Annual Report 2015



Generating Knowledge Transforming Lives





Message From the Director

I am proud to share this annual report and to highlight CanChild's successes over the past year in furthering our mission to maximize quality of life and participation of children and youth with developmental conditions, along with their families, through evidence-based clinical and health services research. In 2015, we expanded the CanChild team, added both a parent and a youth to CanChild's Advisory Board, underwent a new website/brand redesign, and saw numerous successes in research grants and awards. It has been a truly productive year, and I wish to congratulate everyone on their accomplishments.

Throughout this report you will see examples of local and global partnerships resulting from our strong and multidisciplinary network of researchers, families and organizations. You will also read about what CanChild is doing to ensure its continued financial sustainability and to ensure that the work we do is meaningful to those who need it most: families, service providers, and those living with a childhood disability.

Such a wonderful year of achievements only points toward excellence in the year ahead!



Jan Willem Gorter Director

Our 5 Core Functions

1. Take a leadership role in identifying emerging issues for research, practice, policy, and education.

2. Conduct high-quality, innovative research that gives children and youth increased opportunities to thrive at home, at school, and in the community.

3. Effectively transfer the knowledge generated by our evidence-based research into practice at the clinical and health systems levels.

4. Provide education for families and health care providers as a pioneer in the science of translating knowledge and sharing it broadly to those who need it most.

5. Mentor students, post-doctoral fellows, junior researchers, and experts to build capacity for future researchers across the globe.



In 2015, CanChild's operational team kicked off the year with an ambitious project to restructure the CanChild website to be both clean and modern in design as well as innovative and user-friendly across multiple devices.

In choosing a new design, it was determined that the existing CanChild brand would look out of place within a modern, clean website. Additionally, the logo and typeface caused readability issues for smaller screen sizes (e.g., tablets, mobile devices). Therefore it was decided that, along with a website redesign, CanChild would undergo a rebrand excerise.





Launched in October 2015, the rebrand and website redesign project met with overwhelming success and positive public response.

From the clean, user-friendly website to the modern branding across all CanChild presentations and materials, it is clear that CanChild has successfully transitioned to an innovative, forward-looking operation reflective of the research and knowledge translation we do!

Transitions: CanChild Rebrand & Site Redesign

The goal of the rebrand was simple: Create a logo that is readable at various screen sizes and reflects modern design principles of balance and simplicity.

We also envisioned a logo that would present a fresh approach without drastically changing the existing CanChild icon. The result has been an updated brand that looks new yet familiar, and that is innovative yet fitting of CanChild's history.



2015 in Review

News & Accomplishments

CanChild welcomes Research Associates Dr. Nora Fayed (Queen's University) and Dr. Keiko Shikako-Thomas (McGill University), and International Collaborator Dr. Mary Khetani (Colorado State University) to the team in 2015!

Dr. Sandy Hodgetts (University of Alberta) is awarded an Early Career Transition award by the Alberta Centre for Child, Family and Community Research for her research on the SKIP Program: Supporting Kids' Inclusion and Participation (Autism Focus)

A meta-analysis by Dr. Mark Ferro (McMaster University) on risk factors for health-related quality of life in children with epilepsy makes news on NeurologyAdvisor.com.

Dr. Keiko Shikako-Thomas (McGill University) appears on Canada AM to discuss Jooay, an app that helps families find local leisure programs for children with disabilities.



Dr. Barbara Gibson (University of Toronto) is featured in Hospital News for her research on enabling diverse abilities.

Carol DeMatteo (McMaster University) is interviewed by the Hamilton Spectator about concussion policies in schools.

Tram Nguyen (supervised by Dr. Jan Willem **Gorter**) receives a CIHR Michael Smith Foreign Study Supplement, enabling her to study abroad under the supervision of Dr. Iona Novak (The University of Sydney), to develop an international KT network.

An article in <u>Spectrum magazine</u> features the work of Drs. Briano DiRezze and Peter Rosenbaum (McMaster University) on the Autism Classification System.

Dr. John Cairney (McMaster University) was Keynote Speaker at the Ever Active Schools Annual Physical Literacy Summit in Calgary, Alberta, Canada

CanChild researchers at University of Sherbrooke (Dr. Chantal Camden) and McMaster University prepare a Developmental Coordination Disorder (DCD) module to support physiotherapists in developing the knowledge and skills required to implement best DCD practice.

Dr. Eyal Cohen (The Hospital for Sick Children) is the Keynote Speaker at the 15th Annual Practical Pediatrics Conference, presenting on Pediatric complex care: principles and practical tools.

Lisa Rivard (supervised by Dr. Cheryl Missiuna, McMaster University), receives highest prize at the 5th Annual Pursuit Award Ceremony, held at the Bloorview Research Institute in Toronto for her doctoral work exploring where children with and without coordination difficulties pay attention during real-world motor tasks.



Dr. Jan Willem Gorter (McMaster University), was invited to present on the 'F-words' in Childhood Disability at the 13th Congress of the European Forum for Research in Rehabilitation (EFFR) in Helsinki, Finland.



Dr. Barbara Gibson (University of Toronto) receives a Teaching Recognition Award for excellence in student research supervision from the Department of Physical Therapy at University of Toronto.

Dr. Peter Rosenbaum (McMaster University) is the inaugural recipient of the Medal of Excellence in Childhood Disability from the Holland Bloorview Kids Rehabilitation Hospital.



Dr. Mary Law & Debra Stewart (McMaster University) are editors of a new book titled, Theoretical Foundations of Occupational Therapy, 3rd Edition.

The Good 2 Go Transition Program (led by Dr. Khush Amaria (The Hospital for Sick Children) is identified as a Leading Practice by Accreditation Canada.

Dr. Lonnie Zwaigenbaum (University of Alberta) is appointed as Fellow of the Canadian Academy of Health Sciences.

Dr. Iona Novak (University of Sydney) makes news for her research on early intervention breakthrough giving new hope to children with Cerebral Palsy.

Drs. Eyal Cohen (The Hospital for Sick Children), and Lonnie Zwaigenbaum (University of Alberta) are recipients of Canadian Institutes of Health Research (CIHR) Foundation Scheme grants.



Dr. Jill Zwicker (University of British Columbia) receives recognition for being one of the 4% of new investigators in Canada to receive a CIHR Foundation Scheme grant.



Dr. Niina Kolehmain (Newcastle University) receives a Merit Award from the British Association and College of Occupational Therapists.

Dr. Christine Imms (Australian Catholic University) is awarded the Occupational Therapy Australia National Research Excellence Award & becomes Founder and Director of the new Centre for Disability and Development Research: Diversity across the life span.



Drs. Wenonah Campbell and Briano DiRezze (McMaster University) receive Ian and Shirley Rowe Travel Scholarships to present their research at International conferences.

A webinar developed by Dr. Cheryl Missiuna (McMaster University) and the Partnering for Change (P4C) team is made available as a resource on the Ontario Special Needs Strategy (OSNS) website.

Dr. Peter Rosenbaum (McMaster University) is honoured with a President's Award for Excellence in Graduate Supervision by McMaster University.

Dr. Barbara Gibson (University of Toronto) is awarded the Norington Medal by the Australasian Faculty of Rehabilitation Medicine, recognizing international leadership in rehabilitation research by an allied health professional.



2015 in Review: News

& Accomplishments

Dr. John Cairney (McMaster University) is Author and Editor of Developmental Coordination Disorder and its Consequences, the most comprehensive volume to cover the physical health, mental health, and social consequences of DCD in children and to suggest strategic approaches for its management.



