CanChild

2025
ANNUAL REPORT

GENERATING KNOWLEDGE AND TRANSFORMING LIVES

A Message from CanChild's Directors

For more than three decades, knowledge translation has been at the heart of who we are. It has never been an afterthought to our research – it has always been part of the research itself. When CanChild was founded in 1989, our co-founders understood a simple truth: research findings matter only when they reach the clinicians, educators, policymakers, and families whose decisions they shape. We were among the first research centres in the world to put our work on the web, in the 1990s, at a time when many treated a peer-reviewed publication as the finish line. For us, publication was the starting point.

That instinct has compounded into something remarkable. Our validated measurement tools – including the GMFCS, the GMFM, the ACSF-SC and the MPOC – are international standards, available in more than 22 languages. Our F-Words for Child Development framework has been downloaded over 100,000 times, cited in more than 900 publications, and adopted in over 30 countries. Our Family Engagement in Research program has graduated 498 participants across 20 countries. These are not isolated achievements. They are the product of a sustained, deliberate commitment to moving evidence into practice.

This year, the numbers told that story more clearly than ever. Between April 2025 and March 2026, CanChild's websites received approximately 796,000 visits from users in more than 73 countries – making CanChild one of the most visited childhood-disability research websites in the world. Only 25 to 40 percent of that traffic originated in Canada; the rest reached us from the United States, Australia, the United Kingdom, Japan, India, Brazil, and across Europe. Nearly 60 percent of visitors arrived on a mobile device.

What makes these results extraordinary is how they were achieved. CanChild's digital presence is sustained by a core operational team of four, with no dedicated communications role and no paid advertising – roughly 199,000 website visits per staff member every year. This reach is earned, not bought. It is driven entirely by the quality, relevance, and accessibility of the work of CanChild scientists and associate members.

None of this would be possible without our scientists, trainees, partners, and the children, youth, and families who guide everything we do. To all of you: thank you. The tradition we inherited in 1989 is stronger than ever, and we are proud to carry it forward.

Dr. Olaf Kraus de Camargo, MD
Co-Director,
CanChild Centre for Childhood-onset Disability Research

Dr. Briano Di Rezze, PhD, OT Reg(Ont.)
Co-Director,
CanChild Centre for Childhood-onset Disability Research

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About Us

The **CanChild Centre for Childhood-Onset Disability Research** is a research centre dedicated to generating knowledge and transforming the lives of children and youth with developmental conditions and their families.

Since its founding in 1989, CanChild has become an international leader in the field of childhood disability research through innovative research and a commitment to making research findings accessible to a wide range of audiences. 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.

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.

Our Vision

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**

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, anthroplogy, 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.

At the heart of CanChild is a dedicated core staff team of four members who support and sustain the Centre's day-to-day operations, coordination, and knowledge translation activities. This small but highly collaborative team works closely with our broader network of scientists, trainees, and partners to enable research, foster connections, and move evidence into practice.

4 Core Staff Members

Scientists **22**

87 Associate Members

Postdoctoral Fellows **13**

Visiting Scholars **7**

Project Staff **27**

27 PhD Students

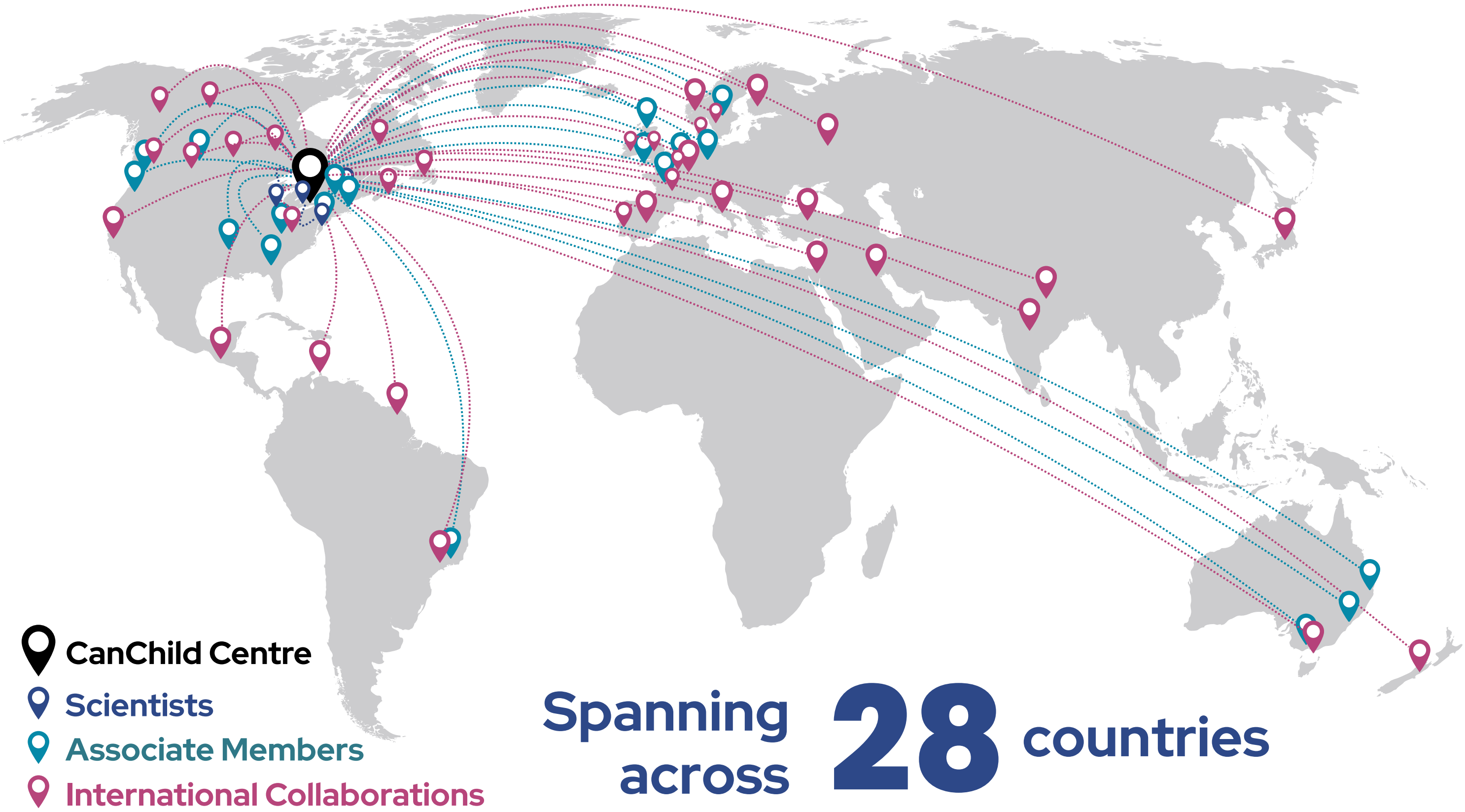
Family & Youth **43** Advisors/Co-Investigators

Student **12** Research Assistants

Together, CanChild functions as both a close-knit team and an expansive global network—amplifying our collective impact across disciplines, sectors, and regions. Through this collaboration, CanChild's work extends far beyond our home institution, contributing to initiatives and partnerships across Canada and internationally.

CanChild Around the World

CanChild continues to strengthen its global presence through a diverse network of collaborations, partnerships, and knowledge exchange initiatives spanning six continents. In 2025, our work extended across North and South America, Europe, the Western Asia, Africa, Asia, and Oceania—reflecting a shared commitment to advancing childhood-onset disability research and improving outcomes for children and families worldwide. Our international collaborations span research, clinical practice, and implementation efforts.



Spanning across 28 countries

In addition to research collaborations, CanChild plays an active role in global knowledge mobilization. In 2025, team members contributed to and led international conferences and events, including meetings in Guatemala and Curaçao, further strengthening connections with global partners.

Ongoing academic collaborations also include co-supervision of doctoral research and the strengthening of international institutional partnerships. In 2025, CanChild established formal Memoranda of Understanding (MoUs) with the Universidade Federal de Juiz de Fora (Brazil), Ankara University and Anadolu University (Türkiye), MSH Medical School Hamburg (Germany), and the South Asia Neurodevelopmental Behavioural Environmental Paediatrics Association (SANBEPA). These agreements provide a foundation for sustained collaboration in research, training, and knowledge exchange across regions.

The Signing of a Memorandum of Understanding (MOU) with CanChild's Co-Drirector, Olaf Kraus de Camargo and Dr. Zaafar Meenai from the South Asia Neurodevelopmental Behavioural Environmental Paediatrics Association (SANBEPA), based in Kathmandu, Nepal.

Visiting Scholars

A cornerstone of our global engagement is the exchange of scholars and trainees. In 2025, CanChild was pleased to host a number of visiting scholars from around the world.

These included Soraia Micaela and PhD student Léia Oliveira from Universidade Nove de Julho (Brazil), Dr. Beatriz Brugnaro Marques (Mackenzie University, Brazil), Michelle Østergard (Aalborg University, Denmark), Assistant Professor Dr. Anwar Almutairi (Kuwait University), Anat Lahaav (Beit Issie Shapiro, Israel), and Soraya Pacheco da Costa (Universidad de Alcalá, Spain), as well as a visiting colleague from France. These exchanges foster meaningful collaboration, mentorship, and cross-cultural learning that enriches both our research and global partnerships.

