

# CHILD-BRIGHT Network Sustainability Report

*Dated September 1, 2020*



**From Network to Movement**





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## About the CHILD-BRIGHT Network

The CHILD-BRIGHT Network, headquartered at the Research Institute of the McGill University Health Centre (RI-MUHC), is an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. Using family- and child-focused approaches, we are creating novel interventions to optimize development, improve health outcomes, and deliver responsive and supportive services. Co-directed by investigators at the BC Children’s Hospital and The Hospital for Sick Children (SickKids), CHILD-BRIGHT is made possible thanks to grant funding from the Canadian Institutes of Health Research (CIHR) under Canada’s Strategy for Patient-Oriented Research (SPOR), and financial support from 28 generous funding partners from public and private sectors across Canada.

### CHILD-BRIGHT’s early work

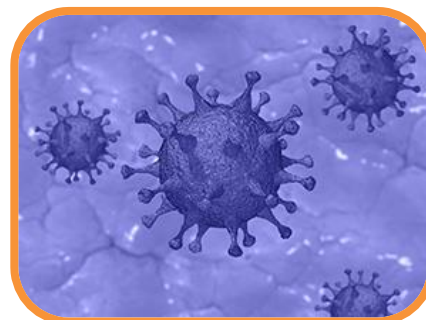
Our funding period began in April 2016. In our first four years as a pan-Canadian SPOR chronic disease network focused on children with brain-based developmental disabilities and their families, we have successfully:



We have also put in place a CHILD-BRIGHT Data Coordinating Centre and a Health Economics Service, both of which support our research projects, as well as executive and central office teams that effectively oversee the day-to-day operations of the network.

Over the past four years, we have watched our network grow. We share successes broadly through our social media channels and through network newsletters. Our social media presence and network newsletter reach has expanded accordingly. We now have more than 2,500 social media followers and more than 1,100 newsletter subscribers. Approximately 330 individuals are now also considered level 3 or 4 members in our engagement metric (see appendix 1), meaning that these members engage, contribute, partner with us and champion our patient engagement cause actively.

Our recent pivot to numerous additional initiatives in support of families during the first months of the pandemic demonstrates our continuing commitment to the well-being of children with disabilities and their families. We developed and maintained a [list of resources](#), published a [rapid review](#), advised a [federal disability advisory](#) group and co-launched the [My COVID Disability Q.](#) Twitter campaign with two partner organizations. This work attests to our agility and responsiveness to contemporary challenges faced by our children, youth, and families.



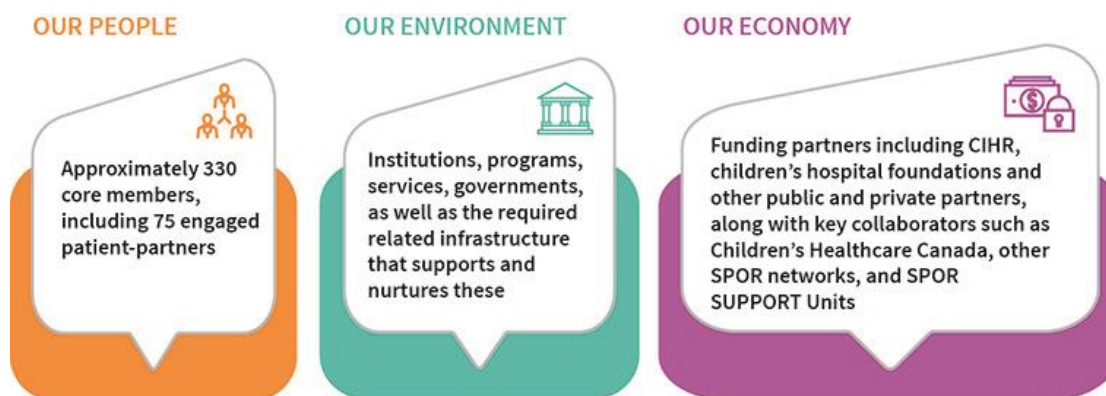
## Turning our sights to sustainability planning

As we move ahead in our mandate and work, we increasingly turn our attention to strategizing the sustainability of this work in the years to come, so we can build upon our successes and reach new goals.

