



CanChild

**2024**

# **ANNUAL REPORT**

GENERATING KNOWLEDGE AND TRANSFORMING LIVES

**CanChild is grateful to our key partners for their financial and resource support:**

McMaster University, the Faculty of Health Sciences, the School of Rehabilitation Science, the Department of Pediatrics, and the McMaster Children's Hospital Foundation.



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# Message from Co-Directors

As we mark CanChild's 35th anniversary, we reflect on a year filled with collaboration, innovation, and purpose that all rooted in our enduring mission: to generate knowledge that makes a difference in the lives of children and youth with disabilities and their families.

In 2024, we led and participated in numerous activities that meaningfully engaged patients, families, and community partners in every aspect of our work, from shaping research questions to co-developing interventions, tools, and training programs. These activities reflect our commitment to advancing equity, accessibility, and meaningful participation.

Our portfolio this year included the continued global growth of the Family Engagement in Research Program, the expansion of the ENVISAGE programs across Canada, Australia, and Croatia, and the development of tools like MPOC 2.0 to better capture family-centred care experiences. The F-words for Child Development initiative continued to grow as a powerful, unifying framework across cultures and sectors. We also advanced inclusive education through the Partnering for Change (P4C) model and strengthened clinical training through our partnership with the Ontario Autism Program to help improve the service landscape. These efforts were made possible through strong local partnerships and an ever-growing network of international collaborators, including researchers, clinicians, families, and organizations across more than 20 countries. This global community allows us to co-create knowledge that is both rigorous and relevant, ensuring our work has broad and lasting impact.

We extend our heartfelt thanks to all those who joined us in 2024. Together, we are building a future where research transforms lives both in Canada and around the world.

Warm regards,



**Dr. Olaf Kraus de Camargo, MD**  
Co-Director of CanChild



**Dr. Briano Di Rezze, PhD, OT Reg(Ont.)**  
Co-Director of CanChild

# About CanChild

## Generating Knowledge and Transforming Lives



At McMaster University's CanChild Centre for Childhood-Onset Disability Research, children, youth and their families are at the centre of everything we do.

They are our focus. They are our passion.

Together we have made a difference in childhood development research in Canada and around the world.

The overarching goal of CanChild is to maximize the quality of life and participation of children and youth with a variety of developmental conditions, along with their families, through evidence-based clinical and health services research.

CanChild's research is about how children with a variety of developmental conditions develop, how to identify children and families at risk based on their needs, and how to best support these children over the lifecourse, in particular during health services transition points such as from hospital to home, from preschool to school and from child health services to adult services. At CanChild, our research measures and evaluates the processes of novel ways of health care delivery and their outcomes to ensure children and families do the best they can during their lifecourse (best health, best care experiences, to the best cost).

### CanChild's Five Pillars of Excellence

1

**Leadership in Emerging Issues**

2

**Innovative Research**

3

**Knowledge Transfer and Implementation**

4

**Knowledge Sharing & Education**

5

**Mentorship and Capacity Building**

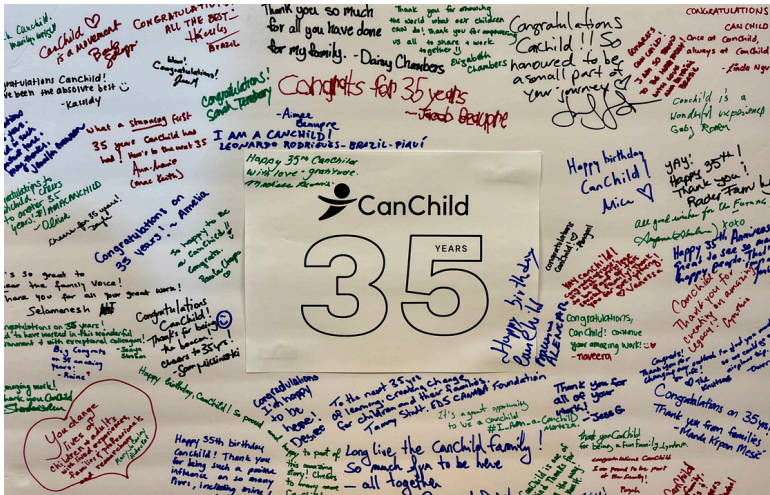
# Celebrating

# 35<sup>YEARS</sup> of CanChild

Over the past 35 years, we've achieved remarkable milestones, from engaging families in research and empowering them to changing the lives of families all over the world. Today, we continue to strive towards generating meaningful knowledge and changing the lives of more families, ensuring that our impact not only endures but expands.



In 2024 as we celebrate our 35th anniversary at CanChild, we honor the powerful stories and lived experiences that have shaped our journey. Every story is a testament to the resilience of the families and communities we serve and the transformative power of our work together.



# The CanChild Team

CanChild's membership is comprised of a multidisciplinary network of Scientists, Research Associates, and International Collaborators from various institutions from around the world. The CanChild team is also made up of PhD Students, Post-Doctoral Fellows, and Research & KT Support. This network includes researchers and clinicians with expertise in pediatrics, rehabilitation medicine (physiatry), occupational therapy, physiotherapy, speech and language pathology, kinesiology, social psychology, epidemiology and biostatistics.

As CanChild co-founder Peter Rosenbaum says "It is not **me** but **we**" – and the impact of that statement is felt within each of our team members. At CanChild we put every effort into embodying that sentiment. Our research is steeped in local and global partnerships, collaborations, and team effort, and we believe those to be the necessary ingredients to produce truly great work.



## Remembering Dr. Mary Jo Cooley-Hidecker

Early in 2025, we lost a member of the CanChild family, Dr. Mary Jo Cooley-Hidecker. Mary Jo was a proud Associate Member at CanChild, amazing educator in the Department of Communication Sciences and Disorders at the University of Kentucky, a researcher and collaborator in childhood disability research (lead developer of the CFCS), and a dear friend. We are thankful for all that she has done to advance our field of childhood disability research, and for the impact that she has had on the many lives of children with disabilities, and their families, as well as on trainees and colleagues at CanChild. She will truly be missed and will never be forgotten.



 **19**  
Scientists

**50** Associate  
Members

 **13**  
Postdoctoral  
Fellows

Staff and  
Research Assistants



**35**



**27** PhD  
Students

Family & Youth  
Advisors/Co-Investigators

**43** 

Student  
Research  
Assistants **12**



 CanChild Centre

 Scientists

 Associate Members

 International Collaborations

Spanning  
across **22** countries

# News, Events and Accomplishments

## January 1, 2024

In recognition of his exceptional contributions to child health research and his international standing in pediatric exercise science, CanChild Scientist, Brian Timmons, has been appointed as the new Scotiabank Chair in Child Health Research at McMaster University. As the Scotiabank Chair, Timmons will continue his mission to promote exercise as medicine, focusing on enhancing the quality of life for children living with chronic conditions.



## February 16, 2024

Nicky Lewis, Chief Executive Officer of Kids Brain Health Network (KBHN), presented on the CanChild/KBHN Family Engagement in Research (FER) program at the House of Commons. Andrea Cross, Connie Putterman, and Donna Thomson (Co-founders of the FER Program) traveled to Ottawa to be in attendance and meet with Members of Parliament. What an impactful opportunity to share insights and experiences about citizen engagement to Canadian policymakers!



## March 18, 2024

CanChild affiliates are among recipients of the Kids Brain Health Network (KBHN) Outstanding Awards for 2023-2024, including Dr. Michelle Phoenix (Outstanding KBHN Mentor/Supervisor Award), Connie Putterman and Dr. Amanda Doherty-Kirby (Outstanding KBHN Leadership Award in Family Engagement in Research), and Dr. Samantha Noyek (Outstanding KBHN Promising Researcher Award).