CanChild World

To support our global community, CanChild continues to expand CanChild World, a comprehensive multilingual resource hub designed to make our work accessible across languages and contexts. This platform brings together a wide range of CanChild materials, including documents, tools, videos, posters, and webinars, translated to better serve professionals, families, and researchers worldwide.

By offering resources in multiple languages, CanChild World helps reduce language barriers and supports more equitable access to knowledge, tools, and evidence-based practices. Whether users are looking for research insights, practical guidance, or family-friendly materials, CanChild World provides trusted content in formats and languages that meet diverse needs.

As part of this initiative, several dedicated language hubs have been developed in collaboration with international partners who volunteer their time for these projects. We are extremely grateful for their dedication to make research more accessible.

CanChild Dutch

De Dutch Hub is bedoeld om mensen in Nederland te helpen onze website te gebruiken en kennis, hulpmiddelen en bronnen te vinden die beschikbaar zijn in het Nederlands.

CanChild German

Das German Hub soll die Inhalte der Arbeit des CanChild-Zentrums auch in deutschsprachigen Ländern leichter zugänglich machen und so eine möglichst breite Verbreitung ermöglichen.

CanChild Brazilian-Portuguese

O Hub em Português Brasileiro no site da CanChild tem como objetivo ajudar as pessoas no Brasil a navegar pelo nosso site e encontrar conhecimentos, ferramentas e recursos disponíveis em português brasileiro.

Together, these efforts strengthen CanChild's ability to share knowledge across borders, supporting a vibrant, international community dedicated to advancing childhood disability research and promoting inclusive, family-centred practices worldwide!

For any inquires about translations of a CanChild tool or measure, please reach out to CanChild World at ccworld@mcmaster.ca

Expanding Global Access: Translations in 2025

In 2025, CanChild continued to expand the global reach and accessibility of its tools and resources through ongoing translation efforts. By working with international collaborators, we are ensuring that families, clinicians, and researchers around the world can access and use CanChild measures and materials in their preferred languages.

This year, several tools and resources were translated or made available in additional languages:

- **Y-PEM** – Brazilian Portuguese and Turkish
- **F-words Lens Tool** – Spanish and Brazilian Portuguese
- **Gross Motor-Family Report (GM-FR)** – Brazilian Portuguese
- **Autism Classification System of Functioning** – Croatian
- **CAPE/PAC** – Danish
- **Gross Motor Function Measure (GMFM) Scoresheet** – Greek
- **About My Child** – Hebrew, French, Dutch and Brazilian Portuguese
- **About My Baby/Toddler** – Hebrew, French and Dutch
- **About Me** – Hebrew, French and Dutch
- **F-words resources** – Greek
- **Child Engagement in Daily Life** - Japanese, Bangla and Turkish

These translation efforts not only broaden access but also support the meaningful implementation and equitable knowledge sharing of CanChild tools and resources across diverse contexts. By prioritizing accessibility and collaboration, we continue to ensure that our work can be adapted, understood, and applied globally.

> **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

CanChild Fellowship

To support new investigations into innovations in pediatric rehabilitation, in 2025, we were excited to launch a new fellowship program. This program is structured to provide funded opportunities for trainees to lead research with a CanChild scientist in collaboration with the Rocket Discovery Centre at KidsAbility. The purpose of the fellowship is to get research fellows to lead applied research that advances childhood disability research while preparing them for careers as independent scientists. Through this program, we hope to support the research required to improve timely access to high-quality, equitable care in pediatric rehabilitation.

CanChild by the Numbers

In 2025, CanChild has consistently been successful in securing funding, publishing papers, and disseminating findings.

Behind every publication, presentation, partnership, and resource is a shared commitment to improving the lives of children and families. The numbers below provide a snapshot of CanChild's impact in 2025. From research and funding achievements to global engagement, knowledge translation, and digital reach. Together, they tell the story of a team creating meaningful change locally, nationally, and around the world.

300+

Publications

250+

Presentations

16

Awards

Grant Applications & Successes

34

grants awarded

>

$12.8M+

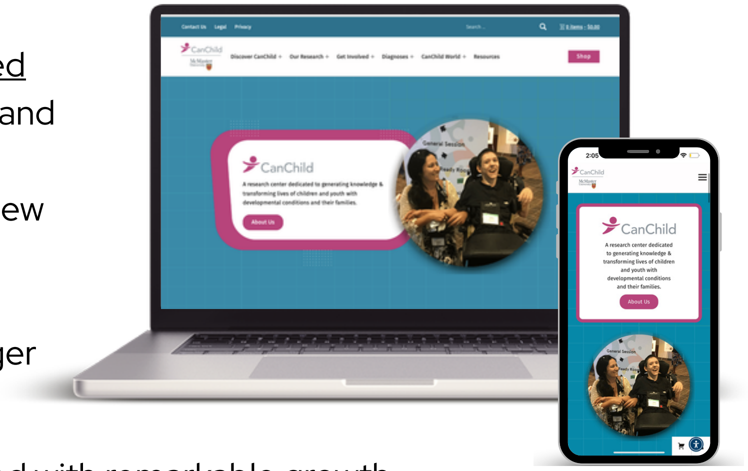
research funding awarded

Operating Budget

$600K

Digital Reach

In 2025, CanChild launched a fully redesigned website to improve accessibility, navigation, and user experience for families, clinicians, researchers, and community partners. The new website streamlined access to our extensive collection of tools, resources, research, and educational materials while creating a stronger foundation for future growth.



A research center dedicated to generating knowledge & transforming lives of children and youth with developmental conditions and their families.

73+

Countries Reached

The redesign coincided with remarkable growth in CanChild's digital reach. Between April 2025 and March 2026, CanChild's websites received nearly **800,000 visits** from users in more than **73 countries**, making CanChild one of the most visited childhood disability research websites in the world. Only 25–40% of website traffic originated from Canada, with users accessing CanChild resources from across the United States, Australia, the United Kingdom, Japan, India, Brazil, and Europe. Mobile users accounted for nearly 60% of all visits, reflecting the diverse and global nature of CanChild's audience.

796,000

Annual Visits

33,400 **Monthly Unique Visitors**

59.9% **Mobile Traffic**

CanChild's digital presence is supported by a core operational team of four staff members, with website content maintained by IT staff and social media and newsletters supported by a student. With no dedicated communications position and no paid advertising budget, CanChild generates approximately **199,000 website visits** per staff member annually. This reach is driven entirely by the quality, relevance, and accessibility of CanChild's tools, frameworks, and educational resources.

Social Media Impact

CanChild's social media platforms continue to play an important role in sharing research, promoting resources, celebrating achievements, and engaging with families, clinicians, researchers, students, and community partners around the world.

In 2025, CanChild's social media content generated **733,074 impressions**, **12,661 post reactions and likes**, and **2,303 shares**, across our social platforms - helping extend the reach of our research and knowledge translation activities.

Through regular posts, campaigns, event promotion, and resource sharing, we continued to connect with audiences across Canada and internationally, fostering conversations that support evidence-informed practice and family-centred care.

733,074
Impressions

12,661
Reactions & Likes

2,303
Shares

Stay Connected!

Stay in touch and be part of the CanChild journey! Follow us on social media to get the latest updates about our research, practical resources, and behind-the-scenes moments. Feel free to contact us...we'd love to hear from you!

- canchild.ca
- canchild@mcmaster.ca
- CanChild Centre for Childhood-onset Disability Research
- @canchildcentre
- facebook.com/canchild.ca
- @canchild.bsky.social

The CanChild Shop

The CanChild Shop provides access to a growing collection of evidence-informed measures, tools, and resources developed by CanChild researchers and collaborators. These products support clinicians, researchers, organizations, and families in advancing assessment, service delivery, participation, and family-centred care. Revenue generated through the CanChild Shop is reinvested directly into research, knowledge translation, and resource development, helping us continue our mission of improving the lives of children and youth with developmental conditions and their families.

CanChild Shop

New and Updated Products in 2025

2025 marked a significant year of growth for the CanChild Shop, with several new and updated tools becoming available:

About My Child questionnaire
(updated version)

About Me questionnaire

About My Baby/Toddler questionnaire

Gross Motor Family Report
GM-FR
GROSS MOTOR FAMILY REPORT

F-words Lens Tool
f-words for Child Development
Manual
The F-words Lens Tool
Introducing a new tool to identify treatment components

PREP Young Adult Supplement
PREP
Pathways & Resources for Engagement & Participation

MPOC 2.0
MPOC 2.0
Measure of Processes of Care

CanChild also assumed stewardship of two internationally recognized classification systems:
Manual Ability Classification System (MACS) and Mini-MACS

To obtain pricing for a CanChild tool or measure, or for any inquiries, please reach out to the CanChild Shop at ccstore@mcmaster.ca

News, Events and Accomplishments

From international conferences and research awards to new collaborations, knowledge translation initiatives, and community partnerships, 2025 was a year of growth, innovation, and meaningful impact at CanChild. Throughout the year, our scientists, associate members, trainees, staff, and collaborators continued to advance childhood disability research while strengthening connections with families, clinicians, organizations, and communities across Canada and around the world.