This sustainability report describes how we, at CHILD-BRIGHT, plan to continue our mission, meet the needs of our citizens and members, grow to meet future needs, and realize our vision. It also highlights how we have involved our members and citizens in this strategic planning.

### Our pillars

In the next five-year phase of CHILD-BRIGHT, we expect not only to maintain the critical infrastructure needed to support our four programs and additional services but to plan and develop new initiatives for greater impact. For this, we will count on our core stakeholders, who constitute our three pillars of sustainability:



### Our premise

We believe that by expanding our impact and helping to change the child health ecosystem (health care, social services, recreation, education, family, and home), we will achieve our vision of brighter futures for children with brain-based developmental disabilities and their families.

We will do this by:

- 01 Using a patient-oriented research approach to create evidence
- 02 Strengthening our partnerships through enhanced engagement
- 03 Mobilizing our collective expertise to influence health care providers and health care decision-makers, to make a real and lasting difference in the lives of patients and families

### Our goal

If we are able to continue on our current trajectory, *CHILD-BRIGHT will become a movement for change: moving patients into research, moving research into improved practice and policy, and moving children and families forward to brighter futures.*

### Our approach

We have great wealth in our social capital as well as in the effective and efficient infrastructure we co-designed with our partners. We will continue to co-build this movement, which will necessitate more diverse voices, more sharply focused and compelling messages, and more receptive listeners. This will require greater depth and wider scope in the work that we support.





### Our aim

We aim to sustain CHILD-BRIGHT for an additional five years in order to:

- 01

Advance the child health patient-oriented research agenda in Canada
- 02

Expand the scope and depth of brain/child/family research for better health and health care
- 03

Mobilize research results to influence policy and clinical practice
- 04

Embrace values of equity, diversity and inclusion, ensuring that the rights of children with disabilities from diverse backgrounds are respected, and their families are empowered
- 05

Harness existing and new partnerships as we shift from network to movement

## Sustainability Planning Undertaken in 2019

### Our cycles

Within this report, we will reference two cycles of funding.

- Phase One

References our current funding cycle under the CIHR SPOR initiative, which runs from 2016 to 2021, with an extension period to 2023.
- Phase Two

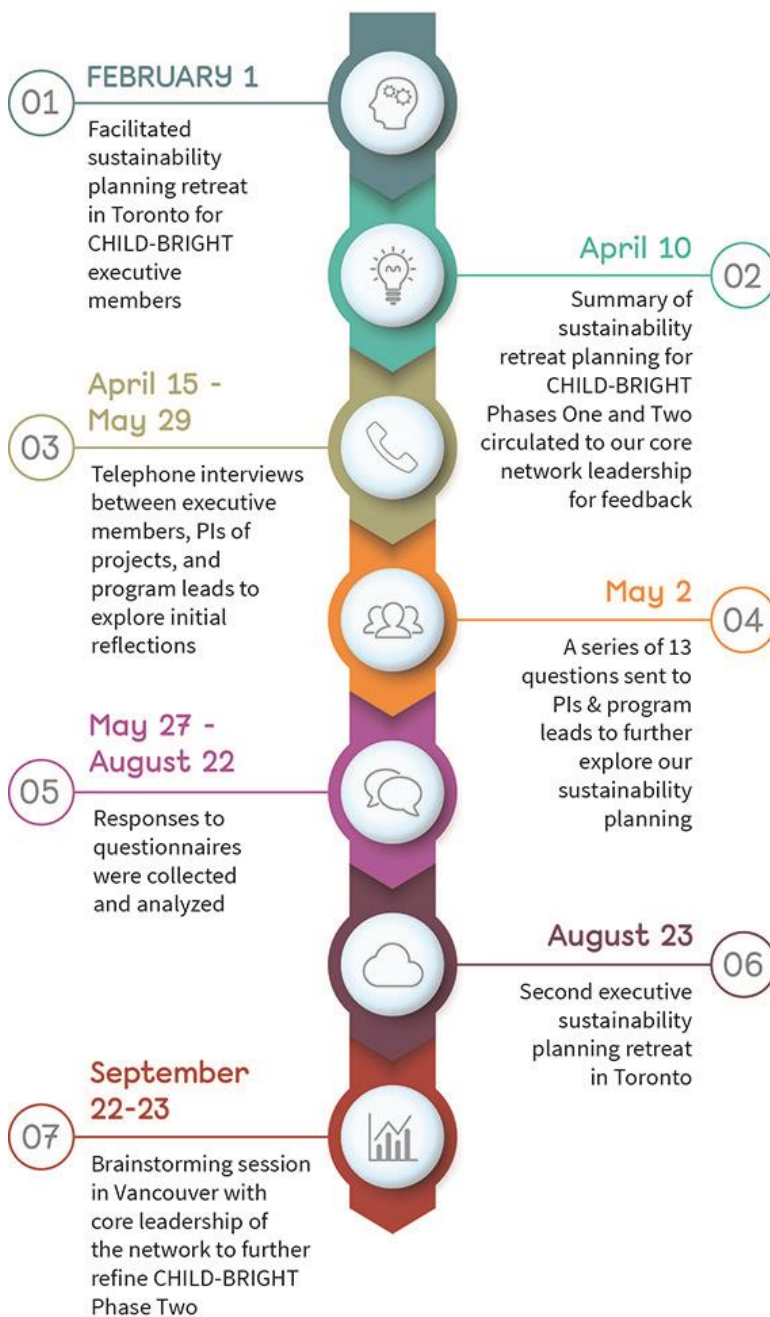
References a future five-year period of funding that we hope to secure to continue to advance and sustain our work.

