

Research Program Report 2014 – 2018



WELCOME TO TVCC'S RESEARCH REPORT

The Thames Valley Children's Centre's (TVCC) Research Program is proud of our continued productivity! This Report illustrates the scientific inquiry that has taken place here at TVCC during the past four years. Summarizing the range and depth of the work done by so many researchers, clients, families, and clinicians is no small task. Capturing the vision of TVCC and its Research Program is simple: Our Clients at Their Best.

At TVCC, we seek to bring understanding, inquiry, and innovation to the work we do with children and youth across Southwestern Ontario. And we also seek to make a difference in the lives of children and families worldwide through our research activities. In this Report, you will find a variety of research inquiries across different clinical areas. We use research to inform our clinical and everyday practice and to help us in our decision-making processes. Our research team is exceptionally productive, supporting front-line clinicians, leadership, and other researchers working with our clients.

We take great pride in the balance we strike between supporting the day-to-day work of TVCC and producing original research of the highest academic standards. Jointly with Western University's Faculty of Health Sciences, we continue to host the popular "Child Health Symposium" annually, bringing together large numbers of students, clinicians, clients, families, and researchers to share information and develop collaborative projects distinguished by high levels of academic and clinical expertise. Please find more details about the symposium inside this Report.

Enjoy reading about our accomplishments thus far, and do not hesitate to contact us for more information if anything sparks your interest. Kathryn Hayman, Research Officer can be contacted at 519-685-8700, or at research@tvcc.on.ca.

Karen Lowry Director, Quality Management

THAMES VALLEY CHILDREN'S CENTRE

TVCC is a regional rehabilitation centre for children and young adults with physical disabilities, communication disorders, developmental delays, and autism spectrum disorders, living primarily in Southwestern Ontario.

We are a community-oriented centre providing assessment, diagnosis, consultation and therapy to help young people reach their potential in terms of independence, self-esteem and participation in society. We serve more than 9,000 children ranging from newborns to young adults, every year.

OUR MISSION:

We will provide rehabilitation services which support participation in all areas of life for children, youth and young adults with physical, communication or developmental needs, and their families, living primarily in Southwestern Ontario by:

- focusing on the strengths of individuals and their families at home, school, workplace and community
- pursuing research, education and advocacy
- partnering in a local and regional system of services

OUR VISION:

Our Clients at Their Best

OUR VALUES:

- We believe people know themselves and their situations best
- We believe people want the best for themselves and others
- We believe people are unique and deserving of respect
- We believe people function best in a supportive environment
- We believe people working in partnership can reach goals that cannot be reached alone

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THE RESEARCH PROGRAM

Research helps determine effective treatment and delivery of services to children with communication, physical, or developmental needs, and their families. It furthers our understanding of childhood disabilities and the issues they raise. Research is a method of:

- asking and answering questions
- uncovering facts and causes
- confirming or disconfirming beliefs
- improving reasoning
- adding to knowledge

According to TVCC's philosophy, research and evaluation activities are an integral part of providing quality services and interventions to clients.

Established in 1988, the Research Program at TVCC provides direct services, consultation, education, and resources to TVCC staff members. The Research Program also engages in research activities with TVCC staff members as well as external researchers. Our clients, their families, and staff members also participate in research.

TVCC's approach to research development is a multi-faceted and needs-based approach, with an emphasis on evaluation activities, where clinicians and researchers partner to evaluate services. Other types of research are also supported, including knowledge generation and sharing activities. The model is based on having staff with a high level of research expertise available to work with leadership and staff from across the Centre.

Thames Valley Children's Centre

Did You Know that the

TVCC Research Program...



has evaluated many of the services provided at TVCC to ensure they are having a real impact on children's lives?

KEY THEME AREAS

The Research Program's two key theme areas are:

- 1. Evaluation of programs, interventions, treatments, and aspects of service delivery
- 2. Investigation of psychosocial aspects of disabilities

KEY GOALS

The four key goals of the research program are:

- To create a strong research climate that promotes TVCC staff members' awareness, enthusiasm, and participation in research and evaluation, and that fosters ongoing critical appraisal
- To provide resources and ongoing, individualized support to TVCC staff members doing research
- To share/disseminate research and evaluation findings internally and externally (e.g., with other children's rehabilitation centres and at professional conferences)
- To develop a reputation for excellence in pediatric rehabilitation research that is an integral part of pediatric services

RESEARCH PROGRAM FUNCTIONS

The Research Program assists staff with research-related and quality assurance activities through direct involvement, consultation, education, and the provision of resources on how to approach all aspects of the research/evaluation process.