These highlights reflect the breadth of CanChild's work and the many accomplishments that shaped the past year – including research funding and honours, presentations and conferences, global partnerships, student achievements, and initiatives focused on improving care, participation, inclusion, and quality of life for children and families. Together, these milestones demonstrate the power of collaboration and the continued dedication of the CanChild community to creating meaningful change through research, education, and knowledge sharing.

January

Dr. Dana Anaby and fellow CanChild members were awarded the CIHR Planning and Dissemination Grant for their project to enhance the accessibility of the Y-PEM, a widely recognized self-reported measure.

February

The F-words team was invited to present a pre-congress course at the CIPEDIA 2025 Conferance in Jundiai, Brazil from February 7-9th. This was a wonderful opportunity to connect, re-connect and collaborate with CanChild friends and family!

CanChild's co-director, Dr. Olaf Kraus De Camargo's, opinion piece was featured in The Hamilton Spectator. CanChild's notable F-words framework and Partnering for Change (P4C) Model were among those featured.

March

Dr. Keiko Shikako was presented with the King Charles III Coronation Medal in recognition of her exceptional contribution to Canada in the field of youth education.

Dr. Monika Novak Pavlic, was awarded a CIHR Post-Doctoral Fellowship Award (2025-27) to explore child engagement in pediatric rehabilitation services with four of Ontario's leading Children's Treatment Centres.

On March 26th, CanChild members attended and presented McMaster Child Health Research Day in Hamilton, Canada - a day filled with insightful discussions, groundbreaking research, and meaningful connections!

March

Dr. Peter Rosenbaum and Dr. Olaf Kraus de Camargo were awarded a 2-year HAHSO grant to pilot a new approach to understanding the support needs of children with developmental disabilities and their families, in partnership with three Ontario Children's Treatment Centres, the project combines CanChild's About My Child questionnaire, the WHO's ICF and AI technology from Finnish company HeadAI.

April

Dr. Kinga Pozniak, Dr. Peter Rosenbaum, Dr. Gillian King, and fellow CanChild members received a CIHR Planning and Dissemination Grant in partnership with SMILE Canada to explore what culturally relevant and safe care looks like to racialized refugee families who have children with disabilities.

Dr. Andrea Cross received a 2-year KBHN Implementation Stream Award for her project focused on implementing the F-words for Child Development framework to advance holistic, strengths-based, and family-centred care across sectors.

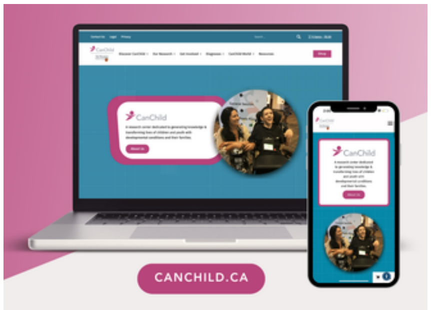
May

CanChild trainees and collaborators were recognized through the KBHN 2024–2025 Special Awards. Alice Soper received the Outstanding Promising Researcher Award, Amanda St. Dennis received the Outstanding Family Leader Award, and Samantha Micsinszki received the Inclusive Researcher/Innovator Award for their contributions to family-centred and inclusive research.

Dr. Olaf Kraus de Camargo participated as a panelist at the first Canadian Young Caregivers Conference and Café Scientifique held in Hamilton, Canada.

June

Dr. Monika Novak Pavlic was awarded the International Trainee Award for Excellence at the Graduate Health Plenary, awarded by the Faculty of Health Sciences, McMaster University.



CanChild launched its newly redesigned website, featuring improved accessibility, streamlined navigation, and enhanced organization of resources for researchers, clinicians, families, and community partners.

CanChild participated in the EACD/IAACD 2025 conference in Heidelberg, Germany, with over 65 contributions across various formats, we connected with our colleagues and partners from around the world.

June

> **While the Order of Canada is always awarded to an individual, the work that I have been doing for the last 35 and more years has clearly been done in a context of a family - a family we call CanChild.**
>
> **- Dr. Peter Rosenbaum,** Co-Founder, CanChild Centre for Childhood-onset Disability Research

We congratulate CanChild's Co-Founder, Dr. Peter Rosenbaum, who was appointed an Officer of the Order of Canada for his transformative contributions to the field of childhood disability. The appointment, was announced on June 30th, 2025 by the Office of the Governor General, and recognizes Peter's impact on how children with disabilities and their families are understood and supported. The Order of Canada is one of the country's highest civilian honours, celebrating individuals whose service has shaped the nation in lasting ways.

In 1989, Peter co-founded the CanChild Centre for Childhood-Onset Disability Research at McMaster University alongside Prof. em. Mary Law (OT) who is also an Order of Canada recipient. They shared a vision for more collaborative, family-centred, and evidence-informed care. Since then, CanChild has grown into an internationally recognized research centre whose tools, frameworks, and programs are used by families and professionals across the globe.

Among Peter's many contributions is the development of the F-words for Child Development framework with colleague Dr. Jan Willem Gorter. Centered around Functioning, Family, Fitness, Fun, Friends, and Future, the F-words have become a widely adopted strengths-based approach to childhood development, translated into more than 35 languages and embraced internationally by clinicians, educators, organizations, and families.

Peter's impact extends far beyond publications and programs. Throughout his career, he has mentored generations of students, clinicians, researchers, and families, fostering a culture of curiosity, collaboration, and compassion. His philosophy of "it is not me but we" continues to shape CanChild's work and community today.

July

CanChild Associate Member Dr. Stelios Georgiades was named a 2025 McMaster University Scholar, recognizing his leadership and contributions to autism and neurodevelopmental research.

August

Dr. Olaf Kraus de Camargo was promoted to Professor of Pediatrics in the Faculty of Health Sciences at McMaster University, recognizing his continued leadership to child health and development.

Dr. Peter Rosenbaum was inducted as a Fellow of the Canadian Academy of Health Sciences (CAHS), one of the highest honours in Canada's health sciences community.

September

Dr. Briano Di Rezze was appointed as the Assistant Dean of Occupational Therapy, within The School of Rehabilitation Science at McMaster University.

Dr. Olaf Kraus de Camargo presented the opening keynote on "Breaking the Mould", at the Kids+ Changemakers Conference, on September 4–5th, in Torquay, Australia.

CanChild Associate Member, Dr. Stelios Georgiades was named to the incoming class of the College of New Scholars, Artists and Scientists of the Royal Society of Canada.

October

Dr. Julia Hanes earned her first ever World Para Athletics Championships medal, with an outstanding throw of 7.51 metres in the women's F33 shot put final to claim the bronze medal!

CanChild Associate Member, Dr. Darcy Fehlings was awarded the 2025 AACPDM Mentorship Award for her outstanding leadership in mentoring trainees and colleagues in the field of childhood-onset disability.

Held on World Cerebral Palsy Day, the 12th Annual CP-NET Science and Family Day Event was a success with presentations from leaders, researchers and persons with lived experience on the theme of activity.

November

CanChild Scientist, Dr. Anne Klassen, was named a Tier 1 Canada Research Chair (CRC) in Patient-Reported Outcomes, recognizing her groundbreaking work to ensure care is guided by the experiences and perspectives of those receiving it.

CanChild was proud to serve as a Sparkle Sponsor at the inaugural Little Lights, Big Hearts Gala, hosted by the Canadian Premature Babies Foundation (CPBF). The event raised funds to support the mental health and wellbeing of parents during and after their baby's NICU journey.

CanChild participated in the KidsAbility Innovation & Research Symposium, with Dr. Michelle Phoenix among the keynote speakers, she presented her work on improving accessibility and engagement in children's rehabilitation services, advancing family-centred care and supporting parents' mental health.

November

CanChild members participated in the International Medical Conference Curaçao 2025, a multidisciplinary event focused on advancing healthcare knowledge through presentations, workshops, and collaboration. CanChild's Co-Director, Dr. Olaf Kraus de Camargo, served as Conference President, emphasizing the importance of collaboration in improving patient outcomes and healthcare wellbeing.

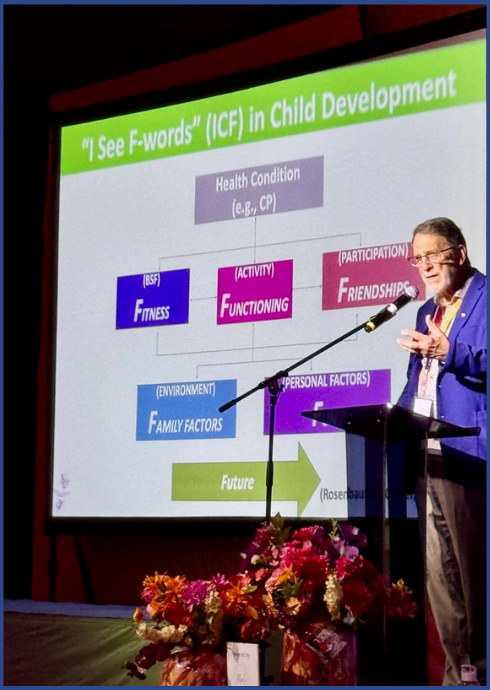
December

CanChild members contributed to and presented at the 6th International Developmental Pediatrics Association (IDPA) Congress in Guatemala City, Guatemala from December 1-4th. The theme of the congress was "Equity and opportunities for all children, with a focus on Indigenous and minority communities"

CanChild staff and friends came together to celebrate the holiday season. The afternoon was filled with connection, laughter, and shared moments. We are grateful for the opportunity to reflect on the year and celebrate together!