Dr. **Olaf Kraus de Camargo** (McMaster University) is part of an editorial team to launch a new website dedicated to disseminating educational material about the <u>ICF (International Classification of</u> <u>Functioning, Disability and Health).</u>

CanChild celebrates World Cerebral Palsy (CP) Day at the 2nd Annual CP-NET Science & Family Day, held at Holland Bloorview Kids Rehabilitation Hospital.



A <u>new video</u> is released in celebration of World CP Day that is a collaborative effort of CP-NET (Childhood Cerebral Palsy Discovery Network), CanChild and individuals with CP and their families.



Dr. **Iona Novak** (University of Sydney) is nominated and earns standing as a Top 10 Finalist in the NSW (Govt) Women of the Year awards.

CanChild Researchers contribute to MacART's inaugural <u>Autism Research Stakeholder</u> <u>Symposium</u> held at McMaster University.

Dr. **Brian Timmons** (McMaster University), in recognition of being an exceptional emerging researcher, is awarded with a prestigious Tier 2 Canada Research Chair in Child Health and Exercise.



Dr. **Eyal Cohen** (The Hospital for Sick Children) is awarded a prestigious Canadian Harkness Fellowship in Health Care Policy and Practice.

Dr. **Peter Rosenbaum** (McMaster University) is presented with a Tribute Award in the category of Advocacy at the Ontario Association of Children's Rehabilitation Services (OACRS) conference.

Dr. **Cheryl Missiuna** (McMaster University) and the P4C team are recognized for authoring one of the top five most downloaded Canadian Journal of Occupational Therapy articles over the past year



Dr. Jan Willem Gorter (McMaster University) is invited to give the <u>Chambers Family</u> <u>Lifespan Lecture</u> at the 69th Annual American Academy for Cerebral Palsy and Developmental Medicine (AACPDM).

It is not *me* but *we* - Peter Rosenbaum













2015 CanChild Annual Report



Autism Spectrum Disorder

Autism Classification System of Functioning

Rosenbaum, P.L. (PI), **Di Rezze B.**, Cooley Hidecker M.J., **Law, M.**, Stratford, P., Szatmari, P. & **Zwaigenbaum L.** (2011-2014). Development of the Autism Classification System of Functioning: Social Communication. Canadian Institutes of Health Research (CIHR). \$374,666.

Rosenbaum, P.L. (PI), **Di Rezze, B.** (co-PI), Georgiades, S., **Zwaigenbaum, L.**, Cooley Hidecker, M.J., **Gentles, S.**, Duku, E.K. (2015-2017). Towards a Functional Classification System for Preschool Children with Autism Spectrum Disorder: A Prospective Examination to Classify Social Communication Abilities. Hamilton Academic Health Sciences Organization (HAHSO). \$192,833.

Children with autism spectrum disorder (ASD) face challenges in the development of social communication abilities—one of the hallmark features of the disorder. There is, however, ambiguity and a lack of a consensus definition for the concept of "social communication." Working collaboratively with parents and professionals, this team have developed a novel, strengths-focused classification tool, the Autism Classification System of Functioning: Social Communication (ACSF:SC). The ACSF:SC empowers parents with the type of information they value most – namely, meaningful insights into their child's functioning. Parents can use such information as they participate with professionals to put appropriate supports in place for their child.

The ACSF:SC was developed and tested among parents and professionals (educators and clinicians) with the support of a 3-year grant from CIHR. A 2-year grant from HAHSO will lead to further development of the measure; The goal has been, and continues to be, addressing this major practical challenge in the field of ASD – the need for precision and consistency in how to discuss and categorize the functional manifestations and impacts of ASD from a strengths-focused view.

Cerebral Palsy

Life-course Study

Stewart, D., **Di Rezze, B.**, **Palisano, R.J.** (co-Pls), **Freeman, M., Gorter, J.W.**, **Klassen, A.F.**, **Nguyen, T.D.** & **Rosebaum, P.L.** (2015-2016). Children grow up: Taking a life-course approach to promote participation and life quality for individuals with Cerebral Palsy from childhood to adulthood. Canadian Institutes of Health Research (CIHR). \$100,000.

The overall objective of this CIHR-funded study is to draw upon the experiential knowledge of young adults with Cerebral Palsy (CP) to develop guidelines for a life-course health development (LCHD) approach that is essential for promoting developmental capacities for future adult roles and healthy adult living for young people with CP. The research team is particularly interested in learning about the interactions between factors concerning 'person' and the 'environment', that young adults with CP perceive to have influenced their developmental capacities.

This research will lead to the development of LCHD guidelines and related knowledge translation products/materials that service providers in health care and community agencies can use with children and youth with CP and their families. These guidelines and products can then be used by the research community to inform the subsequent development and testing of guidelines and interventions that will improve life quality and health outcomes of children, youth and adults with chronic health conditions throughout their whole lifecourse.

Over the period of October -December 2015, the team received research ethics board approval, pilot tested the interview protocol with three adults with CP, revised and refined the interview protocol to focus on healthy living, and commenced recruitment and data collection. The team held monthly team meetings and started working towards a concept paper to illustrate how the LCHD model applies to child-onset conditions.



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Childhood Cerebral Palsy Integrated Neuroscience Discovery Network

Fehlings, D. (PI), Ansari, D., Biddiss, E., Campbell, C., Carter, M., Chau, T., Chen, R., Cheyne, D., De Veber, G., Fehlings, M., Ferro, M., Frid, P., Gorter, J.W., Graham, N., Hall, G., Henkelman, M., Hunt, C., Kawamura, A., Kim, M., Kingsnorth, S., McCormick, A., Menon, R., Mesterman, R., Miller, S., Morshead, C., Murray, S., Palisano, R., Paterson, A., Pelland, L., Raybaud, C., Rosenbaum, P., Samdup, D., Scherer, S., Scott, S., Segalowitz, S., Shroff, M., Strother, S., Taylor, M., van der Kooy, D., Wintle, R., Wright, V. & Young, N. (2013-2018). Childhood Cerebral Palsy Integrated Neuroscience Discovery Network "CP-NET". Ontario Brain Institute (OBI). Integrated Discovery Program. \$7,500,000.

The Childhood Cerebral Palsy Integrated Neuroscience Discovery Network (CP-NET) is an initiative funded by the Ontario Brain Institute. The program is designed to improve understanding of cerebral palsy (CP) and accelerate the development of new treatments.

Clinical Databases Platform (led by Dr. D. Fehlings)

The largest component of CP-NET is the Clinical Databases. Clinicians from 9 clinical sites from across Ontario are recruiting children with CP and acquiring 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.

A comprehensive CP-NET clinical database will allow researchers to study a variety of risk factors for CP, such as clinical risk factors occurring before, during and after childbirth. This data will be collected by conducting a detailed review of the child's neonatal, medical and rehabilitation charts, along with maternal medical and obstetrical records. Other variables evaluated will include socio-demographic information, family history as well as diagnostic data. Clinically acquired imaging data from fMRIs will be obtained and will be read, classified, and coded to create a neuroimaging database. It is hoped that the information collected will support current and future CP-NET research questions and themes. Researchers at CanChild and McMaster University are actively recruiting and assessing children from the Hamilton and Niagara regions and 21 families have consented to participate.

Life Span Platform (led by Dr. S. Miller & Dr. J.W.Gorter)

A Lifespan Platform will concentrate efforts on both extremes of the childhood lifespan with the establishment of two cohorts; a neonatal cohort of children at high risk to develop CP and a cohort of adolescents with CP transitioning to adulthood.



The Adolescent and Young Adult project, MyStory, is led by Dr. Jan Willem Gorter and coordinated at CanChild. Research has shown that youth with disabilities have complex journeys. They often have to navigate new environments with limited guidance, feel pressure to be independent, and lack resources and supports for successful transition into adulthood. Adolescents and young adults aged 16-30 years from across Ontario are being recruited to investigate the course of physical and mental health and wellbeing, and explore brain functioning and development.

