



Family Leadership Program

Program Overview & Highlights

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Updated: Sept 2022

No boundaries

The Family Leadership Program (FLP)

An award-winning program through which volunteer **child, youth and family leaders** partner with the hospital and the Bloorview Research Institute to **co-design, shape, and improve** policies, programs, and services, and advance client and family-centred care.

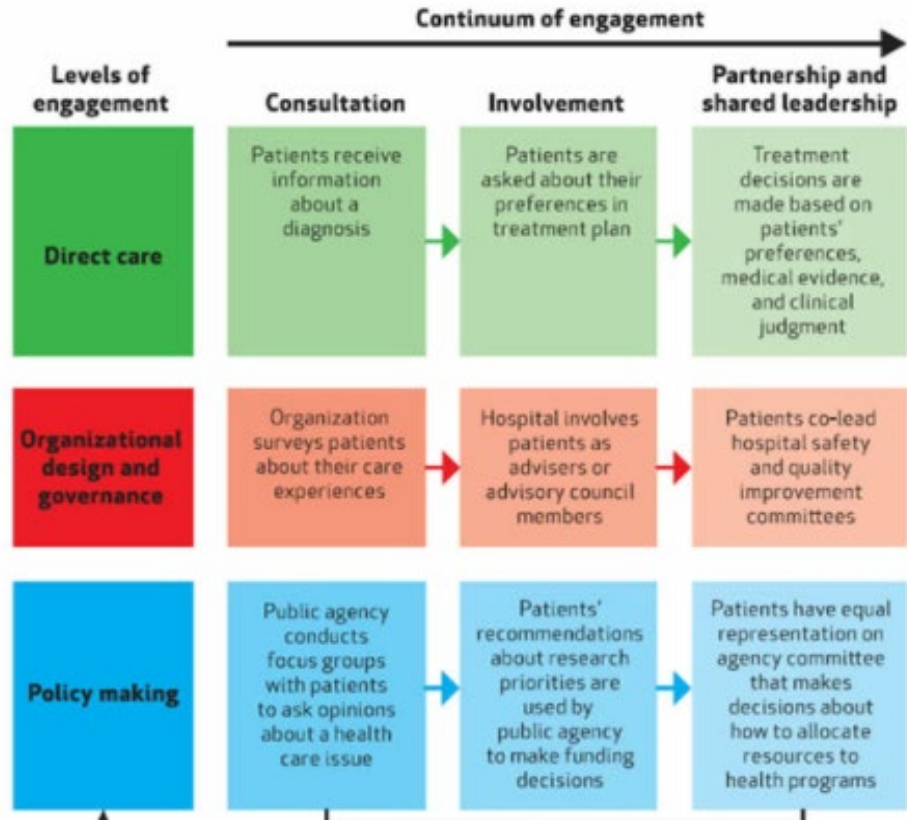


Grounded in Client and Family-Centred Care Practices

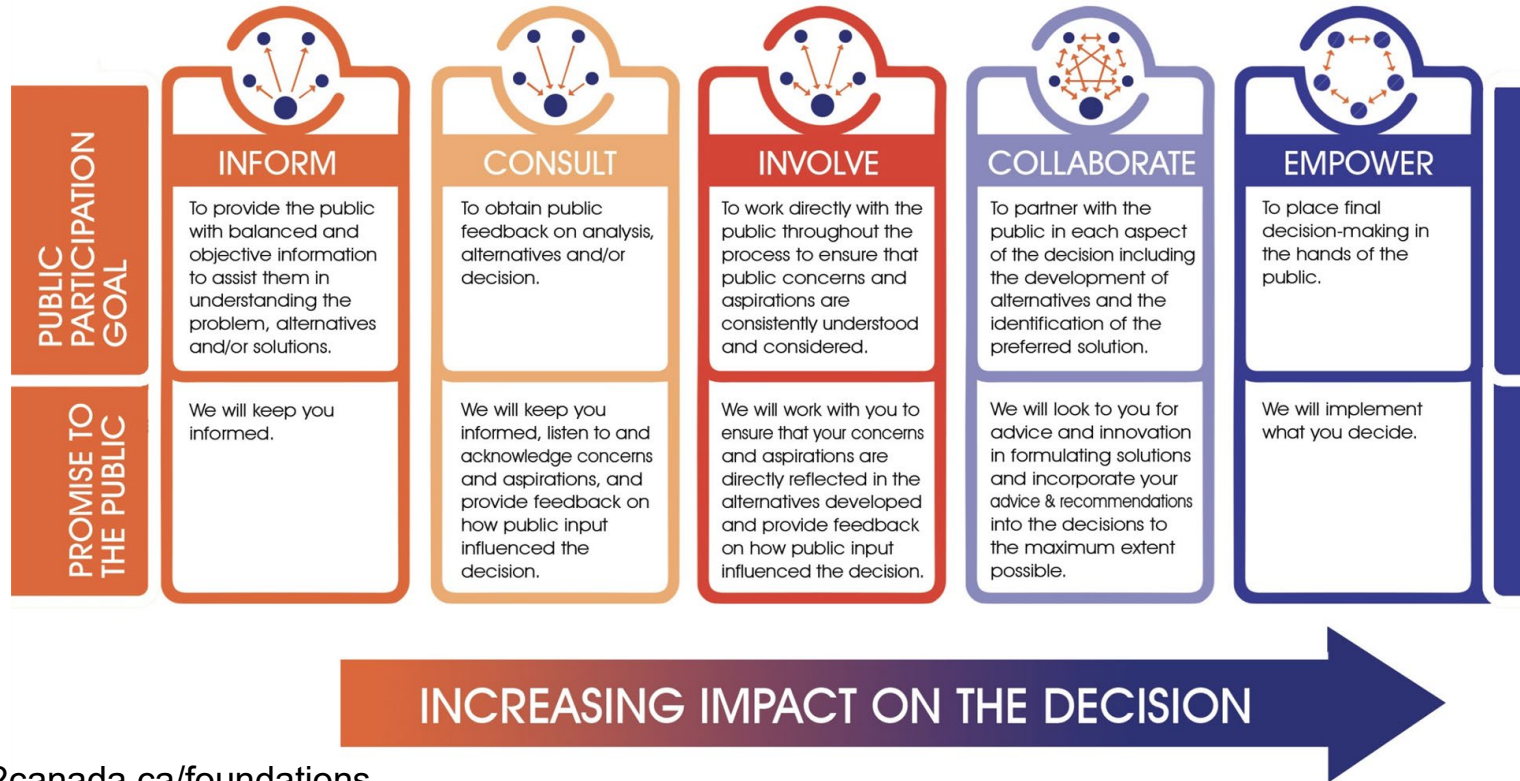
“Healthcare that establishes a *partnership* among practitioners, clients, and their families to ensure that decisions **respect clients’ & families’ wants, needs, and preferences** and that clients and families have the **education and support** they need to make decisions and participate in their own care.”

Our Family Engagement Approach: Focus on Partnership and Shared Leadership

Carman et al. framework (2013):
Illustrates a spectrum for family engagement and its various levels, methods, depths of partnership



According to the IAP2, public participation and engagement occurs along a spectrum



Recognition and Accolades



Leading health care
practice (Accreditation
Canada)



20 Faces of Change
Award (The Change
Foundation)



Sherman Award for
Excellent in Patient
Engagement



Merck Patients First
Award



Partnership Award
(Institute for Patient and