Looking back on the past year, we are reminded that meaningful progress is built through collaboration, curiosity, and community. From local partnerships to international initiatives, the accomplishments of 2025 reflect the dedication of the many individuals and families who continue to shape and strengthen CanChild's work.

Our Research



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 a 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.

Family Centred Services

Family-centred service is an approach to supporting children with special needs that places the entire family at the centre of care.

Approaches to Disability

Functioning, Family, Fitness, Fun, Friends, and Future—the six F-words that help shape a strengths-based approach to child development.

Focus on Family and Youth

We are focused on empowering children, youth, and families through family-centred care, co-design, and meaningful research partnerships.

School and Community Services

Aimed to support families, educators and professionals who provide support to children in schools along with related research initiatives.

Diagnosis Informed Research

We promote 'non-categorical' approaches to child and family development while being involved in many condition-specific research programs.

Participation

Learn about the importance of participation at home, school, and the community among children and youth with developmental conditions.

Life Course Development

The life course approach is a developing research area that examines a person's journey through life, with different transitions along the way.

Self-advocacy

A focus on enabling children, youth, and their families to advocate for their needs.

Knowledge Translation and Implementation Science

We are committed to sharing knowledge and applying implementation science to improve, study, and evaluate knowledge translation efforts.

Family Centred Services

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 became necessary to reassess these measures.

In this study, launched in April 2021, researchers and parent partners explored 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, the team examined 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-centredness and determine how well they meet the expectations of the families they serve. The tool was refined through input from 90 parents and service providers using methods such as the Delphi process and usability testing. After the draft tool was finalized, MPOC 2.0 was then tested with over 250 parents/caregivers from across Canada. Now finalized and available for use, it will empower healthcare providers to better understand and meet the needs of families. Additionally, we have created resources to guide service providers on effectively addressing these needs.

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

For more details, please contact the MPOC 2.0 study team by email at mpoc2@mcmaster.ca

Approaches to Disability

F-words for Child Development

Over the course of 2025, we have continued to experience strong interest in our F-words initiatives – both across Canada and internationally. In just over a decade since the seminal 2012 publication 'The 'F-words' in childhood disability: I swear this is how we should think', the uptake of these ideas has grown exponentially. Requests for training, interest in translations of materials, invitations for presentations, and applications in new fields such as education and advocacy groups and with new communities, including First Nations communities, are all now regular occurrences. We couldn't have done this without the keen interest of families, communities, and organizational partners. Thank you!

Sharing the F-words – So Many Great Collaborations!

The F-words Knowledge Hub, our online repository of a vast and growing array of F-words materials and resources, received more than 107,000 views and 43,000 unique visitors in 2025 alone, representing almost 13% of CanChild's website traffic. We regularly add new materials to the Knowledge Hub, many of which have been shared

ions who are thinking in new ways and developing

wcase real-world applications.

The F-words Lens Tool, developed by colleagues in Brazil, is a new clinical reasoning tool designed to support collaboration between families and healthcare providers. It combines the F-words and the Rehabilitation Treatment Specification System in a way that helps providers, children, and families select intervention ingredients that focus on participation in everyday life!

Our free, online self-paced F-words Foundations Training program, sponsored by the Ontario Ministry of Children, Community and Social Services, has now enrolled over 6,500 people, almost 4,000 of whom have received a certificate of completion.

Again in 2025, the CanChild team has been invited to present F-words concepts at several conferences. A particular highlight was sharing the F-words with global leaders at a medical conference in Curaçao in November 2025, under the theme "Unleashing potential and transforming lives through inclusive rehabilitation."

In June 2025, CanChild, alongside Indigenous and non-Indigenous partners in Manitoba, also presented at the EACD conference in Heidelberg, Germany, on how the F-words have been culturally adapted for their context, and integrated Indigenous worldviews.

> **The F-words help me tell the story of my son, to paint a picture of who he is, what he likes and focus on what he CAN do!**
>
> - Parent testimonal

As well, new training initiatives have begun. In December, a 3-hour F-words online workshop was offered to families and service providers across the world. Family members registered for free, making this an inclusive way to share these ideas. The response to this brief training session was strong and other opportunities will be offered in 2026.

F-words Research – Always Learning!

Our team was successful with two grants to support the implementation and scaling of the F-words. With a generous grant from Kids Brain Health Network, we are actively supporting 25 developmental services, rehabilitation organizations, and community-based partners across Canada who are at various stages of F-words implementation. This 'CAN-Implement F-words' Implementation Support Program seeks to understand these experiences, identify program core components, such as what people find most useful, and how people are applying the content and resources in their F-words implementation activities. This program will carry on until 2027. We also received SSHRC funding to explore and clarify the processes and outputs related to 'culturally' adapting the F-words. We hope to learn from people who are adapting the F-words in diverse contexts across Canada and globally. To further these efforts, we submitted a grant application with 14 international partners to study global F-words implementation and hope to report a positive outcome next year!

In addition, a CanChild master's student, Kassidy Canlas, led a research study using a World Café format to explore parents' use of the F-words, their perceptions of the impact of the F-words on their child and family, and their recommendations for strengthening implementation. While we know anecdotally that families appreciate and use the F-words, this is the first time we are formally studying these questions. The results are rich and will be shared in the upcoming year.

Multiple students have been instrumental in working with us on data analysis from previous studies, and other manuscripts are under development or review. Watch this space for publication announcements next year!

At CanChild, we are very pleased with the interest, uptake, vision and creativity of our global F-words community – colleagues everywhere who continue to partner with us in growing and sharing these ideas. Your contributions – which we do not take for granted – have been invaluable, and we look forward to more great things to come in 2026!

For more details, please reach out by email at fwords@mcmaster.ca

> **The F-words focus on all that is possible when we think positively and work together to find solutions.**
> **They focus on an individual's unique strengths and interests.**
>
> - Clinician testimonal

Focus on Family and Youth

Family Engagement in Research Program

The Family Engagement in Research (FER) Program is an international training program led by family partners and child health researchers at the CanChild Centre for Childhood-Onset Disability Research at McMaster University. Our mission is to train, mentor, and mobilize the next generation of advocates, champions, and leaders in family engagement. What started as a single training course that launched in 2018 has grown to include foundational to advanced-level training courses, a growing international Community Network, and a variety of engagement support services.

Continuing to Build Capacity

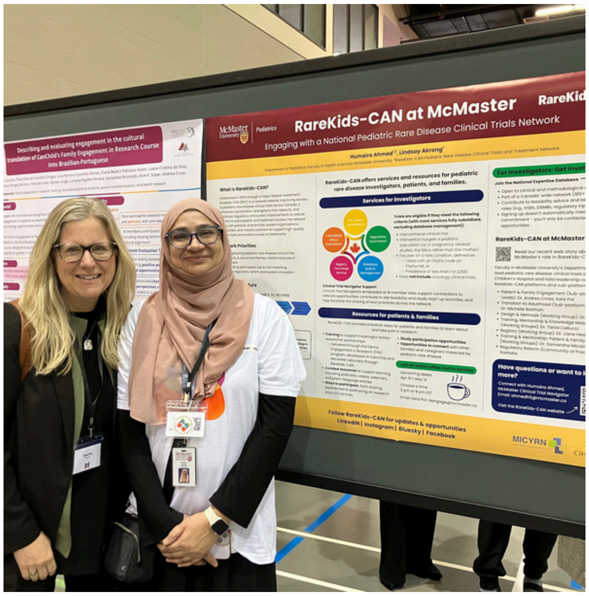
The **Family Engagement in Research (FER) Course** brings together family members and researchers to enhance knowledge and develop skills in family engagement in research. In 2025, we delivered six cohorts of the FER Course, reflecting strong national and international growth. With 154 new graduates trained in 2025—including a variety of learners from diverse backgrounds—we now have a total of 770 graduates since 2018. Graduates span all 10 Canadian provinces, 1 territory, and 24 countries.

The **Family Engagement Leadership Academy,** launched in Fall 2022, supports FER Course graduates in developing leadership skills to advance family engagement across Canada and internationally. In 2025, 12 individuals completed the Leadership Academy – and through generous partnership funding and support, no learner paid out of pocket to complete the course.

We also continued to provide foundational family engagement training, delivering two **Family Engagement Fundamentals** trainings this year: a Children's Treatment Centre in Ontario in March 2025 and a clinical trial research group in the United States in May 2025.