## March 27, 2024

McMaster Child Health Research Day (MCHRD) 2024 brought together Health Sciences students, patient family members, and special guests to celebrate innovative research and compete for awards. This event was a collaborative effort between the McMaster University Department of Pediatrics, the CanChild Centre for Childhood-Onset Disability Research, the Centre for Metabolism, Obesity & Diabetes Research, and the Offord Centre for Child Studies, with support from the McMaster University Faculty of Health Sciences, McMaster Children's Hospital, and Hamilton Health Sciences Research Administration.



## May 29 - June 1, 2024

The EACD 2024 Annual Conference was a spectacular event held in the charming city of Bruges, Belgium, drawing a record-breaking 1,200 attendees! Our CanChild team dazzled with 28 contributions across various formats, making our work, like the F-words and innovative tools such as PEM-CY and PREP, a highlight of many presentations. A heartfelt thanks to all researchers and students for their stellar contributions!



## June 5, 2024

Supported by the Office of the Vice-President, Research, the Societal Impact Seed Grant is designed to drive meaningful campus-society collaborations across the disciplines. Five McMaster researchers were awarded a combined \$85,000 in the inaugural round of the grant. Among the winners are two CanChild teams that have innovative projects:

Wenonah Campbell, Victoria Boyd and Sandra Vanderkaay have partnered with the Ontario Society of Occupational Therapists to co-create a continuing professional development (PD) program that helps Occupational Therapists (OTs) navigate and address inequities in tiered service delivery models.

Michelle Phoenix and CanChild have partnered with SMILE Canada to support children with disabilities and their families who are newcomers to Canada.

## June 19, 2024

CanChild Scientist, Dr. Andrea Cross, received the School of Rehabilitation Sciences Distinguished Alumni Award! This prestigious award recognizes outstanding alumni who have made significant contributions in their fields.

## June 28, 2024

We are incredibly proud to share that Dr. Julia Hanes is off to compete in the Paralympics! Julia's journey with us began as a student under the guidance of Dr. Peter Rosenbaum. She is currently finishing up her medical residency in Physical Medicine and Rehabilitation in British Columbia.

We extend a heartfelt congratulations to Julia on this incredible achievement. We are immensely proud of her and look forward to cheering her on!



## October 23-26, 2024

We were thrilled to attend the 78th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPD), from October 23-26, 2024, in beautiful Quebec City. This year's theme, "Translating Discovery", brought together groundbreaking research and clinical practice, and we are proud that CanChild members contributed to such meaningful discussions. Our team presented innovative work that reflects our dedication to advancing care and improving the lives of individuals with childhood-onset disabilities.



## October 24, 2024

CanChild Associate Member, Dr. Darcy Fehlings, was the recipient of the 2024 AACPDM Lifetime Achievement Award.

This award is given to individuals who have made creative contributions of outstanding significance to the field of medicine and for the benefit of patients with cerebral palsy and other childhood-onset disabilities. Congratulations Darcy!



## October 26, 2024

CanChild's Business and Engagement Officer, Rachel Teplicky, was awarded the 2024 AACPDM Fred P. Sage Award, for her submission, "F-Words Foundation Course." This award is given to the best multimedia submission presenting clinical, research, or educational material in a digital format. Congratulations Rachel!



## October 29, 2024

CanChild celebrated its 35th Anniversary! The event wasn't just about milestones; it was about stories—the powerful, inspiring stories of the families, children, youth and adults with lived experiences who have shaped our work and fueled our mission for over three decades. We were honored to have our keynote speakers and panelists shine a spotlight on lived experiences, participation in schools and communities, and the impact of lifecourse research. The personal journeys shared were a true testament to the importance of our work, and we are so grateful to everyone who participated in making this day one to remember. Here's to many more years of making a difference together!



## November 19, 2024

CanChild's Business and Engagement Officer, Rachel Teplicky, presented at the McMaster Industry Liaison Office (MILO) Innovation Showcase. Rachel highlighted CanChild's remarkable successes in commercialization and shared insights into how our ongoing partnership with MILO has supported our journey to turn research into impactful innovations.

# By the Numbers

In 2024, CanChild has consistently been successful in securing funding, publishing papers, and disseminating findings.

**225** 

**Publications**



**250**

**Presentations**



**Grants  
Awarded**

**51**

**Awards**



**13**

**Operating  
Budget**

**\$682K**

**Engagement**

**430K**

**website visitors**

# Research Highlights

Our research expertise extends to various overarching themes that play an important role in the lives of children and youth with developmental conditions and their families. These areas of research examine issues and approaches from broad perspective, incorporating many aspects that impact the life of the child, the experience of the caregivers, and the service of health care providers. CanChild also focuses on themes that bring children and their families together with researchers, where a mutually beneficial relationship can be fostered through engagement and making research accessible.

**I appreciate and have regularly used resources on many childhood disabilities within my clinical work. They provide an accessible amount of information to parents, educators, and caregivers. The information presented is typically tailored to the intended audience.**



# ENVISAGE:

## ENabling Visions And Growing Expectations

### ENVISAGE – Service Providers

The impetus for this program originated with ENVISAGE-Families parents who consistently advocated for an adapted version of their program so that both parents and service providers would share the same concepts, language, tools and goals as they work together. With funding from CIHR, the ENVISAGE-SP program was developed, evaluated, refined and implemented. In 2024, we delivered the pilot program to a further ten cohorts of SPs across Canada and Australia (beyond the initial groups in the fall of 2023). With active rollout now completed, we are in the process of analyzing the data from both qualitative interviews and quantitative surveys.

The feedback we have received thus far indicates that ENVISAGE-SP provided opportunities for professional growth at any career stage to work in family-centred ways. SPs reported that the program helped them think holistically and relationally, recognizing and respecting the expertise that parents and professionals each bring to the table to optimize child functioning. The program validated and provided confidence to practise in evidence-based ways. SPs expressed hope that both clinicians and families (who had participated in the complementary ENVISAGE-Families version) would have the opportunity to work together. SPs reflected on the kinds of synergies that might develop if healthcare staff in their organizations participated in the program together, and indeed that has already begun to happen (see Train the Trainer below). They also encouraged the ENVISAGE research team to build a Community of Practice to continue supporting cross-disciplinary professional development by sharing ideas and practices. We hope to see this realized in 2025.



**Professionally, it has made me really think about the relationships that I have with the whole family and thinking whole family goals.**



## ENVISAGE – Train the Trainer Program

With support from two leading children's treatment centres in Ontario, the ENVISAGE team, together with our new post-doc researcher, Sam Noyek, developed a new train-the-trainer program to facilitate delivery of both ENVISAGE-Service Providers and ENVISAGE-Families programs at their respective sites. For this initiative, we developed a facilitator guide, a participant welcome guide, and a participant handbook to complement the program resources. Three facilitator teams from each organization, made up of a family partner and service provider, took part in the training. Afterwards, the new facilitators highly rated the value of the programs and reported both enjoyment and appreciation. Since then, two facilitator teams have delivered ENVISAGE-Service Providers to 14 colleagues in their organization, with ongoing support and follow-up from CanChild. Already two cohorts of parents have enrolled in the ENVISAGE-Families program to begin in 2025. As part of the Quality Improvement component of this study, we have been assessing barriers and facilitators to implementation, and program impact and outcomes.