The MyStory Project also contained a gualitative study, called MyVoice, to learn how adults with CP define themselves, their (dis)ability, and health. Three focus groups were held with 16 participants aged 16-29 years to better understand strategies and challenges faced by persons with CP as they develop their personal and social identities, as well as their healthcare. Study results have been shared with stakeholders and study participants, and the team has prepared a paper for submission.

Knowledge Translation Platform (led by Dr. P. Rosenbaum & Dr. J.W. Gorter)

KT strategies are being integrated throughout this research program to ensure findings are highly relevant and useful to all stakeholders involved. Partnerships with parents and families of children/ youth with hemiplegic CP are a key element of the KT plan. A Parent Advisory Committee has been established to ensure that questions of high concern to families are addressed by this research project and that the nature of the KT materials is relevant and accessible in non-technical, familyfriendly language. This includes the development of a CP-NET website (www.CP-NET.org) and newsletter. In addition CP-NET has partnered with the Ontario Brain Institute, the Ontario Federation for Cerebral Palsy, the Ontario Association of Children's Rehabilitation Services (OACRS) and the Heart and Stroke Foundation of Ontario to disseminate research findings to those who most need it: individuals with CP and their families, service providers, and policy makers.

On October 7th 2015, and in celebration of World CP Day, CP-NET hosted families, caregivers, clients, healthcare professionals and researchers at Holland Bloorview Kids Rehabilitation Hospital for the 2nd annual CP-NET Science & Family Day. The day included panels and presentations highlighting CP research and advocacy, a community photo contest and exhibition, and the release of Creating Possibilities for Cerebral Palsy, a video to raise awareness of CP and celebrate all that people with CP can do. Produced by CP-NET in collaboration with children, youth and adults with CP and their families, the video has since been shared in over 70 countries around the world and can be found at www.CP-NET.org



FEATURE: CP-NET Science & Family Day



It is amazing to see the strength of the community and be a member of it - Science & Family Day Participant

On Track Study

Bartlett, D., Chiarello, L., Fiss A., Hanna, S., Jeffries, L., Palisano, R., Westcott, S., & Gorter, J.W. (2012-2017). Developmental trajectories of impairments, associated health conditions, and participation of children with cerebral palsy. Canadian Institutes of Health Research (CIHR). \$1,008,439.

McCoy, S., **Bartlett, D.** (co-Pls), **Chiarello, L.**, **Palisano, R.**, **Jeffries, L.**, **Fiss, A.**, **Hanna, S.** & Bjornson, K. (2013-2016). Developmental Trajectories of Impairments, Health, and Participation of Children with Cerebral Palsy. Patient-Oriented Outcomes Research Institute (PCORI). \$1,906,955.

The On Track Study is a large multi-site collaboration involving researchers, therapists, families, and children with cerebral palsy (CP) from across Canada and the United States. The aim of the study is to describe changes in balance, range of motion limitations, strength, endurance, number and impact of health conditions, and participation in self-care, recreation, and leisure activities over a one-year period in young children with CP aged 18 months through 11 years. The outcomes will be useful for therapists assisting families to determine if children with CP are developing as expected, better than expected, or more poorly than expected, depending on their functional ability levels.

In 2013, this research team was awarded additional funding from PCORI to complement the original On Track Study by increasing data collection in a subsample of children with cerebral palsy across all five Gross Motor Classification System (GMFCS) levels. Rather than having two observations across one year, this subsample will have five observations (6-months apart) across two years, allowing for the establishment of longitudinal developmental curves for impairments, health conditions, and participation variables by estimating the average pattern of change, important individual variations in the pattern of change between children, and the degree of consistency over time within children. These developmental curves will serve as useful tools for families and service providers for discussing questions about how well children are doing in relationship to other children with CP of similar functional ability levels. It is anticipated that study results will also lead to recommendations for rehabilitation service provision for children with CP across functional ability levels.

Enrolment to the On Track study closed in January 2015. In total, 723 families were recruited; Data collection is ongoing until August 2016 and a total of 1,043 study visits were conducted throughout 2015.

Dissemination aims to assist with collaborative decision-making among family members and service providers to efficiently utilize rehabilitation services to meet families' goals. The team feels strongly

about the importance of sharing information throughout the entire research process. With families, this takes the form of newsletters, website postings and individualized family feedback forms after each visit. With assessors, information is shared through ongoing communications, teleconferences and newsletters. Finally, the intention is to share this information with others around the world through publications and presentations at local and international conferences as results are available.



FEATURE: Bringing the Family's Voice to Research

CanChild is dedicated to generating knowledge and translating research that is relevant and meaningful to those who need it most: families and health care providers. How better to address priorities of children and families and translate findings that are feasible to implement in daily life than to involve families as members of the research team? That's just what is happening in the On Track study where seven mothers of children and young adults with cerebral palsy are members of the research team.

How have parents contributed to On Track?

Parents have provided guidance in data collection (e.g., preparing therapists), recruitment, and questionnaire language that is acceptable to families. They have also addressed questions that arise during data collection and contributed to informational communications directed toward participants and therapist assessors.

Parents have participated in focus groups on what families want to know about the development of their children with cerebral palsy; the resulting themes will serve to guide recommendations in applying the developmental trajectories established as part of the On Track study. Parents are also involved in the production of two videos -- one addressing families' questions and sharing of assessments and the other featuring children engaged in family and community activities.

What do parents have to say about Bringing the Family's Voice to Research?

Parent collaboration embeds the language and knowledge of lay people (parents) to inspire directions for new research, asks questions that academic research does not necessarily inquire, and diversifies and deepens the meaning and application of research. - Tina Hjorngaard

Epilepsy

Quality of Life in Children with Epilepsy

Ronen, G., Boyle, M., Cunningham, C., **Lach, L**., **Rosenbaum, P.**, & Streiner, D. (2008-2013). Quality of life in children with epilepsy: What factors are important? Canadian Institutes of Health Research (CIHR), \$795,485.

The Health Related Quality of Life (HRQL) project is a multi-site longitudinal study of 506 participants and their families from pediatric hospitals across Canada. The goal of this study is to quantify the role of specific biomedical and psychosocial child and family variables believed to underlie health outcomes that relate to children's psychosocial adjustment, participation, and health-related quality of life. This includes identifying factors that may be amenable to intervention. This will help clinicians to identify targets for future intervention studies and will better enable people to recognize and act on opportunities for prevention of consequences of childhood epilepsy in order to manage it more effectively and holistically.

Recruitment and follow-up are completed and the team is currently engaged in longitudinal data analysis. A research paper was published in September 2015, and another has been accepted for publication (both papers authored by students involved in the project!):

Mezgebe, M., Akhtar-Danesh, G., Streiner, D., **Fayed, N.**, **Rosenbaum, P.**, & **Ronen, G.** (2015). Quality of life in childhood epilepsy: How does it compare with the quality of life in typical children and children with cerebral palsy? Quality of Life Research, 24, 71.

Kamath, S., **Fayed**, **N**., Goodman, C., Streiner, D., **Ronen**, **G**. (2015) Extracurricular participation among children with epilepsy in Canada. Accepted for publication in Epilepsy & Behavior in 2016.

The STeps for Children and Youth with EPilepsy (STEP) Project

Ronen, G., Rosenbaum, P., Bray, S., **Timmons, B**., & Streiner, D. (2012-2014). Enhanced Physical Activity in Children and Youth with Epilepsy: Exploring Evidence of the impacts on health, functioning, psychological wellbeing and quality of life. Hamilton Academic Health Sciences Organization (HAHSO), \$179,570.