Partnerships and Collaboration

In 2025, our partnerships—both in Canada and around the world—continued to strengthen and open new doors. Two FER Course cohorts were fully sponsored by long-standing partners: 1) the Azrieli Accelerator at the University of Calgary (in collaboration with One Child Every Child), and 2) Towards a Brighter Path for Every Child in Hamilton, funded by the Juravinski Research Institute. Their ongoing support makes it possible for more learners to take part in meaningful family engagement training. Thanks to scholarships from the Kids Brain Health Network, Ontario SPOR Support Unit, and IMPaCT (Increasing capacity for Maternal and Paediatric Clinical Trials), 19 individuals were able to join our international FER Course cohorts without paying out of pocket to take the course, helping ensure the course remains accessible.



Members of our FER team are also leading patient and family engagement activities for RareKids-CAN – A Pediatric Rare Disease Clinical Trials and Treatment Network. Sara Pot and Alicia Hilderley (RareKids-CAN Patient and Family Engagement Facilitators), presented at two conferences this Fall to highlight the network's growing culture of engagement, shared practical tools and lessons learned, and offered attendees concrete strategies to strengthen family partnership within their own contexts. Many FER Course graduates are also involved in this network and are championing meaningful engagement across clinical trials activities. For example, members of RareKids-CAN's first sponsored cohort of the FER Course recently published Staying on TRACK!, a resource that began as a course project and continued to evolve after the course concluded. The article is available in the Canadian Journal of Science Communication (English and French versions).

Additionally, we partnered with IMPaCT to co-create four modules on engagement in pediatric and perinatal clinical trials research. We worked with two FER Course grads and Digital Storytelling Facilitators to ground the training in real patient and family stories!

Adapting & Growing Together

JOIN THE WINTER 2026
FER-YOUTH COURSE

COST: FREE!!

The FER-Youth Course is a **10-week online course** teaching youth, families, and researchers to work together well in research!

Starts January 19, 2026, 100% online via Zoom

For youth (16-25) with disabilities and/or chronic health conditions, families & researchers

Topics include engagement, ethics, overcoming barriers & teamwork

Accessibility, accommodations & support provided

Earn a Certificate of Completion from McMaster University!

Learn more about the FER-Youth Course

Shape the future of youth engagement and apply now

This was also a year of exciting growth and adaptation. With support from a CIHR Healthy Youth Catalyst grant, we collaborated with youth and researchers from across Canada to adapt the FER Course for youth. The first pilot cohort launched in January 2025 with 16 youth learners, and our evaluation will guide how we continue to shape the course for ages 16–25.

Internationally, we were thrilled to collaborate with EPP Brasil to bring the FER Course to a new language and context. In September 2025, six Brazilian researchers and family partners delivered the very first FER Course in Brazilian Portuguese to 29 learners—an important milestone in making family engagement training globally accessible.

epp.brasil and 2 others

INSCRIÇÕES ENCERRADAS!!

CURSO ENGAJAMENTO DE FAMÍLIAS EM PESQUISA

FAMILY ENGAGEMENT IN RESEARCH TRAINING PROGRAM

114 Inscritos

19 Estados+DF

Agradecemos a todos pelo interesse!
Resultado dos selecionados: 25/08!

Parceria Brasil- Canadá

Research Highlights, Community Learning, and Awards

In 2025, we continued to grow the evidence base behind the FER Program. We published a pre–post evaluation showing that learners gained confidence, knowledge, and skills in family engagement, and a follow-up qualitative study revealed that graduates remained actively involved in family engagement work two years later.

This year also offered many opportunities to share our work with others. Members of our team and the broader FER community presented at international meetings at the European Academy of Childhood-onset Disability (EACD) Conference in Germany and at the International Medical Conference in Curacao. Across these two conferences, our team delivered five presentations, including one featuring FER Course graduates from Brazil, Spain, and England who are leading family engagement initiatives in their own contexts. Locally, we shared our learning at several McMaster University rounds and seminars.

Our youth adaptation work also gained attention, leading to multiple presentations, including at the PiPER Conference in Toronto and the Azrieli Accelerator Research Exchange in Calgary. These opportunities help us continue building momentum, strengthening partnerships, and sharing what we're learning with communities across Canada and around the world.

Lastly, three members of our team were recognized with Kids Brain Health Network Outstanding Awards for their exceptional contributions and leadership in neurodevelopmental disability research. Alice Soper was awarded the Outstanding Promising Researcher Award, Amanda St. Dennis was awarded the Outstanding Family Leaders Award, and Samantha Micsinszki was awarded the Inclusive Researcher/Innovator Award.

Our heartfelt thanks go to our FER graduates, partners, collaborators, and community. Your commitment to meaningful family engagement has propelled our program forward and strengthened our impact in ways that truly matter. Together, we're advancing a future where families are meaningfully included in research at every step of the way.

For more details, please contact Sam Micsinszki by email at fer@mcmaster.ca

School and Community Services

Partnering for Change (P4C)

Supporting Inclusion in Schools

Partnering for Change (P4C) is a school-based occupational therapy model developed at CanChild that supports children's inclusion by connecting occupational therapy services to the daily routines, relationships, and activities of school life. P4C is designed to be proactive and collaborative, embedding occupational therapists within schools so they can work alongside educators and families to strengthen learning environments, respond to emerging needs, and support participation and engagement for all children.

PARTNERING for CHANGE

Led by Dr. Wenonah Campbell, the P4C team is completing a five-year study in partnership with 10 Ontario school boards and 10 Children's Treatment Centres, funded by the Ontario Ministry of Children, Community and Social Services. This work has helped clarify how strong relationships between education and health partners can support more inclusive, school-based services that respond to the needs and priorities of children, families, and school communities. It has also produced practical, evidence-informed guidance that explains what helps Partnering for Change work well, and the conditions that support its successful adoption across different school and service contexts.

This guidance is brought together in the P4C Guide for Success, a bilingual, open-access implementation website. The Guide offers practical, easy-to-use tools for occupational therapists, educators, clinical leaders, and families, supporting teams to adopt P4C using clear guidance on what matters most for successful implementation in different school settings.

PARTNERING for CHANGE

McMaster University

CanChild

Building and Sustaining Research Partnerships within Education and Health

Lessons from Partnering for Change

Wenonah Campbell, PhD

Associate Professor, School of Rehabilitation Science
John and Margaret Lillie Chair in Childhood Disability Research
Scientist, *CanChild* Centre for Childhood-Onset Disability Research

October 9, 2025

© Wenonah Campbell, Partnering for Change Research Team, CanChild, McMaster University

Since its launch, the Guide has been accessed by 1,890 users in sixty-five countries, highlighting strong international interest in research-based innovations that support inclusive school-based practice. By making these resources freely available, the P4C team is supporting shared learning and evidence-informed approaches that strengthen collaboration in school-based occupational therapy.

The P4C team continues to foster learning and connection through a range of activities designed to reach and engage practitioners, educators, families, and school communities in different ways. Conference presentations and invited talks support broader awareness of P4C, while mentorship, webinars, and collaborative working groups provide opportunities for sustained engagement and shared learning over time. In 2025, the team launched the P4C Spotlight Webinar series, engaging more than 200 participants from Canada and internationally. Families, educators, and occupational therapy practitioners have also come together in working groups to co-develop practical resources grounded in lived experience. These resources will be released in 2026.

Partnering for Change reflects CanChild's commitment to research that is collaborative, accessible, and grounded in the experiences and priorities of families, educators, and service providers working to support children within school communities. Through sustained partnerships, shared learning, and practical tools, P4C demonstrates how CanChild's research supports meaningful, system-level change in school-based practice and strengthens long-term relationships across education and health systems.

For more details, please contact Leah Dix by email at dixlm@mcmaster.ca

Diagnosis Informed Research

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

CP-NET
Cerebral Palsy Neuroscience
Discovery Network

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 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, as Phase 4. McMaster Children's Hospital is proudly part of three studies/components within the CP-NET program of research.

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, and 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 2025, McMaster recruited 25 new participants into the study and re-consented 11 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 other information.

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 and well-being.

The objectives of this study are to build an Ontario-wide research database of adults with CP that leverages existing infrastructure 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 people with CP as well as specific outcomes related to pain, fatigue, participation, mental health outcomes, and healthcare needs and use.

The study plan and protocol were developed by the study team in collaboration with study advisors (adults with lived experience). The study has been approved, and recruitment began in 2025. In 2025, McMaster recruited 23 new participants into the study. Participating sites for the CP-NET Adult Cohort include Hamilton, Ottawa, London, and Niagara.

CP-NET Knowledge Translation

CP-NET's Advisory Team—an active group of parents and individuals with lived experience—supported program dissemination efforts. In 2025, CP-NET refreshed and launched a new website and hosted the annual CP-NET Science and Family Day, which focused on recreation and physical activity. Keynote addresses were delivered by Dr. Julia Hanes and Dr. Patrick McPhee, and all sessions were recorded and made available on the CP-NET website. The event also featured the launch of a video contest highlighting physical activity opportunities for individuals with CP.

Additionally, the team produced two "In Brief" videos, distributed newsletters featuring research updates, hosted a full-day in-person Advisory Team meeting, and began a systematic review examining barriers and gaps in healthcare utilization among adults with CP. In 2025, three new members joined the Advisory Team.