## ENVISAGE – Integrated Program

Under the leadership of doctoral candidate Alice Soper, the ENVISAGE-Integrated program (Canada) was co-developed in 2024 in conjunction with parents and service providers, with generous funding from the Physicians' Services Incorporated (PSI) Foundation. The 'integrated' format is exploring a new way of delivering the ENVISAGE program where parents and service providers learn with and from each other. We launched the program in Fall 2024 through a feasibility study at a children's treatment centre in Ontario. This feasibility study helped to inform our next steps to conduct a pilot longitudinal study that assesses the impact of the program on parent empowerment, confidence, and family-centred service.



**I love the group discussions and having the opportunity to see the perspective of both sides.**



## ENVISAGE – Croatia

Following the language translation and cross-cultural adaptation of the original Families program for Croatia, and preliminary feasibility pilot testing (2019-2022), Monika Novak-Pavlic and her team launched a three-year research-implementation project in 2024 in partnership with the Special Hospital for Protection of Children with Neurodevelopmental and Motor Disabilities Goljak. With financial support from the City of Zagreb, the primary funder of this project, we successfully completed our planned activities for 2024. These included implementanting ENVISAGE with six groups of parents (n=58), conducting a research study to assess the program’s impact on parent outcomes (n=26) and engaging in knowledge translation activities. The project will continue in 2025 and 2026, with the goal of reaching an additional 100 parents from Croatia.



## ENVISAGE – Families and ENVISAGE – First Peoples Programs

In Australia, the ENVISAGE-Families and ENVISAGE-First Peoples programs continue to be implemented, supported by an additional \$5 million funding from the Department of Social Services in December 2024. These programs have been instrumental in equipping caregivers with knowledge, skills, and confidence, fostering stronger family connections and well-being. Delivered through a robust network of 30 industry partners and 170 dedicated facilitators, ENVISAGE has successfully delivered 225 programs to caregivers across the country. 2024 has been a year of remarkable growth, with a surge in registrations and attendance, reinforcing the program’s proven positive impact on caregivers and families. By the end of December 2024, more than 1,200 caregivers had participated in the program, demonstrating the widespread need and value of this initiative.

We celebrated key milestones, including the successful launch of a Vietnamese-translated group, laying the groundwork for expanding in-language offerings. Our commitment to inclusivity has been further strengthened by forging partnerships with community services to enhance outreach to CALD (Culturally and Linguistically Diverse) communities.

To improve accessibility, we introduced a Plain-English Caregiver Handbook, ensuring that all participants—especially those who have faced barriers to online learning—can fully engage with program content. This handbook complements our interactive online learning platform, reinforcing key concepts and activities explored in small group discussions with peers and facilitators.

The First Peoples Program has been embraced with enthusiasm in Queensland and Western Australia, with its success driving plans for continued delivery in these regions. Additionally, we have forged new partnerships in the Northern Territory and Central Australia, extending our reach to remote and regional communities that previously lacked access to such essential support.



envisage

Consistent caregiver satisfaction and positive outcomes remain at the heart of ENVISAGE's success. Evaluations consistently highlight high levels of satisfaction and measurable improvements in caregiver confidence, resilience, and well-being. With continued expansion and deepening community engagement, ENVISAGE is making a lasting impact, strengthening families, and fostering more connected, empowered communities across Australia.

**For more details, please reach out to Debbie Hughes by email at [envisage@mcmaster.ca](mailto:envisage@mcmaster.ca)**



# Growing into Adulthood with Duchenne Muscular Dystrophy (GrowDMD): Comparing Patient Experiences and Systems to Optimize Care

The GrowDMD project studies the challenges that adolescents and young adults with Duchenne muscular dystrophy (DMD) face when transitioning from the pediatric to adult healthcare system in three partner countries: Germany, Italy, and Canada. The Canadian portion of this international collaboration is led by Dr. Olaf Kraus De Camargo. The project aims to enhance transitional care and increase opportunities for participation for adolescents and young adults with DMD and their caregivers. This study utilizes an integrated knowledge translation process in which researchers, knowledge users, Patient Advocacy Organisations (PAOs) representatives, and patient partners collaborate across all stages of the research process. Conceptually, the study is guided by the World Health Organization (WHO) frameworks of International Classification of Functioning, Disability and Health (ICF) and the International Classification of Health Interventions (ICHI).

In 2024, the international team collected semi-structured interviews with youth diagnosed with DMD, their parents, and healthcare providers involved in the transition process. We are also in the middle of collecting survey data. Preliminary findings were presented at local and international conferences, including World Muscle Society meeting (Prague, Czechia), McMaster Child Health Research Day (Hamilton, Canada), and annual HHS Research Building Bridges Symposium (Hamilton, Canada). The international team also convened for a meeting in Montreal, Canada, with ongoing efforts to publish findings.



*The project received international (European Union's Horizon 2020 research and innovation programme under grant agreement N°825575) and local (Canadian Institutes of Health Research, Federal Ministry of Education and Research of Germany, and Ministry of Health of Italy) funding.*

**For more details, please reach out to Sarah Wellman-Earl by email at [wellman@mcmaster.ca](mailto:wellman@mcmaster.ca)**



## Campus Belonging

In partnership with the University of Alberta, the Campus Belonging project was created to enhance autistic postsecondary (PS) students' sense of belonging within Canadian institutions. Adopting a co-design and community-based participatory approach, the project is structured in two phases. The first phase focuses on understanding the experiences of autistic PS students and university stakeholders, while the second phase aims to bring these groups together to develop sustainable practices that foster an inclusive environment for autistic students at Canadian postsecondary institutions.

The project is currently in the first phase. Focus groups have been completed across McMaster University and the University of Alberta, with a range of university stakeholders involved. The research team is in the process of finalizing the analysis of the focus group results and is working on drafting a manuscript to report on these findings. The co-design phase is planned for 2025, where further collaboration will take place to create strategies for promoting a stronger sense of belonging for autistic students in postsecondary environments.

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**For more details, please reach out to Briano DiRezze by email at [direzzebm@mcmaster.ca](mailto:direzzebm@mcmaster.ca)**



## Covid Time Capsule

The purpose of the COVID Time Capsule study is to identify what services and supports Canadian children/youth with disabilities (ages 8-21) and their families need after the Covid-19 pandemic. We hope to better understand the gaps in access to health services and supports during COVID, what pre-existing gaps and inequities were highlighted or exacerbated by COVID, and what lessons from this experience can inform 'best practices' after COVID.

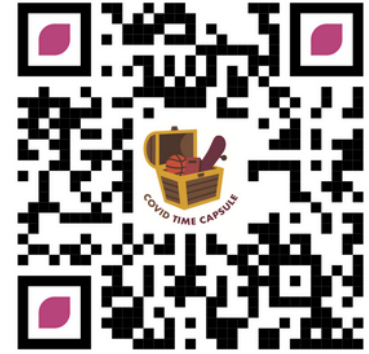
Informed by the principles of patient-oriented research, COVID Time Capsule project is co-designed with youth with disabilities (who are youth advisors or "junior researchers" on the study) and their parents who are co-investigators.

In previous phases of this study, we carried out qualitative interviews with disabled youth and their families. In 2024, we launched the Covid Time Capsule survey that aims to identify in greater detail children and families' needs for health, education and community-related systems of supports. This survey was collaboratively designed with youth and family partners and our multidisciplinary research team. To date, we have administered the survey to over 50 eligible parents/caregivers across Canada.