### Engaging key stakeholders to set our path

Mid-way into our initial five-year mandate as a SPOR network, the executive team reflected on what we had achieved thus far and where we hoped to be at the end of our funding cycle. We undertook several steps in 2019 to begin our sustainability planning in support of both CHILD-BRIGHT phases. The graph on the following page summarizes these steps.

# 2019

## CHILD-BRIGHT Sustainability Planning



## *Sustainability planning steps - detailed*

### 01 FEBRUARY 1, 2019

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The executive team met for a one-day retreat to strategize and articulate our target outcomes for the end of CHILD-BRIGHT Phase One (now extended to March 2023). We also began exploring longer-term outcomes for a potential CHILD-BRIGHT funding cycle of another five years (CHILD-BRIGHT Phase Two).

### 02 April 10, 2019

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We consolidated our desired outcomes for CHILD-BRIGHT Phase One and a potential Phase Two in a document that we distributed to the PIs of our research projects, for review and consideration with their teams. It was also circulated for feedback to the leads of our programs and services.

### 03 April 15-May 29, 2019

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The co-directors on the executive team followed up with PIs and program leads via individual phone interviews to share perspectives and gather initial feedback on the proposed sustainability plan for Phases One and Two. In particular, expectations with respect to engagement of their teams in patient-oriented research training and in the completion of patient engagement surveys were discussed, and data about the involvement of patients in their teams was shared. The executive members emphasized that feedback about the sustainability plan for the current and future cycles would be essential.

### 04 May 2, 2019

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The CHILD-BRIGHT Phase One and Phase Two strategic planning document was recirculated to the research and program teams, together with a strategic direction questionnaire. Thirteen questions accompanied the document, asking for:

- Their project's/program's reactions and ideas related to the sustainability document
- The ways that the network was helpful thus far
- Any unmet needs or supports required (now and in the next cycle)
- Their expected contributions (research, patient engagement) by the end of CHILD-BRIGHT Phase One
- Next steps for their research project to include scalability, policy/practice changes, and potential target users
- Potential future funding partners
- Commercialization opportunities, and
- Other priorities to consider.



## 05 May 27-August 22, 2019

Responses from teams were received by May 27, 2019. Over the course of the summer, the executive team carefully reviewed the extensive feedback received in preparation for a second executive sustainability planning session.

## 06 August 23, 2019

The executive team met in Toronto for a second full-day sustainability planning retreat. There was broad consensus on the proposed desired outcomes for CHILD-BRIGHT Phases One and Two. However, it was felt that a face-to-face meeting with core leadership would be important to further refine the sustainability plan for CHILD-BRIGHT Phase Two. The executive began to make detailed plans for a meeting with these members in September.

