

# CanChild: Research Making a Difference

## Overview of *CanChild* Productivity in 2014

Prepared for
Dr. Stephen Collins, Associate Dean Research
Dr. John Kelton, Dean, Faculty of Health Sciences
Dr. Patty Solomon, Associate Dean School of Rehabilitation Science
Dr. Lennox Huang, Chair, Department of Pediatrics

Submitted on behalf of *CanChild* by Jan Willem Gorter, Director

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#### **Highlights from 2014:**

#### People:

Our Team is growing!

- Drs. Briano DiRezze and Wenonah Campbell were offered Faculty positions within the School of Rehabilitation Science. Dr. Mark Ferro was offered a joint Faculty position in the departments of Psychiatry and Behavioural Neurosciences and Pediatrics. All became Scientists with *CanChild* in 2014.
- Dr. Sandra Hodgetts from the University of Alberta became a *CanChild* Research Associate in 2014! Drs. Lisa Chiarello, Lynn Jeffries, Alyssa LaForme Fiss, and Sally Westcott McCoy became International Collaborators with *CanChild*.

#### **Publications:**

• *CanChild* members have published over 220 articles in peer-reviewed journals in the areas of child health, childhood disability, measurement and knowledge translation (in 2014).

#### **Research Funding:**

• A total of 69 grants were funded to *CanChild* members (as either PI or co-I) in 2014 netting more than \$9 million dollars in new grant funding.

#### **Awards/Recognition:**

#### Students

- CoraLee McLaren was a finalist at the 2014 Holland Bloorview Pursuit Awards in Toronto.
- Michelle Phoenix, *CanChild* PhD student under the supervision of Dr. Peter Rosenbaum, received the award for 'outstanding poster presentation' in the PhD/Fellows category at the Child Health Research Day at McMaster.
- Tram Nguyen (*CanChild* PhD student under the supervision of Dr. Jan Willem Gorter) and Andrea Cross (*CanChild* PhD student under the supervision of Dr. Peter Rosenbaum) were both awarded a special training opportunity in integrated Knowledge Translation (iKT) through the Canadian Child Health Clinician Scientist Training Program (CCHCSP) and the Council for Canadian Child Health Research (CCCHR). This training opportunity took place in Vancouver on June 6 8th 2014.
- Dr. Keiko Shikako-Thomas, *CanChild* Post-Doc Fellow, was awarded travel scholarships through CIHR and AACPDM.

#### CanChild International Collaborators

• Dr. Lisa Chiarello was awarded the Catherine Worthingham award through the American Physical Therapy Association.

#### CanChild Research Associates

- Dr. Dana Anaby was awarded a New Investigator Career Award: Junior 1 Research Scholars through the Fonds de recherche du Québec Santé (FRQS)
- Dr. Gillian King was awarded a Tier 1 Canada Research Chair in Optimal Care for Children with Disabilities.

- Dr. Sandra Hodgetts and Autism Research team (40 members) were awarded the President's Excellence Award for Outstanding Achievements in Research from the Alberta Health Services. She also received a teaching award through the Rehabilitation Medicine Students' Association.
- Dr. Sheila Bennett was awarded the Excellence in Public Education Award, District 8 OSSTF Avon Maitland.
- Dr. Darcy Fehlings was promoted to Professor, Department of Paediatrics at the University of Toronto.

#### CanChild Scientists

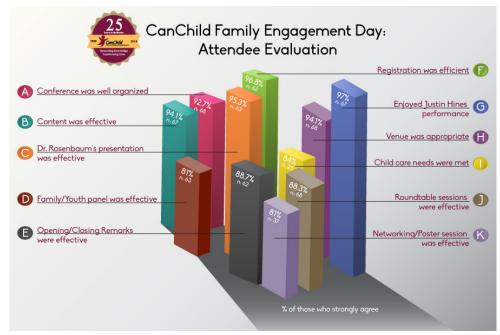
- Dr. Mary Law was named Innovator of the Year at the 2014 Innovation Showcase at McMaster on November 12. This award recognizes her initiatives over the last year to revamp the *CanChild* website and create revenue streams through existing measures and new service offerings. It was acknowledged that this was a team effort from the entire *CanChild* group!
- CanChild Co-Founder and CP-NET Executive Committee Member Dr. Peter Rosenbaum
  received the Lifetime Achievement Award at the American Academy for Cerebral Palsy and
  Developmental Medicine (AACPDM) on September 11, 2014! This award acknowledges
  Peter's "creative contributions of outstanding significance to the field of medicine and for
  the benefit of patients with cerebral palsy and other childhood-onset disabilities." Dr. Darcy
  Fehlings, Scientific Director/Lead of CP-NET and First Vice-President of the 68th Annual
  Meeting of the AACPDM, presented the award.
- Dr. Cheryl Missiuna was awarded the John and Margaret Lillie Chair in Childhood Disability Research.
- Dr. Eyal Cohen was the winner of the Junior Faculty Award for Clinical Excellence in Paediatric Medical Care through the Department of Paediatrics, University of Toronto, Hospital for Sick Children. He also received the Visiting Innovator Award, Center for Child Health Policy at Stanford University.
- Dr. Mark Ferro was awarded the Brain Star Award through the Institute of Neurosciences, Mental Health and Addiction at CIHR. He also received the W. E. Noonan Fellowship, Research Early Career Award through the Hamilton Health Sciences Foundation.
- Dr. Virginia Wright was awarded the Circle of Honour Award 2014 for Outcomes Research and Clinical Collaboration from Holland Bloorview Kids Rehabilitation Hospital.
- Dr. Mary Law was awarded the Lifetime Membership Award through both the Ontario Society of Occupational Therapists as well as the Canadian Association of Occupational Therapists

#### McMaster/Community Involvement

• On June 23rd, 2014, CanChild launched its 25th Anniversary Celebrations! McMaster leaders, CanChild friends, families and supporters gathered to congratulate the team! As part of the event, CanChild unveiled the redesign of the CanChild homepage (www.CanChild.ca), the new communications room, and the winners of the Art Contest.



- In late September, *CanChild* members participated in the Climb-a-thon and Accessible Sport Showcase which was run by the Hamilton Accessible Sports Council
- On Saturday November 22, 2014 families of children with disabilities, service providers, researchers and *CanChild* staff gathered together for a celebratory Family Engagement day *CanChild*: What we "CAN" do together on the McMaster Campus. Activities included live entertainment, food, family/youth panel, "hot topic" roundtables, posters and networking. The day was co-funded by McMaster Children's Hospital Foundation, Holland Boorview Research Institute, the Ontario federation for Cerebral Palsy (OFCP) and an Award from NeuroDevNet, Centre of Excellence in neurodevelopmental disabilities. The day was shared online (live-stream) and recorded: (www.canchild.ca)



#### **Commercialization**

- In 2014, revenues from the sale of *CanChild* measures netted approximately \$37,000.
- CanChild was excited to announce the launch of its new Measurement and Analysis Service
  earlier in 2014. This service, beginning with the Measure of Processes of Care-20 (MPOC20), provides 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.
- CanChild was also delighted to officially open the <u>eStore</u> in late August of 2014! Proceeds
  from the Store help support our knowledge translation activities to improve the lives of
  children and families.

#### **Programmes of Research**

The following pages outline our programmes of research and our progress through 2014.

#### **Autism Spectrum Disorder**



- Rosenbaum PL (PI), Di Rezze B, Cooley Hidecker MJ, Law M, Stratford P, Szatmari P, Zwaigenbaum L. Development of the Autism Classification System of Functioning: Social Communication. CIHR, \$374,666. 2011-2014.
- Rosenbaum PL (PI), Di Rezze B (co-PI), Georgiades S, Zwaigenbaum L, Cooley Hidecker MJ, Gentles S, Duku EK. Towards a Functional Classification System for Preschool Children with Autism Spectrum Disorder: A Prospective Examination to Classify Social Communication Abilities. HAHSO, \$192,833. 2015-2017.

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, we 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.

This tool has been under development for the past 3 years with CIHR grant funding. The study team started off by developing the content of the ACSF:SC and field testing it to ensure that it clearly describes preschool aged children with ASD. Since 2013, the team also tested the reliability of the ACSF:SC and is now in the process of examining its validity. We aim to have the participation from 50 parents and 100 professionals (educators and clinicians) at this final development stage. Our goal has been, and continues to be, to address this major practical challenge in the field of ASD – the need for precision and consistency in how we discuss and categorize the functional manifestations and impacts of ASD from a strengths-focused view.

#### **Cerebral Palsy**

Cerebral palsy (CP) affects 2-3 children per 1000 in the western world (and many more in the developing world). CP is defined in part as "... a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain." (Rosenbaum, 2008)



In 2011, the Ontario Brain Institute funded the Childhood Cerebral Palsy Integrated Neuroscience Discovery Network (CP-NET). The network consists of leading CP researchers from across Ontario including 5 *CanChild* investigators. The purpose of this program is to further our understanding of CP through partnerships between researchers, industry and patient advocacy groups. In 2013, the project was approved

for 5 years of additional funding.

The project consists of 6 platforms: Clinical Risk Factors (collects information on risk variables from neonatal and maternal health records); Neuroimaging Platform (analyzes neuroimaging records); Genomics Platform (collects saliva sample to analyze DNA);. Neurodevelopmental Platform (assesses children using standardized developmental outcome measures including a neurological exam); PsychoSocial/Participation Platform (assessments of mental health and well-being of children and families); and the Knowledge Translation Platform (bring together researchers, industry, patient advocacy groups and families to guide the direction of the project).

*CanChild* has been leading the Knowledge Translation activities since the inception of the project. In 2014, we held three Parent Advisory Meetings, developed Knowledge Translation pieces to help people understand how clinical research works, developed a CP-NET newsletter and organized a CP-NET Family and Science day in conjunction with World CP Day.

The new Adolescent and Young Adult project (funded in Phase 2 of the project) is led by Dr. Jan Willem Gorter and is investigating: the course of physical health (fatigue, pain), mental health (anxiety and depression) and well-being among adolescents and young adults (AYA) with CP; explore brain-behaviour connections (emotional regulation and executive function); and the mechanisms of impaired health and well-being – and in particular the role of chronic stress – on brain functioning and development. To date, fifteen participants have consented to taking part in the fMRI brain behaviour protocol. These will be scheduled in mid-to-late 2015.

*CanChild*/McMaster is also playing a key role in recruiting and assessing children from McMaster Children's Hospital for the other platforms. To date, 28 patients who fit the inclusion criteria have been identified and approached about the study.

## **Developmental Coordination Disorder**

• **Missiuna, C.** (PI), Pollock, N., Bennett, S., \*\*Camden, C., \*\*Campbell, W., McCauley, D., Gaines, R., Cairney, J. *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, 2013-2015.* 

In Ontario, intervention for children with DCD is typically provided by occupational therapists (OT) in school settings and involves one-on-one assessment followed by intervention (most often involving



withdrawal of the child from the classroom) to try and change children's underlying motor impairment. Waitlists in Ontario are extremely long for "School Health Support Services" (SHSS) and wait-times of 18-24 months for an OT are typical. In fact, children with coordination difficulties are the **largest single user group** referred to the Ontario home care system across all paediatric and adult populations.

In 2008/09, *CanChild* brought together over 60 stakeholders, including school board administrators, teachers, special educators, government policy analysts from MOHLTC, MEDU, MCYS, health care decision-makers, health care providers and families to share ideas about what

type of health service was actually needed to support these children in school settings. The program of services that resulted, *Partnering for Change*, is evidence-driven (Missiuna et al., 2012a). OTs build capacity through collaboration and coaching with the school becoming the "client", rather than any individual student. This comprehensive program of services is delivered in school settings to meet the needs of children with DCD.

In 2013, *CanChild* investigators received funding from the Ministry of Health and Long Term Care to continue this work and to evaluate this model with more CCACs and school boards in the province. This project will collect important information that will guide strategic planning and hopefully widespread implementation across Ontario.

The objectives of the current *Partnering for Change* project are to:

- •facilitate earlier identification of children with DCD;
- •build capacity of educators and parents to manage the needs of these children;
- •improve children's ability to participate successfully in school and home environments;
- •facilitate family management to prevent secondary disability.

In the fall of 2013, the Partnering for Change model of service delivery was implemented in 40 schools within three school boards: Peel District School Board, Halton District School Board and the Hamilton Wentworth Catholic District School Board.

In the first school year (November 2013 – June 2014), 15 occupational therapists (OTs) provided service one day/week in 40 schools and offered:

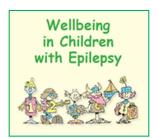
- 385 teacher in-services (formal and informal) to build capacity
- 704 universal design for learning activities at a whole class level; reaching over 17,600 children (based on avg. class size)
- 2980 opportunities to screen small groups of children, trial differentiated instruction and share findings with educators and parents
- 3,329 individual accommodation suggestions for 592 children and shared that knowledge with educators and families

Three hundred and ninety two of the 592 children receiving P4C services were also recruited into the study. Measurement of child, family and educator outcomes is underway using educator and parent pre- and post-standardized measures including: the School Function Assessment (SFA), Child and Family Demographics, DCD-Questionnaire, Strengths and Difficulties Questionnaire, Knowledge Questionnaires, Participation and Environment Measure.

In 2014, qualitative interviews were completed with key stakeholders including 14 school board managers, principals, and special educators; 12 health care coordinators and managers; 5 OTs and 3 research team members after Year 1. Focus groups also were completed with all OTs in Year 1. Additional interviews and focus groups are taking place in the spring of 2015.