For more details, please contact Sarah Hopmans by email at hopmansn@mcmaster.ca

BRIDGE-CPT:

Building **R**elationships through **I**nclusive co-**D**esign to **G**uide **E**ffective **C**ommunication **P**artner **T**raining

The BRIDGE-CPT study ran from November 2025 to May 2026 and focused on co-designing communication support for autistic youth and the people close to them. The study is led by CanChild trainee, Maya Albin, under the supervision of CanChild Scientist, Dr. Michelle Phoenix, alongside a team of autistic youth and adults.

Building **R**elationships through **I**nclusive co-**D**esign to **G**uide **E**ffective **C**ommunication **P**artner **T**raining

BRIDGE-CPT was funded by Maya Albin's SSHRC CGS-D award, an Autism Alliance of Canada Data-to-Policy Fellowship, and a seed grant from McMaster's Equity-based Co-Creation Hub.

The study aimed to understand what autistic youth, speech-language pathologists, and people close to autistic youth, including parents, siblings, and close friends, consider important for creating successful and supportive communication interactions. Participants were invited to share their perspectives in interviews and then work together to co-design resources based on the interview themes.

The Canada-wide study was conducted online between November 2025 and April 2026. There were three study parts, all of which invited the same three groups of participants: (a) autistic youth (ages 15-24); (b) people close to autistic youth; and (c) speech-language pathologists.

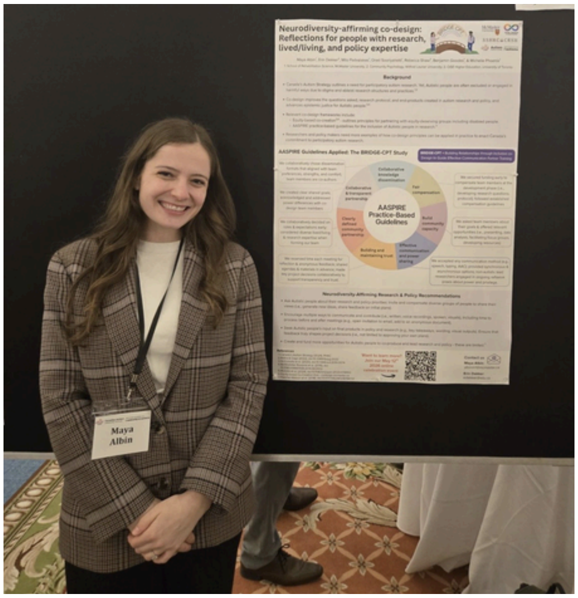
Individual interviews: We began by conducting 40 individual interviews to understand participants' communication experiences and the role that communication partners play in communication with autistic youth. Participants discussed how the environment affects communication, common communication preferences and needs among autistic youth, the importance of non-spoken communication options, and related themes.

Small focus groups: After analyzing the interview data, we invited participants to join one of six two-hour focus groups. Each small focus group included members of all three participant groups and explored one interview theme, with a focus on co-designing resources to teach that theme's content. Resource ideas included infographics, graphic novels, communication booklets, and interactive worksheets about communication needs and supports. Participants shared many creative ideas for teaching people close to autistic youth how to improve their communication.

Large focus group & evaluation of co-design: Afterwards, our team took the ideas from the small focus groups and made prototypes for each resource. For example, the group focused on 'what it means to be autistic' made a graphic novel that portrays a neurotypical alien arriving on a new planet, Neurodiversica, who learns from autistic characters about what life and communication are like for them.

Finally, we presented the prototypes back to participants for feedback and evaluated participants' experiences with the co-design process using the Public and Patient Engagement Evaluation Tool (PPEET).

We continue to share our findings nationally and internationally, including at the ENRICH Symposium, the Canadian Autism Leadership Summit, and the European Academy of Childhood Disability, as well as through local webinars and online dissemination events, including at McMaster University and CAMH. Looking ahead, we are excited to share the co-designed resources widely and publish our findings in academic journals and plain-language summaries.



For more details, please contact Maya Albin by email at albinm1@mcmaster.ca

See here for two free webinars our team delivered!

Talk delivered for the H-CARDD research group at CAMH

McMaster Centre for Equity-Based Co-Creation webinar

Job-Train Program

Launched in 2016, the Job-Train Program (JTP) is a summer employment initiative designed to support autistic high school students in developing meaningful employment skills and pathways to work. The program combines paid work placements and individualized job-related supports to promote skill development, workplace confidence, and successful employment experiences. Since its inception, the JTP has been intentionally iterative, evolving through regular program evaluations and ongoing feedback from autistic youth, families, employers, and job coaches to ensure responsiveness to participant needs and workplace environments.

In its most recent implementation in 2025, the JTP team partnered with six distinct employers across McMaster University to secure paid, six-week work placements for six autistic high school students. These placements provided participants with hands-on, real-world work experience across a variety of job settings. Throughout the placements, students received individualized, on-site job-related support from trained job coaches who assisted with workplace communication and accommodations and supported skill development, while gradually fading supports to encourage independence. Feedback was collected from youth, job coaches, and employers, with a particular focus on understanding effective job coaching practices.

Following the 2025 program delivery, the JTP focused on consolidating lessons learned from prior cycles. Key activities included the refinement and expansion of the JTP training manual to strengthen job coaching practices, incorporating evidence-informed strategies. In addition, the team prepared and submitted a grant application to the Skills Development Fund (SDF) to support program sustainability, scaling, and continued enhancement of employment outcomes for autistic youth.

For more details, please contact Briano DiRezze by email at direzzbm@mcmaster.ca

Campus Belonging Project

In partnership with the University of Alberta, the Campus Belonging project was established to improve the sense of belonging among autistic postsecondary students within Canadian institutions. Adopting a co-design and community-based participatory approach, the project is structured into two phases. The first phase aims to explore the experiences of autistic postsecondary students and university staff, while the second phase aims to unite these groups together to develop sustainable strategies that promote an inclusive environment for autistic students at Canadian postsecondary institutions.

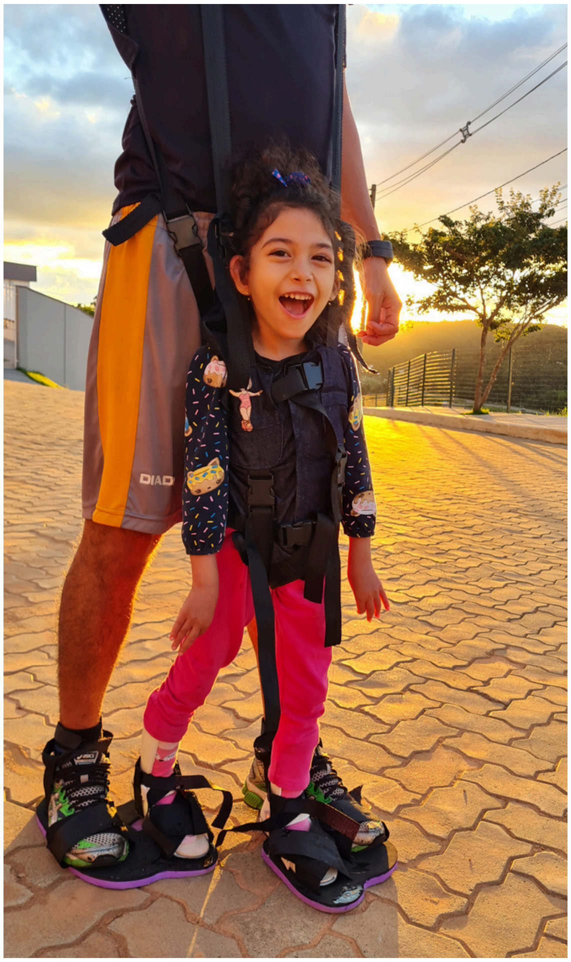
The first phase of the project has been completed. Focus groups were conducted at McMaster University and the University of Alberta, involving a diverse range of university staff. The research team is in the process of drafting a manuscript to present the findings, which will be submitted for peer-reviewed publication. These findings were also presented at the European Academy of Childhood Disability in Heidelberg, Germany, in June 2025. The co-design phase is being further developed, with data collection planned for Spring 2026, during which additional collaboration will aim to establish strategies to enhance the sense of belonging among autistic students in postsecondary environments.

For more details, please contact Briano DiRezze by email at direzzbm@mcmaster.ca

GMFM App+ Redesign Project

The Gross Motor Function Measure (GMFM) is a clinical assessment tool designed and validated to evaluate change in gross motor function in children with cerebral palsy. The GMFM App+ allows users to enter GMFM item values, calculate scores, and generate data displays, making it easier than ever for clinicians to score, track, and interpret motor development over time. By transforming assessment data into accessible, visual formats, the GMFM App+ helps clinicians monitor change, identify patterns in development, and support goal-setting and decision-making in practice.

GMFM App+



In 2025, we completed a Request for Proposals (RFP) process through Strategic Procurement at McMaster University to find a vendor for the GMFM App+ redesign project. This project involves redesigning the existing GMFM App+, which was launched in 2019. Drawing on user feedback gathered since 2019, the redesign aims to enhance functionality, user accessibility, and data analysis capabilities, including potential integration with advanced technologies to support future optimizations. By the end of 2025, the project was awarded to a vendor, and the redesign work had begun.

