

Leadership in Childhood Disability

2012-2017 Wrap-Up Report and Transition to a Bold New Plan



Adam Walser, a registered nurse, and Vithun, a client, hang out in the therapeutic playroom.

1.0 Executive Summary

In 2012, Holland Bloorview Kids Rehabilitation Hospital launched its *Leadership in Childhood Disability* strategic plan, intended to guide the organization's work until 2017. Since inception, much has been achieved as documented in each of the summary reports from the past four years:

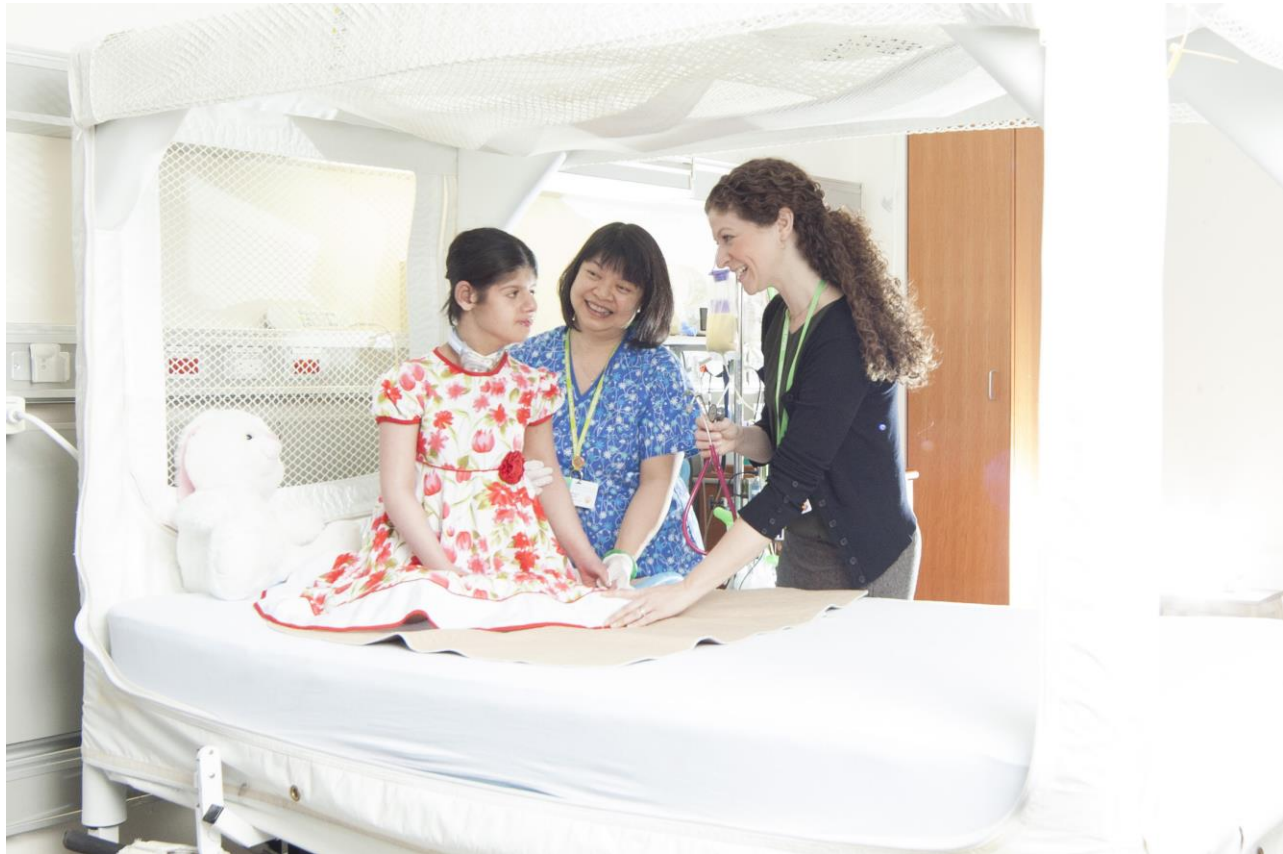
- [year one](#)
- [year two](#)
- [year three](#)
- [year four](#)

(Web location: <http://hollandbloorview.ca/Aboutus/WelcometoHollandBloorview/StrategicPlan>)

This document is intended to provide a high level summary of key accomplishments over the past five years. In doing so, we describe the foundation that will bridge us towards a bold new strategic plan that is close to finalization as this document is being written. While still to be modified and approved, the new plan very much builds on our past accomplishments and successes; it also acknowledges we still have much we can achieve to build the best and most healthy futures for the kids and families we serve.