## 07 September 22-23, 2019

Approximately 50 of our core members gathered in Vancouver for a two-day brainstorming session. We highlighted modifications to our initial sustainability plan proposal, based on written and verbal feedback received from our members. Each member was then assigned to participate in two of five breakout groups, which focused on citizen engagement, knowledge translation, research, capacity building/training, and evaluation, respectively. Each group brainstormed responses to three questions within the framework of the specific focus of their group (i.e. engagement, KT, research, training, and evaluation), to help guide future directions for CHILD-BRIGHT Phase Two. These questions were:

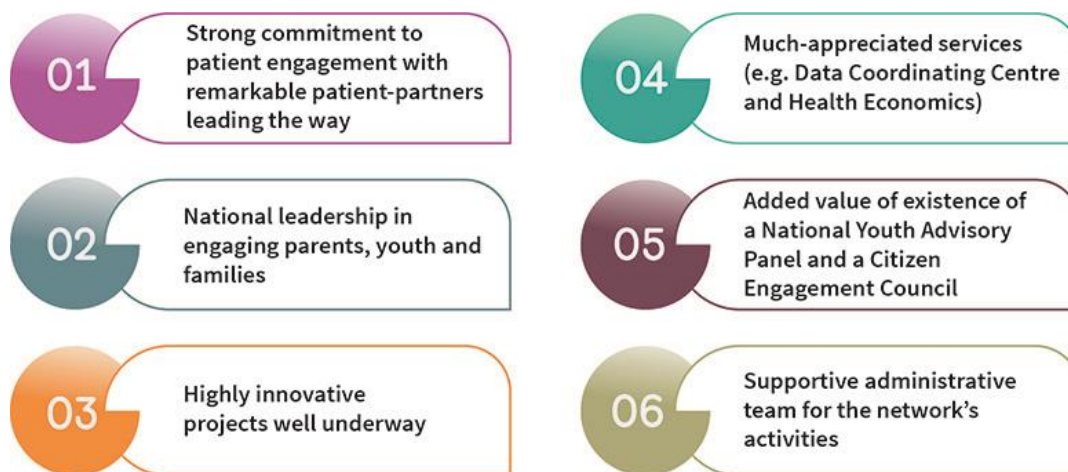
### Q. In your group's assigned domain:

1. What does CHILD-BRIGHT Phase Two success look like?
2. How should the network support the success of your activities in Phase Two? (needs for you and your team)
3. How could you contribute to CHILD-BRIGHT Phase Two's success? (your contribution to the network).





Throughout this stakeholder engagement process, a number of strengths were emphasized:



Some specific areas to address in the short term included:

- Capture more information in our patient profiles; promote and support the leadership of more patient-partners, and improve new patient-partners' orientation to the network
- Articulate the difference between 'project grant' and 'network grant' to include CIHR requirements
- Consider changes to patient engagement measurement (measures, processes)
- Rethink patient compensation for additional network-wide activities
- Add more theme meetings to focus on recruitment, ethics, engagement strategies, and service offerings
- Broaden knowledge translation and training opportunities
- Improve the financial management of the network
- Reconsider the terms used in defining outcomes as they are not currently user-friendly (e.g. first-in-human, ecosystem).



**“Our administrative team is working hard to bring together our different citizens to share their unique perspectives in our various programs and research projects; they help ensure all voices are heard.”**

**Network Director**



## Desired outcomes by the end of CHILD-BRIGHT Phase One

Below are the outcomes we aim to achieve by the end of CHILD-BRIGHT Phase One. Important recommendations to further expand these outcomes emerged from the consultation process. These suggestions are articulated below ('after consultation').