DIRECT AND CONSULTATION SERVICES

Services include providing advice on and carrying out all aspects of the research/ evaluation process (e.g., designing a questionnaire, analyzing data, selecting an agency to apply to for funding, selecting a journal for submission of a manuscript, etc.). Networking and collaboration to conduct research studies are encouraged and facilitated with other researchers in London, in Ontario, across Canada, and internationally. In addition to research and evaluation studies, our researchers provide support for many in-house quality assurance activities at the centre.

Examples of Quality Assurance Activities

- Developmental Resources for Infants: Examining family's experiences transitioning to a new agency
- An evaluation of the Autism Service's IBI Pilot Program: An examination of interprofessional collaboration
- Families' perceptions of the value of Getting Started at TVCC Program's written reports

EDUCATION

Information sessions are arranged in which internal and external researchers share the results of research projects and discuss recently published research findings. These sessions encourage awareness, critical evaluation, and utilization of findings from the research literature. They also provide a forum for researchers to maximize the impact of findings on clinical practice by sharing outcomes with staff members from other TVCC programs and also external individuals and collaborators from other agencies.

DISCOVERY SERIES SESSIONS

The "Discovery" sessions provide researchers with a forum to present the results of their research projects to the TVCC staff.

FACTS TO GO PUBLICATION

Facts to Go are one-page information sheets on research topics written by staff members and published and distributed by the Research Program. The goal is to keep families, staff members, and the community updated on recent trends, issues, and future considerations in the area of childhood disability.

LESSONS LEARNED PUBLICATION

At TVCC, staff evaluate their practices, programs, and services to learn about what works best, and to enhance service delivery. As part of TVCC's knowledge transfer strategy, our *Lessons Learned* publication series provides staff an opportunity to communicate their findings, and share their lessons learned.



Did You Know that the

TVCC Research Program...



has involved hundreds of clients and their parents as participants in research studies over the past thirty years?

We help kids be kids!

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RESEARCH PROGRAM TEAM

STAFFING

The Research Program Team includes:

- A Director
- Centre Researchers
- A Research Officer

The Research Program is part of the Quality Management (QM) Program at the Centre and is under the direction of the QM Program Director. The Research staff members are funded through TVCC's Research Trust Fund and the Child Health Foundation. Project coordinators, data analysts, and research assistants are hired on an "as-needed" basis to work on specific projects and are funded by research project grants.

TEAM MEMBERS

Director

Karen Lowry, M.Cl.Sc (2006-present)

The **Director** provides overall direction to the Research Program, is responsible for the administrative aspects of the Program, and engages in research and writing collaborations with internal and external partners.

Centre Researchers

Janette McDougall, Ph.D. (1995-present) Michelle Servais, Ph.D. (2000-present)

Centre Researchers consult with staff doing research and evaluation projects, coordinate and implement research studies, and engage in research collaborations with internal and external partners.

Research Officer

Kathryn Hayman (2009-present)

The **Research Officer** coordinates administrative aspects of the Research Program, organizes the communication of research information, develops resources and information systems, documents and tracks all research activities, and acts as a resource to researchers.

Research Project Coordinators

Nicole Etherington, Ph.D. (2013-2016) Megan Nichols, M.Sc. (2010-present)

Research Project Coordinators are responsible for the day-to-day operations of a research project including: preparation of materials such as study forms, agendas, and minutes; maintenance of study databases; data collection and entry; data management; data analysis and collaboration in writing of articles and presentations.

A LIFE NEEDS MODEL OF SERVICE DELIVERY

In conjunction with others at TVCC, the Research Program has played an instrumental role in the conceptualization of a model of services needed by children with disabilities, their families, and members of the community who play important roles in these children's lives.

According to the Life Needs Model, the spectrum of services offered by TVCC should be based on the needs of children, their families, and communities. We believe that the family has an important impact on a child's development. We also believe that we must directly intervene at the community level to foster positive attitudes, create understandings, and encourage the development of inclusive legislation.

The Life Needs Model encompasses the who, what, where, why, and how of service delivery for children with disabilities. It specifies the major types of needs of clients, families, and community members (the "who"), which we believe should form the basis of the services we provide. The model integrates a family-centred approach to service delivery (the "how") with the idea that services should be structured to meet the recipients' needs (the "what"). It is a developmental model that focuses on key transitions in children's lives (the "when") and is community-based in nature (the "where").