Leadership in Childhood Disability was built on the four concepts of *transform care, accelerate knowledge, lead the system* and *inspire our people*. What follows is a highlighting of achievements under these four dimensions (and some initiatives that overlap multiple dimensions) as we celebrate a plan that has taken us to new heights in service of the kids and families we have the privilege to partner with.

2.0 Transform Care



(Left to right) Wing-Yi Chow, a registered nurse, and Dr. Andrea Hoffman visit with Malaika, a client.

Five year strategic goals:

- Generate, adopt and share new evidence for clinical care to achieve outstanding client and family outcomes
- Provide exceptional client and family centred care, embracing authentic partnerships with families and ensuring the 'voice of the client' is heard
- Harness emerging technologies and the latest processes to improve efficiency
- Build a new Centre for Leadership in Acquired Brain Injury
- Strengthen the Centre for Leadership in Child Development, building towards an international reputation focused on cerebral palsy and autism
- Grow the Centre for Leadership in Participation and Inclusion and establish its leadership role in new models of wellness, music and arts, and transitions to adulthood

Key Accomplishments

Our commitment to high quality, safe and effective care has always been an integral part of who we are. We put our clients and families first as we lead initiatives and build authentic partnerships to transform care. Our new plan will see us take this philosophy to new heights as we build on past successes:

- Implemented and made accessible a variety of guidelines and tools to enhance care both in the walls of Holland Bloorview and beyond: osteopenia guidelines, hip surveillance clinical care pathway, peer support tool kit and caregiver support tools.
- Developed and implemented eight standards of care via expert advice of our professional practice councils and input from family leaders.
- Launched the Chronic Pain Toolbox, leading to publication of papers in peer reviewed medical literature and invited presentations at provincial, national and international conferences. Holland Bloorview received a mentorship award from the American Academy for Cerebral Palsy and Developmental Medicine to partner with a U.S. organization in implementing this work and it was also recognized by Accreditation Canada as a leading practice.
- Launched an intensive inpatient/day-patient program to treat chronic pain in collaboration with SickKids enabling Ontario children and youth to receive this service closer to home rather than travelling to the United States.
- Led the provincial enhancement of outpatient therapy services for children and youth with spinal cord injury in Ontario.
- Implemented connect2care, a patient information portal that now allows over 1,000 clients or families access to 150 reports that would have previously been mailed.
- Launched a new, transformative, multi-year strategy designed to reimagine how kids with disabilities transition to adulthood. This work, via the Centre for Leadership in Participation and Inclusion, is made possible thanks to the generosity of donors who are investing \$4.8 million.

With respect to client and family centered care (CFCC), a core highlight is the growth of the family leadership program to more than 150 members who each have the opportunity to work on a wide array of projects from strategic planning to government relations. Our family leaders took their expertise beyond our walls through the development of a conference where more than 80 people shared best practices in client and family centered care. Our expertise in CFCC has been recognized by external groups such as the Change Foundation who have profiled us

and given us a *20 Faces of Change* award. We've also been asked by the Ministry of Child and Youth Services to deliver provincial training on our approach to patient centered care. And as part of our upcoming accreditation cycle, family leaders are embedded in each sub-team as we enhance safety and quality across the hospital. Family leaders also worked closely with the Canadian Patient Safety Institute to develop a curriculum that provides patients and families with the knowledge to participate more fully in organization-wide quality and safety initiatives, including accreditation.

Under the *transform care* banner, the Centres for Leadership in Acquired Brain Injury; Child Development; and Participation and Inclusion brought together clinical expertise and scientific excellence to achieve many highlights including:

- Launched Holland Bloorview's Concussion Centre, which brings a unique focus to pediatric concussion by combining initiatives in the fields of research, education and service delivery in a holistic way. Partnerships, recognized expertise and a public presence have paved the way for Holland Bloorview to lead the way in breaking new ground in pediatric concussion.
- Fostered expertise and increased capacity in autism diagnosis and research, including the selection of Holland Bloorview as provincial hub for assessment and diagnosis.
- Advanced thought leadership on music and arts health including sponsoring a think-tank on best practices and programming for leading experts, clients, families and staff; and creation of the first music-clinician scientist position in the Bloorview Research Institute.