<b>01</b>	Enhanced authentic, influential, and partnership-based patient engagement
<p>FEEDBACK RECEIVED DURING THE CONSULTATION PROCESS</p> <p>Authentic engagement of the <b>broad community of citizens</b>, with impact</p>	
<b>02</b>	Greater knowledge about the conduct of 'first-in-human' patient-oriented clinical trials.
<p>FEEDBACK RECEIVED DURING THE CONSULTATION PROCESS</p> <p>To include, <b>sharing knowledge about patient-oriented research</b></p>	
<b>03</b>	<p>New evidence to improve child and family health &amp; well-being relating to:</p> <ul style="list-style-type: none"> <li>a. The brain of the child/youth and parents</li> <li>b. The well-being of the child/youth and parents</li> <li>c. System navigation and empowerment with an emphasis on critical periods of transition</li> </ul>
<p>FEEDBACK RECEIVED DURING THE CONSULTATION PROCESS</p> <p>Link new evidence with <b>stories</b> and with <b>changes in the health care system</b></p>	
<b>04</b>	Readiness to support the <b>rapid uptake</b> of trial results
<p>FEEDBACK RECEIVED DURING THE CONSULTATION PROCESS</p> <p>To include knowledge translation program as a <b>service</b></p>	
<b>05</b>	Improved <b>ecosystem</b> for child health patient-oriented research
<p>FEEDBACK RECEIVED DURING THE CONSULTATION PROCESS</p> <p><b>Supported by network infrastructure</b></p>	
<b>06</b>	Enhance the <b>value</b> of our network by <b>building the diversity of our community</b> for greater collective impact
<p>NO ADDITIONAL FEEDBACK RECEIVED</p>	

For each desired outcome, we proposed strategies, detailed below, for closing the gaps that remain. The success of these strategies will require higher levels of project and member engagement. Deeper engagement within the network thus becomes everyone's responsibility and will define the added value of the network. Actions completed and underway are also included below.

## Patient engagement



### Actions (2019-23)

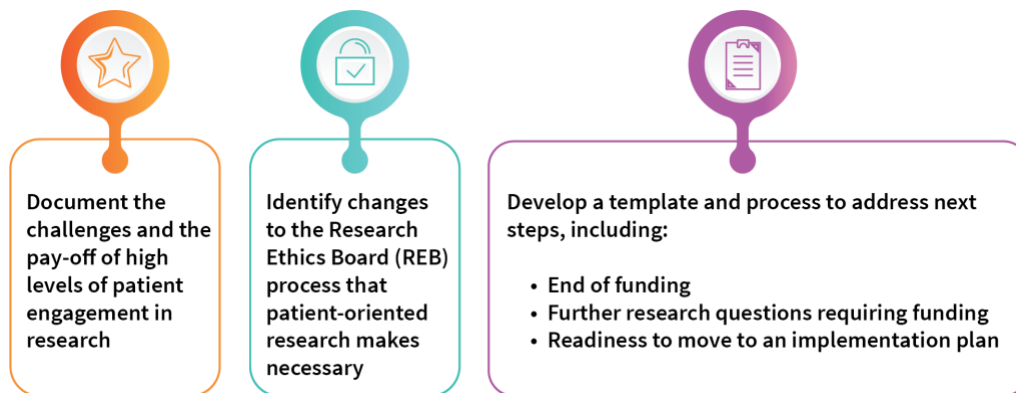
- Compensation expanded beyond engagement in projects and committees to include patient-partner work for the network at large
- Provide feedback to teams regarding training attendance, for greater accountability
- New quantitative measure of patient engagement included as part of annual surveys
- Qualitative interviews on patient engagement experience being introduced
- Tip sheet for engaging youth in research developed by our National Youth Advisory Panel members
- Review of scientific evidence on engaging families of low socioeconomic status and development of surveys to identify ways of increasing the engagement of such families
- Created an accessibility workgroup to address accessibility problems or barriers in network processes and activities
- Ongoing collaboration with the Canadian Child Health Clinician Scientist Program (CCHCSP) and with the Ontario and BC SPOR Support Units to develop online training modules as part of a Patient-Oriented Research Curriculum in Child Health (PORCCH)
- Developed a parent peer mentor role and refined it with the help of both peer mentors
- Created a protocol for exit interviews for patient-partners who left the network and a process for applying what was learned in the interviews
- Formed a recruitment working group that identified resources (especially on social media) and mechanisms (e.g. short videos, blogs by parents about why they enrolled their children in studies, etc.) to help projects improve their recruitment of study participants.