Ronen, G., **Rosenbaum, P.**, Bray, S., **Timmons, B**., & Streiner, D. (2013-2018). Physical Activity in Children and Youth with Epilepsy: Exploring Evidence of the impacts on health, functioning, psychological wellbeing and quality of life. Ontario Brain Institute (OBI), \$250,000.

The STeps for Children and Youth with EPilepsy (STEP) project is a multi-site longitudinal study to explore the influence of increasing physical activity levels, through a pedometer-measured walking program, on health and quality of life in children with epilepsy. It is hypothesized that findings from this study could lead to new, non-pharmacological standards of care for improving health and reducing comorbidities in children with epilepsy.

Participants in the STEP project are enrolled from two pediatric hospitals in Ontario: McMaster Children's Hospital (MCH) and the Children's Hospital of Eastern Ontario (CHEO). In 2015, all follow-up visits were completed for participants enrolled at CHEO. Recruitment is ongoing at MCH, with local epilepsy organizations and independent pediatric neurologists being included for broader reach.



Health Services Research

Partnering For Change

Missiuna, C., Campbell, W., Pollock, N., Bennett, S., Camden, C., Gaines, R., McCauley, D. & Cairney, J. (2015). Dissemination of Results of Partnering for Change. Central West and Hamilton-Niagara-Haldimand-Brant Community Care Access Centres, \$56,139.

Missiuna, C., Hecimovich, C., Bennett, S., Campbell, W., Pollock, N., Camden, C., Gaines, R., McCauley, D. & Cairney, J. (2015). Partnering for Change: An innovative service with relevance to the Special Needs Strategy. Ontario Ministry of Education, \$199,810.

Missiuna, C., Pollock, N., Bennett, S., Camden, C., Campbell, W., McCauley, D., Gaines, R. & Cairney, J. (2013-2015). Implementation and evaluation of Partnering for Change, an innovative model that will transform health service provision for school-aged children with developmental coordination disorder. Ministry of Health and Long-Term Care. \$994,600.

Partnering for Change (P4C) is the name of a new model for delivering integrated rehabilitation services for children with special needs and also of the program of research that has evaluated the development, implementation and evaluation of P4C service model.

In 2015, Dr. Cheryl Missiuna and the P4C team completed the implementation and evaluation study of the P4C model funded by the Ontario Ministry of Health and Long-Term Care. Additional funding was received in 2015 from the Ontario Ministry of Education to allow for additional evaluation and from the Central West and Hamilton Niagara Haldimand Brant Community Care Access Centres for dissemination of the project results.

The P4C model of service is an innovative, collaborative, evidence-informed model that uses a needsbased, tiered approach to provide rehabilitation services for children with special needs in schools. Working collaboratively with educators and families, therapists provide support to whole schools and help create classroom environments that encourage successful participation and academic achievement of children.

P4C was initially developed as a model of support for children with Developmental Coordination Disorder (DCD) because they were the largest group of children in Ontario who were on waitlists for School Health Support Services. Although this was the population of children first studied, our research has shown that the P4C model of service delivery is of value for children with many diverse needs.



KT PRODUCT HIGHLIGHT: Findings From P4C

The Ontario Ministry of Health and Long Term Care funded a 2-year study led by CanChild and Cathy Hecimovich, CEO of the Central West Community Care Access Centre, to evaluate Partnering for Change across 3 regions in Ontario. Working collaboratively with colleagues at the Central West, Hamilton Niagara Haldimand Brant, and Toronto Central Community Care Access Centres (CCACs), the team evaluated Partnering for Change (P4C) in 40 schools in three school boards for 2 school years. The Ontario Ministry of Education funded further evaluation of the P4C model of service in the 2014–2015 school year.

The project findings were presented in an online, interactive report that can be viewed on any computer, iPad or tablet. This ensured that the results were freely available to the varied stakeholders interested in the project findings.

<u>Click here</u> to read the Partnering for Change Implementation and Evaluation Final Report, 2013–2015, submitted by Dr. Cheryl Missiuna and Cathy Hecimovich, on behalf of the Partnering for Change Team.

P4C Service Delivery Model

The goals of the Partnering for Change service delivery model are to:

1) facilitate earlier identification of children with special needs;

2) build capacity of educators and parents to understand and manage children's needs;

3) improve children's ability to participate in school and at home;

4) facilitate self and family management to prevent secondary consequences.



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PARTNERING FOR CHANGE: P4C

 $\ensuremath{\mathbb{C}}$ Missiuna, Pollock, Campbell, Levac and Whalen, CanChild, McMaster University, 2016

Teens Reaching Adulthood: Needs and Support for Improved Transitional care In ONtario (TRANSITION)

Gorter, J.W., **Amaria, K.**, Cassidy, C., **Di Rezze, B.**, Doyle-Lisek, S., Grant, C., Grewal, K., Guttman, B., Kingsnorth, S., **Klassen, A.**, Krantz, C., **McCauley, D.**, Speechley, K., Taube-Schiff, M. & Weaver, C. (2014-2016). Teens Reaching Adulthood: Needs and Support for Improved Transitional care In Ontario – TRANSITION Study. Ontario Child Health Support Unit (OCHSU). \$77,280

The journey from childhood to adult life involves reaching milestones, as well as assuming new roles and responsibilities. For the rapidly growing population of youth with chronic health conditions/ disabilities, transition into the adult healthcare system is an important dimension of this journey. Sadly patients and families often describe the transfer of care as 'falling off a cliff' due to the lack of sufficient preparation, information, supports, and skills to facilitate the process.

Although most providers encourage youth with chronic health conditions to assume responsibility for their own health, few discuss transfer to an adult provider and put in efforts to ensure continuity. Moreover, our current health care system is not designed to prevent complications in chronic conditions in youth, and health care providers lack the knowledge and information to assure effective clinical management, and to eliminate health disparities. When youth transitions are met with barriers/challenges, transitioning adolescents are at increased risk for poor health outcomes, most of which are preventable, and financial costs are often incurred by the patient/family and the healthcare system.

A meeting with over 30 stakeholders, including patients and parents, identified transition "gaps" in Ontario, built an Ontario Transition Research Agenda, and developed a methodological platform to address the most urgent research questions. The group unanimously agreed on the need to develop an approach to improve transition that is collaborative and individualized based on patient need, as well as a method of risk stratification to ensure that optimal care is delivered.

A protocol was designed to 1) measure "transition readiness" in adolescents and young adults between the ages of 12-25 with a range of different chronic or complex health conditions, 2) further validate the TRANSITION-Q across 7 healthcare centres in Ontario, and 3) triangulate the "transition readiness" responses of participants, parents/caregivers, and healthcare providers. Data collection is underway and final analyses are expected to be completed by September 2016.

FEATURE: Using Social Media to Engage Families

In June 2014, the 'Parents Participating in Research (PPR)' online advisory committee launched on Facebook. Connecting diverse parents of children with a (dis)ability together with researchers at CanChild, the pupose of the group has been to exchange knowledge for improved research as well as better lives of children and their families. The PPR community has grown from inception to an established community with active engagement and knowledge exchange.

As of April 1, 2015, the group was comprised of 96 participants (2 parent moderators, 13 researchers and 81 family members), and over a 9-month period made 432 original posts (64% generated by family members). Benefits to participation in the group have been shared by both parents and researchers, and a manuscript is currently in preparation to share these findings.





Mild Traumatic Brain Injury (mTBI)

Safely Returning Children and Youth to Activity After Concussion

DeMatteo, C. (PI), Bock, N., Connolly, J., Cupido, C., Giglia, L., Hall, G., Mazurek, M., Noseworthy, M., Singh, S., Thabane, L., & **Timmons, B**. (2014-2017). Safely Returning Children and Youth to Activity After Concussion. Canadian Institutes of Health Research (CIHR). \$591,518.

