 (Met a lot)	5 (Completely met)
1. To receive and have access to information about all changes in my child's health/condition in a timely manner.	<input type="checkbox"/>	1	2	3	4	5
2. To have information on my child's medical and rehabilitation needs (e.g., daily activities, medications, therapy, equipment, technology, etc.).	<input type="checkbox"/>	1	2	3	4	5
3. To have information on how my child's health/condition will impact his/her abilities in the future and into adulthood, including information on prognosis.	<input type="checkbox"/>	1	2	3	4	5
4. To have information explained in terms and in a language I can understand.	<input type="checkbox"/>	1	2	3	4	5
5. To understand what to expect from rehabilitation, including who is on my child's team, expected length of treatment, goals of treatment, family participation, etc.	<input type="checkbox"/>	1	2	3	4	5
6. To have questions answered thoroughly and respectfully in a timely manner.	<input type="checkbox"/>	1	2	3	4	5
7. To have access to ongoing information about my child's physical challenges (e.g., weakness, headaches, sensory challenges, stiffness/hypertonia, hypotonia, equipment needs, problems with vision or walking, etc.)	<input type="checkbox"/>	1	2	3	4	5
8. To have access to ongoing information about any challenges my child may have with thinking (e.g., confusion, memory, insight, learning, reasoning, concentration, communication, etc.).	<input type="checkbox"/>	1	2	3	4	5
9. To have information on current research regarding my child's health/condition.	<input type="checkbox"/>	1	2	3	4	5