During the past year, we developed a number of knowledge translation materials to share what we have learned on this study. Youth and family partners and research team collaboratively presented our findings at international and local conferences, including poster presentations at the European Academy of Childhood Disability (EACD) and Children's Healthcare Canada annual conferences, as well as a panel discussion at the American Academy for Cerebral Palsy and Developmental Medicine (AACPD).



Additionally, with the support of Children's Healthcare Canada, we hosted a townhall where healthcare providers, educators, policymakers, parents, and researchers worked together to discuss the findings and identify the next steps to implement the change in services and supports. We have submitted two manuscripts: one on school-related challenges submitted to the International Journal of Inclusive Education, and an adapted youth-friendly version of our previously published manuscript submitted to Frontiers for Young Minds.



You can watch presentations and find links to short video clips outlining the study findings on the study website and our YouTube channel.

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**For more details, please reach out to Kinga Pozniak by email at [pozniakk@mcmaster.ca](mailto:pozniakk@mcmaster.ca)**

## Job Training Program

Launched in 2016, the Job-Train Program (JTP) is a summer vocational program designed to provide autistic high school students with employment skills training, paid work placements, and job-related support. Over the years, the JTP has continuously evolved, refining its approach through ongoing feedback and evaluations.

In the most recent iteration of the JTP in 2024, the JTP team secured paid work placements across six distinct employers at McMaster University for six autistic high school students. Each placement lasted six weeks, providing students with hands-on experience while receiving additional support from trained job coaches. In this version of the JTP extensive feedback was collected from student participants, job coaches, and employers to gain insights into job coaching.

A scoping review examining key job coaching attributes from the published literature is currently underway to determine the key components of job coaching. A significant part of this ongoing work involves exploring the voices of autistic youth to identify best practices of job coaching. All of this will directly inform the development of a comprehensive job coach training manual and evaluation tool that will be pilot tested in 2025. The funding provided by the Hamilton Health Sciences (HHS) Foundation played a pivotal role, not only facilitating the program's successful implementation but also in supporting its research endeavours.

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**For more details, please reach out to Briano DiRezze by email at [direzzebm@mcmaster.ca](mailto:direzzebm@mcmaster.ca)**

## Measure of Processes of Care (MPOC 2.0)

The Measure of Processes of Care (MPOC 2.0) project aims to understand what parents expect and value in healthcare services today. Originally developed in 1996 by CanChild researchers, the MPOC tool measured parents' experiences with health services for their children both across Canada and internationally. However, with evolving healthcare landscapes, it is necessary to reassess these measures. In this ongoing study, launched in April 2021, researchers and parent partners delve into the current expectations of parents, especially amidst the prevalence of online information and the growing desire for family involvement in healthcare decisions. Through surveys and consultations, we explored what today's parents, particularly those with children with disabilities, require and anticipate from healthcare services.



Based on our findings, we've crafted MPOC 2.0, a new assessment tool tailored for healthcare organizations to gauge their family-centeredness, determining how well they meet the expectations of the families they serve. We've meticulously refined this tool through input from 90 parents and service providers, utilizing methods like the Delphi process and usability testing. With a finalized draft of the new tool, MPOC 2.0 was then tested with over 250 parents/caregivers from across Canada. It is now in the validation phase of the study where the research team will work to further refine the measure. Once finalized, it will empower healthcare providers to better understand and meet the needs of families. Additionally, we'll create resources to guide service providers on effectively addressing these needs.

*This project is funded by the Canadian Institutes of Health Research.*

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**For more details, please reach out to Sarah Wellman-Earl by email at [wellman@mcmaster.ca](mailto:wellman@mcmaster.ca)**

I am so grateful for your wonderful team and your comprehensive website! I consider the website my go to source for information about family centred services. I have reviewed the Family Centred Services sheets frequently over the years. I also regularly refer clients, families, professional students and other therapists to the sheets as well.



## Transforming School-Based Occupational Therapy: Partnering for Change

Imagine schools where occupational therapists are not occasional visitors, but trusted partners fully integrated into everyday educational practices. Over the past year, the Partnering for Change (P4C) research team at CanChild has been working to achieve exactly this. With funding from the Ontario Ministry of Children, Community and Social Services, our team, led by Dr. Wenonah Campbell, conducted a realist evaluation of the P4C occupational therapy service model in collaboration with 10 schools and 10 Children's Treatment Centres. Over two years, occupational therapists and therapy assistants implemented P4C across varied school environments in Ontario.

Our study aims to generate practical insights and tools by understanding how, when, and why P4C works best. Through rigorous analysis of extensive data—including 152 interviews, 700 surveys, 250 reflective journals, 566 service logs, and 19 administrative reports on wait times and waitlists—we have developed a comprehensive theory explaining how P4C achieves positive outcomes. The P4C Implementation Theory outlines a phased approach to embedding tiered occupational therapy services into schools. Each phase builds upon the previous one, creating conditions where relationships are fostered, collaborations strengthened, and needs-based services are delivered to create lasting impact for children and families, educators and schools, therapists and organizations, and the health and education systems.

Implementation begins with committing and preparing, where organizations communicate and coordinate their activities, ensuring the alignment of staffing, workflows, and professional development to support P4C. Next therapists introduce P4C in schools, building relationships and gaining deeper insight into student and school needs.



Effectively implementing P4C means that therapists maintain a consistent and regular presence in schools, working alongside educators and engaging with families to deliver coordinated, needs-based services at all tiers. They assess children in authentic school environments, using dynamic assessments to guide interventions and monitor progress over time.

Over time, as occupational therapy becomes fully integrated into the school community, lasting impacts are achieved. Ongoing collaboration builds the skills and confidence of educators, therapists, and children, ensuring occupational therapy remains an essential part of inclusive education. All children are provided with equitable and timely support, enabling them to actively participate, learn, and thrive.

Looking ahead, our team is finalizing a new implementation guide and practical resources to support organizations in adopting the transformative P4C service delivery model. Stay tuned for these exciting developments!



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For more details, please reach out to Leah Dix by email at [dixlm@mcmaster.ca](mailto:dixlm@mcmaster.ca)

## Project BEYOND

(Body-function Enhancement for YOUTH through participation in real-world contexts)

Following earlier work where we successfully examined the impact of participation-based interventions on a range of body functions, our team received four-year CIHR funding for a larger cross-provincial study testing the impact of the Pathways and Resources for Engagement and Participation (PREP) intervention among 150 youth with physical disabilities across Quebec and Ontario. Project BEYOND builds on our expertise in innovative clinical trials that offer an alternative to traditional efficacy studies. Our earlier work showed that targeting interventions at the activity/participation level can improve impaired body functions, such as balance, attention, and anxiety—crucial components in rehabilitation. This larger, more rigorous CIHR study aims to further explore the impact of participation on body functions.



In Project BEYOND, we have partnered with major youth rehabilitation organizations. In Quebec, we are collaborating with the [CIUSSS West-Central Montreal](#), six other public health and social services centers ([CIUSSS/CISSS](#)), a hospital, and four community organizations spanning rural and urban areas. In Ontario, our partnership with [Empowered Kids Ontario](#) and key community stakeholders—including youth, clinicians, and managers—will enable us to investigate the impact of an 8-week community-based activity individually selected by the youth (e.g., drawing classes, video editing, volunteering with horses, going to the gym), on three key body functions: motor skills, behavior, and emotions. Changes in body functions (e.g., movement, attention, mood) will be measured multiple times before, during, and after engagement in the chosen activity.