The decision surrounding when to return to activity following Mild Traumatic Brain Injury (mTBI)/concussion is one of the most controversial topics in concussion management for adults and is even more complicated for children and youth. Children who sustain mTBI are being provided with management strategies and return to activity guidelines that have been designed for adult athletes. This population is at high risk for repeat injuries within a short period of time as well as



prolonged symptoms affecting their school and leisure participation and success. In January 2014, funding was awarded by Canadian Institutes of Health Research to evaluate the innovative Return to School and Return to Activity guidelines that were developed as part of a previous CanChild KT project. Interim analyses were presented in local and international conferences in 2015, and the study is currently in an active recruitment stage.

Improving the Diagnosis and Treatment of Child and Adolescent mTBI

Gagnon, I. (PI), Friedman, D., Beauchamp, M.H., Christie, B.R., **DeMatteo, C. A.**, Fait, P., Hung, R., Juncker, D., Keightley, M., Marcoux, J., McFadyn, B.J., Mok, E., Mrazik, M., Pelland, L.C., Ptito, A., Singh, S. K., Sirois, K., Stroman, P.W., Swaine, B.R., Taneja, C., Tator, C., Zabjek, K., & Zemek, R. (2013-2018). Generating Innovation through the use of common data: improving the diagnosis and treatment of child and adolescent MTBI in Canada. Canadian Institutes of Health Research, Team Grant: Mild Traumatic Brain Injury in Children & Youth - Fonds de rech QC, \$766,895.

The goal of this grant is to create a culture of national collaboration, data collection and rapid clinical uptake of innovation in discovery. The overall goal is to enhance the ability to conduct multicentre research and provide evidence-based care across Canada to assist in diagnoses and treatment

of pediatric mTBI. Two sub-studies were derived from this Team Grant, and CanChild functions as a research site collaborating with other centres across Canada. The first study entitled "Generating Innovation through the use of common data: improving the diagnosis and treatment of child and adolescent mTBI in Canada" aims to establish the feasibility and utility of collecting common data elements for children and adolescents in seven pediatric mTBI follow-up programs across Canada. This sub-study was in active participant recruitment in 2015. The second study entitled "Comparing Approaches to Rehabilitation for Children and Youth with Persisting Symptoms Following Concussion" focuses on children and youth with persisting concussion symptoms. **Recruitment was completed in November 2015 for the CanChild site. The protocol for the second study was published in BMJ Open in 2015**:

Reed, N., Greenspoon, D., Iverson, G., **DeMatteo, C**., Fait, P., Gauvin-Lapage, J., Gagnon, I., & Hunt, A. (2015). Management of persistent post-concussion symptoms in youth: A randomized control trial protocol. BMJ Open, 5:e008468.

Concussion Research Team (L to R):

Rachael Leighfield, Chia-Yu Lin, Kenneth Curtis, Carol DeMatteo, Sarah Randall, Rachel Ho, Everett Clarridge, Caroline Beacham, & Conor Sheridan

Evidence-based Tools for Diagnosing and Managing Children with Concussion/mTBI

DeMatteo, C. (PI), **Cairney, J., Hanna, S., Law, M.**, Mahoney, W., & **Missiuna, C.** (2011-2012). Education is the Key to Protecting Children's Brains, Canadian Institutes of Health Research (CIHR), \$99,915.00.

The goal of this completed project was to develop evidence-based tools to diagnose and manage children with concussion/mild traumatic brain injury in hopes of preventing further injury and returning children/youth to activity safely. A Knowledge Broker worked in partnership with 39 family physicians, pediatricians and allied health professionals to implement these tools into practice. A scoping review was also completed to gather evidence around mTBI and determine what management strategies are currently in place. Two papers on the development of Return to Activity and Return to School Guidelines were published in 2015:

DeMatteo, C., Stazyk, K., Singh, S., Giglia, L., Hollenberg, R., Malcolmson, C., Mahoney, W., Harper, J., **Missiuna, C., Law, M.**, & McCauley, D. (2015). Development of a conservative protocol to return children and youth to activity following concussive Injury. Clin Pediatr (Phila), 54(2), 152-163.

DeMatteo, C., Stazyk, K., Giglia, L., Mahoney, W., Singh, S., Hollenberg, R., Harper, J., Missiuna, C., **Law, M., McCauley, D.**, & Randall, S. (2015). A balanced protocol for return to school for children and youth following concussive injury. Clin Pediatr (Phila), 54(8), 783-792.



Engagement of Families Impacted by Neurodevelopmental Disorders

Gorter, J.W., **Rosenbaum, P.**, **McCauley, D.** (2015-2018). The Knowledge Translation Core: Maximizing the Impact of Research and Training in Neurodevelopmental Disorder. NeuroDevNet: McMaster Family Engagement Component of the KT Core. Networks of Centres of Excellence. \$163,263.

How does a clinician know what a child with cerebral palsy wants out of their health and social care? How can understanding the needs of a mother of a child with autism help her obtain the services she needs as opposed to the services she has access to? How can the Ministry of Child & Youth Services learn from a young adult living and learning with Fetal Alcohol Spectrum Disorder? Engaging with stakeholders who are dealing with these questions every day is one approach that moves beyond listening to understanding and then to action. Supported by NeuroDevNet, McMaster leads the family engagement component of a national Stakeholder Engagement project that includes York University (focus on broad cross-sector consultation) and McGill University (focus on policy dialogue and rapid policy response; includes CanChild member **Keiko Shikako-Thomas**).

Through social media and rapid public response, CanChild is engaging families and youth in research, improving family/youth research literacy, building capacity of researchers to work with families/youth, and improving access to information for families. In 2015, CanChild continued to grow its network of stakeholders (e.g., via its 'Parents Participating in Research' Facebook group), and began to plan for its second Family Engagment Day to be held in early 2016.

FEATURE: The 'F-words' in Childhood Disability: A familyresearcher partnership

In 2012, Drs. **Peter Rosenbaum** and **Jan Willem Gorter** published a paper titled: "The 'F-words' in Childhood Disability: I swear this is how we should think!" Inspired by over two decades of CanChild research and continual discussion amongst members of the CanChild family, the paper features six 'F-words' the authors argue should be the focus in childhood disability - Function, Family, Fitness, Fun, Friends, and Future.

The 'F-words' are based on the World Health Organizations (WHO's) International Classification of Functioning, Disability and Health (ICF) framework. The ICF framework shows how body structure and function, activity, participation, environmental factors and personal factors are interrelated and equally influence our health and functioning. This holistic approach encourages us to focus on factors that are important to all children's development - their participation, activities, and environment.

Researchers and families are partnering together to spread awareness on the 'F-words' in childhood disability; Since July 2012 the 'F-words' paper has been downloaded more than 6,000 times, presented more than 60 times to local, national, and international audiences (many of them parents), and an 'F-words' video has received more than 2,000 views! It was exciting to learn that in recognition of a growing interest in these ideas, the publisher made the 'F-words' paper downloadable for free for all of December 2015!



Andrea Cross, a PhD student supervised by Dr. Peter Rosenbaum, who has been integral to the dissemination of the 'F-words' alongside the team's parent experts, had the following to say about her experiences at CanChild and her involvement in this partnership:

My research training with CanChild has been exceptional. I feel fortunate to be part of such a supportive research community and the CanChild family. CanChild has provided me with the opportunity to participate in multiple collaborative research projects and KT initiatives. Through these experiences I have developed friendships, built working partnerships, and grown as both an individual and a researcher.