Family-Centred Care)



Innovative Team Award
(The Beryl Institute)



Organizational Leadership
Award (Children's
Healthcare Canada)

Milestones in our partnership journey



5 Guiding Principles of Client and Family Engagement



Inclusiveness

Family engagement integrates a diversity of family perspectives.



Co-develop

Stakeholders work together from the beginning to identify opportunities for improvement, set priorities, and implement solutions.



Transparency

Goals and expectations for all team members should be clearly identified and communicated.



Support

Adequate support and flexibility are provided to all members of the team to ensure that they can contribute fully.



Mutual respect

Acknowledge and value each other's expertise and experiential knowledge.

What we do: The Family Leadership Program Team



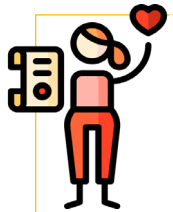
Volunteer Management

- Recruit, select, and train Family Leaders
- Provide ongoing professional development
- Manage volunteer database system, activities, tracking, and information



Family Partnership

- Match Family Leaders to opportunities
- Provide ongoing support to Family Leaders
- Coordinate the Family Advisory Committee and Research Family Engagement Committee



Recognition & Appreciation

- Celebrate the time, efforts, and talents of our Family Leaders with Spotlight Awards, gift cards, thank you notes, formal recognition events, award nominations.