Project BEYOND is a cross-provincial study testing the impact of the PREP intervention. We aim to recruit 75 youth with physical disabilities aged 10-18 years in each province for a total sample of 150 youth. Throughout 2024, we were recruiting in 7 sites within the Quebec public healthcare and social services system (RSSS). We are also working with community organizations in and around Montreal who have agreed to help share information about the project, including [CIVA](#) (Centre d'intégration à la vie active), [Spina Bifida Hydrocéphalie Québec](#) and [Inspirations](#). Throughout 2024, we were working with 7 sites within Empowered Kids Ontario, laying groundwork with ethics, contracts and recruitment logistics. Training of Ontario OT therapists and PT assessors, and recruitment of Ontario participants is planned for 2025.

To facilitate recruitment in clinical sites, our young adult patient partner, Dr. Julia Hanes, has worked with us to develop a recruitment video in [English](#) and in [French](#) as an additional strategy for recruitment sites to inform potential participants about the study and highlight the benefits of participation. This video may be used in clinical waiting rooms where there are monitors, shared through organizational newsletters, or may be shared directly with youth and families.

Evidence from interviews with youth to support the impact of participation on body functions was presented by our team at the 2024 Participation – Inclusion in Action Conference in Singapore. Findings from this study will guide clinicians, families, and policymakers in selecting practical approaches that promote participation while also providing motor and mental health benefits from a single intervention. Such real-world treatment approaches involving activities of choice can enhance motivation, improve compliance, and reduce the burden on the healthcare system, youth, and families.

*This project is funded by [Canadian Institutes of Health Research](#) (CIHR 186179; 2023-2027)*

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**For more details, please reach out to Barb Galuppi by email at [galuppi@mcmaster.ca](mailto:galuppi@mcmaster.ca)**

## F-words for Child Development

The F-Words for Child Development continue to thrive, fostering collaboration, communication, and connection within a growing global community. In 2024, our team expanded its reach, welcomed new voices, and strengthened lasting relationships within the F-Words community. Through research, implementation support, and knowledge mobilization, we are continuously evolving to meet the needs of families, service providers, and organizations dedicated to holistic child development.



First, we undertook the third phase of research on evaluating the online F-words Foundations Program. In this phase, parents and service providers participated in two versions of the training: online self-paced learning and F-words Conversations, which combined the online modules with virtual facilitated sessions. This study, supported by Kids Brain Health Network and the Brain Canada Foundation, has concluded data collection and analysis, revealing overwhelmingly positive feedback throughout all phases. Manuscripts detailing findings are currently under development.

Second, we concluded data collection and analyses for our F-Words Implementation Study. This study was conducted between 2021-2024 with organizations in Ontario, Manitoba, and New Zealand. We assessed the implementation of F-words strategies within different organizational contexts. Feedback from 57 service providers highlighted the acceptability, feasibility, and appropriateness of F-Words implementation, averaging a rating of 4.2/5. Key facilitators of F-words implementation included F-words champions, leadership support, and alignment with organizational values. Common barriers included the COVID-19 pandemic, limited F-words awareness among families, and competing priorities among service providers.

Tailored strategies—such as embedding F-words in program documents, ongoing training, developing family materials, and networking with other sites—have played a critical role in adoption. Manuscripts on these findings are currently in progress.



The F-Words Implementation Support Program has expanded significantly in 2024. We provided support to organizations across British Columbia and Ontario, tailoring strategies and approaches to meet organizational needs. This included F-words and Implementation foundational training, coaching, and consultation to develop program-specific implementation plans.

In February, we launched the international, online F-Words Implementation Community of Practice. This virtual space allows teams and individuals worldwide—including those from Canada, New Zealand, Spain, Brazil, and Ireland—to share implementation experiences and best practices. Now boasting over 75 members, this community continues to foster innovation and collaboration. If you are interested in joining this community, please contact Vanessa Tomas ([tomasvm@mcmaster.ca](mailto:tomasvm@mcmaster.ca)).

Throughout 2024, our team actively shared F-words knowledge through workshops, invited talks, and conference presentations. We led training sessions for diverse groups, including the SAAAC Autism Centre, E'Mino Bmaad-Zijig Gamig Health Centre, British Academy of Childhood Disability Southwest Regional, Glenrose Rehabilitation Hospital, and the Cerebral Palsy Association of BC. Our collaboration with the Cerebral Palsy Association of BC enabled us to educate staff and caregivers on inclusive education and self-care strategies.

Additionally, we presented at multiple national and international conferences, including events in Australia, Belgium and Germany. Our ongoing engagement has led to invitations for 2025, demonstrating the impact and reach of the F-words initiative. We also expanded our Knowledge Hub, launching two new videos: [F-words for Child Development: From the Voice of a Parent](#) and [The ICF and F-Words: Learning Through Family Stories](#).

**I've been inspired by the F-Words with particular interest in how it can promote a shared understanding of child/human development across multiple sectors. It provides a shared language for families, service providers (including schools), researchers which provides lots of potential for deeper collaboration leading to truly effective outcomes for children, youth and families.**



Our 2024 publications include Perspectives in Childhood-Onset Disabilities: integrating 21<sup>st</sup> century concepts to expand our horizons and F-words Ingredients of Non-Invasive Interventions for Young Ambulant Children with Cerebral Palsy (scoping review). A major highlight of the year was receiving the prestigious Fred P. Sage Award at AACPDM in Quebec City for the F-words Online Training Program, awarded for the best multimedia submission presenting clinical, research, or educational material in a digital format.

As part of CanChild's 35th Anniversary celebrations, our team participated in a panel discussion highlighting the impact of F-words on families and researchers. This moving collaboration of researchers, clinicians and family partners was a tribute to work that has been done and inspiration for work in the future. Julia Hanes' keynote presentation at this event also brought forward elements of the F-words. She revisited her iconic environmental factors slide—reminding us of the power of advocacy and lived experience in shaping inclusive practices.



As we continue to innovate, we remain committed to collaboration and knowledge sharing. Thirteen years after its inception, the F-Words framework continues to inspire new ideas and partnerships. We are excited about the future, welcoming ongoing feedback and engagement from families, service providers, and researchers worldwide. As we move forward, we invite everyone to dream big, connect, and co-create a future that puts the whole person at the center of health and development.

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For more details, please reach out by email at [fwords@mcmaster.ca](mailto:fwords@mcmaster.ca)

## Family Engagement in Research Program

Co-founded by a dedicated team of family leaders and health researchers, the [Family Engagement in Research \(FER\) Program](#) is an international training program led by CanChild Centre for Childhood-Onset Disability Research at McMaster University and developed in partnership with [Kids Brain Health Network](#) and McMaster Continuing Education.



We offer foundational to advanced-level training courses (including two McMaster University Certificate of Completion courses), a growing international Community Network, and a variety of engagement support services. We prioritize equitable access to learning by implementing inclusive practices, creating accessible content, and welcoming individuals of all backgrounds and experience levels.

Our mission is to train, mentor, and mobilize the next generation of advocates, champions, and leaders in family engagement.

## Family Engagement Training and Engagement Support

The [Family Engagement in Research \(FER\) Course](#) brings together family members and researchers to enhance knowledge and develop skills in family engagement in research. With 182 new graduates trained in 2024 from diverse backgrounds, including international cohorts in the Netherlands and Australia, and a total of 616 graduates since 2018 across 10 Canadian provinces and 23 countries, the course is making a global impact. Studies evaluating the course's effectiveness and adaptations are ongoing. Learn more about the FER Course in our [recent publication](#) and [impact video](#).

The [Family Engagement Leadership Academy](#) was launched in Fall 2022 to support FER Course graduates in becoming leaders in family engagement across Canada and internationally. To date, 55 individuals have completed the Leadership Academy, and a pilot study was conducted in 2024 to evaluate the course's effectiveness and adaptations. In May 2024, we hosted an instructional course at the European Academy of Childhood Disability in Bruges, Belgium that focused on building leadership capacity in family engagement in child health research.