Holland Bloorview also led excellence in practice innovation through national partnerships with two academic graduate institutions. We have graduated 12 advanced standing occupational and physio-therapists who were supported to obtain their Master's degrees while working at Holland Bloorview.

Cumulatively, we are poised to transform care in new and meaningful ways as we embark on a new strategic plan.

3.0 Lead the System



(Left to right) Emily; Premier Kathleen Wynne, MPP (Don Valley West); Liam; Julia Hanigsberg and Imaani show their support for Capes for Kids during the Premier's visit to the hospital in February 2017.

Five year strategic goals:

- Create new, innovative models of care in collaboration with system partners to support improved navigation and timely access to appropriate services for children with disabilities
- Forge new linkages with partners in community, health and education sectors to facilitate seamless transitions to adulthood
- Advocate for a provincial focus on equity in access and removal of barriers for children and youth with disabilities and their families

Key Accomplishments

We know that our impact extends far beyond the walls of Holland Bloorview. Over five years, we used our leadership position to drive system change both within the community and throughout Ontario.

Community leadership:

- To bridge the gap in transition to adult services, an innovative program has been established with our spina bifida program and the Anne Johnston Health Station, providing community-based primary care and life skills support to more than 60 young adults as they move to independence. The success of this program has led to ongoing base funding to ensure its sustainability and growth. A transition program for adult clients with muscular dystrophy has also been established with West Park Hospital.
- Working in collaboration with community providers – including supportive housing agencies, adult service providers, community care access centres and the regional health authority - we've broken new ground to transition young adults over 18 from complex care received at Holland Bloorview to supported living in the community. Partners include Safehaven, Reena and March of Dimes.
- As noted in *transform care*, we've launched a transition strategy to create leading practices and programs, generate research and create bridging programs to adult services.
- We've created programs that extend Holland Bloorview's expertise beyond our walls: *artsXpress*, a program offering in Markham that explores music and the arts ; *Igniting Fitness Possibilities* offered at Miles Nadal JCC, Variety Village and others to promote passion for physical activity and; *Robotics*, a partnership with FIRST Robotics Canada to spur interest in robotics and STEM (science, technology, engineering and math) for children with a wide range of disabilities.

Provincial Leadership:

- The Integrated Complex Care Model (ICCM) was developed and implemented with SickKids, Holland Bloorview and the Community Care Access Centres. ICCM is designed to serve the children and youth with the greatest complexity at home, in hospital and in schools through the creation of seamless and coordinated care delivered by “one team.” The Provincial Council for Maternal and Child Health used the ICCM model to establish Complex Care for Kids Ontario, a broad provincial framework intended to further align and standardize care pathways and service models across the province for kids with complex needs.
- Holland Bloorview was selected as the provincial hub to design, deliver and evaluate the implementation of an innovative intensive therapy program for children and youth with incomplete spinal cord injury across the province, delivered through the local children’s treatment centre (CTC) in each community. As the program hub, we hold accountability for program coordination, staff training, distribution of equipment to CTCs and program evaluation.
- Along with Children’s Hospital of Eastern Ontario – Ottawa Children’s Treatment Centre and SickKids, we have co-founded Kids Health Alliance to bring leadership to and greater coordination for the variety of pediatric health-care providers that families encounter in their health-care journey.
- We’ve partnered with more than 15 education and community based agencies to influence and have input on the province-led Special Needs Strategy designed to enhance integrated and coordinated access to rehabilitation and therapy across the sectors of health, education and community services for school-aged children across Ontario.
- Provided counsel in shaping Ontario’s Autism Program via membership on expert advisory panels.
- Increased system capacity through training of community pediatricians in autism diagnosis and training of community pediatricians in medication management.

Over the course of five years, Holland Bloorview has established a firm foundation as an active voice in shaping pediatric health care both within the community and the province. We are poised to do even more in the next five years.