Staff Education & Training

- Deliver CFCC training at New Staff, Interprofessional, and BRI Trainee Orientations
- Provide Authentic Partnerships Training
- Co-facilitate simulations on client and family-centred care



Evaluation & Reporting

- Implement annual experience survey on family engagement and partnership
- Provide performance reports on activities and achievements of program



Engagement Consultations

- Consult on family partnership framework, opportunities, and practices within HB and in the health care system
- Foster new partnership opportunities in initiatives, programs, and projects

Who are our Family Leaders?

Families and caregivers with lived experience of paediatric disability who have received services at Holland Bloorview



Diverse lived experiences across:

- Paediatric diagnoses, illnesses, and disabilities
- HB services accessed
- Inpatient and outpatient units
- Cultural backgrounds
- Migrant status
- Languages spoken at home
- Geographical location

Short- and long- term co-
design, partnership, and/or
consultation on committee,
project, initiative, & materials

**Family
Advisor**

Short-term and/or one-time
consultation in the research
process

**Family
Advisor**

Long-term partnership on a
study and/or research lab;
potential co-authorship

**Family
Partner**

1:1 virtual peer support,
resource navigation,
inpatient family support

**Family
Mentor**

Family Leader Roles

Co-teaching, co-facilitation,
and coaching in an
educational context with
clinicians, families and
learners

**Family
as Faculty**

Sharing family story as
learning opportunity for
scientists and trainees

**Lived
Experience
Educator**

**Family
Advisory
Committee**

**Research
Family
Engagement
Committee**



Family Leader Engagement during a Global Pandemic¹²

Health Literacy

Review of client-facing documents

Weekly inpatient letters,
Tip Sheets

Consultation & feedback on policies and processes

Masking, caregiver presence, return to school

Represent family perspective on committees

Pandemic & Recovery Planning, Virtual Care

Participated in Hiring Panels

Senior management, program level

Family as Faculty co-facilitated & co-taught events

Paperwork Parties, Transitions workshops

Lived Experience Story Presentations

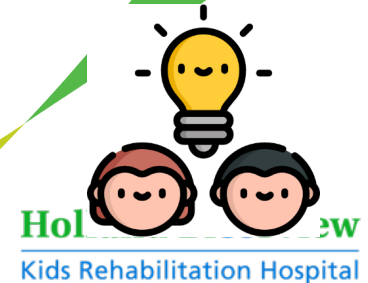
New staff, students

Family partnership with Bloorview Research Institute

Grant applications, Consultations

Social Advocacy

Children's Healthcare Coalition, Media Interviews



A helpful guide on how to engage with Family Leaders at the hospital

When you would like to partner with a Family Leader who can....

- Join your committee and working group as an active member
- Review your family-facing materials using a health literacy lens
- Co-design a better aspect of your service or program
- Meet with you one-on-one and provide family feedback
- Join your hiring panel and support recruitment efforts

Family Advisor

- Co-facilitate a family workshop
 - Co-teach a session on client and family-centred care to students, clients, or staff
 - Co-design learning experiences for families, students or staff
 - Share lived experiences and then facilitate a discussion
- **This role involves \$25/hr honoraria & completed training on teaching and facilitation in a learning context**

Family as Faculty

- Connect with families in the clinical areas as a peer support
 - Provide one-to-one support with finding resources and services
 - Help develop and facilitate a family inpatient or outpatient support group
- **This role involves completed training on how to provide peer support to families and caregivers.**

Family Mentor

How you can engage Family Leaders along the public participation spectrum

Inform

Submit a program update for inclusion in our bi-weekly Family Leader newsletter

Share an announcement at a Family Advisory Committee or Research Family Engagement Committee

Consult

Share a quick survey through the Virtual Advisory

Submit a request to consult a Family Leader on your project

Present at Family Advisory Committee or Research Family Engagement Committee and gather feedback

Involve

Submit a request for a Family Leader to join your committee, project, or working group as a full member

Submit a request for a Family Leader to conduct a health literacy review of your family-facing materials

Collaborate

Submit a request for multiple Family Leaders to join your committee as full members

Submit a request for a Family as Faculty to co-design and co-facilitate an educational solution

Co-lead a committee or project goal with a Family Leader(s)

Empower

Co-lead a Family Advisory Committee goal with a Family Leader

Create a Family Leader leadership group that directly advises and works with your project team. For example, creation of the Family Leader Accreditation Group during Accreditation cycles.

Do you want to partner with a Family Leader? We are here to support you.

- Contact familypartner@hollandbloorview.ca to speak with a member of our team about your engagement idea.
- In HB Connect, access and complete Family Leader request forms for hospital-based and BRI-based requests.
- When you submit a request, we work with you to match the most suitable Family Leader to your initiative, based on lived experience and skills.
- We provide ongoing support to you and the Family Leader, and we track the contributions for our annual reporting.