Our Family Engagement Fundamentals courses, developed collaboratively in 2022 and launched in 2023, provide foundational training to a wider audience, both online and in-person, to increase awareness and understanding of family engagement principles. To date, we have delivered foundational training courses to seven organizations including Children's Treatment Centres in Ontario, as well as research projects across Canada, and research networks within the United States.

We provide tailored engagement support and consultation to help individuals, groups, and organizations embed family engagement practices into their work. In 2024, we worked with two children's treatment centres offering strategic guidance and actionable resources to create sustainable and meaningful research and healthcare partnership.



## Family Engagement Community Network

What sets the Family Engagement in Research (FER) program apart is our vibrant Community Network. Learners don't just join us for a 10-week course—they become part of our FER community, a network of like-minded individuals passionate about meaningful family engagement. Through ongoing connections, shared resources, and collaboration opportunities, our community supports members long after the course ends, fostering growth, innovation, and sustained impact. We employ various channels of knowledge mobilization such as a monthly newsletter (>800 subscribers), online community events, and social media.



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For more details, please reach out by email at [fer@mcmaster.ca](mailto:fer@mcmaster.ca)

## Ontario Autism Program

In partnership with the Ontario Autism Program at the Ron Joyce Children's Health Centre, we aimed to deliver a series of workshops on interdisciplinary training. These workshops were designed to significantly enhance the clinical workforce through increased clinical placements (occupational therapy, speech-language pathology, applied behavior analysis, clinical psychology, etc.). The partnership also aimed to facilitate interprofessional workshops for preceptors and clinical trainees. Two workshops were delivered in February and October 2024 on the F-words foundation and implementation in practice by the F-Words team at CanChild.

About 50 clinicians, preceptors, clinical staff, and three to five clinical trainees on placement from the Autism Program at the Ron Joyce Centre participated in these workshops. An evaluation survey was distributed at the end of each workshop to understand the participants' satisfaction with the content, their perceived benefits and challenges of using the content in their practice, and their interaction with clinical trainees. The funding was provided by the Ministry of Children, Community and Social Services (MCCSS) in Ontario, Canada, through the Ontario Autism Program Workforce Capacity Fund—Innovation Stream. Funding was also awarded in 2024 to continue to develop workshops from CanChild work – for 2025 it will be for a novel workshop detailing the "About Me" and "The Youth KIT" tools and how to apply them in clinical practice and placement. Following the conclusion of this work, we will conduct the evaluation analysis once the third workshop is delivered.

Also in 2024, alongside delivering the workshops, we conducted a scoping review to identify outcomes and associated methods for evaluating interprofessional collaboration or interdisciplinary clinical training in pediatric rehabilitation. This scoping review is significant as it will provide a comprehensive overview of the current evaluation methods and outcomes in the field of pediatric rehabilitation, thereby helping researchers and clinicians select the most suitable tools and outcomes for their evaluation purposes. The review is in the final edition phase for submission to a journal.

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## Transition Projects

Our Transition Projects aim to improve healthcare transitions for youth with brain-based disabilities by developing e-health technology to empower youth and by learning from the challenges and opportunities for transitional care during the COVID-19 pandemic.

### CHILD-BRIGHT READYorNot™ Brain-Based Disabilities Project

This initiative, led by Dr. Jan Willem Gorter MD, PhD, FRCP(C) and Dr. Ariane Marelli MD, MPH, FRCPC, was part of the CIHR-SPOR-funded CHILD-BRIGHT Network, which addresses the needs of families and the need for systematically well-designed research approaches to co-create evidence-based e-health transition interventions through ongoing youth, parent/caregiver, and healthcare stakeholder engagement. To develop better ways to support youth with brain-based disabilities (BBD) as they transition from pediatric to adult health care, we created the MyREADY Transition™ BBD App in collaboration with patients, families, healthcare stakeholders, and industry partners. In the second part of the project, we evaluated the App in a randomized controlled trial (RCT) in four regions: Alberta, Ontario, Quebec, and the Maritimes.



*This project received the support of the CHILD-BRIGHT Network, CIHR's Strategy for Patient-Oriented Research initiative, and our partner support from Montreal Children's Hospital Foundation, McMaster University Faculty of Health Sciences, New Brunswick Health Research Foundation, McMaster Children's Hospital Foundation and Hamilton Health Sciences, and Centre hospitalier universitaire mère-enfant.*

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## Transition to Adulthood during COVID:

### Learning from Canadian Youth with Special Healthcare Needs and their Families to Foster Effective Transitional Care Interventions

Amidst the COVID-19 pandemic, young people with special health needs faced unique challenges like health concerns, disrupted routines, and social isolation. This [project](#) explored the positive and negative impacts of COVID-19 on the health of Youth with Special Health Care Needs (YSHCN) as they transitioned from pediatric to adult health services, seeking to understand the pandemic's effects on healthcare and other life transitions.

Our approach involved three main steps: qualitative interviews, a quantitative survey, and dissemination activities. In the first step, we interviewed 21 Canadian YSHCN and families to find out about their pandemic experiences and lessons learned. These insights guided the development of a survey, which 516 participants then completed to identify recommendations for enhancing healthcare transitions. We used an integrated Knowledge Translation (iKT) approach where YSHCN and their parents were active research team members, collaborating on every stage of the research process, from developing the research question and methodology to data collection, interpretation of findings, and dissemination of results.

These efforts culminated in virtual Town Hall discussions in February 2024, where we shared our findings and discussed ways to improve healthcare experiences and transitional care interventions in the future. The priorities, recommendations, and strategies that were identified through this study can be used to inform professional practice, policy, guideline development, and program changes. The study aimed to learn from positive and negative healthcare transition experiences during the COVID-19 pandemic to inform the development of the best possible healthcare for YSHCN. We aim to support transition and reduce the burden on YSHCN and families when planning and undergoing transitions to adult healthcare systems. Findings suggest that YSHCN and their families want consistency and continuity and assurance that their best interest is central to their care.

To share our findings more widely in 2024, key dissemination highlights included a [project report](#), [video summary](#), and a [Children's Healthcare Canada Spark Live webinar "Lessons learned during the pandemic: Lighting the way to build better healthcare transition programs"](#). We continue the conversation in the context of the [Canadian Transition Hub](#) to determine next steps in this program of work.

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**For more details, please reach out to Barb Galuppi by email at [galuppi@mcmaster.ca](mailto:galuppi@mcmaster.ca)**

## Childhood Cerebral Palsy Integrated Neuroscience Discovery Network (CP-NET)

The Childhood Cerebral Palsy Integrated Neuroscience Discovery Network ([CP-NET](#)) is an initiative funded by the [Ontario Brain Institute](#). Through multiple research platforms, the program aims to improve our understanding of cerebral palsy (CP) and accelerate the development of new treatments. In 2023, CP-NET was funded for an additional 5 years until 2028 (Phase 4). [McMaster Children's Hospital](#) is proudly part of three studies/components under the CP-NET program of research.



**CP-NET**

Cerebral Palsy Neuroscience  
Discovery Network

### Clinical Database – Understanding Risk Factors for Cerebral Palsy

The Clinical Database Platform is the largest component of CP-NET (component of 'Individual & Family Level'). The study is led by Dr. Darcy Fehlings at [Holland Bloorview Kids Rehabilitation Hospital](#). The aim of the study is to create a large database of information about clinical risk factors, neuroimaging, genetics, neurodevelopmental factors as well as the psychosocial and participation dimensions of children's lives. It is hoped that the information collected will support current and future CP-NET research questions and themes.