Research to date has shown: that this new model is relevant for children who have significant daily motor, self-care, and academic challenges; facilitates equal access to services, eliminates wait lists, and serves large numbers of children with a diverse array of special needs. Moreover, the many stakeholders involved in the research and implementation of this service model have indicated that the core principles and features of P4C are relevant to all health professionals and educators seeking an integrated framework for rehabilitation service provision in Ontario.

#### **Epilepsy**



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

This Health Related Quality of Life (HRQL) project is a multi-site longitudinal study with subjects enrolled from pediatrics hospitals across Canada, involving families from British Columbia, Alberta, Manitoba, Saskatchewan, Ontario, and Quebec. A total of 506 participants and their families from across these 6 provinces were be recruited. Through this study we propose to quantify the role of specific biomedical and psychosocial child and family variables that we believe underlie health outcomes that relate to the child's psychosocial adjustment, participation, and health-related quality of life. This study uses a multivariate longitudinal design to examine simultaneously several determinants of outcomes in childhood epilepsy.

By conducting this study, we hope to identify the variables that are empirically associated with outcomes in children and youth with epilepsy, as well as the relative importance of these outcomes over time. We anticipate being able to identify moderating and mediating factors, including those potentially amenable to intervention. These findings will help clinicians to identify targets for future intervention studies. This in turn, will better enable people to recognize and act on opportunities for primary and secondary prevention of the consequences of childhood epilepsy, in order to manage childhood epilepsy more effectively and holistically.0

Over the past year, we have completed study recruitment, as well as the first three sets of follow-up visits. We are now focused on following participants for their remaining two visits. We published our methods paper in August, 2014.

• Ronen GM, Streiner DL, Boyle MH, Cunningham CE, Lach L, Verhey LH, Fayed N, Chen K, Rosenbaum PL, and the QUALITÉ Group: (Connolly M, Bello-Espinosa LE, Rafay MF, Appendino JP, Shevell M, Carmant L). Outcomes trajectories in children with epilepsy: hypotheses and methodology of a Canadian longitudinal observational study. *Pediatric Neurology*. 2014:50:38-48.

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- Ronen G, Rosenbaum P, Bray S, Timmons B, & Streiner D. Enhanced Physical Activity in Children and Youth with Epilepsy: Exploring Evidence of the impacts on health, functioning, psychological wellbeing and quality of life. HAHSO: \$179,570, 2012-2014.
- Ronen G, Rosenbaum P, Bray S, Timmons B, & Streiner D. *Physical Activity in Children and Youth with Epilepsy: Exploring Evidence of the impacts on health, functioning, psychological wellbeing and quality of life.* OBI: \$25,000, 2014-2018.

This project explores the relationship between increased physical activity (PA), epilepsy and comorbidity factors, quality of life and psychological well-being in a pedometer-monitored enhanced walking program combined with motivational strategies.

We plan to (i) undertake a prospective randomized control trial to evaluate the effects of increasing PA levels through a modern pedometer-measured walking program, and (ii) follow this by assessment of the sustainability of the program. Results from the enhanced PA group will be compared to results from the existing PA level of the control group.

We hypothesize that a motivational program to increase the levels of PA over 6 months will result in sustainably enhanced PA. In turn, this will positively and simultaneously influence brain-health and reduce co-morbidities in children with epilepsy, leading to improved health and life quality in childhood, potentially continuing into adulthood.

Evidence from this study could inform significant changes in clinical care in the near future leading to some non-pharmacological new standards of care. These new standards could lead to a reduction in current and future co-morbidities and, at no extra cost to the Provincial Government.

#### **Family Centred Care**

In 2014, we announced the Measurement and Analysis Service for the Measure of Processes of Care (MPOC-20). This service includes consultation, implementation of an evaluation using the MPOC, data analysis, interpretation and reporting. The Ministry of Children and Youth Services contacted us with a request for *CanChild* to conduct an evaluation of the Applied Behavioural Analysis (ABA)-based Services and Supports program across Ontario. Over the fall, we engaged in contract negotiations with the ministry with a final contract signed in early 2015.

#### **Knowledge Translation**

In partnership with Bloorview Research Institute, we launched a call for a joint *CanChild* – Bloorview Postdoctoral Fellowship (2014-2016). In December 2013, Dr. Coralee McLaren was selected as the inaugural recipient of this award. Dr. McLaren has a background in both nursing and dance, as well as a doctoral degree in rehabilitation science. She is supervised by Drs. Cheryl Missiuna and Barbara Gibson, Cora will conduct her own very exciting research project looking at environments, from all perspectives, for children with disabilities in school settings. In fact, in January of 2014 she was granted a CIHR Operating Grant to investigate how children with diverse dis/abilities respond to dance-play events.

CanChild has also implemented strategies to increase partnerships with families and youth. Dr. Dianne Russell worked in close collaboration with a parent of three children, one of whom has a disability, as well as a young adult living with a disability to increase awareness of CanChild research. This partnership has resulted in the development of the Parents Participating in Research Facebook page. The purpose of this group is to provide input on project planning, research direction, input on the current state of special needs parenting, supports and services as well as how to translate research knowledge to best serve parents and youth living with disability.

#### **Mild Traumatic Brain Injury**

The goal of this 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. In order to facilitate rapid uptake, a Knowledge Broker worked in partnership with 39 family physicians, pediatricians and allied health professionals to implement these tools into practice.

As part of this project a scoping review was complete to gather evidence about mTBI and determine what management strategies are currently in place, and an article outlining the development of Return to Activity Guidelines was also published. The Return to School Guidelines article was also submitted in 2014 (and subsequently published in 2015).

- **DeMatteo, C., McCauley, D., Stazyk, K., Adamich, J., Randall, S., Missiuna, C.** (2014). Post-concussion Return to Play and Return to School guidelines for children and youth: A scoping methodology. Disability & Rehabilitation. Aug21:1-6.
- **DeMatteo, C.**, Stazyk, K., Singh, S., Giglia, L., Mahoney, W., Hollenberg, R., Malcolmson, C., Harper, J., **Missiuna, C.**, **Law, M.**, **McCauley, D.** (2014) Return to activity protocol for children after CONCUSSION: A conservative approach. *Clinical Pediatrics early online* http://cpj.sagepub.com/content/early/2014/11/21/0009922814558256

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

The decision regarding return to activity following Mild Traumatic Brain Injury (MTBI)/concussion is one of the most difficult and controversial areas in concussion management for adults and even more complicated for children and youth. Children who sustain a 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, we received funding from CIHR to evaluate innovative Return to School and Return to Activity guidelines that were recently developed as part of another *CanChild* KT project. The study is currently at the active recruitment phase.

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• 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. *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, 2013-2018.

The goal of this Team Grant is to create a culture of national collaboration, data collection and rapid clinical uptake of innovation in discovery. Our overall goal is to enhance our ability to conduct multi-centre research and provide evidence-based care across Canada that will assist in diagnoses and treatment of pediatric MTBI. Two sub-studies are currently underway 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 7 pediatric mTBI follow-up programs across Canada. 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. Both studies are presently at the active recruitment phase.

#### **Participation**

In 2014, *CanChild's* Participation research teams engaged in a number of knowledge translation activities related to previous research grants.

The Participation and Environment Measure team focused on activities to increase awareness of and access to the Participation and Environment Measure for Children and Youth (PEM-CY). The PEM-CY User's Guide was finalized and the measure was added to the *CanChild* e-store. Work has continued on PEM-CY translations, with 11 completed to date. The team is collaborating with a programmer to develop an electronic version of the PEM-CY for use in research and program evaluation. This version, which is based on the successful parent version, will be available in 2015. In addition, the team consulted with a group from the Canadian Association of Pediatric Health Centres (CAPHC) about including the PEM-CY in a national database for children and youth with chronic conditions.

Members of the Participation and Environment Measure team are now working on developing an app for parents based on the PEM-CY's companion measure for young children – the Young Children's Participation and Environment Measure. This app will enable parents to set participation goals for their child and develop plans to put the goals into action.

The Participation Intervention Study team completed data analysis and published the findings of their study involving youth with physical disabilities. In this study, youth set participation goals and worked with an occupational therapist to develop strategies that focused on changing the environment and the task to enable them to meet these goals. This team is currently working on a manual to describe this successful therapy approach.

#### **Transition to Adulthood**

• **Gorter JW (PI)**, Punthakee Z (Co-PI), Brill H, Don-Wauchope A, Grant C, **Stewart D**, **Rosenbaum P**. Extension Grant: The utilization, utility and impact of a Transition Coordinator and the Youth Kit© among adolescents with chronic health conditions as they transition to adulthood. A pilot study. Funded by AFP Innovation Grant. \$196,493. 2011-2013

Led by Dr. Jan Willem Gorter ([CanChild/Pediatrics]), our research team completed a four-year prospective cohort study that followed youth with a variety of chronic health conditions as they transitioned from pediatric to adult healthcare. TRACE (Transition to Adulthood with Cyberguide Evaluation) was designed to empower youth through the use of two novel transition interventions: the Youth K.I.T. (Keeping It Together), which is an organizational tool for youth, and an online transition mentor. In so doing, the study responded to the established needs for improving transition process (due to the widely reported adverse health outcomes) and for evaluating effectiveness of transition interventions.



One hundred and thirty study visits with 50 participants were completed at two sites (the McMaster Children's Hospital in Hamilton and the Hospital for Sick Children in Toronto). Nine pediatric clinics in Hamilton and 5 clinics in Toronto were involved in the study. With 20 chronic conditions being represented, this study used a rather unique cross-condition, non-categorical approach. Data collection was complete in October 2013. Results of the study were written up and dissemination activities were carried out through 2014 and a manuscript was submitted to BMJ-Open in December 2014, which was accepted and published

#### in 2015:

Gorter JW, Stewart D, Cohen E, Hlyva O, Morrison A, Galuppi B, Nguyen T, Amaria K, Punthakee Z; TRACE Study group. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. BMJ Open.

• Gorter, JW. Teens Reaching Adulthood: Needs and Support for Improved Transitional care In Ontario – TRANSITION Study. Ontario Child Health Support Unit - \$77280, 2014-2016.

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 was held on November 14, 2014, that brought together over 30 stakeholders, including patients and parents, to:

- Identify transition "gaps" in Ontario;
- Build an Ontario Transition Research Agenda;
- Develop a methodological platform to address the most urgent research questions.

The group unanimously agreed that we need to develop:

- an approach to improve transition that is collaborative and individualized based on patient need:
- a method of risk stratification to ensure that optimal care is delivered.

Moving forward, our group plans to start building a method of risk stratification by first determining who the adolescents are that are transitioning out of pediatric healthcare system and determining their transition needs, and defining successful and unsuccessful transitions.

## **Our Team**

## Scientists, Research Associates, & International Collaborators

## McMaster University

Name	Position	Department	Discipline
Jan Willem Gorter	Director	Pediatrics	Physiatry
Peter Rosenbaum	Co-Founder	Pediatrics	Developmental Pediatrics
Mary Law	Co-Founder	SRS	Occupational Therapy
John Cairney	Scientist	Family Medicine	Social Psychology
Wenonah Campbell*	Scientist	SRS	Speech & Language
Carol DeMatteo	Scientist	SRS	Occupational Therapy
Briano DiRezze*	Scientist	SRS	Occupational Therapy
Mark Ferro*	Scientist	Psychiatry and	Epidemiology
		Behavioural	
		Neuroscience/	
		Pediatrics	
Steve Hanna	Scientist	CE&B	Biostatistics
Anne Klassen	Scientist	Pediatrics	Health Services Research
Cheryl Missiuna	Scientist	SRS	Occupational Therapy
Nancy Pollock	Scientist	SRS	Occupational Therapy
Debra Stewart	Scientist	SRS	Occupational Therapy
Brian Timmons	Scientist	Pediatrics	Kinesiology
Stephen Walter	Scientist Emeritus	CE&B	Biostatistics
Olaf Kraus de Camargo	Research Associate	Pediatrics	Developmental Pediatrics
Ronit Mesterman	Research Associate	Pediatrics	Developmental Pediatrics
Gabriel Ronen	Research Associate	Pediatrics	Child Neurology

## Universities & Organizations in Canada

Name	Position	Department	Discipline
Dana Anaby	Research	Physical and Occupational	Occupational Therapy
	Associate	Therapy, McGill University	
Doreen Bartlett	Scientist	Physical Therapy, Western	Physical Therapy
		Ontario	
Sheila Bennett	Research	Teacher Education, Brock	Special Education
	Associate	University	
Jamie Brehaut	Research	Clinical Epidemiology and	Cognitive Psychology
	Associate	Biostatistics, University of	
		Ottawa	
Jan Burke-Gaffney	Research	Hamilton Family Network	Parent Advisor
	Associate		
Eyal Cohen	Scientist	Hospital for Sick Children	Hospitalist
Johanna Darrah	Research	Physical Therapy, University of	Physical Therapy
	Associate	Alberta	

Darcy Fehlings	Research	Bloorview Research Institute	Developmental
	Associate		Pediatrics
Robin Gaines	Research	CHEO Research Institute	Speech & Language
	Associate		
Barbara Gibson	Research	Bloorview Research Institute	Physical Therapy
	Associate		
Sandra Hodgetts*	Research	Occupational Therapy,	Occupational Therapy
	Associate	University of Alberta	
Marilyn Kertoy	Scientist	Communication Sciences and	Speech & Language
		Disorders, Western Ontario	Pathology
Gillian King	Research	Bloorview Research Institute	Social Psychology
	Associate		
Dafna Kohen	Research	Statistics Canada	Senior Research
	Associate		Analyst
Lucyna Lach	Research	Social Work, McGill University	Social Work
	Associate		
Sanjay Mahant	Research	Hospital for Sick Children	Pediatrics
	Associate		
Nancy Thomas-	Research	Bloorview Research Institute	Speech & Language
Stonell	Associate		
Virginia Wright	Scientist	Bloorview Research Institute	Physical Therapy
Lonnie Zwaigenbaum	Research	Pediatrics, University of Alberta	Pediatrics
	Associate		
Jill Zwicker	Research	Occupational Science and	Occupational Therapy
	Associate	Occupational Therapy,	
		University of British Columbia	