The key aim of the Life Needs Model (the "why") is to support clients' participation in all areas of life, thereby supporting them in "being their best" and being satisfied with their quality of life. The Life Needs Model has promoted a broad understanding of the needs of children and families by providing a visual map of the types of services necessary to achieve community participation and quality of life.



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CHILD HEALTH SYMPOSIUM

On May 22, 2014, the Faculty of Health Sciences at Western University and the TVCC presented the first Child Health Symposium. Since then we have held five Child Health Symposiums alternating venues between Western University and the TVCC. The following were successful one day events that provided an opportunity for researchers, clinicians, and students from all disciplines to:

- Share their knowledge, ideas and best practices for service delivery
- Present current research interests and questions
- Learn more about the child health research happening in our community
- Network and build relationships and collaborations with other professionals working in the area of child health in the community

THEMES AND HIGHLIGHTS

2014 - Collectively Creating Connections and Collaborations: Research and Best Practices in Child Health

The Keynote speaker was **Peter Rosenbaum**, MD, FRCP(C) (Professor of Pediatrics at McMaster University and has held a Tier 1 Canada Research Chair since 2001. Dr. Rosenbaum is also the co-founder of *CanChild* Centre for Childhood Disability Research in 1989 at McMaster University.)

2015 - Connecting with Youth: Research and Best Practices in Child Health

The Keynote speaker was **Irwin Elman** (Ontario's Provincial Advocate for Children and Youth)

2016 - Resilience Building in the Family and Community

The Keynote speaker was Dan Edwards (Motivational Speaker)

2017 - Optimizing Child Health: Address Stress for Success

The Keynote speaker was **J. Bruce Morton**, PhD (Professor, Department of Psychology, Western University Associate Scientist, Children's Health Research Institute)

2018 - The 'P-Words': Play, Physical Activity, People, Participation, and Possibilities

Keynote speaker was **Jan Willem Gorter**, MD, PhD, FRCP(C) (Director and a Scientist at CanChild Centre for Childhood Disability Research; Scotiabank Chair in Child Health Research)

COMMITTEE MEMBERS

A special 'thank you' goes out to the Child Health Symposium Organizing Committee Members! Current Committee Members are *italicized and bold*.

Andrew Johnson^{2,3} 2014-2015 Professor, School of Health Studies

*Carrie Connell*¹ 2014-2018 Education and Program Coordinator

Doreen Bartlett² 2014-2015 Professor, School of Physical Therapy

Gordon MacDonald² 2014-2018 Research Officer, Faculty of Health Sciences Helene Berman^{2,3} 2014-2017

Associate Dean (Research)

Helen Kerr² 2014 Administrative Assistant

Janette McDougall^{1,2} 2014-2018 Researcher

John LaPorta^{1,2} 2014-2018 Chief Executive Officer

Karen Faragher¹ 2018 Recreation Therapist

Karen Lowry^{1,2} 2014-2018 Director of Quality Management

Kathryn Hayman¹ 2014-2016 Research Officer

Kevin Shoemaker² 2018 Associate Dean (Research)

Kimberly Simpson² 2014 **Research Coordinator** Kristen Reilly² 2017 **Graduate Student** Michelle Servais^{1,2,3} 2014-2018 Researcher Nicole Chabot² 2015-2018 Research Coordinator, Faculty of Health Sciences and Research Development and Services Nicole Turner^{1,2} 2015-2018 Youth Engagement Leader; Student Ruth E. Martin² 2014 Professor, School of Communication Science Disorder Shauna Burke² 2014-2018 Assistant Professor, School of Health Studies Sherrilene Classen² 2014

Director, School of Occupational Therapy

Shiela Moodie²

2017-2018 Assistant Professor, School of Communication Sciences and Disorders

Trish Tucker² 2014-2018 Assistant Professor, School of Occupational Therapy

Thames Valley Children's Centre¹; Western University²; CHS Organizing Co-Chairs³

RESEARCH PROJECT APPROVAL PROCESS

At TVCC, all internal and external research projects involving TVCC clients and/or their families and requiring informed consent must be approved by:

- A university ethics review committee
- TVCC's Research Advisory Committee

TVCC has guidelines regarding: collaborative endeavours between outside investigators and TVCC staff members, the approval process for proposals originating within the Centre, and the approval process for proposals from outside the Centre that involve TVCC clients and their families.