Our team is happy to speak with you!



Find me on HB Connect >> CFIC >> Family Leadership

Holland Bloorview
Kids Rehabilitation Hospital

A Rapid Response Family Leader's Experience

We were given many tangible opportunities to contribute and collaborate on different aspects of the hospital's response to the pandemic.

I personally volunteered to be part of a rapid-response team of Family Leaders who supported timely feedback on short-notice requests. I also provided input into virtual care as part of a multi-disciplinary/departmental steering committee.

Being a part of this important work makes me feel even more connected to Holland Bloorview not just as a hospital, but as a community.

~Meredith Sandles, Rapid Response Family Leader



Family Engagement in Research Framework

It is our **vision** that all research at Holland Bloorview will be informed and co-designed by clients and families in collaboration with researchers and staff.

Our **objective** is to enable family engagement in all aspects of the research process from conceptualization (thinking about research) to dissemination (sharing) of results .

Holland Bloorview's Family Engagement in Research Framework



Vision

Research at Holland Bloorview will be informed and co-designed by children, youth and families in collaboration with researchers and staff.

Objective

To enable family engagement in all aspects of the research process from conceptualization to dissemination of results.

Guiding Principles

Transparency
Co-Design
Support
Inclusiveness
Mutual Respect

Driven by...

- Holland Bloorview's culture of co creating with children, youth, families and alumni
- Guidance from the Research Family Engagement Committee (RFEC)
- Ethical guidelines for partnering with clients and families in research
- Up to date, evidence-based best practices, guiding principles and research
- Continuous and rigorous monitoring and evaluation
- Constant communication and consultation with the research community

References

1. Lorem ipsum dolor sit amet, consectetur adipiscing elit, nibh euismod tincidunt ut laoreet magna aliquam erat volutpat.
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Bloorview
RESEARCH INSTITUTE

Contact familypartner@hollandbloorview.ca
hollandbloorview.ca

Key Family Leader Roles in Research



Family Leaders can take on 1 or more of the following roles in research engagement:

Family Advisor: Provides advice or insight at a single point in time during the research process. Examples include reviewing a grant application, sitting on a panel, reviewing study material and providing feedback.

Family Partner: Participates as an active member of the research team throughout the research process. Examples include *co-investigator*, *knowledge user*, *collaborator* or *content expert*.

Lived Experience Educator: Educates researchers, research staff and trainees throughout the research process through sharing lived experiences. Examples include sharing family stories at meetings or communicating research results as part of a workshop or presentation.

Family engagement in research framework now on HB website!

Search: Holland Bloorview research family engagement committee



Learn more



Holland Bloorview's Family Engagement in Research Framework

A framework to support authentic and meaningful partnerships among families, staff, and researchers to advance childhood disability research.

↓ [**Download Framework**](#)

Guiding Family Engagement in Research

This Guide has been designed for all families, researchers, research staff and trainees seeking to use the Holland Bloorview Family Engagement in Research Framework.

↓ [**Download Guide**](#)

Guiding Family Engagement in Research:

A Framework from Holland Bloorview Kids Rehabilitation Hospital

A framework to support authentic and meaningful partnerships among families, staff, and researchers to advance childhood disability research.