4.0 Accelerate Knowledge



Dr. Jan Andrysek, a scientist, and Calvin, a student, examine an All-Terrain Knee, one of the recent developments out of the PROPEL lab.

Five year strategic goals:

- Conduct transformational research in pediatric rehabilitation, with a focus on areas of strategic clinical importance, such as brain science
- Become a recognized leader in attracting and training the very best of the next generation of experts in disability by embracing best practice models in teaching and learning and providing an exceptional student experience
- Generate new linkages with academic, industry and system partners to accelerate knowledge generation, translation and evaluation, and commercialization of innovations

Key Accomplishments

Momentum in teaching, learning and research at Holland Bloorview continues to grow as we accelerate new knowledge generation in the field of childhood disability. Key accomplishments over five years will facilitate a smooth pivot to a new plan that will see us break new ground through discovery and accelerated adoption of knowledge:

Page
10

- Establishment of a system-leading Research Family Engagement Committee (RFEC) that has grown to over 50 family leaders serving as advisors, communicators and reviewers. The framework has garnered attention from across Canada as well as the United States and Australia. RFEC leadership has led to the development of a comprehensive web tool for information on Holland Bloorview research.
- Secured two new Canada Research Chairs, including our first ever at the Tier I level. Additionally, three new hospital-university research chairs were established: the Holland Family Chair in Acquired Brain Injury, the Raymond Chang Foundation Chair in Access Innovations, and the Dr. Stuart D. Sims Chair in Autism.
- Reached major milestones in commercialization activities including licensing of three technologies, streamlining of patent portfolio, completing an externally-led intellectual property (IP) scan, development of IP policy, setting up web tools to track commercial activity, cultivation of industry partnerships including MaRs Innovation and securing donor funding to develop a new access and commercialization strategy for small market innovations.
- Launched the Centre for Leadership in Innovation and established an effective operating model for all Centres for Leadership that combines scientific, academic and operational excellence and promotes innovation, scholarly output and piloting of new ideas.
- Enhanced research capacity through recruitment of three new clinician scientists in strategic areas of opportunity (brain stimulation and acquired brain injury); appointment of three new clinician investigators, five clinical study investigators and 18 clinical team investigators.
- Scholarly output in the form of citations and authored articles has also increased in a wide range of areas including autism, weight management, cerebral palsy and participation and inclusion, to name but a few.
- Recognition of Holland Bloorview as a leader in pediatric disability excellence continues to grow as we've invested in having accomplishments highlighted in mainstream media as well as in scientific journals.

- Recognized as a top 40 research hospital, ranking 11th nationwide in the category of institutional intensity (research dollars as a percentage of total hospital spending) and number two in growth of research activity over the past two years.

Within the connected realm of teaching and learning:

Page
11

- Established a one-stop shopping resource centre for all student needs to ensure an optimal experience.
- Identified faculty development as a priority and ensured leading practice skill training is available to our staff, allowing them enhance the student and trainee experience.
- Implemented simulation as a powerful tool in student and staff education and entrenched the practice within staff hiring and new staff orientation practices.
- Advanced knowledge translation practices to fast-track care pathways through our Evidence to Care program including the launch of the Chronic Pain Toolbox (noted in *transform care*) and a peer support tool; tools have been downloaded by families and clinicians from 20 countries around the world.
- Enhanced educational scholarship in childhood disability through international presentations, publications and collaborations.
- Launched a student-led concussion clinic that provides a training environment for the next generation of health-care providers and ensures children and parents get timely access to important information in the recovery process. Students are delivering presentations to schools, sports leagues and community centres as part of their proactive outreach.
- Implemented a student home visiting program to provide experiential learning for students and deepen understanding of client and family centered care. Over 40 of our clinical students were matched with clients and families to learn about their life at home.

Our efforts to accelerate knowledge in our fields of expertise through research, teaching and learning, position us well as we move towards a new plan with aspirational goals.

5.0 Inspire Our People



(Left to right) Christine, a student; Lisa Kakonge, a speech language pathologist, and Christina, a client, work together to further Christina's therapy goals.