Guidelines also exist to ensure client confidentiality in research studies and to ensure that TVCC staff members make the initial contact with parents and clients when their participation is sought in a research study.

The approval process ensures that the proposed research fits with TVCC's Vision and Mission. It also ensures that the many ongoing projects at the Centre do not burden the clients/ participants and that the investigator has received agreement/approval from the appropriate TVCC Program Director. Outside investigators also require the cooperation of a Centre staff member as a Research Contact.

Investigators are required to complete TVCC's form "Application for Approval of a Research Study." Approximately every two months, TVCC's Research Advisory Committee reviews the proposals and decides whether to approve them.

RESEARCH ADVISORY COMMITTEE

The Research Advisory Committee (RAC) was established in 1988 to review and approve protocols for all internal and external research studies involving TVCC clients and/or their families. The Committee also acts as a resource with respect to the strategic direction of the Research Program.

The RAC ensures that all research projects meet the criteria for project approval before being allowed to approach TVCC clients through the Research Contact.

The Committee consists of a minimum of five members:

- A TVCC researcher (Chair)
- TVCC's medical director
- A TVCC medical consultant
- Faculty members from the Western University
- Members of a rehabilitation discipline

RESEARCH ADVISORY COMMITTEE 2014-2018

Dr. Laura Brunton (*Member: 2018-present*) Assistant Professor School of Physical Therapy

Western University

Dr. Megan Cashin (*Member*: 2014-present) Paediatric Orthopaedic Surgeon Children's Hospital, London Health Sciences Centre

Dr. Allyson Page (Dykstra) (*Member: 2012-2016*) Associate Professor

School of Communication Sciences and Disorders Western University

Dr. **Pamela Frid** (*Member: 2003-present*) Medical Director Thames Valley Children's Centre

Dr. Waleed Kishta (*Member: 2016-2017*) Paediatric Orthopaedic Surgeon Children's Hospital, London Health Sciences Centre

Dr. Janette McDougall (Chair: 2005-present) Researcher, Research Program Thames Valley Children's Centre

Dr. Michael Miller (*Member: 2016-present*) Research Associate London Health Sciences Centre

Dr. Jamie Seabrook (*Member: 2014-2017*) Associate Professor Brescia University College

Dr. Trish Tucker (*Member: 2011-2018*) Assistant Professor School of Occupational Therapy Western University

Thank You! We would like to acknowledge the contributions of the many individuals who make sure that research at TVCC is meaningful and of high quality. Sincere thanks are extended to the investigators on staff, clients and families, our collaborators, the TVCC Board of Directors, and the Research Advisory Committee.

We help kids be kids!

PROJECTS APPROVED BY RAC

The following **26** studies were reviewed by the Research Advisory Committee and were approved to proceed. Current TVCC staff members are *italicized* and **bolded**. Former TVCC staff are *italicized* only.

DECEMBER 2014

- Parents' experiences and perceptions when classifying their children with cerebral palsy: Advice for service providers (Natalie Scime, Doreen Bartlett, Robert Palisano, Laura Brunton).
- A Phase 3, randomized, double-blind, sham-procedure controlled study to assess the clinical efficacy and safety of ISIS 396443 administered intrathecally in patients with later-onset spinal muscular atrophy (Craig Campbell, Sharan Goobie).
- A Phase 2 randomized, double-blind, placebo-controlled, multiple ascending dose study to evaluate the safety, efficacy, pharmacokinetics and pharmacodynamics of PF-06252616 in ambulatory boys with Duchenne muscular dystrophy (Craig Campbell, Cam-Tu Nguyen).

FEBRUARY 2015

The electronic monitoring of environmental triggers of unwanted behaviours (Cathy Chovaz, Ken McIsaac, Robert Nowosielski, Katie Hart).

MARCH 2015

- Optimizing life success through residential immersive life skills programs for youth with disabilities (*Gillian King*, Amy McPherson, Shauna Kingsnorth, Jan Willem Gorter).
- Infant and child feeding resource needs assessment (Colleen O'Connor, Janet Madill, Cathy Verkley, Susan Bird).

MAY 2015

Numerical cognition in children with and without cerebral palsy (Daniel Ansari, *Pamela Frid*, Craig Campbell).