## Universities Outside Canada

Name	Position	Department/University	Discipline
Robert Palisano	Scientist	Physical Therapy & Rehabilitation Drexel University, US	Physical Therapy
Gary Bedell	International Collaborator	Occupational Therapy, Tufts University, US	Occupational Therapy
Lisa Chiarello*	International Collaborator	Physical Therapy & Rehabilitation Drexel University, US	Physical Therapy
Wendy Coster	International Collaborator	Occupational Therapy Boston University, US	Occupational Therapy
Adrienne Harvey	International Collaborator	Royal Children's Hospital, Australia	Physical Therapy
Christine Imms	International Collaborator	Australian Catholic University, Australia	Occupational Therapy
Lynn Jeffries*	International Collaborator	Rehabilitation Sciences, University of Oklahoma, US	Physical Therapy
Marian Jongmans	International Collaborator	Social and Behavioural Sciences, Utrecht University, Netherlands	Health Psychology
Marjolijn Ketelaar	International Collaborator	University Medical Center Utrecht, Netherlands	Rehabilitation

Name	Position	Department/University	Discipline
Niina Kolehmainen	International	University of Aberdeen, Scotland	Occupational Therapy
	Collaborator		
Lena Krumlinde	International	Karolinska Institutet, Astrid	Occupational Therapy
Sundholme	Collaborator	Lindgren Children's Hospital,	
		Sweden	
Alyssa Laforme Fiss*	International	Physical Therapy,	Physical Therapy
	Collaborator	Mercer University, US	
Livia Magalhaes	International	Federal University of Minas Gerais,	Occupational Therapy
	Collaborator	Brazil	
Chris Morris	International	Peninsula Cerebra Research Unit,	Orthotics
	Collaborator	University of Exeter, UK	
Eva Nordmark	International	Department of Health Sciences,	Physiotherapy
	Collaborator	Lund University, Sweden	
Iona Novak	International	Cerebral Palsy Alliance, Australia	Occupational Therapy
	Collaborator		
Olaf Verschuren	International	Rehabilitation Centre de	Rehabilitation
	Collaborator	Hoogstraat, Netherlands	Medicine
Sarah Westcott	International	Rehabilitation Medicine,	Physical Therapy
McCoy*	Collaborator	University of Washington, US	

<sup>\*</sup>Indicated new members in 2014.

## **CanChild Research and Knowledge Translation Support**

#### **Permanent**

Name	Position	FTE
Dayle McCauley	Research Coordinator	1.0
Nathan Nash	Business Development	1.0 (as of Oct)
Rachel Teplicky	Knowledge Translation/Business	0.4 (as of Sept)
	Development	
Betty Yundt	Knowledge Translation Coordinator	0.2 (until Nov)

### Casual

Name	Position	FTE
Dianne Russell	Research & Knowledge Exchange Specialist	0.4 (until Dec)
Mary Beaudoin	Development Officer	0.4 (until Aug)
Affaf Ahtisham	Application Developer and Web Manager	0.8 (until Aug)

#### Publications in 2014<sup>1</sup>:

#### **Published**

- 1. Aaron, C., **Chiarello, L., Palisano, R.**, Gracely, E., O'Neil, M., & Kolobe, T. (2014). Relationships among Family Participation, Team Support and Intensity of Early Intervention Services. *Physical & Occupational Therapy in Pediatrics*, 34(4), 343-355.
- 2. Abdulsatar, F., Walker, R., **Timmons, B.**, & Choong, K. (2014). "Wii-Hab" in critically ill children: A pilot study. Journal of Pediatric Rehabilitation Medicine, 6(4), 193-204.
- 3. Ahuja, B., **Klassen, A.**, Satz, R., Malhotra, N., Tsangaris, E., Ventresca, M., & **Fayed, N.** (2014). A review of patient-reported outcomes for children and adolescents with obesity. Quality of Life Research, 23(3), 759-70.
- 4. Allard, A., Fellowes, A., Shilling, V., Janssens, A., Beresford, B., & **Morris**, **C.** (2014). Key health outcomes for children and young people with neurodisability: qualitative research with young people and parents. *BMJ Open*, *4*(4).
- 5. Almasri, N., O'Neil, M., & **Palisano, R**. (2014). Predictors of Needs Families of Children with Cerebral Palsy. *Disability and Rehabilitation*, 36(3), 210-9.
- 6. **Anaby, D., Law, M., Coster, W.**, Bedel, G., Khetani, M., Avery, L., & **Teplicky, R**. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school and community. *Archives of Physical Medicine and Rehabilitation*, 5(95), 908-917.
- 7. Anagnostou, E., **Zwaigenbaum, L.**, et al. (2014). Autism spectrum disorder: advances in evidence-based practice. *Canadian Medical Association Journal*, 186(7), 509-19.
- 8. Arim, R., **Kohen, D.**, Garner, R., **Lach, L.**, **Brehaut, J.**, MacKenzie, M., & **Rosenbaum, P.** (2014). Psychosocial functioning in children with neurodevelopmental disorders and externalizing behavior problems. *Disability and Rehabilitation*, 37(4), 345-54.
- 9. Axelsson, A., **Imms, C.,** & Wilder, J. (2014). Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: parents' and personal assistants experiences. *Disability and*

<sup>&</sup>lt;sup>1</sup> Only publications that are relevant to child health, childhood disability or knowledge translation are included in this list.

- Rehabilitation, 36(25), 2169-2177.
- 10. Bailey, S., Boddy, K., Briscoe, S., & Morris, C. (2014). Involving disabled children and young people as partners in research: a systematic review. *Child: Care Health Development. Advanced online publication.*
- 11. Ballantyne, M., Benzies, K., **Rosenbaum, P.**, & Lodha, A. (2014). Mothers' and health care providers' perspectives of the barriers and facilitators to attendance at Canadian neonatal follow-up programs. *Child: Care, Health & Development*. Advanced online publication.
- 12. Ballantyne, M., Stevens, B., Guttmann, A., Willan, A., & **Rosenbaum, P**. (2014). Maternal and infant predictors of attendance at Neonatal Follow-Up programmes. *Child: Care, Health & Development*, 40(2), 250-8.
- 13. **Bartlett, D., Chiarello, L., McCoy, S., Palisano, R., Jeffries, L., Fiss, A., Rosenbaum, P.,** & Wilk, P. (2014). Determinants of Gross Motor Function of Young Children with Cerebral Palsy: A Prospective Cohort Study. *Developmental Medicine and Child Neurology*, 56(3), 275-82.
- 14. **Bartlett, D.**, **Chiarello, L.**, **McCoy, S.**, **Palisano, R.**, **Jeffries, L.**, **Fiss, A.**, **Rosenbaum, P.**, & Wilk P. (2014). Determinants of self-care participation of young children with cerebral palsy: a prospective cohort study. *Developmental Neurorehabilitation*, 17(6), 403-13.
- 15. Batey, C., **Missiuna, C.**, **Timmons, B.**, Faught, B., Hay, J., & **Cairney, J.** (2014). Self-efficacy toward physical activity behaviour of children with and without Developmental Coordination Disorder. *Human Movement Science*, 36, 258-71.
- 16. **Batorowicz, B.**, Campbell, F., von Tetzchner, S., **King, G.**, & **Missiuna, C.** (2014). Social participation of school-aged children who use communication aids: the views of children and parents. *Augmentative and Alternative Communication*, 30(3), 237-51.
- 17. Bennett, T., Szatmari, P., Georgiades, K., **Hanna, S.**, Janus, M., Georgiades, S., Duku, E., Bryson, S., Fombonne, E., Smith, I., Mirenda, P., Volden, J., Waddell, C., Roberts, W., Vaillancourt, T., **Zwaigenbaum, L.**, Elsabbagh, M., Thompson, A., and The Pathways in ASD Study Team. (2014). Do Reciprocal Associations Exist between Social and Language Pathways in Preschoolers with Autism Spectrum Disorders? *Journal of Child Psychology and Psychiatry*. Advanced online publication.
- 18. Bennett, T., Szatmari, P., Georgiades, K., Hanna, S., Janus, M., Georgiades, S., Duku, E., Bryson, S., Fombonne, E., Smith, I., Mirenda, P., Volden, J., Waddell, C., Roberts, W.,

- Vaillancourt, T., **Zwaigenbaum, L.**, Elsabbagh, M., Thompson, A., & The Pathways in ASD Study Team. (2014). Language Impairment and Early Social Competence in Preschoolers with Autism Spectrum Disorders: A Comparison of DSM-5 Profiles. *Journal of Autism and Developmental Disorders*. Advanced online publication.
- 19. Berry, J., Hall, M., Neff, J., Goodman, D., **Cohen, E.**, Agrawal, R., Kuo, D., & Feudtner, C. (2014). Children with medical complexity and Medicaid: Spending and cost savings. *Health Affairs*, 33(12), 2199-206.
- 20. Beveridge, B., Feltracco, D., Struyf, J, Strauss, E., Dang, S., Phelan, S., **Wright, V.,** & **Gibson B.** (2014). "You gotta try it all": Parents' experiences with robotic gait training for their children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*. Advanced online publication.
- 21. Bongers, B., Werkman, M., Blokland, D., Eijsermans, M., Van der Torre, P., Bartels, B., **Verschuren, O**., & Takken, T. (2014). Validity of the Pediatric Running-Based Anaerobic Sprint Test to Determine Anaerobic Performance in Healthy Children. *Pediatric Exercise Science*. Advanced online publication.
- 22. Bonnard, M., & **Anaby**, **D**. (2014). Key enabling skills for diverse students: Possibilities for school-based occupational therapy. *Occupational Therapy NOW*, 16(2), 28.
- 23. Bork, P., Harwood, D., & **Bennett, S**. (2014). Using Play as a Key to Unlocking the Silence for Children with Selective Mutism. *Canadian Children*, 39(3), 24.
- 24. Breau, L., Clark, B., Scott, O., Wiles, C., Reynolds, S., Ricci, F., Sonnenberg, L., **Zwaigenbaum, L.**, Rashid, M., & Goez, H. (2014). Social Communication Features in Children Following Moderate to Severe Acquired Brain Injury: A Cross-Sectional Pilot Study. *Journal of Child Neurology*, 30(5), 588-94.
- 25. Brian, J., Roncadin, C., Duku, E., Bryson, S., Smith, I., Roberts, W., Szatmari, P., Drmic, I., & **Zwaigenbaum**, **L**. (2014). Emerging cognitive profiles in high-risk infants with and without Autism Spectrum Disorder. *Research in Autism Spectrum Disorders*, 8(11), 1557-1566.
- 26. Bult, M., **Verschuren, O.,** Lindeman, E., **Jongmans, M.**, & **Ketelaar, M.** (2014). Do children participate in the activities they prefer? A comparison of children and youth with and without physical disabilities. *Clinical Rehabilitation*, 28(4), 388-96.
- 27. **Cairney, J.**, Veldhuizen, S., Kwan, M., Hay, J., & Faught, B. (2014). Biological age and sex-related declines in physical activity during adolescence. *Medicine and Science in Sport and Exercise*, 46(4), 730-5.

- 28. **Camden, C.**, Léger, F., Morel, J., & **Missiuna, C.** (2014). A service delivery model for children with DCD based on principles of best practice. *Physical and Occupational Therapy in Pediatrics*. Advanced online publication.
- 29. Camden, C., Shikako-Thomas, K., Nguyen, T., Graham, E., Thomas, A., Sprung, J., Morris, C., Russell, D. (2014). Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disability and Rehabilitation*. Advanced online publication.
- 30. **Camden, C.,** Wilson, B., Kirby, A., Sugden, D., & **Missiuna, C.** (2014). Best practice principles in management of children with developmental coordination disorder: Results of a scoping review. *Child: Care, Health and Development*, 41(1), 147-59.
- 31. Chang, H., **Chiarello, L.**, **Palisano, R.**, Orlin, M., Bundy, A., & Gacely, E. (2014). The Determinants of Self-Determined Behaviors of Young Children with Cerebral Palsy. *Research in Developmental Disabilities*, 35(1), 99-109.
- 32. Chawarska, K., Shic, F., Macari, S., Campbell, D., Brian, J., Landa, R., Hutman, T., Nelson, D., Ozonoff, S., Tager-Flusberg, H., Young, G., **Zwaigenbaum, L.**, Cohen, I., Charman, T., Messinger, D., Klin, A., Johnson, S., & Bryson, S. (2014). 18-Month Predictors of Later Outcomes in Younger Siblings of Children with Autism Spectrum Disorder: A Baby Siblings Research Consortium Study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(12), 1317-1327.
- 33. **Chiarello, L., Palisano, R., Westcott McCoy, S., Bartlett, D.,** Wood, A., Kang, L., Chang, H., & Avery, L. (2014). Child Engagement in Daily Life: A Measure of Participation for Young Children with Cerebral Palsy. *Disability and Rehabilitation,* 36(21), 1804-16.
- 34. Chirico, D., Wade, T., **Cairney, J.**, Klentrou, P., & O'Leary, D. (2014). Evidence of a hyperkinetic state in children with elevated blood pressure. *Annals of Human Biology*. Advanced online publication.
- 35. **Claridge, E., McPhee, P., Timmons, B.**, Ginis, K., MacDonald, M., & **Gorter, J.W**. (2014). Quantification of Physical Activity and Sedentary Time in Adults with Cerebral Palsy. *Medicine and Science in Sports and Exercise*. Advanced online publication.
- 36. **Cohen, E.** (2014). Glucocorticoids for bronchiolitis-should they be used?: ...reducing waste in child health one intervention at a time. *Evidence-based Child Health: a Cochrane Review Journal*, 9(3), 496-7.