Strategic Goals

- Foster meaningful engagement among staff, clients and families to co-create models of collaboration and shared decision making
- Create an environment where the spirit of inquiry is demonstrated everywhere, every day
- Become a magnet hospital for clinical education and research talent
- Build a culture that empowers staff to engage in teaching, learning and research initiatives that advance the care of children with disabilities

Key Accomplishments

Every day, we are reminded that success can only be accomplished with the ongoing commitment, dedication and support of our people. A strong, energized corporate culture, founded on a spirit of inquiry, engagement, shared decision making and learning is what sets the stage for our transition to a new plan. Key accomplishments include:

- Increased compassionate care through the implementation of Schwartz Centre Rounds - a first for a Canadian hospital. Overwhelming anecdotal and empirical feedback shows that the opportunity to discuss the social and emotional aspects of delivering health care in this setting has had a positive impact. A Holland Bloorview-led research study is being conducted to further understand the impact of Schwartz Rounds.
- Enhanced standing as a magnet hospital for top talent. Efforts and evidence highlighting success include: overall employee engagement survey scores moving from 68 per cent (2011) to 83 per cent (2016); development of an employment brand entitled, "Join a world of possibility," to drive recruitment; recipient of numerous workplace awards (Canada's 10 Most Admired Corporate Cultures, Top Employer for Young People and GTA Top Employer); and over 10,000 peer-to-peer "Spotlight" recognition awards given by employees, volunteers and families.
- Enhanced equity, diversity and inclusion (EDI) efforts through training, surveying of best practices, piloting of an EDI lens to guide our work, policy review and execution of an internal campaign focused on respect in the workplace. Also implemented cultural awareness training within research via training on topics including engagement of aboriginal and indigenous populations and implicit bias (how attitudes or stereotypes affect decision making and actions).
- Created new development opportunities for staff through education modules on change and transformational leadership. We also implemented a new program to support the development of a coaching culture and career development partnerships between employees and managers.
- Fostered a culture of innovation through the establishment of a Centre of Leadership in Innovation that drove strategy development, education, leadership training and internal and external environmental scans designed to imbue the organization with an innovation culture and a spirit of inquiry.

- Drove collaboration and teaching/learning philosophy through cross-functional learning opportunities; integration and appointment of several clinical and academic/scientific roles; creation of in-person and online resources to facilitate collaboration; increased use of simulation as a learning tool; launch of frontline peer-to-peer coaching program; expanded breadth of learning opportunities for research trainees and graduate students; and implementation of a new teaching excellence competency model.

As we transition to a new strategic plan, we will continue to go the extra mile to provide an inspirational environment that challenges and rewards our people. By doing so, we will continue to attract and retain an outstanding team driven to achieve more for the kids and families we serve.

As we've seen for the duration of the 2012-17 plan, the Holland Bloorview team will drive achievement and impact for the coming five years and beyond. The influence of hundreds of team members is already being felt as we galvanize around building a new plan from the ground up. And the message so far is clear: we want to build on our success, drive change and innovation and elevate our status as world leaders in childhood disability to new heights.

6.0 Conclusion



Cynthia McClure, a clinician, with Alexis, a client, in one of our therapeutic gymnasiums.

Holland Bloorview is a global leader in research, client and family integrated care, building capacity and learning for developmental pediatrics, and providing services and supports that enable each child and family to imagine a meaningful future. The accomplishments of the past five years underscore our long-lasting and unbreakable commitment to provide *Leadership in Childhood Disability*.

Yet as we recognize these accomplishments, we acknowledge that for many clients and families, there is still a disparity between the experience they have at Holland Bloorview and what they encounter upon discharge. For this reason, with focus and purposeful intent, we are creating a new strategic plan that builds on the strong foundation we've built and pushes us to another level of leadership.

Through the current strategic planning process, we've generated over 900 'touchpoints' – connections and input, both in-person and digitally – from children, family leaders, volunteers, health-care providers, researchers, educators, leaders, and peer alumni. What we've heard is a deep desire for Holland Bloorview to take the lead on transforming the lived experience of kids and young adults with disabilities by amplifying the impact of our expertise in every domain: research; teaching; capacity

building with other providers, workplaces, community settings and schools; translating evidence into practice; scaling innovative programs, technology and knowledge; challenging stigma; and creating strong collaborations with stakeholders, including government and policy makers.

The years ahead promise excitement, challenges, inspiration and hope. As we continue to reach for the stars in all that we do, we remain grounded in keeping the kids and families that we serve at the centre of all that we do.