Examples of Family Engagement in Research

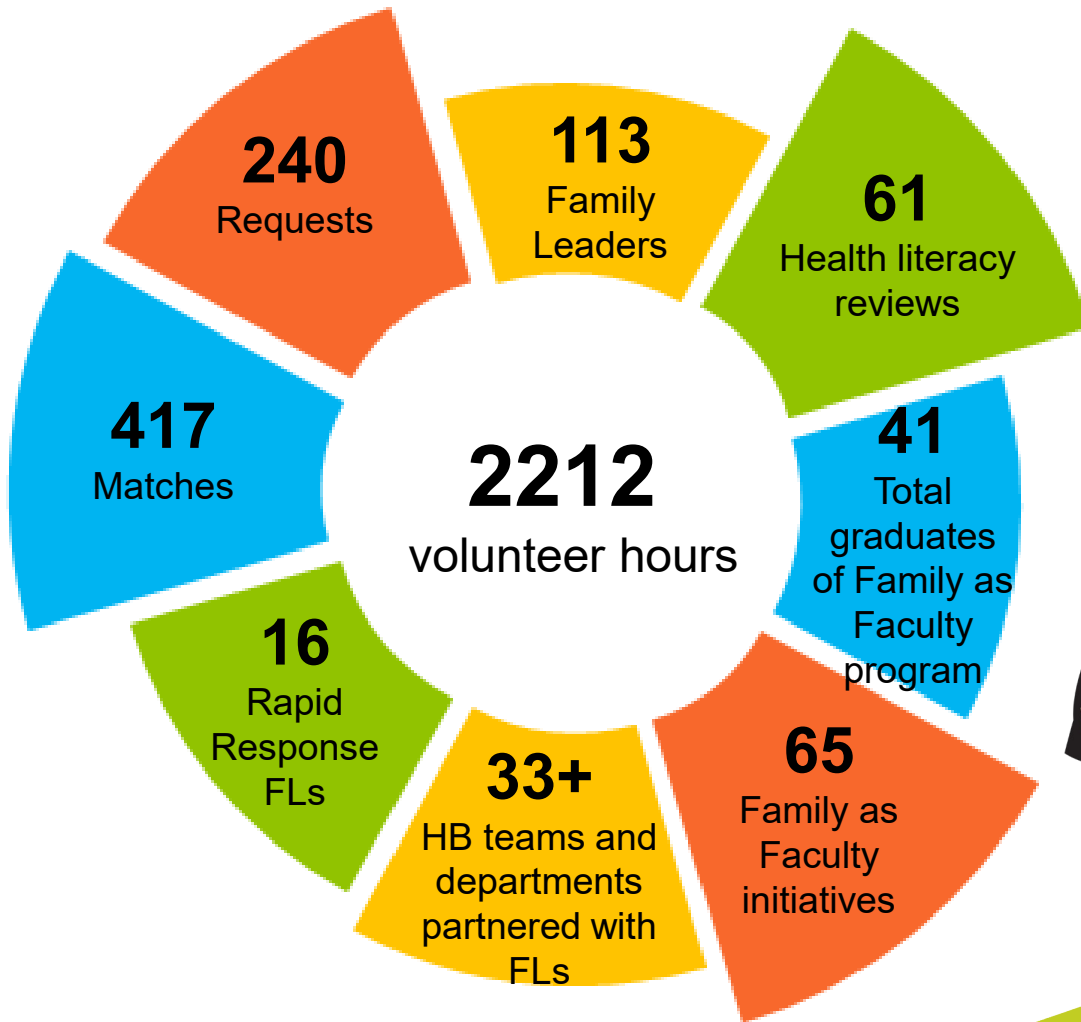
- Advise on functionality and design of a mobile application to help children with autism spectrum disorder with sleep training.
- Support as a Family Partner on a long-term research project which supports children with cerebral palsy and complex communication needs.
- Review a scientist's research proposal and provide meaningful feedback.
- Support in-person research at Holland Bloorview which examines the language and motor abilities of children with Autism.



<https://hollandbloorview.ca/stories-news-events/news/research-and-safety-go-hand-hand>

Holland Bloorview
Kids Rehabilitation Hospital

2021 - 2022 Program Snapshot



Thank you for your ongoing partnership and engagement of our Family Leaders and Family as Faculty across the hospital and BRI!



FLP Performance Dashboard – on HB Connect



Find me on HB Connect >>
CFIC >> Family Leadership



Family Leadership Program Dashboard | Q3 FY2021-22

Highlights

- **Operations:** Completed upgrade and full transition of Family Leader profiles, qualifications, and data to new volunteer management system called Better Impact.
- **Family as Faculty (FAF):** Streamlined feedback process to better support staff partnerships with FAF; 17 patient and family partner graduates across Holland Bloorview, CAMH, SickKids, and CHEO.
- **Family Leader Accreditation Group:** Partnered with staff across 6 standards teams over the past year.
- **Salute & Celebrate:** 30 Family Leaders celebrated 5, 7, 10, 15 year milestones.

113 Active Family Leaders
↑ 2% from Q2

55 New Requests for Family Partnership
↓ 7% from Q2

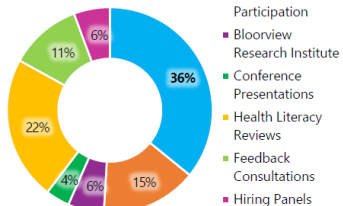
115 Family Leaders Matched to New Initiatives
↓ 3% from Q2

753 New Quarterly Volunteer Hours
↑ 8% from Q2

42 Committees with Family Leaders

Holland Bloorview
Kids Rehabilitation Hospital

New Activity across Engagement Types



Gratitude Moment

"Having the privilege to partner with family leaders in the rapid review process of weekly inpatient letters has been such a turn-key, collaborative and invaluable benefit and experience."