For more details, please contact Barb Galuppi by email at galuppi@mcmaster.ca

launchit
SOLUTIONS

Participation

Project BEYOND:

Body-function **E**nhancement for **YO**uth through participatio**N** in real-worl**D** contexts

Project BEYOND, led by Dr. Dana Anaby, is a cross-provincial study testing the impact of the Pathways and Resources for Engagement and Participation (PREP) intervention. PREP aims to enhance participation in different settings among clients with various conditions throughout their lifespan by modifying aspects of the environment rather than directly addressing impairments in body functions.

In Quebec, we are collaborating with the CIUSSS West-Central Montreal, six other public health and social services centers (CIUSSS/CISSS), a hospital, and community organizations spanning rural and urban areas (including CIVA Centre d'intégration à la vie active and Inspirations). In Ontario, recruitment is underway in the Kitchener-Waterloo, Brantford, Hamilton, Mississauga, Toronto, Kingston and Ottawa regions, with promotion through Empowered Kids Ontario, Easter Seals Ontario, and community organizations.

These recruitment collaborations have enabled us to investigate the impact of an eight-week community-based activity individually selected by the youth, such as drawing classes, video editing, volunteering with horses, or going to the gym, on three key body functions: motor skills, behaviour, and emotions. Changes in body functions, including movement, attention, and mood, are measured multiple times before, during, and after engagement in the chosen activity.

This project is funded by the Canadian Institutes of Health Research (CIHR 186179; 2023– 2027)

For more details, please contact Barb Galuppi by email at galuppi@mcmaster.ca

Our 2025 Highlights!

- By December 2025, we recruited 68 youth with physical disabilities aged 8 to 18 years across Ontario and Quebec.
- Eligibility criteria were expanded to include youth as young as 8 years, with any level of upper and/or lower extremities mobility restrictions.
- Along with interviews with youth and parent participants, we also added interviews with the community instructors who facilitated the participation.
- Interview data enrich our understanding of the PREP intervention experience and can further explain under what conditions under which the intervention is more or less successful.

Life Course Development

Transition Hub

Established in 2019 through a collaboration between Children's Healthcare Canada and CanChild, the Transition to Adult Healthcare Hub (Transition Hub) has engaged more than 250 clinicians, researchers, decision-makers, parents, and youth committed to improving the transition to adult healthcare.

In 2025, the Health Quality Indicators team recruited 146 participants to take part in a modified online Delphi process to assess the importance and feasibility of collecting data for identified candidate health indicators. Following this multi-round, multi-stakeholder process, a consensus meeting was convened, resulting in the identification of a final set of quality indicators.

Concurrently, the Environmental Scan team prepared and submitted a CIHR grant application aimed at developing a centralized repository of transition-to-adulthood resources, with a focus on ensuring availability in both official languages. The Steering Committee also commenced work on a comprehensive business case to support the long-term sustainability of the Hub.

Finally, dissemination efforts included a short oral presentation on the Transition Hub at the International Medical Conference in Curaçao in November 2025 as well as a peer-reviewed publication submitted to Child Care Health and Development stemming from the COVID and Transition study (paper published in May 2026).

For more details, please contact Dayle McCauley by email at dmccaul@mcmaster.ca

Road to Adult Arthritis Care

Road to Adult ARTHRITIS CARE

In 2025, the Road to Adult Arthritis Care team, led by Dr. Michelle Batthish, launched a new website, to support youth, caregivers, and healthcare professionals during the transition from pediatric to adult care.

The team also licensed and translated the Transition Toolkit, which is now available as a free download in 7 languages. Although developed in the context of arthritis care, the toolkit is not disease-specific and can be used by adolescents and families managing a range of chronic illnesses. Developed for adolescents aged 14–18 and their parents, the Transition Toolkit was informed by expert input and existing resources from other pediatric centres. It is designed to support adolescents and families as they prepare for the transition from pediatric to adult care. The toolkit includes two components: a "Parent Guide" and a "Transition Road Map." The "Parent Guide" explains the transition process and outlines practical ways parents can support their adolescents during this period. The "Transition Road Map" helps parents guide adolescents in building readiness for transition across five key areas: self-advocacy, medication management, overall health and safety, lifestyle and behaviours, and future planning. Each area includes a checklist to support adolescents in gradually developing greater independence.

YOUTH TRANSITION ROAD MAP

Transition to Adult Care

CanChild
Generating Knowledge
Transforming Lives

McMaster Children's Hospital
HAMILTON HEALTH SCIENCES

McMaster University

For more details, please contact Dr. Michelle Batthish by email at batthim@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. The study utilizes an integrated knowledge translation process in which researchers and knowledge users, including Patient Advocacy Organizations (PAOs) representatives, collaborate across all stages of the research process.

Conceptually, the study is guided by the World Health Organization (WHO) frameworks of the International Classification of Functioning, Disability and Health (ICF) and the International Classification of Health Interventions (ICHI). In 2025, the international team collected survey data from youth diagnosed with DMD and their parents. Preliminary findings were presented at local and international conferences, including the European Academy for Childhood-onset Disability (Heidelberg, Germany) and the Duchenne Switzerland Conference (Nottwil, Switzerland). The team also published a review of the gaps and challenges in the transition of care for youth with Duchenne.

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 contact Anna Swain by email at minchena@mcmaster.ca

Knowledge Translation and Implementation Science

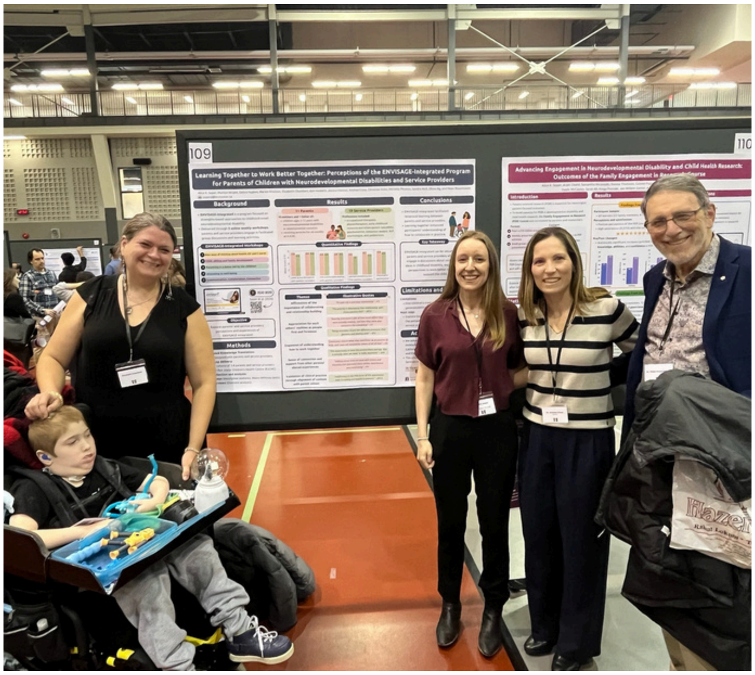
ENVISAGE:

ENabling VIsions And Growing Expectations

CanChild's engagement with the ENVISAGE program began almost a decade ago when the program was first developed. Co-created and co-delivered by clinician-researchers and caregivers in Canada and Australia, ENVISAGE-Families was originally designed to introduce caregivers of young children with neurodevelopmental disabilities to a number of contemporary concepts about health, development, parenting, and communicating with people about their child's and family's strengths and needs. The program has since expanded to include a service-provider analogue (ENVISAGE-SP), a Croatian version, a First People's program in Australia, and an exploratory version of an 'integrated' ENVISAGE program involving caregivers and service providers participating together. Evaluations across these versions of the program consistently validate their impact on participants' sense of empowerment, and on caregivers' sense of competence and confidence in parenting their children. Interest in the program continues to grow across Australia, Canada and in several other countries.

ENVISAGE in Canada

After completing facilitator training in 2024, 12 new program leaders from two Children's Treatment Centres (KidsAbility and Children's Treatment Network) in Ontario delivered the ENVISAGE-Families program throughout 2025 to 74 parents receiving services at their centres. In 2025, an implementation study evaluating the implementation process and impact of ENVISAGE-Families in these centres was conducted, with data analysis currently underway.



> **Taking [the] ENVISAGE program gave me the confidence to parent my autistic child and strengthened my trust in my own parenting….The program reinforced [that] change is constant, and only my family and I can shape this journey to be positive and meaningful. ENVISAGE helped redirect my focus toward what truly matters, rather than what my child cannot do now.**
>
> - Testimonial from a caregiver who participated in the study

Kids Included, a nonprofit Early Learning and Inclusion Program in Alberta, also engaged with ENVISAGE in Canada to deliver ENVISAGE for Service Providers (ENVISAGE-SP) to its staff. We partnered with this organization to complete an implementation study of ENVISAGE-SP delivery within one centre.

In 2025, we applied for a CIHR Project Grant to evaluate the ENVISAGE-Families program for families on waitlists for developmental services in Canada. Although the grant was not funded, we received a CIHR Strategy for Patient-Oriented Research: Priority Announcement Award to begin this work. The funding will be used to translate the ENVISAGE-Families program into French so that the program and trial can be delivered in both English and French.