FEBRUARY 2016

Managing persistent concussion symptoms in children and youth: A multidisciplinary approach to a multifaceted problem-revisiting a chart review (*Sara Somers, Janice Gray, Mary Ellen Kendall, Janette McDougall, Pamela Frid, Stacy McDougall*).

The teen quality of life survey (T-QOL): Developing a brief questionnaire for adolescents (*Janette McDougall*).

JUNE 2016

- How do individuals with cerebral palsy and their families prefer to receive and use evidencebased information to individualize services to optimize outcomes? (Tianna Deluzio, Doreen Bartlett, Alisiyay Daya, Deb Lucy).
- On with the show: Exploring participation experiences of young people with and without disabilities (*Beata Batorowicz*, *Gill Steckle*, *Kelli Vessoyan*).

DECEMBER 2016

- Trial readiness and endpoints assessment in congenital myotonic dystrophy (TREAT-CDM) (Craig Campbell, Eugenio Zapata, Delia Ceballos).
- A double-blind, placebo-controlled, multicentre study with an open-label extension to evaluate the efficacy and safety of SRP-4045 and SRP-4053 in patients with Duchenne muscular dystrophy (Craig Campbell, Eugenio Zapata).
- A phase 1b/2 randomized, double-blind, placebo-controlled study of ACE-083 in patients with facioscapulohumeral muscular dystrophy (FSHD) (Craig Campbell, Eugenio Zapata, Delia Ceballos). A two part seamless, open-label, multicenter study to investigate the safety, tolerability, pharmacokinetics, pharmacodynamics and efficacy of Ro7034067 in infants with type1 spinal muscular atrophy (Craig Campbell, Eugenio Zapata).
- A two-part seamless, multi-centre randomized, placebo-controlled, double-blind study to investigate the safety, tolerability, pharmacokinetics, pharmacodynamics and efficacy of Ro7034067 in type2 and 3 spinal muscular atrophy patients (Craig Campbell, Eugenio Zapata).
- A phase 2, double-blind, randomized, placebo-controlled, multiple dose study of CK-2127107 in two ascending dose cohorts of patients with spinal muscular atrophy (SMA) (Craig Campbell, Eugenio Zapata, Christine Shoesmith).

APRIL 2017

A randomized, double blind, placebo-controlled study to assess the efficacy, safety, and tolerability of BMS-986089 in ambulatory boys with Duchenne muscular dystrophy (Craig Campbell, Eugenio Zapata).

OCTOBER 2017

Engagement in the pediatric rehabilitation intervention process: Its nature, measurement, and role in the determination of outcomes (*Gillian King*, Virginia Wright, Jenny Ziviani, Lisa Chiarello, Heidi Schwellnus, Roger Ideishi, Matthew McLarnon).

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DECEMBER 2017

- Children and teens in charge of their health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities (Amy McPherson, Elaine Biddiss, Paige Church, *Gillian King*, Desiree Maltais, Chantal Merette, Helene Moffet, Fiona Moola, Heidi Schwellnus).
- Constructing and validating the interRAI 0-3 for the developmental and mental health needs of children and families (Shannon Stewart, Sarah Cloutier, Jo Ann Iantosca).

FEBRUARY 2018

- A phase 3, randomized, double-blind, placebo-controlled efficacy and safety study of Ataluren in patients with nonsense mutation Duchenne muscular dystrophy and open-label extension (Craig Campbell, Eugenio Zapata, Salma Remtulla).
- A randomized, double-blind study to evaluate the efficacy and safety to Tideglusib versus placebo for the treatment of children and adolescents with congenital myotonic dystrophy (Craig Campbell, Eugenio Zapata, Salma Remtulla).
- The facilitators and barriers of physical activity engagement for youth and young adults with childhood onset physical disabilities (Joy MacDermid, *Janette McDougall*, Matt Downs).

JUNE 2018

- Determining the natural course of fatigue in children and adolescents with cerebral palsy (Laura Brunton, Elizabeth Condliffe).
- Health concerns of adolescents and adults with childhood onset physical disability (Caitlin Cassidy, Laura Brunton).

PROJECTS

There were **46 research projects** that involved TVCC clients, their families, and TVCC staff members as participants underway between **1 April 2014 and 30 September 2018** that went through a formal ethics review process. The studies are separated into two categories: Internal Projects and External Projects.

Internal Projects are those projects on which TVCC staff members were involved as principal investigators or co-investigators.

External Projects are those projects that only have external researchers and did not have any TVCC staff members as investigators.