- 37. **Cohen, E.**, & Patel, H. (2014). Responding to the rising number of children living with complex chronic conditions. *CMAJ*, 186(16), 1199-200.
- 38. Constand, M., MacDermid, J., Dal Bello-Haas, V., & **Law, M**. (2014). Scoping review of patient-centered care approaches in healthcare. *BMC Health Services Research*, 14(1), 271.
- 39. Crompton, K., Elwood, N., Kirkland, M., Clark, P., **Novak, I.**, & Reddihough, D. (2014). Feasibility of trialling cord blood stem cell treatments for cerebral palsy in Australia. *Journal of Paediatrics and Child Health*, 50(7), 540-4.
- 40. **Cunningham, B.J.,** & **Rosenbaum, P.** (2014). Measure of processes of care: a review of 20 years of research. *Developmental Medicine & Child Neurology*, 56(5), 445-52.
- 41. **Darrah, J.**, **Bartlett, D.**, Maguire, T., Avison, W., & Lacaze-Masmonteil, T. (2014). Have infant gross motor abilities changed in 20 years? A re-evaluation of the Alberta Infant Motor Scale normative values. *Developmental Medicine and Child Neurology*, 56(9), 877-81.
- 42. **Darrah, J.**, Wiart, L., **Gorter, J.W.**, & **Law, M.** (2014). Stability of serial range-of-motion measurements of the lower extremities in children with cerebral palsy: can we do better? *Physical Therapy*, 94(7), 987-95
- 43. Darzins, S., **Imms, C**., Di Stefano, M., Taylor, N., Pallant, J. (2014). Evaluation of the internal construct validity of the Personal Care Participation and Resource Tool (PC-PART). *BMC Health Services Research*, 14, 543.
- 44. **DeMatteo, C.**, Gjertsen, D., Bain, J., & Harper, J. (2014). Wondering and waiting after Obstetrical Brachial plexus Injury: Are we underestimating the effect of the traumatic experience on the families? *Canadian Journal Plastic Surgery*, 22(3), 183-187.
- 45. **DeMatteo, C.**, Greenspoon, D., Levac, D., Harper, J.A., & Rubinoff, M. (2014). Evaluating the Nintendo Wii for assessing return to activity readiness in youth with mild traumatic brain injury. *Physical & Occupational Therapy in Pediatrics*, 34(3), 229-244.
- 46. **DeMatteo, C., McCauley, D., Stazyk, K., Adamich, J., Randall, S., Missiuna, C.** (2014). Post-concussion Return to Play and Return to School guidelines for children and youth: A scoping methodology. *Disability & Rehabilitation*, 37(12), 1107-12.

- 47. deRuiter, W., **Cairney, J.**, Leatherdale, S., & Faulkner, G. (2014). A Longitudinal Examination of the Interrelationship of Multiple Health Behaviours. *American Journal of Preventive Medicine*, 47(3), 283-289.
- 48. Dhaliwal, J., Noseworthy, N., Holt, N., **Zwaigenbaum, L.**, Avis, J., Rasquinha, A., & Ball, G. (2014). Attrition and Pediatric Obesity Management: An Integrative Review. *Childhood Obesity*, 10(6), 461-473.
- 49. Donald, K., Kakooza, A., Wammanda, R., Mallewa, M., Samisa, P., Babakir, H., Bearden, D., Majnemer, A., **Fehlings, D**., Shevell, M., Chugani, H., & Wilmhurst, J. (2014). Pediatric Cerebral Palsy in Africa: Where are we? *Journal of Child Neurology*. Advanced online publication.
- 50. Doralp, S., & **Bartlett, D**. (2014). Infant Movement Motivation Questionnaire: Development of a measure evaluating infant characteristics relating to motor development in the first year of life. *Infant Behaviour and Development*, 37(3), 326-333.
- 51. Elison, J., Wolff, J., Reznick, J., Botteron, K., Estes, A., Gu, H., Hazlett, H., Meadows, A., Paterson, S., **Zwaigenbaum, L.**, Piven, J. (2014). Repetitive Behavior in 12-month-olds later Classified with Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(11), 1216-24.
- 52. Elsabbagh, M., Yusuf, A., Prasanna, S., **Shikako-Thomas, K**., Ruff, C., & Fehlings, M. (2014). Community engagement and knowledge translation: Progress and challenge in autism research. *Autism*, 18(7), 771-81.
- 53. Farhat, F., Masmoudi, K., **Cairney, J.**, Hsairi, I., Triki, C., & Moalla, W. (2014). Assessment of cardiorespiratory and neuromotor fitness in children with developmental coordination disorder. *Research in Developmental Disabilities*, 35(12), 3554-61.
- 54. **Fehlings D.** (2014). To Boldly Go. *Developmental Medicine & Child Neurology*, 56(9), 800.
- 55. **Fehlings D.** (2014). Red, yellow, green: Can a traffic light system help systematic reviews? *Developmental Medicine and Child Neurology*, 56(4), 401-2
- 56.**Ferro, M**. (2014). Adolescents and young adults with physical illness: a comparative study of psychological distress. *Acta Paediatrica*, 103(1), 32-37.
- 57. **Ferro, M**. (2014). Missing data in longitudinal studies: cross-sectional multiple imputation provides similar estimates to full-information maximum likelihood.

- Annals of Epidemiology, 24(1), 75-77.
- 58.**Ferro, M**. (2014). Risk factors for health-related quality of life in children with epilepsy: a meta-analysis. *Epilepsia*, 55(11), 1722-1731.
- 59. **Ferro, M.**, Boyle, M., Alati, R., Scott, J., & Dingle, K. (2014). Maternal psychological distress partially mediates physician visits in a population-based sample of adolescents with asthma. *Journal of Asthma*. Advanced online publication.
- 60. **Ferro, M.**, Boyle, M., Dingle, K., & Scott, J. (2014). The Child Behavior Checklist and Youth Self-Report in adolescents with epilepsy: testing measurement invariance of the attention and thought problems subscales. *Epilepsy & Behavior*, 31, 34-42.
- 61. **Ferro, M.**, Chin, R., Camfield, C., Wiebe, S., Levin, S., & Speechley, K. (2014). Convulsive status epilepticus and health-related quality of life in children with epilepsy. *Neurology*, 83(8), 752-757.
- 62. Filliter, J., Longard, J., Lawrence, M., **Zwaigenbaum, L.**, Brian, J., Garon, N., Sith, I., Roncadin, C., Roberts, W., & Bryson, S. (2014). Positive Affect in Infant Siblings of Children Diagnosed with Autism Spectrum Disorder. *Journal of Abnormal Child Psychology*, 43(3), 567-75.
- 63. **Fiss, A., Chiarello, L., Bartlett, D., Palisano, R., Jeffries, L.**, Almasri, N., & Chang, H. (2014). Family ecology of young children with cerebral palsy. *Child Care Health and Development*, 40(4), 562-571.
- 64. **Freeman, M., Stewart, D.,** Shimmell, L., **Missiuna, C., Burke-Gaffney, J.,** Jaffer, S., **Law, M.** (2014). Development and evaluation of The KIT: Keeping It Together<sup>™</sup> for Youth (the 'Youth KIT') to assist youth with disabilities in managing information. *Child: Care, Health and Development*, 41(2), 222-9.
- 65. Galvão, B., Veloso, M., Carvalho, L., & **Magalhães, L**. (2014). Perspectiva dos pais sobre as consequências funcionais do Transtorno do Desenvolvimento da Coordenação (TDC): revisão da literatura. *Cadernos de Terapia Ocupacional da UFSCar*, 22, 187-193.
- 66. Georgiades, S., Boyle, M., Szatmari, P., **Hanna, S.**, Duku, E., **Zwaigenbaum, L.**, Bryson, S., Fombonne, E., Volden, J., Mirenda, P., Smith, I., Roberts, W., Vaillancourt, T., Waddell, C., Bennett, T., Elsabbagh, M., Thompson, A. & Pathways in ASD Study Team. (2014). Modeling the Phenotypic Architecture of Autism Symptoms from Time of Diagnosis to Age 6. *Journal of Autism and Developmental Disorders*, 44(12), 3045-55.

- 67. Germani, T., **Zwaigenbaum, L.**, Bryson, S., Brian, J., Smith, I., Roberts, W., Szatmari, P., Roncadin, C., Sacrey, L., Garon, N., & Vaillancourt, T. (2014). Brief Report: Assessment of Early Sensory Processing in Infants at High-Risk of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 44(12), 3264-70.
- 68. **Gibson, B.** (2014). Parallels and problems of normalization in rehabilitation and universal design: enabling connectivities. *Disability and Rehabilitation*, 36(16), 1328-33.
- 69. **Gibson, B.**, **King, G.**, Kingsnorth, S., & McKeever, P. (2014). The 'placement' of people with profound impairments across the lifespan: re-thinking age criteria. *BMC Medicine*, 12(83).
- 70. **Gibson, B.**, Mistry, B., Smith, B., Yoshida, K., Abbott, D., Lindsay, S., & Hamdani, Y. (2014). Becoming men: Gender, disability, and transitioning to adulthood. *Health*, 18(1), 93-112.
- 71. Glazebrook, C., & **Wright, V**. (2014). Further development of the Challenge Module, a measure of advanced motor skill in children with cerebral palsy. *Pediatric Physical Therapy*, 29(26), 201-213.
- 72. Glegg, S., **Hanna, S.**, et al. (2014). Using virtual reality in clinical practice: A multisite exploratory study. *NeuroRehabilitation*, 35(3), 563-77.
- 73. **Gorter, J.W., Stewart, D.,** Woodbury Smith, M., **King, G.,** Wright, M., **Nguyen, T., Freeman, M.,** & Swinton, M. (2014). Pathways toward positive psychosocial outcomes and mental health for youth with disabilities: A knowledge synthesis of developmental trajectories. *Canadian Journal of Community Mental Health,* 33(1), 45-61.
- 74. **Gorter, J.W.,** & **Timmons, B.** (2014). Measurement of habitual physical activity and sedentary behaviour of youth with cerebral palsy: work in progress. *Developmental Medicine and Child Neurology*, 56(9), 911.
- 75. Granek, L., Rosenberg-Yunger, Z., Dix, D., Klassen, R., Sung, L., **Cairney, J.**, & **Klassen, A.** (2014). Caregiving, single parents and cumulative stresses when caring for a child with a cancer. *Child: Care, Health & Development* 40(2), 184-94.
- 76. Gray, C., Barnes, J., Cowie Bonne, J., Cameron, C., Chaput, J., Faulkner, G., Janssen, I., Katzmarzyk, P., Kolen, A., Manske, S., Salmon, A., Spence, J., **Timmons**, **B.**, & Tremblay, M. (2014). Results from Canada's 2014 Report Card on Physical Activity for Children and Youth. *Journal of Physical Activity and Health*. Advanced online publication.
- 77. Gray, C., Larouche, R., Barnes, J., Colley, R., Cowie Bonne, J., Arthur, M., Cameron, C., Chaput, J., Faulkner, G., Janssen, I., Kolen, A., Manske, S., Salmon, A., Spence, J., **Timmons, B.,** & Tremblay, M. (2014). Are we driving our kids to unhealthy habits?

- Results of the Active Healthy Kids Canada 2013 Report Card on Physical Activity for Children and Youth. *International Journal of Environmental Research and Public Health*, 5(11), 6009-20.
- 78. Gulati, S., Dix, D., & **Klassen, A**. (2014). Demands and rewards of working within multidisciplinary teams in pediatric oncology: The experiences of Canadian health care providers. *The Qualitative Report*, 19(36), 1-15.
- 79. Hackett, K., Newton, J., Deane, K., Rapley, T., Deary, V., **Kolehmainen, N.**, Lendrem, D., & Ng, W. (2014). Developing a service user informed intervention to improve participation and ability to perform daily activities in primary Sjögren's syndrome: a mixed-methods study protocol. *BMJ Open*, 4(8), 6264.
- 80. Hajna, S., Leblanc, P., Faught, B., Merchant, A., **Cairney, J.**, Hay, J., & Liu, J. (2014). Associations between family eating behaviours and body composition measures in peri-adolescence: results from a community-based study of school-aged children. *Canadian Journal of Public Health*, 105(1), 15-21.
- 81. Hamdani, Y., Mistry, B., & **Gibson, B**. (2014). Transitioning to Adulthood with a Progressive Condition: Best Practice Assumptions and Individual Experiences of Young Men with Duchenne Muscular Dystrophy. *Disability and Rehabilitation*. Advanced online publication.
- 82. Hines, M., Swinburn, K., McIntyre, S., **Novak, I.**, & Badawi, N. (2014). Infants at risk of cerebral palsy: A systematic review of outcomes used in Cochrane studies of pregnancy, childbirth and neonatology. *Journal of Maternal-Fetal & Neonatal Medicine*, 11, 1-13.
- 83. **Hodgetts, S.,** McConnell, D., **Zwaigenbaum, L.**, & Nicholas, D. (2014). The impact of Autism Supports and Services on Mother's Occupational Engagement. *OTJR: Occupation, Participation & Health*, 34(2), 81-92.
- 84. **Hodgetts, S., Zwaigenbaum, L.**, & Nicholas, D. (2014). Profile and Predictors of Service Needs for Families of Children with Autism. *Autism*. Advanced online publication.
- 85. Hoffman, A., Matlow, A., Schroff, M., & **Cohen, E.** (2014). Factors impacting sameday cancellation of outpatient pediatric magnetic resonance imaging under anesthesia. *Pediatric Radiology*, 45(1), 99-107.
- 86. Jachyra, P., Atkinson, M., & **Gibson, B**. (2014). Gender performativity during interviews with adolescent boys. *Qualitative Research in Sport, Exercise and Health*, 6(4), 568-582.