“Contributing to research can be a healing experience for families who have gone through a difficult health journey. Knowledge translation from the family/patient perspective is enhancing the evolution of research and making it more accessible for both the researcher and the families.”

**Parent-Partner**

## First-in-human trials



### Actions (2019-23)

- Parent peer mentor gathering of evidence on challenges and benefits, from the perspectives of parent-partners
- Patient engagement measurement workgroup created to review current measurement approaches and feedback, and to suggest better approaches to evaluating benefits and challenges
- Research project presented and submitted for publication on patient engagement experience in one of our trials
- Collaborating in a national project looking at harmonizing child health research ethics across Canada; our role in the team is to provide the perspectives of patient-partners who are children/youth and parents
- Sharing of experiences among PIs about patient-oriented research experiences and strategies in theme meetings
- Financial consultant hired to assist with the consolidation of financial information to inform our objectives, our strategic decision making with respect to allocation of resources to complete Phase One objectives, and to inform our Phase Two planning
- A multi-stakeholder research priority setting task force was created to determine research priorities for Phase Two.



“We are going to help children with chronic disease live longer, healthier, more successful lives. We will involve patients in the process, will listen to their needs, and will help ensure their voices are part of the conversations moving medicine forward and improving outcomes.”

Youth

## New evidence (three themes)



## Actions (2019-23)

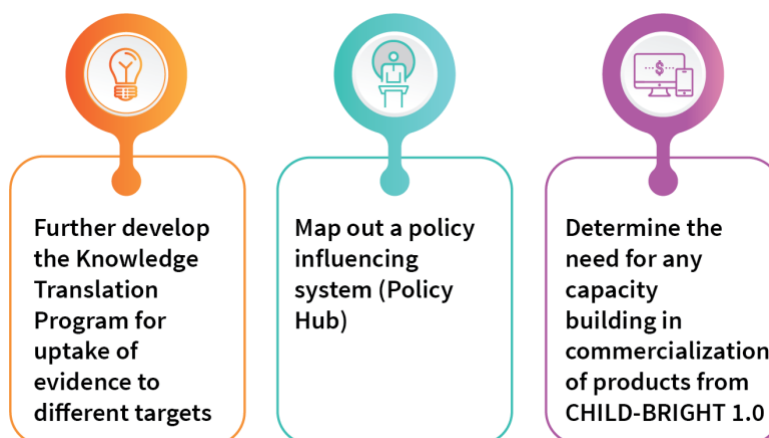
- Hired an additional communication team member to assist with documenting and sharing stories
- Participated in webinars hosted by Children’s Healthcare Canada on research successes
- Expanding our National Youth Advisory Panel, and developing a consultation service that can be available to child health researchers outside of our network
- Undertaking an individualized approach by the KT program team to develop a KT dissemination plan for each project and identify support needs
- KT program reaching out to each project team to assist in planning KT strategies once their project is completed
- Periodic surveillance of the impacts of the ongoing pandemic, particularly with reference to sustained funding to complete the project.



“Youth provide a perspective about technology usability and engagement that adults simply do not have.”

Researcher

## Positioning for rapid uptake and use by decision makers



### Actions (2019-23)

- Creating a hub to promote bidirectional exchanges between network and policy makers, to expand our influence and increase capacity for translation of our work into policy (Policy Hub)
- Partnered with the SPOR Evidence Alliance to conduct time-sensitive rapid reviews
- Strengthening our partnership with Children’s Healthcare Canada to promote uptake of new knowledge to target users in health care. The Children’s Healthcare Canada CEO now also sits on our Network Steering Committee.
- Created an implementation science and policy workgroup to align current efforts in policy making and to provide strategic guidance for CHILD-BRIGHT Phase Two in implementation/uptake of knowledge created by the network in Phase One.



“Through our research programs, we promote the fundamental human rights of children with disabilities such as the right to health, the right to develop in nurturing communities, and the right to play.”