INTERNAL PROJECTS

The following is a list of the **21** internal research projects underway between 1 April 2014 and 30 September 2018 that involved TVCC staff members as named investigators.

- Names of current TVCC staff members are *italicized and bolded*.
- Names of former TVCC staff members are *italicized* only.

1. The impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions

 Investigators: Janette McDougall^{1,2}, Virginia Wright³, & Linda Miller²
 Affiliations: Thames Valley Children's Centre¹, Western University², Bloorview Research Institute³

Status: Completed, 2009-2018 **Funding**: Canadian Institutes of Health Research (\$742,340)

It is critical for clients, service providers, and policy makers to understand the key factors influencing changes in life quality for children and youth with chronic conditions. This five-year study examined changes in QOL for youth with chronic conditions. It included a gualitative and guantitative component. The guantitative component addressed two unexplored research areas: 1) the nature (trajectories) of QOL for youth with chronic conditions over a three-year period, and 2) the factors that influence QOL over time for these youth. Four hundred and thirty-nine youth aged 11 to 17 years (and one of their primary caregivers) who received services from eight children's treatment centres participated. Participants were assessed at four time points. Two QOL trajectories were found for youth: high and stable (86%) and low and stable (14%), while three trajectories were identified for parents: high and stable (37%), moderate and stable (46%), and low and stable (17%). Relative to the high and stable trajectory group, being classified to the moderate or low and stable groups was predicted by: emotional symptoms, pain, youth self-determination, youth spirituality, school productivity, family social support for youth, family functioning, and home/community barriers. For the qualitative component of the study individual interviews, followed by a focus group, were conducted with 18 youth. The factors that youth identified in the qualitative part of this project as being important to their QOL were mirrored by those factors found to be related to QOL in the quantitative part of the project. Findings suggest youth experience stable global perceived QOL across time, but some individuals maintain stability at lower than ideal levels which is related to ongoing personal and environmental influences. Universal programs to safeguard resilience for all youth and targeted programs to enhance certain youths' global perceived QOL are warranted.

2. Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem

Investigators: *Sara Somers* & *Janice Gray* Affiliation: Thames Valley Children's Centre Status: Completed, 2010-2014

Program staff members were interested in identifying possible trends in the demographics of referrals to the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). An additional objective was to look for possible complex concussion profiles in an effort to explore factors that may be related to concussion recovery. A retrospective chart review was conducted of all concussion referrals received by the program over two years to obtain demographic data (i.e., age, gender), as well as

information regarding number and duration of symptoms reported. The chart review identified that 65 (47%) of the 139 referrals to PABICOP over the past two years were diagnosed as concussion. Youth in the 13–18 year old age group were at highest risk for sustaining concussion and for having ongoing and complex sequelae. Furthermore, despite more males than females sustaining concussions in all age groups, ongoing and complex sequelae were more prominent among females than males in the 13–18 year old age group. Understanding trends in the data allows program staff members to provide a more targeted proactive multidisciplinary approach to educating and supporting children and youth, and their families, schools, and communities toward alleviating stress and other difficulties associated with recovery from concussion.

3. Myoblast transplantation in Duchenne and Becker muscular dystrophy patients

Investigators: Craig Campbell¹, Shannon Venance¹, Guido Filler¹, Daniel Skuk², *Cheryl Scholtes*³, & Rhiannon Taranik¹, Ashrafunissa Janmohammad¹, *Linda Bolack*³, Jacques Tremblay², Jack Puymirat²

Affiliations: Children's Hospital London Health Sciences Centre¹, University of Laval², Thames Valley Children's Centre³

Status: Underway, Started-2010

Funding: Jesse's Journey, Canadian Institutes of Health Research (\$540,000)

At the molecular level, Duchenne and Beckers muscular dystrophy (DMD and BMD) are caused by a severe deficiency of dystrophin. Dystrophin deficiency causes skeletal muscle degeneration that is clinically expressed by a progressive generalized paresis in childhood, leading to paralysis in the adolescence and death around the age of 25 years. In this study, participants with Duchenne and Becker muscular dystrophy will be injected with donor myoblast cells in a single skeletal muscle to evaluate the safety and efficiency of myoblast transplantation to increase muscle strength and dystrophin protein expression under immunosuppression using Tacrolimus.