McMaster Children's Hospital is one of four clinical sites across Ontario recruiting for the Clinical Database study. Phase 4 of the study has been approved, and recruitment began in 2024. In 2024, McMaster recruited 10 new participants into the study, and re-consented 14 participants from Phase 3 to continue into Phase 4.



## CP-NET Clinical Database Platforms – Phase 4 Adult Cohort

The Adult Clinical Database Platform of CP-NET is a new study beginning for Phase 4. The Adult Cohort will recruit adults with CP from rehabilitation centres across Ontario. A standardized patient database will include demographics, medical history and function in activities of daily life, among others. This breadth of data collection not only enables improved understanding of key medical factors affecting adults living with CP, but also their associations with socioeconomic status, pain, community participation, quality of life and mental health/well-being.

The objectives of this study are to build an Ontario-wide research database of adults with cerebral palsy that will leverage existing infrastructures to integrate a wide range of clinical, neurodevelopmental, psychosocial and participation measures; and to allow researchers to explore the natural history of adult life for those with CP as well as specific outcomes related to pain, fatigue, participation, mental health outcomes, and healthcare needs/usage through the collected data.

The study plan/protocol was developed by the study team, with help from the study advisors (adults with lived experience). Ethics applications have been submitted to all sites, and we are currently finalizing all approvals and contracts for the study. We hope to begin recruitment in 2025.

Participating sites for the CP-NET Adult Cohort include Hamilton, Ottawa, London, and Niagara.

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**For more details, please reach out to Sarah Hopmans by email at [hopmansn@mcmaster.ca](mailto:hopmansn@mcmaster.ca)**

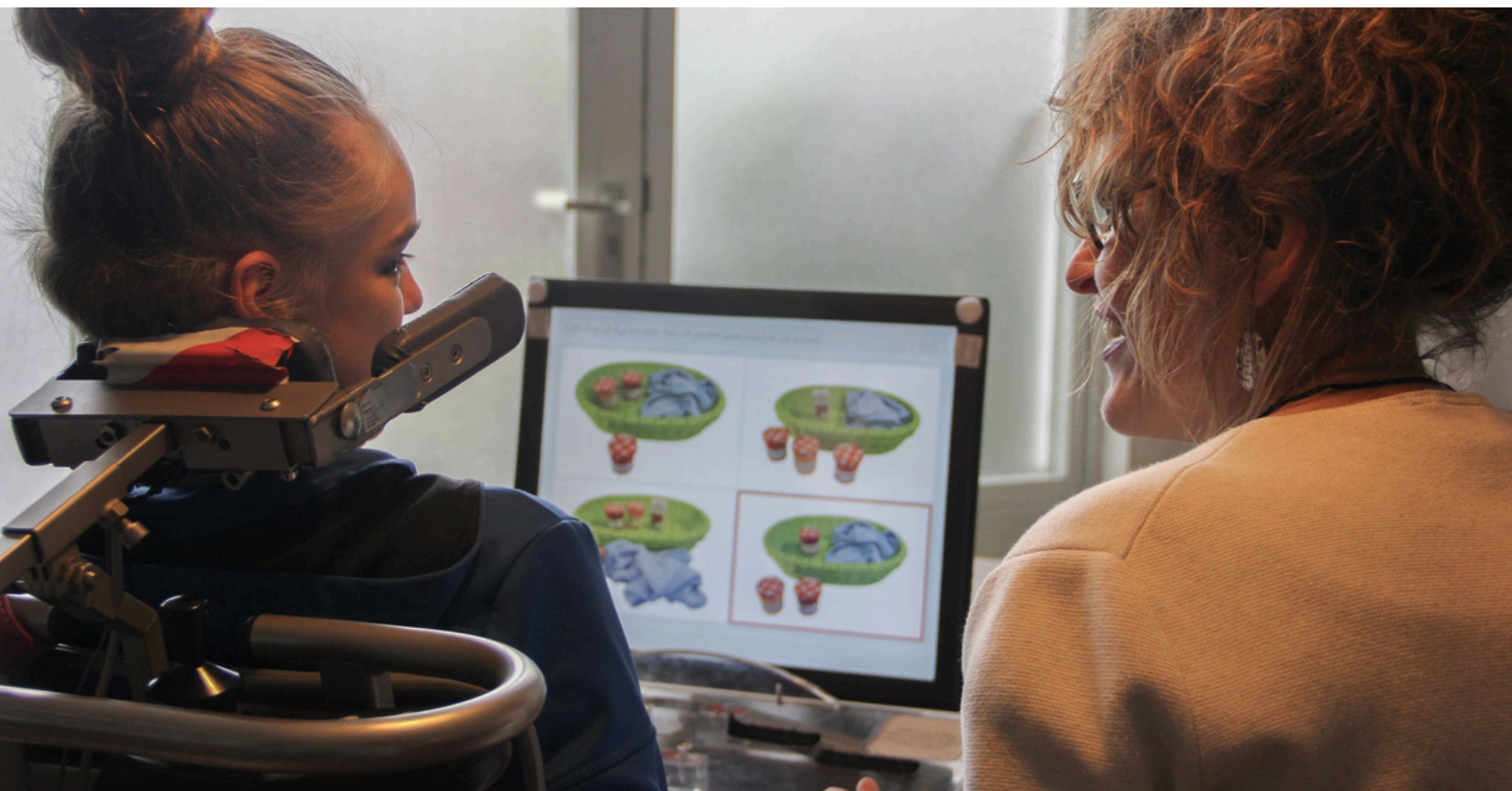


## C-BiLLT

### (Computer-Based instrument for Low motor Language Testing)

From 2018-21, researchers at CanChild completed linguistic and cultural validation for, and then tested, the validity, reliability, and feasibility of the Canadian English Version of the C-BiLLT (Computer-Based instrument for Low motor Language Testing - CAN). The C-BiLLT is an innovative Dutch tool that uses alternative access methods to assess spoken language comprehension in children and youth with CP who are non-speaking. The tool is the first of its kind to provide a reliable, evidence-based assessment for these children, opening doors to better support, treatment, and education.

Participants in the Canadian validation study were recruited from Hamilton schools, daycares, McMaster Children's Hospital Clinics, the Ron Joyce Children's Health Centre as well as from the broader community. The results showed that the C-BiLLT - CAN was valid and reliable, indicating that it was an appropriate tool for measuring language comprehension in English-speaking children in Canada. However, results of the study also indicated that further testing of the C-BiLLT-CAN in the Canadian clinical context was needed, as participant recruitment was limited for children with CP due to the COVID-19 pandemic. A manuscript was written and published in the Journal of Pediatric Rehabilitation Medicine. The study was funded by the Hamilton Academic Health Sciences Organization.



Further research to understand how the original Dutch C-BiLLT was being used in practice in Europe was conducted throughout 2021, including a cross-sectional survey and an interview study. The survey was completed by 90 clinicians in the Netherlands, Norway, and Belgium where the C-BiLLT was routinely used. This study described how the C-BiLLT was being used by clinicians and reported on its implementation status. In a follow-up interview study, clinicians' capabilities, motivation, and behaviours regarding C-BiLLT use were explored in more detail to understand how these factors impacted the adoption, implementation, and use of the test in clinical practice. The study identified a need for additional implementation supports for clinicians who use the test with its intended population (i.e., children with CP and limited motor and speech abilities), particularly when those children also had significant visual impairments. A manuscript describing the results of the survey study was published in *Augmentative and Alternative Communication* and the interview study was published in *BMC Health Services Research*.