Researcher

## An ecosystem for child health patient-oriented research



### Actions (2019-23)

- Aligning with other SPOR entities to develop a proposal for a national training entity on patient-oriented research with one of our co-directors as co-PI
- Developed training targets (in %) for each team, to help set expectations
- Determining research themes and projects for CHILD-BRIGHT Phase Two with leadership of our priority-setting task force and extensive citizen engagement—including membership on the task force.
- Developing new partnerships and strengthening existing partnerships with organizations that have national influence.



"I hope to learn more about patient-oriented research & knowledge translation. The application of these two methods could lead to advancement in current clinical practices and could optimize patient-related outcomes."

**Trainee**



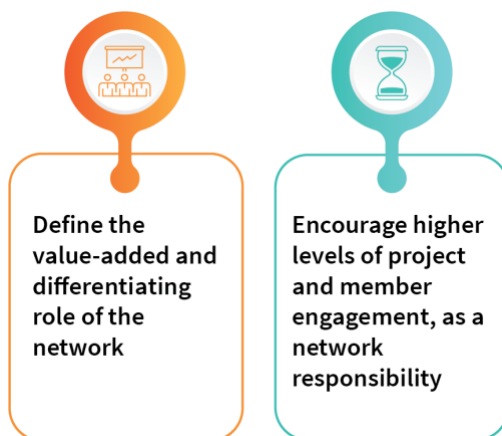
"Hearing the stories and speaking with parents about obstacles they've overcome allowed the intervention to be more specific to the needs of children with disabilities and their families. Specifically, there were many things that these parents experience that can't be found in a book that made their advice invaluable to our project."

**Summer student**





## Value of the network



### Actions (2019-23)

- Writing personal stories about the added value of the network
- Engage policy makers to better determine CHILD-BRIGHT's value to them and to identify the most effective communication and collaboration approaches for working with them and their teams
- Continuing to onboard new citizens to broaden our reach
- Enhance the membership's awareness of our assets
- Revisiting our governance structure to reflect greater network engagement and responsibilities of members
- Responded proactively to new patient-partner needs during the pandemic, to optimize access to evidence and credible information to empower families.



"I feel a sense of excitement at the end of teleconference meetings because I feel I'm a part of something that could truly make a change, make a difference. That momentum stays with me and fuels me to dive back into the daily ritual of therapy and appointments and schedules that support my son."

**Parent-Partner**

## Envisioning CHILD-BRIGHT Phase Two

### *Mobilizing a Movement for Change*

CHILD-BRIGHT Phase One is addressing the challenge of moving research discoveries into human trials and clinical studies using patient-oriented research approaches to enhance relevance and impact. CHILD-BRIGHT Phase Two will continue some of that work, but the focus will shift to moving the results of completed work into wider application. **This will require the development of some new competencies within the network as well as outreach to a broader set of partners.**

While funding from SPOR remains the cornerstone of the network's resources in the foreseeable future, we recognize **the need to obtain funding from additional sources if the network is to both strive and be sustainable.** To achieve that funding, the value of the network will need to be clearly articulated.

The following initial ideas with respect to CHILD-BRIGHT Phase 2 were shared

### Research

- While the shift is to implementation, some 'first-in-human' clinical trial projects must be continued to provide opportunities for researchers with patient-oriented research capability and to ensure a ready supply of projects for implementation
- The process of implementation science will be studied, including knowledge mobilization to key target users (clinicians, health service managers, policy makers) and toward commercialization
- New ways of clustering the implementation projects will be considered e.g., based on methodology/intervention approach, such as coaching
- Desire to be more innovative: create a 'proof of concept' fund for smaller higher-risk projects
- Intent is to bring new researchers into the network through a competitive process for selecting new projects.

### Knowledge Translation

- Need to start considering now how to build the brand and influence decisions. This includes broadening communication to government, media, health administrators, heads of children's treatment centres, health-oriented organizations, etc.
- Identify the role of the network 'core' in providing access to/connecting with the organizations, and developing elements well-positioned to influence policy and practice
- Role is to facilitate and enable commercialization which could include developing the effectiveness of researchers in this regard.

