

With our partners, from 2016 to 2021, here's how the CHILD-BRIGHT Network created positive changes for children with brain-based developmental disabilities and their families



Children and youth with brain-based developmental disabilities

- Developed and executed 13 innovative patient-oriented research projects dedicated to improving the health and well-being of children and youth with brain-based disabilities.
- Created spaces for youth voices to be heard in research by developing the CHILD-BRIGHT National Youth Advisory Panel (NYAP). NYAP members have lived experience with a brain-based developmental disability and inform research development throughout the network.
- Helped our youth members further their reach by launching the NYAP's external consultation service for researchers engaging youth in patient-oriented research across Canada.
- Developed a series of tip sheets for youth partners (including siblings of youth with brain-based developmental disabilities), parents, and researchers engaging in patient-oriented research.



Parents and families

- Fostered meaningful patient engagement, notably through the creation of the CHILD-BRIGHT Citizen Engagement Council (CEC), composed of youth and young adults with brain-based developmental disabilities and parents of youth with brain-based developmental disabilities.
- Launched patient engagement measurement strategies including three surveys and a qualitative interview that looked at the engagement and partnership experiences of our patient-partners and other stakeholders over the years.
- Create a parent peer mentor role to guide and support parent-partners in our projects.



Next generation of patient-oriented researchers

- Built a cohesive network of patient-oriented researchers across Canada.
- Created a summer studentship program, supplemented by a targeted patient-oriented research (POR) training curriculum to provide students with practical POR experience.
- Supported 7 graduate student fellows to engage in pediatric brain-based neurodevelopmental research and develop critical skillsets in POR.
- Created the Training Innovation Fund for teams to develop innovative tools and resources that would grow POR capacity within our network and beyond.
- Collaborated with key partners to develop the Patient-Oriented Research Curriculum in Child Health (PORCCH), a series of online and self-directed modules aimed at enhancing the ability of multiple stakeholder groups to engage in POR.
- Launched an innovative Collaborative Mentorship Grant, which supports collaborations between researchers and patient-partners.
- Collaborated with multiple SPOR-funded entities to develop a National Training Entity in POR.



Policy makers & other stakeholders

- Engaged with researchers and knowledge users to explore new strategies to implement and disseminate CHILD-BRIGHT's research findings.
- Developed a KT Library that will include CHILD-BRIGHT KT products. The library will be used as a tool to disseminate research findings and will offer training resources to help researchers build their KT capacity (anticipated launch date: Fall 2021).
- Hosted two Policy Forums to connect policy makers from across Canada with patient-partners, service providers, and researchers in order to tackle important issues related to the care of children and youth with neurodevelopmental disabilities.