ENVISAGE-Families in Australia

In Australia, the Department of Social Services funded a national rollout of ENVISAGE-Families beginning in 2023, with an initial $6.9 million grant. In 2025, a further $5 million was granted to continue the work until 2027. In collaboration with 30 delivery partners, almost 2,000 caregivers across all states and territories have participated in the program. Almost 200 facilitators have been trained to deliver the program, including 15 facilitators who are delivering ENVISAGE-First Peoples. In total, over 350 programs have been delivered since January 2023, including 24 First Peoples' cohorts and six cohorts for culturally and linguistically diverse families in either plain English, Vietnamese or Arabic.

ENVISAGE-Croatia

In 2025, the ENVISAGE-Croatia team continued its research-implementation project, delivering the ENVISAGE program in partnership with the Special Hospital for Protection of Children with Neurodevelopmental and Motor Disabilities Goljak, with ongoing financial support from the City of Zagreb.

During this year, ENVISAGE-Families Croatia was implemented with 58 parents across six groups, alongside continued research activities examining parent outcomes and ongoing knowledge translation efforts to support sustainable delivery of the program within the Croatian context.

ENVISAGE-Integrated

In 2025, the ENVISAGE-Integrated team offered an innovative version of the program. Led by a McMaster doctoral student and building on an initial feasibility study of the program at Children's Treatment Network with 12 participants, including parents of children with neurodevelopmental disabilities and service providers (Soper et al., 2026), we are continuing to explore the potential added value of having parents and service providers complete the program together. Guided by identified feasibility challenges and encouraged by participants' positive experiences during the feasibility study, we made minor adaptations to the ENVISAGE-Integrated program and recruitment procedures. The adapted program was delivered in Spring 2025 at Ron Joyce Children's Health Centre to 30 parents of children with neurodevelopmental disabilities and service providers. Five cohorts were co-facilitated by caregiver and service-provider members of the ENVISAGE-Integrated team. Survey and interview data collected between March and December 2025 indicated positive impacts, including increased parental connectedness, validation of service-provider practice, and enhanced comfort with communication, perspectives on disability, and varied implementation of ENVISAGE concepts and tools into daily life and clinical practice over time (to 6 months).

The collaborative process of working within a team of caregivers and service providers was presented in June 2025 at the European Academy for Childhood-Onset Disability.

Presentations and Publications

A highlight for CanChild members of the ENVISAGE program in 2025 was presenting with our Australian colleagues of ENVISAGE-Families: Empowering caregivers, families and communities raising children with developmental concerns or disabilities at the European Academy of Childhood-onset Disability.

This year has seen our team working on the analysis of the ENVISAGE-SP program, a CIHR-funded study across Canada and Australia. Forthcoming publications include a qualitative analysis of the early post-program impact, ENVISAGE-Service Providers: Creating opportunities to change how service providers think, talk about, and approach childhood disability.

For more details, please contact Debbie Hughes by email at envisage@mcmaster.ca

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

Pediatric Feeding Disorders Study

Through the Pediatric Feeding Disorders Study, a team at Hamilton Health Sciences (HHS) McMaster Children's Hospital (MCH) and scientists from the CanChild Centre for Childhood-onset Disability Research at McMaster University are collaborating with the Sunnybrook Health Sciences Centre Neonatal Follow-Up Clinic, parent partners (recruited through CanChild and Sunnybrook), Feeding Matters and the Alberta Health Services Pediatric Eating And Swallowing (PEAS) team.

Our initiative focuses on developing an early identification pathway for feeding challenges in high-risk infants, embedded within the neonatal follow-up clinic (NFUC). This aligns with other established early-identification pathways, including those for cerebral palsy, social communication, family well-being, and attachment, where validated tools are integrated into regular clinic visits rather than creating new, stand-alone clinics or dedicated feeding visits. The overall goal of our project is to enhance early detection, empower families, and support timely intervention and referral to community or specialized services as needed, without substantially increasing visit length.

In 2025, we conducted a comprehensive needs assessment and literature review, systematically identified appropriate tools, and discussed these findings at an in-person meeting. The process included parent collaboration on clarity, accessibility, and length. The Infant and Child Feeding Questionnaire (ICFQ) from Feeding Matters was the tool selected to bring forward for a quality improvement study. We have worked with the HHS Health Information Technology Services (HITS) team to integrate the ICFQ into the Epic electronic health record system flowsheet. Looking ahead to the coming year, we will continue preparing for study implementation by developing clinician training materials and compiling resources to support parents waiting for services.

We are grateful to the William Birchall Foundation for their generous funding support.

For more details, please contact Barb Galuppi by email at galuppi@mcmaster.ca

The CONNECTS Project:

COdesign with **N**ewcomer **N**arratives for **E**quitable **C**hildren's **T**herapeutic **S**ervices

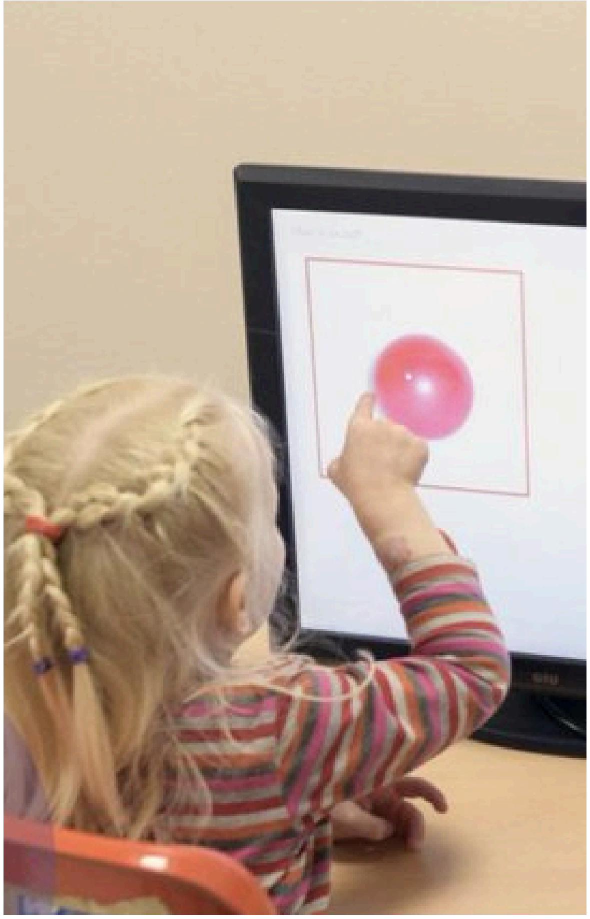
The CONNECTS project (COdesign with Newcomer Narratives for Equitable Children's Therapeutic Services) was funded by a McMaster Societal Impact Seed Grant. The project is led by Dr. Michelle Phoenix (CanChild Scientist and Associate Professor, McMaster University), Dr. Sukaina Dada (CEO, SMILE Canada), and PhD student Morteza Soleyman. The project works with newcomer caregivers of children with disabilities and service providers to co-develop resources and recommendations that improve access to culturally responsive services. The project involved 43 participants and was conducted in Farsi, Arabic, Urdu, and Somali, with translation into English. The methods and results were presented at the World Federation of Occupational Therapy Congress in Bangkok, Thailand, by Dr. Phoenix, Dr. Dada, and Dr. Reitzel. The work has also been accepted at the European Academy of Childhood-onset Disability (EACD) conference in Galway, Ireland.

For more details, please contact Dr. Michelle Phoenix by email at phoenimp@mcmaster.ca

C-BiLLT:

Computer-Based instrument for Low motor Language Testing

From 2018 to 2021, 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 opportunities for improved 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, and 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, the results 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 and was affected by 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 support 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 have 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 the 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. For 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. The feasibility of the C-BiLLT-CAN Offline was evaluated according to clinicians' and families' perceptions of its practicality, acceptability, and adaptation. Work to develop the clinical training manual and online training platform also began. Feasibility testing continued into 2025 and ended in March.

The C-BiLLT-CAN Offline did not meet a priori feasibility criteria. End users provided feedback suggesting its practicality and acceptability were lacking, and clinicians reported making significant procedural adaptations during feasibility testing, indicating the need for further investigation prior to clinical implementation. The team identified remaining knowledge gaps, including identification and prioritization of key feasibility issues, development of troubleshooting strategies, and impressions of new access methods and customizations.

In Fall 2025, we obtained ethics approval to host focus groups with clinicians involved in feasibility testing to address these knowledge gaps. Three focus groups were conducted with a total of 12 clinicians in January 2026. Data analysis is underway, with dissemination and formalization of next steps planned for Summer/Fall 2026.

For more details, please contact Sarah Hopmans by email at hopmansn@mcmaster.ca

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 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.

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GENERATING KNOWLEDGE
AND TRANSFORMING LIVES

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

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CanChild Centre for Childhood-onset Disability Research, McMaster University recognizes and acknowledges that it is located on the traditional territories of the Mississauga and Haudenosaunee nations, and within the lands protected by the 'Dish with One Spoon" wampum agreement.