A particular and perhaps unique experience has been the engagement - in the course of my own doctoral studies - with families who are equal partners on the research with my academic mentors. The contributions of the parents to the content and quality of our work has been invaluable, and has taught me lessons no course would ever provide.

CanChild Revenue for 2015

To ensure the long-term sustainability of CanChild's knowledge exchange and translations activities, an online **Shop** was launched in 2014, as well as a **Measurement and Analysis Service** providing consultation, electronic data collection, analysis and reporting to organizations for a fee. The new service benefits families by assisting organizations to provide services that are more family-centred, a best practice in pediatric rehabilitation.

Measurement and Analysis Service for the Measure of Processes of Care (MPOC-20)

(2015-2016). Supporting the Ministry of Children & Youth Services to assess the effectivesness of ABA-based services and supports using the Measures of Processes of Care (MPOC-20). Ontario Ministry of Children and Youth Services.

In early 2015, CanChild was contracted by the Ontario Ministry of Children and Youth Services to conduct an evaluation of of the Applied Behaviour Analysis (ABA)-based Services and Supports program across Ontario. Using the Measure of Processes of Care (MPOC), a 20-item tool to measure parents' perceptions of the extent to which services are family-centred, CanChild received responses from 3450 of 6299 families across Ontario who were invited to participate in the first year of data collection (June 1 to April 15, 2016). The response rate of 55% is very good for surveys of this type!

CanChild has received funding to continue this evaluation for the upcoming year and plans to use this positive experience to grow CanChild's Measurement and Analysis Service.



2015 Business Update

In 2015, almost **120,000** unique visitors to the CanChild website, generating over **660,000** page views.

Beyond the CanChild homepage, the most frequently visited pages highlight the Gross Motor Function Classification System (GMFCS) and Developmental Coordination Disorder (DCD).

40% of visitors to the CanChild website in 2015 were new users.

The top 15 countries represented as regular users of the CanChild website include (number of sessions in 000s):

- 1. United States (77.3)
- 2. Canada (74.2)
- 3. United Kingdom (24.5)
- 4. Australia (19.1)
- 5. India (6.6)
- 6. Ireland (5.7)
- 7. Netherlands (3.4)
- 8. Brazil (3.2)
- 9. Philippines (3.1)
- 10. Spain (2.7)

As part of CanChild's website redevelopment, improvements to the online Shop in 2015 included:

- overall design enhancements, including identifiable icons for each measure/tool
- more efficient automated processes for purchasing both digital and shippable products
- user-friendly interface with advanced search options
- improvements to backend operations



2015 Grants

Alberta Ministry of Community and Social Services. (\$153,098) (2015-17). Building employer capacity in advancing employment opportunity for persons with developmental disabilities. S. Hodgetts (PI), D. Nicholas (co-PI), M. Clarke, L.Plue.

American Academy of Cerebral Palsy and Developmental Medicine Pedal-with-Pete Research Grant. (\$11,210) (2015-16). Development of ICF-based multimedia education modules and their impact on parents' knowledge and attitude towards their children with Cerebral Palsy. P. Jindal (Student lead), J. MacDermid, P. Rosenbaum, B. Di Rezze, A. Narayan.

Applied Health Research Questions ICES Grant. (\$16,211) (2015). Missed critical congenital heart disease (CCHD) in Ontario. E. Cohen (PI), A. Guttmann (PI), A. Mukerju, M. Geraghty, V. Shah, A. Jain.

Associated Medical Services. AMS Phoenix Project Call to Caring Grants. (\$39,116) (2015-16). Enhancing Care for Young People with Muscular Dystrophy: Addressing the Human Dimensions of Progressive Illness Experience. B. Gibson (PI), L. McAdam, T. Abrams.

Bloorview Research Institute Catalyst Grant. (\$10,000) (2015-16). Exploring youth and parent engagement in a friendship enhancing intervention. S. Keenan (PI), C. McDougall, G. King.

Canada Research Chairs Program. (\$500,000) (2015-20). Canada Research Chair (Tier 2) in Child Health & Exercise Medicine. B. Timmons.

Central West and Hamilton-Niagara-Haldimand-Brant Community Care Access Centres. (\$56,139) (2015-16). Dissemination of Results of Partnering for Change. C. Missiuna (PI), W. Campbell, N. Pollock, S. Bennett, C. Camden, R. Gaines, D. McCauley, J. Cairney.

Canadian Institutes of Health Research (CIHR) (\$100,000) (2015-16). Children Grow Up: Taking a Life-course Approach to Promote Participation and Life Quality for Individuals with Cerebral Palsy from Childhood to Adulthood. D. Stewart (PI), B. Di Rezze (PI), R.J. Palisano (PI), M. Freeman, J.W. Gorter, A.F. Klassen, T.D. Nguyen, P.L. Rosenbaum.

Canadian Institutes of Health Research (CIHR), Foundation Scheme Programmatic Grants. (\$997,729) (2015-21). Health Outcomes of Children with Medical Complexity and their Caregivers. E. Cohen (PI), J. Berry, J. Brehaut, A. Guttmann, A. Lim, S. Mahant, N. Major-Cook, D. McNeil, J. Morinis, D. Nicholas, M. Offringa, E. Peebles, J. Ray, **P. Rosenbaum**, R. Stremler, L. Stromquist, T. To, S. Vigod, L. Williams, W. Wodchis.

Canadian Institutes of Health Research (CIHR), Foundation Scheme Programmatic Grants. (\$1,583,584) (2015-22). A Foundation Grant to Improve Early Detection, Diagnosis and Treatment of Autism Spectrum Disorder. L. Zwaigenbaum (PI).

Canadian Institutes of Health Research (CIHR), Foundation Scheme Programmatic Grants. (\$5,332,277) (2015-22). Pathways to Better Developmental Health in Autism Spectrum Disorder: Phase III. P. Szatmari (PI), L. Zwaigenbaum (Co-I).

Canadian Institutes of Health Research (CIHR), Foundation Scheme Programmatic Grants. (\$3,500,000). Genomes to Outcomes in Autism Spectrum Disorders. S. Scherer (PI). L. Zwaigenbaum (Co-I).

Canadian Institutes of Health Research (CIHR), Foundation Scheme Programmatic Grants. (\$684,197) (2015-20). Using Brain Mapping to Examine Predictors of Developmental Coordination Disorder and Response to Intervention. J. Zwicker (PI), T. Oberlander, D. Giaschi, B. Bjornson, R. Brant, S. Miller, R. Grunau, A. Synnes, K. Fitzpatrick, M. Mackay, S. Glegg, I. Montgomery, M. Brown-Lum.

Canadian Institutes of Health Research (CIHR). (\$378,411) (2015-18). Prevalence and social determinants of developmental outcomes among 5-year-old children with health disorders: a Pan-Canadian study. M. Janus, T. Bennett, C. Birken, M. Brownell, R. Coplan, E. Duku, **M.** Ferro, B. Forer, S. Georgiades, J.W. Gorter, M. Guhn, J. Maguire, J. Pei, R. Santos.

Canadian Institutes of Health Research, SPOR Networks in Chronic Disease (\$50,000) (2015). Letter of Intent, CHILD-BRIGHT. D. Goldowitz (PI), J.W.Gorter, C. Fuller, P. McGrath, M. Shevell.

Department of Health (Australian Government) (\$1,214,189 AUD). A multicentre randomized controlled trial investigating embedded simulation in occupational therapy clinical practice education. C. Imms (PI).