- 87. Jackman, M., **Novak, I.**, & Lannin, N. (2014). Effectiveness of functional hand splinting and the cognitive orientation to occupational performance (CO-OP) approach in children with cerebral palsy and brain injury: two randomised controlled trial protocols. *BMC Neurology*, 14(1), 144.
- 88. Jackman, M., **Novak, I.,** Lannin N. (2014). Effectiveness of hand splints in children with cerebral palsy and brain injury: Systematic review with meta analysis. *Developmental Medicine and Child Neurology*, 56(2), 138-147.
- 89. **Janssens, A., Williams, J., Tomlinson, R., Logan, S., & Morris, C.** (2014). Health outcomes for children with neurodisability: what do professionals regard as primary targets? *Archives of Disease in Childhood, 99(10), 927-32.*
- 90. Jarus, T., Ghanouni, P., Caswell, S., Bickerton, L., Abel, R., Fomenoff, S., Davidson, S., Lundberg, J., & **Zwicker, J.** (2014). Effect of internal versus external focus of attention on implicit motor learning in children with developmental coordination disorder. *Research in Developmental Disabilities*, 37, 119-126.
- 91. **Jeevanantham, D.,** Dyszuk, E., & **Bartlett, D**. (2014). The Manual Abilities Classification System: A scoping review. *Pediatric Physical Therapy*. Advanced online publication.
- 92. Jivraj, J., Sacrey, L., Newton, A., Nicholas, D., & **Zwaigenbaum, L**. (2014). Assessing the Influence of Researcher-partner Involvement on the Process and Outcomes of Participatory Research in Autism Spectrum Disorder and Neurodevelopmental Disorders: A scoping review. *Autism*, 18(7), 782-93.
- 93. Kang, L., **Palisano, R.**, **King, G.**, & **Chiarello, L**. (2014). Understanding Optimal Participation of Children with Physical Disabilities: An Interactive Model. *Disability and Rehabilitation*, 36, 1735-1741.
- 94. Kelly, G., Mobbs, S., Pritkin, J., Mayston, M., Mather, M., **Rosenbaum, P.**, Henderson, R., & Forsyth, R. (2014). Gross Motor Function Measure-66 trajectories in children recovering after severe acquired brain injury. *Developmental Medicine & Child Neurology*. Advanced online publication.
- 95. **Ketelaar, M., Gorter, J.W.**, Westers, P., **Hanna, S.**, & Verhoef, M. (2014). Developmental trajectories of mobility and self-care capabilities in young children with cerebral palsy. *Journal of Pediatrics*, 164(4), 769-774.
- 96. Khetani, M., Cliff, A., Schelly, C., Daunhauer, L., & **Anaby, D.** (2014). Decisional Support Algorithm for Collaborative Care Planning using the Participation and Environment Measure for Children and Youth (PEM-CY): A Mixed Methods Study.

- *Physical & Occupational Therapy in Pediatrics.* Advanced online publication.
- 97. Killeen, H., Shiel, A., **Law, M**., Segurado, R., & O'Donovan, D. (2014). The impact of preterm birth on participation in childhood occupation. *European Journal of Pediatrics*, 174(3), 299-306.
- 98. **King, G., Batorowicz, B.**, Rigby, P., McMain-Klein, M., Thompson, L., & Pinto, M. (2014).

  Development of a measure to assess youth self-reported experiences of activity settings (SEAS). *International Journal of Disability, Development and Education*, 61(1), 44-66.
- 99. **King, G., & Chiarello, L.** (2014). Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. *Journal of Child Neurology*, 29(8), 1046-1054.
- 100. **King, G.,** Currie, M., & Petersen, P. (2014). Parent and child engagement in mental health services to children and families: A motivational framework. *Child and Adolescent Mental Health,* 19(1), 2-8.
- 101. **King, G.**, Desmarais, C., Lindsay, S., Piérart, G., & Tétreault, S. (2014). The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. *Disability and Rehabilitation*. Advanced online publication.
- 102. King-Dowling, S., **Missiuna, C.**, Rodriguez, M., Greenway, M., & **Cairney, J.** (2014). Co-occurring motor, language and emotional-behavioral problems in children 3-6 years of age. *Human Movement Science*. Advanced online publication.
- 103. **King, G., Gibson, B.,** Mistry, B., Pinto, M., Goh, F., Teachman, G., & Thompson, L. (2014). An integrated methods study of the experiences of youth with severe disabilities in leisure activity settings: The importance of belonging, fun, and control and choice. *Disability and Rehabilitation*, 36(19), 1626-1635.
- 104. **King, G.**, McPherson, A., Kingsnorth, S., **Stewart, D.**, Glencross-Eimantas, T., **Gorter, J. W.**, Jones-Galley, K., Morrison, A., & Isihi, A. (2014). Residential immersive life skills programs for youth with disabilities: Service providers' perceptions of experiential benefits and key program features. *Disability and Rehabilitation*, 37(11), 971-80.
- 105. **King, G.,** Rigby, P., **Batorowicz, B.,** McMain-Klein, M., Petrenchik, T., Thompson, L., & Gibson, M. (2014). Development of a direct observation Measure of Environmental Qualities of Activity Settings. *Developmental Medicine and Child Neurology*, 56, 763-769.

- 106. **King, G.**, et al. (2014). Developing authentic clinical simulations for effective listening and communication in pediatric rehabilitation service delivery. *Developmental Neurorehabilitation*. Advanced online publication.
- 107. **King, G.**, Specht, J., Petersen, P., Servais, M., Stewart, S., Young, G., & Brown, H. (2014). The development of expertise in children's mental health therapists and teachers: Changes in perspective and approach. *Educational Research*, 56(3), 277-294.
- 108. Kingsnorth, S., **King, G.**, McPherson, A., & Jones-Galley, K. (2014). A retrospective study of past graduates of a residential life skills program for youth with physical disabilities. *Child: Care, Health & Development*. Advanced online publication.
- 109. **Klassen, A.**, Grant, C., Barr, R., Brill, H., **Kraus de Camargo, O.**, **Ronan, G.**, Samaan, M., Mondal, T., Schlatman, A., Tsangaris, E., Athale, U., Wickert, N., & **Gorter, J.W**. (2014). Development and Validation of a Generic Scale for use in Transition Programs to Measure Self-Management Skills in Adolescents with Chronic Health Conditions: The TRANSITION-Q. *Child: Care, Health and Development*. Advanced online publication.
- 110. **Klassen, A.**, Rosenberg-Yunger, Z., Syed, I., D'Agostino, N., Barr, R., Greenberg, M., Granek, L., & Nathan, P. (2014). Developing transition readiness scales for childhood cancer survivors to better prepare them to transition to long-term follow-up care as adults. *Health Expectations*. Advanced online publication.
- 111. Knights, S., Datoo N., Kawamura, A., Switzer, L., & **Fehlings, D.** (2014). Further evaluation of the scoring, reliability, and validity of the hypertonia assessment tool (HAT). *Journal of Child Neurology*, 29(4), 500-504.
- 112. Knights, S., Graham, N., Switzer, L., Hernandez, H., Ye, Z., Findlay, B., Xie, W., **Wright, V**., & **Fehlings, D**. (2014). An innovative exergame cycling program to promote cardiovascular fitness and health-related quality of life in youth with cerebral palsy. *Disability & Rehabilitation*. Advanced online publication.
- 113. Knight, S., **Harvey, A.**, Towns, S., Payne, D., Lubitz, L., Rowe, K., Reveley, C., Hennel, S., Hiscock, H., & Scheinberg, A. (2014). How is Paediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Diagnosed and Managed by Paediatricians? An Australian Paediatric Research Network Study. *Journal of Paediatrics and Child Health*, 50(12), 1000-7.
- 114. **Kolehmainen, N**., & McAnuff, J. (2014). "I should have discharged him but I felt guilty": a qualitative investigation of clinicians' emotions in the context of implementing occupational therapy. *Implementation Science*, 9, 141.

- 115. Kruijsen-Terpstra, A., **Ketelaar, M**., Boeije, H., **Jongmans M., Gorter, J.W**., Verheijden, J., Lindeman, E., & **Verschuren, O**. (2014). Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review. *Child: Care, Health and Development*, 40(6), 787-96.
- 116. Kruijsen-Terpstra, A., **Ketelaar, M.**, **Verschuren, O.**, Smits, D., **Jongmans, M.**, & **Gorter, J.W.** (2014). Determinants of Developmental Gain in Daily Activities in Young Children with Cerebral Palsy. *Physical & Occupational Therapy in Pediatrics*. Advanced online publication.
- 117. Kuo, D., Goudie, A., **Cohen, E**., Houtrow, A., Agrawal, R., Carle, A., & Wells, N. (2014). Inequities in health care needs for children with medical complexity. *Health Affairs*, 33(12), 2190-80.
- 118. Kuo, M., Magill-Evans, J., & **Zwaigenbaum**, **L**. (2014). Parental mediation of television viewing and videogaming of adolescents with Autism Spectrum Disorder and their siblings. *Autism*. Advanced online publication.
- 119. Lauzier, F., Muscedere, J., Deland, E., Kusogiannis, D., Jacka, M., Heels-Ansdell, D., Crowther, M., Cartin-Ceba, R., Cox, M., Zytaruk, N., Foster, D., Sinuff, T., Clarke, F., Thompson, P., **Hanna, S.,** & Cook, D. (2014). Thromboprophylaxis patterns and determinants in critically ill patients: a multicentre audit. *Critical Care*, 18(2).
- 120. **Law, M.**, & **Darrah, J.** (2014). Emerging Therapy Approaches An Emphasis on Function. *Journal of Child Neurology*, 29(8), 1101-1107.
- 121. Law, M., Hanna, S., Anaby, D., Kertoy, M., King, G., & Xu, L. (2014). Health-related quality of life of children with physical disabilities: A longitudinal study. *BMC Pediatrics*, 14(26), 1-10.
- 122.LeGrow, K., Hodnett, E., Stremler, R., & **Cohen, E.** (2014). Evaluating the feasibility of a parent-briefing intervention in a pediatric acute care setting. *Journal of Specialists in Pediatric Nursing*, 19(3), 219-28.
- 123. Legrow, K., Hodnett, E., Stremler, R., McKeever, P., & **Cohen, E**. (2014). Bourdieu at the bedside: briefing parents in a pediatric hospital. *Nursing Inquiry*, 21(4), 327-35.
- 124.LeGrow, K., Hodnett, E., Stremler, R., **Cohen, E.**, & Victor, C. (2014). Psychometric testing of the family satisfaction with decision making subscale (FS-ICU/DM) in an acute care pediatric hospital setting. *European Journal for Person Centered Healthcare*, 2(3).
- 125. LeRoy, K., Boyd, K., De Asis, K., Lee, R., Martin, R., Teachman, G., & **Gibson, B**. (2014). Balancing hope and realism in family-centered care: Physical therapists' dilemmas in negotiating walking goals with parents of children with cerebral palsy.

- *Physical & Occupational Therapy in Pediatrics.* Advanced online publication.
- 126. Levac, D., **Camden, C.**, Glegg, S., **Rivard, L.**, & **Missiuna, C.** (2014). Best Practice Recommendations for the Development, Implementation, and Evaluation of Online Knowledge Translation Resources in Rehabilitation. *Physical Therapy*. Advanced online publication.
- 127. Lewis, J., Evans, A., Pruett, J., Botteron, K., **Zwaigenbaum, L.**, Estes, A., Gerig, G., Collins, L., Kostopoulos, P., McKinstry, R., Dager, S., Paterson, S., Schultz, R., Styner, M., Hazlett, H., & Piven, J. (2014). Network Inefficiencies in Autism Spectrum Disorder at 24 months. *Translational Psychiatry*, 4, 388.
- 128.Li, M., Mazhar, S., Messina, S., Moyse, J., Kelly, W., Cormier, I., & **Anaby**, **D**. (2014). Validating the Youth-Report Version of the Participation and Environment Measure for Children and Youth (PEM-CY): Preliminary Findings. *REVUE erg-GO*, 3, 30-35.
- 129. Lindsay, S., Tetreault, S., Desmarais C., **King, G.,** & Pierart, G. (2014). Social workers as 'cultural brokers' in providing culturally sensitive care to immigrant families raising a child with a physical disability. *Health and Social Work,* 39(2), 10-20.
- 130.Lindsay, S., Tetreault, S., Desmarais, C., **King, G.,** & Pierart, G. (2014). The cultural brokerage work of occupational therapists in providing culturally sensitive care. *Canadian Journal of Occupational Therapy*, 81(2), 114-123.
- 131.Lionel, A., +41 authors, **Zwaigenbaum**, **L.**, +40 authors, & Scherer, S. (2014). Disruption of the ASTN2/TRIM32 locus at 9q33.1 is a risk factor in males for autism spectrum disorders, ADHD and other neurodevelopmental phenotypes. *Human Molecular Genetics*, 23(10), 2752-68.
- 132. Lubetzky-Vilnai, A., Ciol, M., & **Westcott McCoy, S**. (2014). Statistical Analysis of Clinical Prediction Rules for Physical Therapy Interventions: Current State of the Literature. *Archives of Physical Medicine and Rehabilitation*, 95(1), 188-196.
- 133. Mahon, A., & **Timmons, B**. (2014). Application of stable isotope tracers in the study of exercise metabolism in children. *Pediatric Exercise Science*, 26(1), 3-10.
- 134. Makepeace, E., & **Zwicker**, **J.** (2014). Parent perspectives of occupational therapy assessment reports. *British Journal of Occupational Therapy*, 77, 538-545.
- 135. **Magalhães, L**., Dunn, L., & Mancini, M. (2014). Internal Structure of the Children Helping Out: Responsibilities, Expectations, and Supports (CHORES) Measure. *The American Journal of Occupational Therapy*, 68(3), 286-95.