Drs Cunningham and Chau received CIHR funding to continue supporting implementation of the C-BiLLT-CAN in Canada (2022-2026). The project is entitled "Innovative language assessment for children with low motor and speech function: Engaging stakeholders to understand the necessary conditions for implementing the C-BiLLT in Canada". With this grant, and by integrating knowledge gained regarding practice needs identified in previous studies, the team is working to identify and address barriers to C-BiLLT-CAN use in Canada and develop and assess user experience for a virtual training for Canadian clinicians.

The project's three aims are to (1) understand Canadian clinicians' and families' current language comprehension assessment experiences and needs, as well as their perceived barriers and facilitators to using the C-BiLLT-CAN; (2) modify the C-BiLLT-CAN's accessibility (access methods) and customization options and assess the feasibility of the adapted C-BiLLT-CAN for Canadian children with CP; and (3) develop and pilot an online training for clinicians to support implementation in Canada. The project involves a collaboration between researchers, clinicians, and family research partners. This study is approved at 8 sites in Canada (6 in Ontario, 1 in New Brunswick, 1 in Alberta).



In 2022, the team obtained ethics approval to work on this study at 8 sites in Canada (6 in Ontario, 1 in New Brunswick, 1 in Alberta), and data collection for Aim 1 began by collecting information from Canadian families and clinicians via online surveys and focus groups. In 2023, Aim 1 was completed and Aim 2 began. Aim 1 focus groups were completed, and four manuscripts were submitted for publication. For Aim 2, a new version of the C-BiLLT-CAN was created called the C-BiLLT-CAN Offline. The C-BiLLT-CAN Offline allows for many new access methods and customizations for test administration. It also allows clinicians to complete the test without internet access (offline), which was identified as a key barrier in Aim 1. In 2024, clinicians at the 8 partner sites were trained to use the C-BiLLT-CAN Offline, and feasibility testing began. Work to develop the clinical training manual and online training platform also began. Feasibility testing continued into 2025 and ended in March. The next steps are to finish developing and then pilot the clinical training manual and online training platform.

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For more details, please reach out to Sarah Hopmans by email at [hopmansn@mcmaster.ca](mailto:hopmansn@mcmaster.ca)

## Back2Play App

The randomized controlled trial (RCT) of the Back2Play app, which compares youth with concussions using the app on an Apple Watch to those receiving standard care, has been completed and the data analyzed. A total of 181 participants were recruited from the Hamilton community, McMaster Children's Hospital, and Montreal Children's Hospital. Participants were monitored until they were symptom-free or for a maximum of three months post-injury if they did not achieve full recovery. The Back2Play app utilized CanChild evidence-based protocols to guide youth aged 10-18 in safely returning to activity and school (RTA/RTS) after a concussion. This interactive app was designed to thoroughly track concussion symptoms and provide real-time activity data to assist children and youth in following these protocols. In contrast, the control group reported their symptoms daily and completed surveys regarding their cognitive and physical activities, but they did not receive the ongoing suggestions offered by the app.



The study yielded some intriguing and mixed results. While no significant difference was observed in reinjury rates (sustaining another head injury) between the two groups, the app users engaged in significantly more physical ( $p=0.024$ ) and cognitive activities ( $p=0.001$ ) during their recovery. Conversely, the control group achieved symptom resolution more quickly ( $p=0.04$ ), albeit in smaller numbers. A greater proportion of participants in the app group reported returning to full activity at the symptom-free follow-up ( $p=0.03$ ). These findings indicate that the Back2Play app effectively supports progression through the RTA and RTS stages while encouraging physical and cognitive engagement. The app represents an innovative tool for facilitating a return to daily activities following a concussion. Notably, participants rated the Back2Play app above the 90th percentile on the System Usability Scale (SUS) and found it beneficial for their recovery.



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**For more details, please reach out to Kathy Stazyk by email at [stazyk@mcmaster.ca](mailto:stazyk@mcmaster.ca)**



## Transition Hub

Transition to adult healthcare can be a stressful time for youth. A poor transition can lead to disengagement with services, poor adherence to treatment, and costly and unnecessary healthcare utilization (Toulany, Gorter, Harris, 2022). In partnership with Children's Healthcare Canada, CanChild created the Health Hub in Transition to Adult Healthcare (or Transition Hub). This thriving network has approximately 250 members including researchers, healthcare providers, youth, parents and decision makers all passionate about improving the transition to adult healthcare experience for youth and their families.



Throughout 2024, we had several initiatives underway.

**Health Quality Indicators:** Led by Dr. Alene Toulany and Jackie Pidduck, this initiative is constructing a framework to help healthcare providers and institutions measure performance. Funding was awarded for this work in 2023, and throughout 2024 the team worked to obtain ethics, establish contracts, recruit for the KT panel, and recruit for the online modified delphi which occurred in early 2025.

**Environmental Scan:** Led by Drs. Lin Li and Alison Luke, this initiative worked to gather information about the programs, services and resources available across Canada to support youth in their transition to adult healthcare. In 2024, we published the results of this work "Landscape of healthcare transition services in Canada: a multi-method environmental scan" in BMC Health Services Research. The next steps for this work is to collate the information into a central repository.

**Sustainability:** Our Chair, Dr. Anne Fournier, is working to build a business plan to support the financial sustainability of the Transition Hub.

**Knowledge Translation:** Work of the Transition Hub was presented at the Parachute Conference, the CanChild 35th anniversary as well as a poster at the 2024 American Academy for Cerebral Palsy and Developmental Medicine.

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# Support Us!

We've reached remarkable milestones, engaging and empowering families through research that changes lives worldwide. Our mission is to generate impactful knowledge and expand our reach to touch even more families. While grants fund much of our research, your donations are essential to support our ability to spread our findings and amplify the voices of children and families globally.


## How you can support us

We invite you to join us in making a difference. Your donation can help us:

- Enable patient and family partners to participate in scientific conferences
- Disseminate reports of lived experience through our networks to raise awareness
- Make our results and tools available in French and other languages


Every contribution, big or small, helps us continue our work and create a lasting impact. Thank you for your generosity and continued support.

**Donate Now**



CanChild has consistently modelled generosity in knowledge sharing, and a spirit of authentic collaboration. That approach has made it possible for people like me, working in very different contexts, to engage meaningfully with your work and make it our own. I have had the pleasure to benefit from the knowledge and wisdom of others associated with CanChild.

- **Dr. Roopa Srinivasan**, Senior Developmental Pediatrician, Chief Officer, Early Childhood Development and Healthcare Ecosystems, Ummeed Child Development Center, Mumbai, India



I had a conversation with an educator yesterday who has changed her practice based on learning about the F Words from her college professor. When I talk to people about using these ideas in our work, they are truly life changing. Recently, I was speaking with one of the RCs on my team about an intake meeting she just had with a new family, and she said the parents were over the moon about getting to talk about their child using the F Words. In her words, the parents were "beaming!". If that's not what it's all about, I don't know what is! Not only are the F Words making a positive impact in the families we support, but there's rarely a week that goes by that I don't get an opportunity to "light up" when I talk about these ideas and how they can support the experience of children and families in our services.

- **Evelyn Bursey**, Manager, Inclusion Services, Community Living North Halton, Milton, ON, Canada



This Report was produced & designed by Daniela Klobucar, Dayle McCauley, Jessica Geboers and Danijela Grahovac.

**Special thank you goes out to all CanChild members and staff who contributed to this report!**

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