4. An open-label extension study of the long-term safety, tolerability, and efficacy of Disaperson in Canadian and US subjects with Duchenne muscular dystrophy

Investigators: Craig Campbell¹, Sharan Goobie¹, *Cheryl Scholtes²*, *Wendy McDonald*², & Rhiannon Taranik¹

Affiliation: Children's Hospital London Health Sciences Centre¹, Thames Valley Children's Centre²

Status: Closed, 2010-2016

Funding: Glaxo-Smith Kline (\$197,100)

Participants with Duchenne muscular dystrophy received subcutaneous injections of Antisense oligonucleotide (AON)-induced exon skipping drug. This study was being done to assess the safety and efficacy of GSK2402968 versus placebo. This exon-skipping drug was to work at the DNA level to allow restoration of the mutated dystrophin reading frame, producing dystrophin synthesis, and was to hopefully convert severe DMD into a milder BMD phenotype. The patients are now getting this drug as part of the special access program.

5. Duchenne muscular dystrophy: Double-blind randomized trial to find optimum steroid regimen

Investigators: Craig Campbell¹, Ashrafunissa Janmohammad¹, Rhiannon Hicks¹, *Cheryl Scholtes*², Teresa Rooney¹, & Lisa Coutu¹

Affiliations: Children's Hospital London Health Sciences Centre¹, Thames Valley Children's Centre²

Status: Completed, 2012-2018

Funding: National Institutes of Health (\$3,393,979)

Duchenne muscular dystrophy (DMD) is the most common childhood muscular dystrophy with a birth incidence worldwide of 1 in 3,500 live male births. It is an X-linked recessive disorder, affecting almost exclusively boys. Corticosteroid therapy has demonstrated the ability to increase muscle strength in boys with DMD, slowing the progression of the disease, and allowing boys to maintain ambulation longer than those not receiving corticosteroid treatment. Although accepted as standard of care there is great variation among prescribing physicians regarding dose, frequency and which steroid is prescribed. This study compared 3 steroid regimens for 3 years to establish which steroid regimen had the best results, while minimizing the undesirable side effects that are common with corticosteroid use. The age range for this study of 4-7 reflected the population for which advice on corticosteroid treatment is of maximal clinical relevance.

6. Childhood hemiplegic cerebral palsy integrated neuroscience discovery network "CP-NET"

Investigators: Craig Campbell¹, Ravi Menon², Darcy Fehlings³, *Pamela Frid*^{2,4}, *Jennifer McLean*⁴, *Jacqueline Ogilvie*^{1,4}, & Rhiannon Hicks¹

Affiliations: Children's Hospital London Health Sciences Centre¹, Western University², Holland Bloorview Kids Rehabilitation Hospital³, Thames Valley Children's Centre⁴ Status: Underway, Started-2012

Funding: Ontario Brain Institute (\$1,500,000)

Participants with hemiplegic cerebral palsy (CP) will be assessed under four experimental platforms. General information will be gathered from neonatal, obstetrical, and health records. Brain scans will be reviewed to identify when/how cerebral injuries occurred. This information will be paired with the patient's developmental profile and genetic markers to better understand the associations between cerebral lesions, risk factors and developmental patterns. The experimental testing of constraint induced movement therapy in two groups of children will be assessed with the novel use of functional MRI. This enables treatment strategies to be matched to patterns of brain injury, and allows effective treatments to be started at appropriate stages of development to improve functioning. This study aims to generate a registry of health information of patients with hemiplegic CP in order to improve the understanding of CP and accelerate the development of new treatment strategies. The ultimate goal is to improve the lives of children with hemiplegic CP and their families.

7. A phase 3 efficacy and safety study of Ataluren (PTC124) in patients with nonsense mutation dystrophinopathy

Investigators: Craig Campbell¹, Sabeeh Alvi¹, Ashrafunissa Janmohammad¹, Rhiannon Hicks¹, *Cheryl Scholtes*², & *Wendy McDonald*²

Affiliations: Children's Hospital London Health Sciences Centre¹, Thames Valley Children's Centre²
 Status: Underway, Start-2013

Funding: PTC Therapeutics (\$8,573/client)

Duchenne muscular dystrophy (DMD) causes muscle degeneration in boys leading to the loss of ambulation as well as a decline in cardiac and respiratory function. There is currently no cure for boys with DMD, only therapies to slow the progression of the disease such as corticosteroids. This study aims to evaluate the safety and efficacy of Ataluren PTC124. Boys with DMD have a mutation in the dystrophin protein causing them to produce incomplete dystrophin proteins. Ataluren is a drug that promotes read through of nonsense mutations, which restores a full length dystrophin protein, which theoretically should improve the muscle physiology and ultimately the strength of boys with DMD.