- 136. **Magalhães, L**., & Gontijo, B. (2014). Assessing Gross Motor Development of Brazilian Infants. *Pediatric Physical Therapy*, 26(1), 48-55.
- 137. Maltais, D., Wiart, L., Fowler, E., **Verschuren, O**., & Damiano, D. (2014). Health-related physical fitness for children with cerebral palsy. *Journal of Child Neurolgy*, 29(8), 1091-100.
- 138. McAnuff, J., Boyes, C., & **Kolehmainen**, N. (2014). Family-clinician interactions in children's health services: a secondary analysis of occupational therapists' practice descriptions. *Health Expectations*. Advanced online publication.
- 139.McDougall, J., **Wright, V**., DeWitt, D., & Miller, L. (2014). ICF-Based Functional Components and Contextual Factors as Correlates of Perceived Quality of Life for Youth with Chronic Conditions. *Disability & Rehabilitation*, 36(25), 2143-2151.
- 140. Missiuna, C., Cairney, J., Pollock, N., Campbell, W., Russell, D., Macdonald, K., Schmidt, L., Heath, N., Veldhuizen, S., & Cousins, M. (2014). Psychological distress in children with developmental coordination disorder and attention-deficit hyperactivity disorder. *Research in Developmental Disabilities*, 35(5), 1198-207.
- 141. **Missiuna, C., & Campbell, W.** (2014). Psychological aspects of developmental coordination disorder: Can we establish causality. *Current Developmental Disorders Reports*, 1(2), 125-131.
- 142. Moreira, R., **Magalhães, L**., & Alves, C. (2014). Effect of preterm birth on motor development, behavior, and school performance of school-age children: a systematic review. *Jornal de Pediatria (Impresso)*, 90(2), 119-134.
- 143. Moreira, R., **Magalhães, L**., Dourado, J., Lemos, S., & Alves, C. (2014). Factors influencing the motor development of prematurely born school-aged children in Brazil. *Research in Developmental Disabilities*, 35(9), 1941-51.
- 144. Morgan, C., **Novak, I.,** Dale, R., Guzzetta, A., & Badawi, N. (2014). GAME (Goals Activity Motor Enrichment): protocol of a single blind randomised controlled trial of motor training, parent education and environmental enrichment for infants at high risk of cerebral palsy. *BMC Neurology*, 14, 203.
- 145. **Morris, C., et al.** (2014). Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting. *Health Services and Delivery Research*, 15(2).
- 146. Muskat, B., Burnham, R., Nicholas, D., Roberts, W., Stoddart, K., & **Zwaigenbaum, L**. (2014). Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian

- pediatric hospitals. Autism, 19(4), 482-90.
- 147. Nguyen, T., Baker, J., Obeid, J., Raha, S., Parise, G., Pedder, L., & **Timmons**, B. (2014). The effects of resting and exercise serum from children with cystic fibrosis on C2C12 myoblast proliferation in vitro. *Physiological Reports*, 2(6).
- 148. Nguyen, T., Obeid, J., Baker, J., Takken, T., Pedder, L., Parise, G., & **Timmons, B**. (2014). Reduced fat oxidation rates during submaximal exercise in boys with cystic fibrosis. *Journal of Cystic Fibrosis*, 13(1), 92-8.
- 149. Ni, L., **Fehlings, D.,** & Biddiss, E. (2014). Design and evaluation of virtual reality-based therapy games with therapeutic relevance and user experience for children with cerebral palsy. *Games for Health*, 3(3), 162-71.
- 150. Nicholas, D., Attridge, M., **Zwaigenbaum, L.**, & Clarke, M. (2014). Vocational Support Approaches in Autism Spectrum Disorder: A Review of Recent Literature. *Autism.* Advanced online publication.
- 151. Ninan, A., Stewart, S., Theall, L., **King, G.,** Evans, R., Baiden, P., & Brown, A. (2014). Psychotropic medication monitoring checklists: Use and utility for children in residential care. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 23(1), 38-47.
- 152. Nixon, S., Cockburn, L., Acheinegeh, R., Bradley, K., Cameron, D., Mue, P., Samuel, N., & **Gibson, B**. (2014). Using Postcolonial Perspectives to Consider Rehabilitation with Children with Disabilities: The Bamenda-Toronto Dialogue. *Disability and the Global South: Special Issue on 'Disabling Childhoods'*. In Press.
- 153. Njelesani, J., Cameron, D., **Gibson, B.**, Nixon, S., & Polatajko, H. (2014). A critical occupational approach: Offering insights on the sport-for-development playing field. *Sport in Society: Cultures, Commerce, Media, Politics*, 17(6), 790-807.
- 154. **Novak, I.** (2014). Evidence-based diagnosis, health-care and rehabilitation for children with cerebral palsy. *Journal of Child Neurology*, 29(8) 1141-1156.
- 155. **Novak, I.** (2014). Evidence to practice commentary: New evidence in coaching interventions. *Physical & Occupational Therapy in Pediatrics*, 34(2), 132–137.
- 156. **Novak, I.** & Berry, J. (2014). Evidence to practice commentary: Home program effectiveness evidence. *Physical & Occupational Therapy in Pediatrics*. Advanced online publication.
- 157. Obeid, J., Balemans, A., Noorduyn, S., **Gorter, J.W., & Timmons, B.** Objectively measured sedentary time in youth with cerebral palsy compared with age-, sex-, and season-matched youth who are developing typically: An explorative study.

- Physical Therapy, 94(8), 1163-7.
- 158. Obeid, J., Nguyen, T., Walker, R., Gillis, L., & **Timmons, B**. (2014). Circulating endothelial cells in children: Role of fitness, activity and adiposity. *Medicine and Science in Sports and Exercise*, 46(10), 194-80.
- 159. **Palisano, R., Chiarello, L., Westcott McCoy, S., Bartlett, D.,** & An, M. (2014). Use of the Child Engagement in Daily Life and Ease of Caregiving for Children to Evaluate Change in Young Children with Cerebral Palsy. *Physical & Occupational Therapy in Pediatrics*. Advanced online publication.
- 160. Parmar, A., Kwan, M., Rodriguez, C., **Missiuna, C.**, & **Cairney, J.** (2014). Psychometric properties of the DCD-Q-07 in children ages to 4-6. *Research in Developmental Disabilities*. Advanced online publication.
- 161. Phelan, S., **Wright, V.,** & **Gibson, B.** (2014). Representations of Disability and Normality in Rehabilitation Technology Promotional Materials. *Disability and Rehabilitation*, 36(24), 2072-9.
- 162. **Phoenix, M.,** & **Rosenbaum, P.** (2014). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child: Care, Health and Development*. Advanced online publication.
- 163. Pinto, D., Delaby, E., Merico, D., **Zwaigenbaum, L,**. Szatmari, P., Sutcliffe, J., Hallmayer, J., Gill, M., Cook, E., Buxbaum, J., Devlin, B., Gallagher, L., Betancur, C., & Scherer, S. (2014). Convergence of Genes and Cellular Pathways Dysregulated in Autism Spectrum Disorders. *American Journal of Human Genetics*, 94(5), 677-94.
- 164. Piškur, B., Daniels, R., **Jongmans, M**., **Ketelaar, M**., Smeets, R., Norton, M., & Beurskens, A. (2014). Participation and social participation: are they distinct concepts? *Clinical Rehabilitation*, 28(3), 211-20.
- 165. Poulsen, A., Ziviani, J., Kotaniemi, K., & Law, M. (2014). 'I think I can': measuring confidence in goal pursuit. *British Journal of Occupational Therapy*, 77(2), 64-66.
- 166. Prehn, J., McEwen, I., **Jeffries, L.**, Jones, M., Daniels, T., Goshorn, E., & Marx, C. (2014). Decreasing sound and vibration during ground transport of infants with very low birth weight. *Journal of Perinatoloty*, 35(2), 110-4.
- 167. Quigley, L., Lacombe-Duncan, A., Adams, S., Hepburn, C., & **Cohen, E**. (2014). A qualitative analysis of information sharing for children with medical complexity within and across health care organizations. *BMC Health Services Research*, 14, 283.
- 168. Radia George, C., **Imms, C.,** & Taylor, N. (2014). Inter-rater reliability and clinical utility of the Personal Care Participation Assessment and Resource Tool (PC-

- PART). American Journal of Occupational Therapy, 68(3), 334-343.
- 169. Randall, K., **Bartlett, D.**, & **Westcott McCoy, S**. (2014). Head-to-head comparison of the Early Clinical Assessment of Balance and the Pediatric Reach Test in Young Children with Cerebral Palsy. *Pediatric Physical Therapy*, 26, 332-337.
- 170. Randall, K., **Bartlett, D.**, & **McCoy, S**. (2014) Measuring Postural Stability in Young Children with Cerebral Palsy: A Comparison of Two Instruments. *Pediatric Physical Therapy*, 26(3), 332-337.
- 171. Randall, M., **Imms, C.,** Carey, L., & Pallant, J. (2014). Rasch analysis of the Melbourne Assessment of Unilateral Upper Limb Function. *Developmental Medicine and Child Neurology*, 56(7), 665-672.
- 172. Reinthaler, E., et al. incl. **Ronen G**. (2014). Analysis of ELP4, SRPX2 and interacting genes in typical and atypical Rolandic epilepsy. *Epilepsia*, 55(8), 89-93.
- 173. Reinthaler, E., et al. incl. **Ronen G.** (2014). Duplications Confer Risk for Typical and Atypical Rolandic Epilepsy. *Epilepsia*, 55(8), 89-93.
- 174. Restall, G., Cantin, N., **Law, M.**, Montgomery, I., Phelan, S., **Zwicker, J.**, & **Anaby, D**. (2014). The Knowledge Translation Café at the 2014 CAOT Conference: Closing the gaps between presenters and participants. *Occupational Therapy NOW*, 16(4), 18-19.
- 175. **Rivard, L., Camden, C., Pollock**, **N.,** & **Missiuna, C**. (2014). Knowledge to practice in developmental coordination disorder: Utility of an evidence-based online module for physical therapists. *Physical and Occupational Therapy in Pediatrics*. Advanced online publication.
- 176. **Rivard, L., Camden, C., Pollock, N., & Missiuna, C.** (2014). Working with physical therapists to develop and evaluate an evidence-based online module for developmental coordination disorder (DCD): Bridging the knowledge-to-practice gap. *Physical and Occupational Therapy in Pediatrics: Special Issue on Developmental Coordination Disorder*. Advanced online publication.
- 177. **Rivard, L., Missiuna, C., McCauley, D., & Cairney, J.** (2014). Descriptive and factor analysis of the Developmental Coordination Disorder Questionnaire (DCDQ '07) in a population-based sample of children with and without Developmental Coordination Disorder. *Child: Care, Health and Development,* 40(1), 42-49.
- 178. **Rosenbaum**, **P.** (2014). Identifying causation: the role of the clinical expert. *Developmental Medicine & Child Neurology*, 56(1), 4.

- 179. **Rosenbaum**, **P**. (2014). What causes cerebral palsy? *BMJ*, 349, 4514.
- 180. **Rosenbaum, P., & Camden, C.** (2014). Recursos para facilitar la practica basada en las evidencias en rehabilitación pediátrica (Resources to facilitate evidence-based practice in pediatric rehabilitation). *Revista Colombiana de Medicina Fisica y Rehabilitación*, 24(1), 68-74.
- 181. **Rosenbaum, P.**, Eliasson, A., Hidecker, M., & **Palisano, R.** (2014). Classification in Childhood Disability: Focusing on function in the 21<sup>st</sup> Century. *Journal of Child Neurology*, 29(8), 1036-45.
- 182. Sabarre, C., Rassekh, S., & **Zwicker, G**. (2014). Vincristine and fine motor function of children with acute lymphoblastic leukemia. *Canadian Journal of Occupational Therapy*, 81, 256-264.
- 183. Sacrey, L., Armstrong, V., Bryson, S., & **Zwaigenbaum, L**. (2014). Impairments to visual disengagement in autism spectrum disorder: A review of experimental studies from infancy to adulthood. *Neuroscience and Biobehavioral Reviews*. Advanced online publication.
- 184. Sadeghi, S., **Fayed, N**., & **Ronen, G**. (2014). Patient-reported outcomes (PRO) measures in pediatric epilepsy: A Content Analysis using World Health Organization Definitions. *Epilepsia*, 55(9), 1431-1437.
- 185. Schiariti, V., Sauve, K., **Klassen, A.**, O'Donnell, M., Cieza, A., & Mâsse, L. (2014). 'He does not see himself as being different': the perspectives of children and caregivers on relevant areas of functioning in cerebral palsy. Developmental Medicine and Child Neurology, 56(9), 853-61.
- 186. Schwellnus, H., **King, G.**, & Thompson, L. (2014). Client-centred coaching in the pediatric health professions: a critical review. *Disability and Rehabilitation*. Advanced online publication.
- 187. **Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C.** (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology*, *56*(3), 245-251.
- 188. Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., & Morris, C. (2014). Communicating with disabled children when inpatients: Barriers and facilitators identified by parents and professionals in a qualitative study. *Health Expectations*. Advanced online publication.
- 189. Shepherd, T., **King, G.**, Servais, M., Bolack, L., & Willoughby, C. (2014). Clinical scenario discussions of listening in interprofessional health care teams.