Department of Occupational Science & Occupational Therapy Research Initiative Cerebral Palsy using General Movements Fund (UBC). (\$5,000) (2015-16). Effectiveness Scoring App. I. Novak (PI). of Cognitive Orientation to Occupational Performance (CO-OP) in Very Preterm National Institutes of Health (NIH) NINDS Preschool-age Children with Developmental R01 NS091056-01A1 (\$1,425,375 USD) (2015-Coordination Disorder: A Pilot Study. J. Zwicker 20). Quantifying patient-specific changes in neuromuscular control in cerebral palsy. K. Steele (PI), M. Schwartz, M. Ciol, **S. Westcott-McCoy**. (PI). M. MacKay, D. Cuthbert, A. Synnes.

Fonds de Recherche Société et Culture de Québec (FRQSC): Actions Concertées - Approches et pratiques favorisant la persévérance et la réussite scolaires. (\$59,233) (2015-16). Comment organiser les services pour mieux soutenir les élèves handicapés ou en difficulté d'adaptation ou d'appretissage (HDDA): Principes et stratégies efficaces. D. Anaby (PI), C. Camden (Co-PI), S. Shaw, J.C. Kalubi, C. Missiuna, W. Campbell, S. Bennett, M.Bonnard, C. Hui, G. Kelso, L. Bonneau, E. Lauzon.

Glenrose Rehabilitation Hospital Foundation Clinical Research Grant. (\$6,500) (2015). Development of the "Autism Social Participation Classification System" (ASPCS) for Pre-school Children with Autism Spectrum Disorder. L. Zwaigenbaum (PI).

Hamilton Academic Health Sciences Organization (HAHSO). (2015-17). Towards a Functional Classification System for Preschool Children with Autism Spectrum Disorder: A Prospective Examination to Classify Social Communication Abilities. P.L. Rosenbaum (PI), B. Di Rezze (co-PI), S. Georgiades, L. Zwaigenbaum, M.J. Cooley Hidecker, S. Gentles, E.K. Duku. (2015-2017). \$192,833.

Hamilton Health Sciences Foundation. (\$50,000) (2015-16). Multimorbidity in youth receiving mental health services. M. Ferro (PI), M. Boyle, K. Georgiades, A. Gonzalez, J.W. Gorter, E. Lipman, R. Van Lieshout.

Health Research Council of New Zealand. (\$784,464 NZD) (2015-18). Enabling participation for disabled children and young people. Health Research Council of New Zealand. K. Witten (PI), B. Gibson, M. Carroll, S. Oliver, R. Mavoa, L. Kearns, J. Lin, N. Kayes.

IMPACT for CP Macquarie Group Grant. (\$200,090 AUD) (2015). General Movements and Brain MRI relationshipsin term infants. I. Novak (PI).

IMPACT for CP Macquarie Group Grant. (\$129,090 AUD) (2015). Early Diagnosis of

National Institutes of Health (NIH) NIBIB, R01 EB021935 01 (\$1,560,138 USD) (2015-19). Ubiquitous rehabilitation to monitor and improve muscle activity and movement after neurologic injury. K. Steele (PI), V. Kelly, **S.** Westcott-McCoy, N. Lu, N. Sun, S. Saponas.

Networks of Centres of Excellence (NCE). (\$1,221,446) (2015-18). NeurodevNet: Autism Spectrum Disorders Research Program - Optimizing Development and Outcomes in Children and Youth with ASD. L. Zwaigenbaum (PI).

Networks of Centres of Excellence (NCE). (\$218,000) (2015-18). NeuroDevNet. TotTech: Tangible, Organizing and Therapeutic Technologies to Engage Children. H.F.M. Van der loos (PI), **J. Zwicker**.

Networks of Centres of Excellence (NCE). (\$163,233) (2015-18). NeuroDevNet: McMaster Family Engagement Component of the KT Core. J.W. Gorter (PI), P. Rosenbaum, D. McCauley.

Norman Saunders Complex Care Initiative Grant Competition. (\$23,304) (2015-16). The experiences and expectations of family caregivers and health care providers of advance care planning in children with medical complexity (CMC). A.R. Orkin (PI), E. Cohen, A. Rapoport, K. Netten, S. Adams.

Norman Saunders Complex Care Initiative Grant Competition. (\$24,695) (2015-16). The role of whole genome sequencing as a diagnostic tool for children with medical complexity. R. Hayeems (PI), S. Meyn (PI), S. Bowdin, J. Orkin, E. Cohen, Stavropoulos, C. Marshall, R. Basran, N. Monfared, W. Ungar, R. Cohn.

2015 Grants

Norman Saunders Complex Care Initiative Grant Competition. (\$17,048) (2015-16). The experience of caregivers of children with medical complexity receiving blenderized tube feeding: a qualitative study. J. Orkin (PI), J. Soscia (PI), S. Adams, E. Cohen, J. Friedman, K. Gallagher, P. Marcon, D. Nicholas.

Ontario Ministry of Children and Youth Services. (\$1,065,437) (2015-16). Special Needs Strategy, Developmental Screen (Phase 2). J. Cairney (PI), J. Clinton (Co-I), C. Rodriguez, S. Veldhuizen, C. Missiuna, W. Campbell, K. Nair, H. Clark, A. Levinson, D. Streiner.

Ontario Ministry of Education. (\$199,810) (2015). Partnering for Change: An innovative service with relevance to the Special Needs Strategy. C. Missiuna (PI), C. Hecimovich (Principal Knowledge User), S. Bennett, W. Campbell, N. Pollock, C. Camden, R. Gaines, D. McCauley, J. Cairney.

Orthopaedic Research and Education Foundation (OREF). (\$32,000 US) (2015-16). Development and validation of patient reported outcome instrument for children with lower limb deformities. A. Cooper, J. Kopec, K. Mulpuri, C. Harpreet, A. Klassen.

Plastic Surgery Foundation. (\$49,978 USD) (2015-16). Development of the FACE-Q Kids PRO Instrument, A. Klassen (PI), K. Wong (co-PI), C. Forrest, K. Davidge, G. Borschell, R. Zuker, L. Giglia, A. Pusic.

Réseau Provincial de Recherche en Adaptation-Réadaptation (REPAR), Partenariat de recherche clinique en ergothérapie (OEQ/REPAR). (\$14,951) (2015-17), Facilitating Participation of Students with Physical Disabilities in Schools: Profile of School-based Occupational Therapy Practice, Service Delivery Methods and Strategies for Collaboration with School Stakeholders. M. Bonnard (PI), **D. Anaby**, S. Patella.

Sick Kids Foundation New Investigator Grant (\$300,000) (2015-18). Improving Outcomes for Children with Developmental Coordination Disorder. J. Zwicker (PI). T. Oberlander, D. Giaschi, B. Bjornson, R. Bran.

Women and Children's Health Research Institute (WCHRI). (\$15,000) (2015-16). 'This is my Child': A Pilot Study of a Communication Tool aimed at Supporting Emergency Department Care of Pediatric Patients. W. Craig (PI), L. Zwaigenbaum (Co-I).

Women and Children's Health Research Institute (WCHRI). (\$10,000) (2015-16). Understanding Early Developmental Trajectories in Autism: From Infancy to Age 8. L. Zwaigenbaum (PI).

Women and Children's Health Research Institute (WCHRI). (\$120,000) (2015-18). Optimizing Development and Outcomes in Children and Youth with Autism Spectrum Disorder. L. Zwaigenbaum (PI).

A total of **41** grants were awarded to CanChild members (as Principal Investigator or Co-Investigator) in 2015.