## Capacity Building

- Continue to build capacity to conduct patient-oriented research trials and engage with policy makers
- Training graduate students (highly qualified personnel) to be more competent in patient-oriented research trials
- Training Research Ethics Boards in the reasons and the ways patient-oriented research is changing ethical assessments of proposed trials
- Leadership development for patient-oriented research leaders: succession planning, training and mentoring parents to take on leadership roles in the network – and beyond
  - Highly individualized approach for those expressing interest
  - Consider creation of a Leadership Learning Community for patient-oriented research
  - Make additional necessary changes to compensation guidelines.

## Diverse & Inclusive Citizen Engagement in Patient-Oriented Research

- Encourage diversity and inclusivity: include under-represented communities
  - Broaden the citizen engagement parent/youth demographic  
Engage more broadly across the system to include more influencers of health care system: policy makers, health system decision-makers, and clinicians.
  - Leverage learnings from our Prenatal Opioid Exposure and Neonatal Abstinence Syndrome project team: needs assessment in First Nations communities
  - Integrate patients/parents from disadvantaged socioeconomic backgrounds
- Keep building youth engagement
- Plan for broader and deeper engagement of patient-partners in the earliest phases of research
- Determine and support citizen role(s) in the uptake of research findings.

## Evaluation for Impact

- Introduce mechanisms to develop implementation science and monitor implementation
- Further build health economics capability in order to assess the cost-effectiveness of interventions and to increase the uptake of research findings
- Measure the success of the individuals within the network
  - Determine whether *researchers* conducting patient-oriented research find their research more meaningful
  - Determine whether *parents and youth* are or feel more empowered and effective as research partners
- More grant submissions (in child health) to CIHR and elsewhere using a patient-oriented research approach
- More citations of papers that involved a patient-oriented research approach.



## Building a Movement

- Measure cohesion of network community, working towards common goals
- Increase the awareness of CHILD-BRIGHT through children’s health care networks, governments, community organizations, media, public
- Building on the ‘tipping point’ theory popularized by Malcolm Gladwell; increase the sphere of influence of our network so that we may ‘tip’ the balance of childhood disability research and bring about change in practice and policy



“I feel privileged to be part of an incredible team whose efforts and dedication have not only inspired me but have instilled hope within me, that a greater future exists for families touched by autism. My participation in the study has encouraged me to reflect on the journey and the challenges we have faced since our son's diagnosis, and given me the opportunity to use this experience to make a positive impact on the development of future services.”

Parent-partner

Sustainability for CHILD-BRIGHT means amplifying the impact of our patient-oriented research program to achieve our vision for a brighter future for children with brain-based developmental disabilities and their families.





## Appendix 1: CHILD-BRIGHT Engagement Metric

### Levels of Engagement

#### HELP US RAISE AWARENESS

1

- Stay informed about CHILD-BRIGHT through the website ([child-bright.ca](http://child-bright.ca)) and through the CHILD-BRIGHT newsletter
- Help raise awareness by following CHILD-BRIGHT on social media

#### PARTICIPATE AND LEARN

2

- Learn about CHILD-BRIGHT by attending CHILD-BRIGHT events in person or online (training sessions, webinars, scientific cafés, CHILD-BRIGHT conferences, etc.)
- Participate (or facilitate my child's participation) in a CHILD-BRIGHT research study
- Participate by submitting questions, comments or ideas to CHILD-BRIGHT and/or by sharing or commenting on CHILD-BRIGHT social media posts and website content

#### CONTRIBUTE & PARTNER WITH US

3

- Contribute by responding to CHILD-BRIGHT surveys or by attending a focus group
- Contribute by submitting content destined for CHILD-BRIGHT publications (website, newsletter, report to community, etc.)
- Get involved in CHILD-BRIGHT events as a sponsor or a speaker
- Collaborate as a team member (patient-partner, trainee, researcher, employee, other) on a CHILD-BRIGHT research project, or as a committee member in a network program

#### CHAMPION OUR CAUSE

4

- Lead initiatives that help CHILD-BRIGHT achieve and grow its mandate and visibility, as a principal investigator, mentor, chairperson, or funding partner



[www.child-bright.ca](http://www.child-bright.ca)

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