- *International Journal of Listening,* 28(1), 47-63.
- 190. **Shikako-Thomas, K.** (2014). Measuring environmental qualities: an innovative approach. *Developmental Medicine and Child Neurology*, 56(8), 708-709.
- 191. Shikako-Thomas, K., Kolehmainen, N., Ketelaar, M., Bult, M., & Law, M. (2014). Promoting Leisure Participation as Part of Health and Well-Being in Children and Youth with Cerebral Palsy. *Journal of Child Neurology*, 29(8), 1125-1133.
- 192. **Shilling, V., Bailey, S., Logan, S., & Morris, C.** (2014). Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health and Development. Advanced online publication.*
- 193. Siller, M., Morgan, L., Turner-Brown, L., Baggett, K., Baranek, G., Brian, J., Bryson, S., Carter, A., Crais, E., Estes, A., Kasari, C., Landa, R., Lord, C., Messinger, D., Mundy, P., Odom, S., Reznick, S., Roberts, W., Rogers, S., Schertz, H., Smith, I., Stone, W., Watson, L., Wetherby, A., Yoder, P., & **Zwaigenbaum, L**. (2014). Designing Studies to Evaluate Parent-Mediated Interventions for Toddlers with Autism Spectrum Disorder. *Journal of Early Intervention*. Advanced online publication.
- 194. Smits, D., **Gorter, J.W**., van Schie, P., Dallmeijer, A., **Ketelaar, M**, & PERRIN+ study group. (2014). How do changes in motor capacity, motor capability, and motor performance relate in children and adolescents with cerebral palsy? Archives of *Physical Medicine and Rehabilitation*, 95(8), 1577-84.
- 195. **Stewart, D., Law, M., Young, N.**, Forhan, M., Healy, H., **Burke-Gaffney, J.**, & **Freeman, M.** (2014). Complexities during transitions to adulthood for youth with disabilities: person-environment interactions. *Disability and Rehabilitation*, 36(23), 1998-2004.
- 196. Stone, N., Obeid, J., Dillenburg, R., Milenkovic, J., MacDonald, M., & **Timmons, B**. (2014). Objectively-measured physical activity levels of young children with congenital heart disease. *Cardiology in the Young*, 25(3), 520-5.
- 197. Tan, S., van Meeteren, J., **Ketelaar, M**., Schuengel, C., Reinders-Messelink, H., Raat, H., Dallmeijer, A., Roebroeck, M., & PERRIN+ study group. (2014). Long-term trajectories of health-related quality of life in individuals with cerebral palsy: a multi-center longitudinal study. *Archives of Physical Medicine and Rehabilitation*, 95(11), 2029-39.
- 198. Tan, S., Wiegerink, D., Vos, R., Smits, D., Voorman, J., Twisk, J., **Ketelaar, M.**, Roebroeck, M. & PERRIN+ study group. (2014). Developmental trajectories of social participation in individuals with cerebral palsy: a multicentre longitudinal study. *Developmental Medicine and Child Neurology*, 56(4), 370-7.

- 199. Teachman, G., & **Gibson**, **B**. (2014). Communicative Competence in the field of Augmentative and Alternative Communication; a review and critique. *International Journal of Language & Communication Disorders*, 49(1), 1-14.
- 200. Teachman, G., Mistry, B., & **Gibson, B**. (2014). Doing qualitative research with people who have communication impairments. *SAGE Research Methods Cases*. Advanced online publication.
- 201. Thomas, A., & **Law, M**. (2014). Evidence-based practice supports among Canadian occupational therapists. *Canadian Journal of Occupational Therapy*, 81(2), 79-92.
- 202. Thomson, L., **Fayed, N.**, Sedarous, F., & **Ronen, G**. (2014). Adolescents and emerging adults with epilepsy: life quality and health status during the years of transitions. A scoping review. *Developmental Medicine and Child Neurology*, 56(5), 421-433.
- 203. Tonkin, B., Ogilvie, B., Greenwood, S., **Law, M**., & **Anaby, D**. (2014). The participation of children and youth with disabilities in activities outside of school: A scoping review. *Canadian Journal of Occupational Therapy*, 34(4), 457-470.
- 204. Veldhuizen, S., **Cairney, J.**, Hay, J., & Faught, B. (2014). Relative age effects in fitness testing in a general school sample: How relative are they? *Journal of Sport Sciences*, 33(2), 109-15.
- 205. Veldhuizen, S., Wade, T., Hay, J., Faught, B., & **Cairney, J**. (2014). When and for whom are relative age effects important? Evidence from a simple test of cardiorespiratory fitness. *American Journal of Human Biology*, 26(4), 476-80.
- 206. **Verschuren, O., Darrah, J., Novak, I., Ketelaar, M.**, & Wiart, L. (2014). Health-Enhancing Physical Activity in Children With Cerebral Palsy: More of the Same Is Not Enough. *Physical Therapy*, 94(2), 297-305.
- 207. **Verschuren, O.**, Peterson, M., Leferink, S., & **Darrah, J.** (2014). Muscle activation and energy-requirements for varying postures in children and adolescents with cerebral palsy. *The Journal of Pediatrics*, 165(5), 1011-6.
- 208. **Verschuren, O.**, & Takken, T. (2014). The muscle power sprint test. *Journal of Physiotherapy*, 60(4), 239.
- 209. Ward, K., **Chiarello, L., Bartlett, D., Palisano, R., Westcott McCoy, S.**, & Avery, L. Ease of Caregiving for Children: A measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy. *Research in Developmental Disabilities*, 35, 3403-3415.

- 210. Weeks, M., **Cairney, J.**, Wild, T., Ploubidis, G., Naicker, K., & Colman, I. (2014). Early-life predictors of internalizing symptom trajectories in Canadian children. *Depression and Anxiety*, 31(7), 608-16.
- 211. Weeks, M., Wild, T., Ploubidis, G., Naicker, K., **Cairney, J.**, North, C., & Colman, I. (2014). Childhood cognitive ability and its relationship with anxiety and depression in adolescence. *Journal of Affective Disorders*, 152-154, 139-45.
- 212. Weiss, T., Tirosh, E., & **Fehlings, D.** (2014). Role of virtual reality for cerebral palsy. *Journal of Child Neurology*, 29(8), 1119-1124.
- 213. Wolff. J., Botteron, K., Dager, S., Elison, J., Estes, A., Gu, H., Hazlett, H., Pandey, J., Paterson, S., Schultz, R., **Zwaigenbaum, L.**, & Piven, J. (2014). Longitudinal patterns of Repetitive Behavior in Toddlers with Autism. *Journal of Child Psychology and Psychiatry*, 55(8), 945-53.
- 214. Wong, R., McEwan, J., Finlayson, D., Chung, S., Wan, L., Salbach, N., Kirkwood, G., Meschino, C., & **Wright, V**. (2014). Reliability and Validity of the Acquired Brain Injury Challenge Assessment (ABI-CA) in Children. *Brain Injury*, 28(13-14), 1734-1743.
- 215. **Wright, V.**, & Majnemer, A. (2014). A toolbox of outcome measures for children with cerebral palsy: Why, what, and how to use? *Journal of Child Neurology*, 29(8), 1055-1065.
- 216. **Wright, V.**, **Rosenbaum, P., Fehlings, D., Mesterman, R.**, Breuer, U., & Kim, M. (2014). The Quality Function Measure: reliability and discriminant validity of a new measure of quality of gross motor movement in ambulatory children with cerebral palsy. *Developmental Medicine & Child Neurology*, 56(8), 770-8.
- 217. Zaidman-Zait, A., Mirenda, P., Duku, E., Szatmari, P., Georgiades, S., Volden, J., **Zwaigenbaum, L.**, Vaillancourt, T., Bryson, S., Smith, I., Fombonne, E., Roberts, W., Waddell, C., Thompson, A., & Pathways in ASD Study Team. (2014). Examination of Bidirectional Relationships between Parent Stress and Two Types of Problem Behavior in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 44(9), 1908-17.
- 218. Zemek, R., Eady, K., Moreau, K., Farion, K., Solomon, B., Weiser, M., & **DeMatteo, C.** (2014) Knowledge of pediatric concussion among front-line primary care providers. *Pediatrics and Child Health*, 19(9), 475-80.
- 219. Zhu, Y., Wu, S., **Cairney, J.**, Li, Y., Chen, W., & Chen, F. (2014). High risk for obesity in children with a subtype of developmental coordination disorder. *Research in Developmental Disabilities*, 35, 1727-1733.

- 220. **Zwaigenbaum, L.**, et al. (2014). Early Head Growth in Infants at Risk of Autism: A Baby Siblings Research Consortium Study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53(10), 1053-62.
- 221. **Zwicker, J.**, Rehal, H., Sodhi, S., Karkling, M., Paul, A., Hilliard, M., & Jarus, T. (2014). Effectiveness of a summer camp intervention for children with developmental coordination disorder. Physical and Occupational Therapy in Pediatrics. Advanced online publication.
- 222. Zwinkels, M., **Verschuren, O.**, Janssen, T., **Ketelaar, M.**, & Takken, T. (2014). Exercise training programs to improve hand rim wheelchair propulsion capacity: a systematic review. *Clinical Rehabilitation*, 28(9), 847-61.

#### **Books**

Law, M. & MacDermid, J., editors (2014). *Evidence-based rehabilitation: A guide to practice, 3rd edition.* Thorofare, NJ: Slack Incorporated.

### **Book Chapters**

Lach LM, Rosenbaum P, Bailey S, Bogossian A, MacCulloch R. (2014) Chapter 1.4. Parenting a Child with Cerebral Palsy: Family and Social Issues. In: Cerebral Palsy. (Eds) Bernard Dan, Margaret Mayston, Nigel Paneth, Lewis Rosenbloom. London: Mac Keith Press.

Majnemer, A., Shikako-Thomas, K. Novak I. et al. (2014) Concepts of Participation and Environment in Relation to Childhood Disability (Chapter 5). New York: UNICEF (In press).

Majnemer, A., Shikako-Thomas, K. Novak I. et al. (2014) Assessing participation and environment in children with disabilities (Chapter 6). New York: UNICEF (In press).

Rosenbaum P. (2014) Chapter 1.2. Cerebral Palsy: Definition and Clinical Classification. In: Cerebral Palsy. (Eds) Bernard Dan, Margaret Mayston, Nigel Paneth, Lewis Rosenbloom. London: Mac Keith Press.

Rosenbaum P and Morris C. (2014) Chapter 3.8. Resources for Families. In: Cerebral Palsy. (Eds) Bernard Dan, Margaret Mayston, Nigel Paneth, Lewis Rosenbloom. London: Mac Keith Press.

Rosenbaum P (2014) Chapter 9 Issues in childhood disability: A forty-year perspective on a changing field. In: Saigal S (Ed.) Preemie Voices. Yong men and women born very prematurely describe their lives, challenges and achievements. Vitoria BC: Friesen Press.Steenbeek D, **Gorter JW, Ketelaar M**, Galama K, Lindeman E. (2014) Goal Attainment Scaling in paediatric rehabilitation. Chapter 8. In Richard J Siegert, William Levack. Rehabilitation Goal Setting: Theory, Practice and Evidence (hardcover), Taylor & Francis Group. Florida, US. July 2014 Cat/ISBN: K12930/9781439863299. P 143-160. Wiegerink D, **Gorter JW**, & Roebroeck M. (2014) Sexual development, sexual health, needs,

and lived experiences. Chapter 38. In: Cerebral Palsy. Editors: Bernard Dan, Margaret Mayston, Nigel Paneth, Lewis Rosenbloom. Mac Keith Press, London, UK ISBN: 978-1-909962-38-5 September 2014.