Ashley Cruz, Senior Media Relations Specialist

Family Leader Roles across Holland Bloorview

Clinical & Non-Clinical Programs

- **Family Advisor** – short/long term co-



Family Leadership Program Dashboard | Q4 FY2021-22



Two new Family as Faculty simulations co-developed with Family Leaders, simulation professionals, and Teaching & Learning. Simulations will be used to deepen learning and strengthen competencies.



For the third year, six Family as Faculty co-taught 20+ Masters of Social Work students in a disability practice course at the University of Toronto. This course was co-designed by Family as Faculty.



Research Family Engagement Committee meetings hosted "Scientist Stories" to strengthen mutual understanding and relationships among scientists, trainees, and families.



During Capes for Kids 2022, Family Leaders joined forces with the Client and Family Integrated Care team to raise a record \$12,157.04, helping the HB Foundation reach its fundraising goal of \$1 million.

113 Active Family Leaders
No change from Q3

76 New Requests for Family Partnership
↑ 38% from Q3

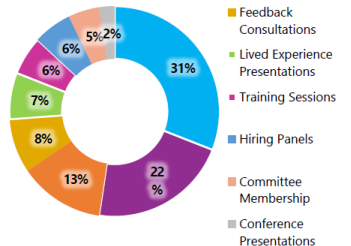
140 Family Leaders Matched to New Initiatives
↑ 22% from Q3

775 New Quarterly Volunteer Hours
↑ 3% from Q3

103 Family Leaders on 41 Committees

Holland Bloorview
Kids Rehabilitation Hospital

New Activity across Engagement Types



Family Leader Roles across Holland Bloorview

- **Clinical & Non-Clinical Programs**
- **Family Advisor** – short/long term co-design, feedback, and/or consultation; committee membership
- **Family as Faculty** – co-teaching & co-facilitating family and clinician education
- **Family Mentor** – 1:1 family support, resource navigation

Bloorview Research Institute

- **Family Advisor** – short term and/or one time consultation
- **Family Partner** – long term partnership on study/research
- **Lived Experience Educator** – sharing family story at research meeting

To learn about family engagement or refer someone to join the Family Leadership Program, email the team at: familypartner@hollandbloorview.ca

Contact: Clara Ho, Manager of Client and Family-Centred Care & Partnerships. Email: cho@hollandbloorview.ca Phone: x6420

Refreshed Family Mentor Program

- Trained Family Mentors provide HB families and caregivers with one-to-one in-person and virtual emotional support and resource navigation sessions.
- Family Mentors moderate a new Family Support Network on Facebook that is a safe and welcoming space for HB families to connect with each other.



www.hollandbloorview.ca/familymentor

Holland Bloorview
Kids Rehabilitation Hospital

Connect with a Family Mentor today

Family Mentors listen, provide emotional support, and most importantly, help you feel less alone in your caregiving journey.

Family Mentors have lived experiences as a parent/caregiver of a current or former Holland Bloorview client. They are trained to provide peer support to other caregivers and family members of Holland Bloorview clients. They are passionate about connecting with families, being good listeners, and providing helpful tips. Family Mentors can meet with you in-person or virtually.

Holland Bloorview
Kids Rehabilitation Hospital

Recognizing our Rapid Response Family Leaders

"Having the privilege to partner with family leaders in the rapid review process of weekly inpatient letters has been such a turn-key, collaborative and invaluable benefit and experience.

The communications team is so grateful for this partnership and the learnings garnered from their feedback."

Ashley Cruz, Senior Media Relations Specialist

Recognizing our Family as Faculty

"Family as Faculty were key in the co-creation and facilitation of the Nursery Schools Transition to School Family Workshop.

They were instrumental in co-identifying transition to school questions in earlier virtual support groups to inform the workshop topics; their inclusion of lived experiences in the workshop and follow-up virtual support groups on the topic ensured the Nursery Schools team were meeting the ongoing transitional needs and questions of families."

Laura Howson-Strong, Early Learning and Development Leader



Student appreciation for Family Leaders

"Simply put, the family leaders offer us their lens. Their insights, gained through embodied and lived wisdom, have contributed significant and invaluable amounts of growth and education to my practicum experience.

I believe that their voices ripple into the care we provide; guiding us to practice with elevated empathy and compassion."

Student, Student-Led Learning Environment