Grants with a CanChild Principal Investigator netted:

\$7.5 Million CAD \$1.5 Million AUD \$50 Thousand us







What We CAN Do Together





2015 CanChild Annual Report

CanChild Team

Director Jan Willem Gorter

Co-Founders Mary Law Peter Rosenbaum

Scientists

Doreen Bartlett John Cairney Wenonah Campbell Eyal Cohen Carol DeMatteo Briano di Rezze Mark Ferro Steven Hanna Marilyn Kertoy Anne Klassen Cheryl Missiuna Robert Palisano Nancy Pollock Dianne Russell Debra Stewart Brian Timmons Stephen Walter Virginia Wright

Research Associates Khush Amaria Dana Anaby Sheila Bennett Jamie Brehaut Jan Burke-Gaffney Chantal Camden Nora Fayed



Darcy Fehlings Barbara Gibson Gillian King Olaf Kraus De Camargo Sanjay Mahant Gabriel Ronen Nancy Thomas-Stonell Jill Zwicker

International Collaborators

Gary Bedell Wendy Coster Adrienne Harvey Lynn Jeffries Marjolijn Ketelaar Niina Kolehmainen Livia C. Magalhaes Christopher Morris Iona Novak Olaf Verschuren

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Robin Gaines Sandy Hodgetts Dafna Kohen Lucyna Lach Ronit Mesterman Keiko Shikako-Thomas Lonnie Zwaigenbaum



Postdoctoral Fellows

Stephen Gentles Danielle Levac Lisa Rivard

Lisa Chiarello
Alyssa LaForme Fiss
Christine Imms
Marian Jongmans
Mary Khetani
Lena Krumlinde-Sundholm
Sarah Westcott McCoy
Eva Nordmark
Barbara Piskur

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Selected Publications

Adair B, Ullenhag A, Keen D, Granlund M & Imms C (2015). The effect of interventions aimed at improving participation outcomes for children with impairments: A systematic review. Dev Med Child Neurol, 57(12), 1093-104. doi: 10.1111/dmcn.12932

Allen S, Smith I, Duku E, Vaillancourt T, Szatmari P, Bryson S, Fombonne E, Volden J, Waddell C, **Zwaigenbaum L**, Roberts W, Mirenda P, Bennett T, Elsabbagh M & Georgiades S (2015). Behavioural pediatrics feeding assessment scale in young children with Autism Spectrum Disorder: Psychometrics and associations with child and parent variables. J Pediatr Psychol, 40(6), 581-90. doi: 10.1093/jpepsy/jsv006

An M, Palisano RJ, Dunst CJ, Chiarello LA, Yi CH & Gracely EJ (2015). Strategies to promote family-professional collaboration: Two case reports. Disabil Rehabil, 17, 1-15. doi:10.3109/09638288.2015.1107763

Anaby D, Law M, Teplicky R & Turner L (2015). Focusing on the environment to improve youth participation: Experiences and perspectives of occupational therapists. Int J Environ Res Public Health, 12, 13388-98. doi:10.3390/ijerph121013388

Anaby DR, Law MC, Majnemer A & Feldman D (2015). Opening doors to participation of youth with physical disabilities: An intervention study: Favoriser la participation des adolescents ayant des handicaps physiques : Étude d'intervention. Can J Occup Ther, 83(2), 83-90. doi: 10.1177/0008417415608653

Anaby D, Korner-Bitensky N, Law M & Cormier I (2015). Focus on participation for children and youth with disabilities: Supporting therapy practice through a guided knowledge translation process. Br J Occup Ther, 78, 440-9. doi: 10.1177/0308022614563942

Arim RG, Kohen DE, Garner RE, Lach LM, Brehaut JC, MacKenzie MJ & Rosenbaum PL (2015). Psychosocial functioning in children with neurodevelopmental disorders and externalizing behavior problems. Disabil Rehabil, 37(4), 345-54. doi: 10.3109/09638288.2014.919361

Askari S, Anaby D, Bergthorson M, Majnemer A, Elsabbagh M & Zwaigenbaum L (2015). Participation of children and youth with Autistic Spectrum Disorder: A scoping review. J Autism Dev Disord, 2, 103-14. doi: 10.1007/s40489-014-0040-7

Ballantyne M, Benzies K, **Rosenbaum P** & Lodha A (2015). Mothers' and health care providers' perspectives of the barriers and facilitators to attendance at Canadian neonatal follow-up programs. Child Care Health Dev, 41(5), 722-33. doi: 10.1111/cch.12202

Bamm EL, Rosenbaum P, Wilkins S & Stratford P (2015). Performance of the Measures of Processes of Care for Adults and Service Providers in Rehabilitation Settings. Patient Relat Outcome Meas, 6, 157–65. doi: 10.2147/ PROM.S81361

Barry JG, Hall M, **Cohen E**, O'Neill M & Feudtner C (2015). Ways to identify children with medical complexity and the importance of why. J Pediatr, 167(2), 229-37. doi:10.1016/jpeds.2015.04.068

Batorowicz B, King G, Mishra L & Missiuna C (2016). An integrated model of social environment and social context for pediatric rehabilitation. Disabil Rehabil, 38(12), 1204-15. doi: 10.3109/09638288.2015.1076070. Epub 2015 Sep 10.

Bedell G & McDougall J (2015). The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic health conditions. Dev Neurorehabil, 18, 375-82. doi: 10.3109/17518423.2103.855273

Berg M, Dolva AS, Kleiven J & Krumlinde-Sundholm L (2016). Normative scores for the Pediatric Evaluation of Disability Inventory in Norway. Phys Occup Ther Pediatr, 36(2) 131-43. doi: 10.3109/01942638.2015.1050149. Epub 2015 Sep 01.

Beveridge B, Feltracco D, Struyf J, Strauss E, Dang S, Phelan S, Wright V & Gibson BE (2015). "You gotta try it all": Parents' experiences with robotic gait training for their children with <u>cerebral palsy.</u> Phys Occup Ther Pediatr., 35(4), 327-41. doi: 10.3109/01942638.2014.990547

Bonnard M & Anaby D (2015). Enabling participation of students through school-based occupational therapy services: Towards a broader scope of practice. Br J Occup Ther, 1-5. doi: 10.1177/0308022615612807. Epub 2015 Dec 16.

Brian J, Bryson S & Zwaigenbaum L (2015). Autism Spectrum Disorder in infancy: Developmental considerations in treatment targets. Curr Opin Neurol, 28(2), 117-23. doi: 10.1097/WCO.000000000000182

Brian J, Bryson S, Smith I, Roberts W, Roncadin C, Szatmari P & Zwaigenbaum L (2015). Stability and change in Autism Spectrum Disorder diagnosis from Age 3 to middle childhood in <u>a high-risk sibling cohort.</u> Autism, 1-5. doi: 10.1177/1362361315614979. Epub 2015 Dec 18.

Cairney J, Missiuna C, Timmons BW, Rodriguez C, Veldhuizen S, King-Dowling S, Wellman S & Le T (2015). The Coordination and Activity Tracking in Children (CATCH) study: Rationale and design. BMC Public Health, 15(1), 1266. doi:10.1186/s12889-015-2582-8.

Camden C, Leger G, Morel J, & Missiuna C (2015). A service delivery model for children with DCD based on principles of best practice. Phys Occup Ther Pediatr, 35(4), 412-25. doi:10.3109/01942638.2014.978932

Camden C, Rivard L, Pollock N & Missiuna C (2015). Knowledge to practice in developmental coordination disorder: Impact of an evidencebased online module on physical therapists' self-reported knowledge, skills, and practice. Phys Occup Ther Pediatr, 35(2), 195-210. doi:10.3109/01942638.2015.1012318

Camden C, Wilson BN, Kirby A, Sugden D & Missiuna C (2015). Best practice principles for management of children with developmental coordination disorder: Results of a scoping review. Child Care Health Dev, 41(1), 147-59. doi:10.1111/cch.12128.

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In 2015, CanChild members published more than

150

articles in peer-reviewed journals in the areas of child health, childhood disability, measurement and knowledge translation.

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