# **CanChild Grant Funding<sup>2</sup>**

## **New Funding for 2014:**

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
Feasibility and acceptability of a telehealth intervention in adolescents with chronic fatigue syndrome: A pilot randomised controlled trial.	АН	MCRI Emergin Researcher Grant	\$22,000 (AUS)	2014	1 year	AUS
Development and Validation of Distress Screening Tools for use by Canadian Adolescent and Young Adult (AYA) Cancer Patients & Survivors	AK	C17 Research Network	\$149,554	2014	2 year	McMaster
Moving Together: Choreographic mappings of children with diverse dis/abilities and their neurological responses to a dance -play event.	BG, CMcL, CM	CIHR	\$180,000	2014	3 years	Bloorview
NHMRC Centre of Research Excellence in Cerebral Palsy led by Professor Dinah Reddihough	АН	NHMRC	Not available	2014	4 years	AUS
Exploring parent-health care provider decision making practices for children with complex health care needs receiving home care services: A pilot study.	BG, EC	Norman Saunders Complex Care Initiative	\$26,152	2014	1 year	Sick Kids
Cardiovascular Health in children with chronic inflAMatory condition: role of Physical activity, fltness and inflammatiON: The CHAMPION Study	ВТ	Heart and Stroke Foundation of Canada Grant-in- Aid	\$263,229	2014	2 years	McMaster

 $<sup>^2</sup>$  Only grant funding relevant to childhood disability, child health or knowledge translation has been included in this report.  $42\ of\ 51$ 

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
School-age Kids health from early investment in Physical activity: The SKIP Study	BT, JC	CIHR	\$769,424	2014	5 years	McMaster
Safely returning children and youth to activity after concussion.	CDM, BT	CIHR	\$591,519	2014	3 years	CanChild/ McMaster
Supporting physical activity in the child care environment: The SPACE Study.	ВТ	CIHR	\$342,801		3 year	Western
Program evaluation of Specialisterne Employment Model for individuals with ASD	BDR	Ontario Trillium Foundation	\$390,000	2014	2 years	York
Mild Traumatic Brain Injury –Concussion in Children	CDM	Ontario Child Health Support Unit (OCHSU)	\$65,454	2014	2 years	СНЕО
A novel assessment method for cognitive function in concussion	CDM	Arts Research Board (ARB), Collab/Partnershi ps Research - ARB Major Seed Project	\$8,946	2014	1 year	McMaster
Community of Practice on Social Participation for Children and Teenagers with Disabilities (Communauté de pratique Axée sur la Participation Sociale des Enfants-Adolescents (CAPSEA) ayant des incapacités)	CC	FRQSC	\$52,742	2014	2 years	Quebec
CP2: Engaging Community Partners for Children's Participation (Engager les partenaires communautaires pour favoriser la participation des enfants qui ont la paralysie cérébrale)	KST, CC, LL	REPAR	\$35,000	2014	1 year	Quebec (McGill)
CP2: Engaging Community Partners for Children's Participation	KST, CC, LL	CIHR	\$12,500	2014	1 year	Quebec (McGill)
Toward a system of Early Identification to Optimize Child Development: Developmental Screening and Surveillance in the Early Years.	JC, CM, WC	Ontario Ministry of Children and Youth Services	\$609,628	2014	1 year	McMaster

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
Comment organiser les services pour mieux soutenir les élèves handicapés ou en difficulté d'adaptation ou d'appretissage (HDDA): Principes et stratégies efficacies.	DA, CC, CM, WC, SB	FRQSC	\$59,233	2014	1 year	Quebec (McGill)
Improving Social Participation for Children with ASD in Elementary School: Proposal Development.	SHod, CM, LZ	Alberta Centre for Child, Family and Community Research	\$10,000	2014	1 year	U of Alberta
Involving families in developing ideas for research, designing collaborative studies, seeking research grants and producing outputs directly useful to families.	ChM	Cerebra	£796,303	2014	5 years	UK
The use of portable inertial measurement sensors to measure upper limb function in children with cerebral palsy: A validation and reliability study.	CI	Curtin University	\$8,000 (AUS)	2014	1 year	AUS
Québec Knowledge Translation in Rehabilitation Strategic Initiative	AT, DA, KST	REPAR	\$20,000	2014	1 year	Quebec (McGill)
Optimizing life success through residential immersive life skills programs for youth with disabilities	GK, JWG, DS	SSHRC	\$412,867	2014	4 years	Bloorview
An Exploration of Care Mapping Among Families of Children with Medical Complexity.	EC, SM	Norman Saunders Complex Care Initiative	\$24,515	2014	1 year	Sick Kids
An exploration of care mapping among families of children with medical complexity (CMC).	EC, SM	Associated Medical Services	\$20,000	2014	1 year	Sick Kids
Core set of outcomes for children with severe neuro-disability and gastrostomy tube dependency: A tool of standardized outcomes for clinical research and practice.	EC, SM	Norman Saunders Complex Care Research Grant Competition	\$26,500	2014	1 year	Sick Kids

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
The experience of caregivers of children with medical complexity receiving blenderized tube feeding: a qualitative study.	EC	Norman Saunders Complex Care Research Grant Competition	\$11,730	2014	1 year	Sick Kids
The EXPLORING SLEEP Study: A Study EXPLORING the Experiences and Perceptions of End-Users in the Development of a SLEEP Promoting Intervention among Family Caregivers of Children who Depend on Medical Technology.	EC	Norman Saunders Complex Care Research Grant Competition	\$10,949	2014	1 year	Sick Kids
Thompson family fund raising for pediatric epilepsy research	GR	Thompson Family Fund Raiser	\$50,000	2014	1 year	McMaster
Engagement in the pediatric rehabilitation intervention process: Its nature, measurement, and role in the determination of outcomes	GK, VW, LC	Canadian Institutes of Health Research	\$616,110	2014	5 years	Bloorview
Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families	GK	Institute of Coaching, McLean Hospital, Harvard Medical School Affiliate	\$25,640	2014	1 year	Bloorview
A trial of coaching with children and youth with cerebral palsy focused on enabling participation in recreation and leisure activities	GK	Canadian Occupational Therapy Foundation	\$5,000	2014	1 year	Bloorview
"A scoping review of the role of parental hope in the delivery of pediatric rehabilitation services,"	GK	SSHRC	\$700	2014	1 year	Bloorview
An arts-mediated program for children with and without disabilities: Service providers' use of strategies to create an inclusionary space	GK	Centre for Leadership in Participation and Inclusion with the support of the Holland Bloorview	\$5,000	2014	1 year	Bloorview

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
		Kids Rehabilitation Hospital Foundation				
"Family-oriented services for parents of children and youth with disabilities: A scoping review of programs and services to promote caregiver wellness and optimize children's outcomes,"	GK	Centre for Leadership in Participation and Inclusion with the support of the Holland Bloorview Kids Rehabilitation Hospital Foundation	\$4,500	2014	1 year	Bloorview
"Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences of families and service providers,"	GK	Centre for Leadership in Participation and Inclusion with the support of the Holland Bloorview Kids Rehabilitation Hospital Foundation	\$18,000	2014	1 year	Bloorview
Umbilical cord blood stem cells for treatment of cerebral palsy	IN	Cell Care & Cerebral Palsy Foundation	\$872,351 (AUS)	2014	?	AUS
REACH: Randomised trial of Rehabilitation very EArly in Congenital Hemiplegia	IN	NHMRC Project Funding	\$939,038 (AUS)	2014	?	AUS
Making a difference to families caring for children with neurodevelopmental disorders (NDD)	JWG, DM	NeuroDevNet	\$29,448	2014	6 months	CanChild

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
Transition Research	JWG	OCHSU	\$76,608	2014	2 years	CanChild
Increasing Awareness and Improving Outcomes of Children with Developmental Coordination Disorder in British Columbia	JZ	Michael Smith Foundation for Health Research Scholar Award	\$450,000	2014	5 years	UBC
PROMPT Identification of Cerebral Palsy: Primary-care Referral Of Motor-impaired children: Physician Tools	DF, KST	CIHR	\$330,576	2014	4 years	McGill
Policy court: Where participation and policiies meet at the MALL (Mall as a Living Lab of Rehabilitation)	KST	Centre de Recherche Interdisciplinaire en Réadaptation (CRIR)	\$15,000	2014	6 months	McGill
Understanding Determinants of Participation in Leisure and Recreational Activities by Children with Physical Disabilities	LC	National Science Council of Taiwan	26,100	2014	1 year	Taiwan
Neurological Outcome of Hypoglycemia in Neonatal Encephalopathy	JZ	CIHR	\$703,747	2014	5 years	Sick Kids
Mapping the Brain and Improving Outcomes for Children with Developmental Coordination Disorder	JZ	CCHCSP	\$25,000	2014	5 years	UBC
Disclosing their child's diagnosis of autism spectrum disorder to others: Family processes and perceived outcomes	LZ, SH	Women and Children's Health Research Institute Innovation Grant	\$50,000	2014	2 years	U of Alberta
Improving Social Participation for Children with ASD in Elementary School: Proposal Development	SH, LZ	Alberta Centre for Child, Family & Community Ressearch (ACCFCR)	\$10,000	2014	1 year	U of Alberta
Autism Treatment Network: Edmonton Site	LZ, SH	Autism Speaks	\$420,000 US	2014	3 years	U of Alberta

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
An Exploratory Examination of the Transition to Adulthood in Autism Spectrum Disorder	LZ	Alberta Centre for Child, Family & Community Research (ACCFCR)	\$39,787	2014	1 year	U of Alberta
DJ Fiero	MKet	De Hoogstraat OnderzoeksFonds RevalidatieFonds	3000€ 21000€	2014	6 months	Netherlands
Family Needs	MKet	De Hoogstraat OnderzoeksFonds	3600€	2014	6 months	Netherlands
Impact of pediatric epilepsy surgery on health- related quality of life	MF	CIHR	\$697,290	2014	4 years	Sick Kids
Mental health of children with chronic illness,	MF	Psychiatry and Behavioural Neurosciences, Startup Grant - McMaster	\$60,000	2014	3 years	McMaster
Psychiatric comorbidity in children with chronic illness: A pilot study	MF, JWG	CIHR Hamilton Health Sciences (HHS), Personnel - Career Awards	\$118,656 \$50,000		2 years 1 year	McMaster
Multimorbidity In youth receiving mental health services, Grant, Hamilton Health Sciences, Research - New Project, \$50,000.00	MF, JWG	Hamilton Health Sciences, Research - New Project	\$50,000	2014	2 years	McMaster
Depressive symptoms in youth with physical illness during that transition from adolescence to adulthood, Grant, , \$37,600.00	MF, JWG	Hamilton Health Sciences, Research - New Project	\$37,600	2014	1 year	McMaster
Clinic to community liaison in child epilepsy care: A feasibility study	NF	Ontario Brain Institute	\$250,000	2014	5 years	Western
Functional recovery in critically ill children.	JWG,	HAHSO	\$200,000	2014	2 years	McMaster

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
	NF					
Brock-Niagara Assistive Technology Initiative	SB	Ontario Job Creation Partnership; Ministry of Training, Colleges and Universities	\$2,456	2014	1 year	Brock
The Avon Maitland District School Board Inclusion Coaching Project	SB, KW	Avon Maitland District School Board	\$10,000	2014	1 year	Brock
Evaluation of the effectiveness of robotic gait training and gait-focused physical therapy programs for children with cerebral palsy: A mixed methods RCT	VW, DF, DL	CIHR	\$873,105	2014	5 years	Bloorview
Igniting Fitness Possibilities: An inclusive community-based program for youth with disabilities and typically developing youth.	VW	National Bank Children's Foundation	\$100,000	2014	3 years	Bloorview
Developing and pilot-testing an inclusive recreational sports program for preadolescent children with physical disabilities.	VW	SSHRC	\$74,133	2014	2 years	Bloorview
Igniting Fitness Possibilities: A series of pilot implementations of a community-based inclusive physical activity program for youth	VW	Milos Raonic Foundation; Goodlife Kids Foundation	\$20,000 \$10,000	2014	2 years	Bloorview
Igniting Fitness Possibilities: A pilot study to develop and test the feasibility of a community-based inclusive physical activity program for youth - implementation at University of Toronto Sports Camps	VW	SSHRC	\$75,000	2014	2 years	Bloorview
Igniting Fitness Possibilities: A pilot implementation at Abilities Centre (Whitby) of a community-based inclusive physical activity program for youth	VW	Ontario Sport and Recreation Fund – Ontario Government	\$46,000	2014	1 year	Bloorview

Project Name	CanChild Invest.	Funding Source	Amount	Start Date	Duration	Funding Held At
Igniting Fitness Possibilities: A pilot implementation at Variety Village of a community-based inclusive physical activity program for youth.	VW	Chillin for Kids - Bloorview Childrens Rehabiltation Hospital Foundation	\$58,500	2014	1 year	Bloorview
Development of the Family Needs Assessment Pediatric Version- Phase I for Acquired Brain Injury	VW	Bloorview Childrens Rehabiltation Hospital Foundation	\$6,100	2014	1 year	Bloorview
Exploring a virtual reality based video game with haptic feedback for sensory-motor rehabilitation of young people with cerebral palsy	VW, DF	BRI-CIRRIS	\$22,500	2014	1 year	Bloorview

Total grants funded in 2014 by *CanChild* Scientists, Research Associates or International Collaborators

Total new grant funding in 2014 (*CanChild* member as PI or co-I): 69

\$9,335,299 (CAD); \$420,000(US); \$1,841,389 (AUS); 27,600 (EURO); 796,303 (GBP)

### Current Ongoing Projects Located at CanChild (funded prior to 2014 and ongoing through 2014):

**Fehlings, D**. (Lead), 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., *Childhood Cerebral Palsy Integrated Neuroscience Discovery Network «CP-NET»*. Funded by the Ontario Brain Institute. \$7,500,000. 2013-2018.

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

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. *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, 2013-2018.

**Gorter, J.W**., MacDonald, M., **Timmons, B.**, *Stay-FIT 20-40 years: A cross-sectional study to determine physical activity and cardiovascular health in adults (aged 20-40 years) with cerebral palsy*. Funded by the Ontario Federation for Cerebral Palsy. \$46,134, 2012-2014.

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

McCoy, S., Bartlett, D. (co-PIs), Chiarello, L., Palisano, R., Jeffries, L., Fiss, A., Hanna, S. and Bjornson, K. Developmental Trajectories of Impairments, Health, and Participation of Children with Cerebral Palsy. Funded by Patient-Oriented Outcomes Research Institute (PCORI) contract. \$1,906,955 (direct and indirect; \$1,493,692 direct). 2013 -2016.

**Ronen, G.M. (PI),** Streiner, D.L., **Rosenbaum, P.,** Cunningham, C., Boyle, M., & Lach, L. *Outcome Trajectories in Children with Epilepsy: What Factors are Important? a multi-site longitudinal study.* Funded by CIHR. \$153,497.00 annually. 2008-2014.

**Ronen, G.M. (PI)**, **Timmons, B.**, Bray, S., **Rosenbaum, P.,** & Streiner, D.L. *Enhanced physical activity in children with epilepsy: potential impacts on health, functioning, psychological well being and quality of life*. Funded by Ontario Brain Institute Collective intractable epilepsy research program. \$99,900.00. 2012-2013.

**Rosenbaum, P., DiRezze, B.,** Cooley-Hidecker, M.J., **Law, M.,** Stratford, P., Szatmari, P., & **Zwaigenbaum L**. The development of a functional classification system for preschool aged children with Autism Spectrum Disorder. Funded by Canadian Institutes of Health Research Operating Grant. \$391,601. Apr 2011 – Sept 2014.