8. Development of a listening skill simulation intervention for pediatric rehabilitation therapists

Investigators: *Gillian King*^{1,2,3}, *Michelle Servais*^{4.5}, *Tracy Shepherd*^{1,4,6}, Sheila Moodie⁵, *Patricia Baldwin*⁴, Colleen Willoughby⁴, *Linda Bolack*⁴, & Deborah Strachan⁷, & Kathryn Parker¹

 Affiliations: Holland Bloorview Kids Rehabilitation Hospital¹, Bloorview Research Institute², University of Toronto³, Thames Valley Children's Centre⁴, Western University⁵, Centralized Equipment Pool⁶, Independent Consultant⁷

Status: Completed, 2013-2018

Funding: Ontario Simulation Network's Research & Innovation (\$24,855)

Listening and communication skills are core competency areas for all health professionals. Being able to listen mindfully, sensitively and with authentic intent enables health care providers to understand clients' worldviews, needs, priorities, concerns and hopes; thus establishing a common ground that assists clients in making informed decisions and moving forward. Although pediatric rehabilitation therapists' listening skills are essential to children's and parent's satisfaction with services, and the quality of children's outcomes, few simulation interventions have targeted training of listening skills in rehabilitation. This mixed-methods pilot study focused on (1) developing a DVD of simulated therapist-client interactions exemplifying problematic listening-related situations in the pediatric intervention context, and (2) conducted a pilot study using these simulations in a comprehensive, state-of-the-art educational intervention that included repeated exposure to a series of listening skill simulations, guided debriefing in interprofessional discussion groups, and individualized coaching designed to enhance the listening skills of practicing clinicians and move these skills into practice. The outcomes of

the present project also included the development of a series of listening skill simulations and videos ready for dissemination and use in educational interventions. The intervention was found to significantly impact clinicians' listening behaviours. Participants unanimously agreed that the intervention was intense, challenging, valuable, and a highly impactful learning experience that resulted in immediate changes to their clinical and interprofessional practice.

9. A randomized, double-blind, placebo-controlled, phase 3 trial of Tadalafil for Duchenne muscular dystrophy

Investigators: Craig Campbell¹, Sabeeh Alvi¹, Ashrafunissa Janmohammad¹, Rhiannon Hicks¹, Theresa Rooney¹, *Cheryl Scholtes*², & *Wendy McDonald*²

Affiliations: Children's Hospital London Health Sciences Centre¹, Thames Valley Children's Centre²
 Status: Completed, 2013-2016

Funding: Eli Lilly (\$18,443/client)

This was a phase 3, global, multicentre, randomized, double-blind, placebo-controlled, parallel, 3-arm study to determine the efficacy and safety of Tadalafil once daily in boys with DMD who are already receiving treatment with corticosteroids. DMD is a muscular dystrophy that causes muscle degeneration in boys leading to the loss of ambulation as well as a decline in cardiac and respiratory function. There is currently no cure for boys with DMD, only therapies to slow the progression of the disease such as corticosteroids. This study aimed to evaluate the safety and efficacy of Tadalafil and the ability to lessen the decline in ambulation ability.

10. Toward improvement of augmentative and alternative communication services for young people with complex communication needs

Investigators: Steve Ryan^{1,2,3}, Kim Bradley¹, Michael Hillmer⁴, Shauna Kingsnorth¹, *Carrie Laskey*⁵, Anne Marie Renzoni¹, *Michelle Servais*⁵, *Tracy Shepherd*^{1,5}, & Karen Ward¹
 Affiliations: Holland Bloorview Kids Rehabilitation Hospital¹, Bloorview Research Institute², University of Toronto³, Ontario Ministry of Health and Long-Term Care⁴,

Thames Valley Children's Centre⁵

Status: Completed, 2013-2017

Funding: Canadian Institutes of Health Research (\$181,682)

Few parent-report measures exist that are designed to detect AAC outcomes in young people with complex communication needs. The alliance of researchers and clinicians developed and tested a health measurement scale for parents called the Family Impact of Assistive Technology Scale for Augmentative communication (FIATS-AAC). The purpose of the questionnaire is to detect the effect of communication interventions on the lives of children and their families. In all, 45 parents completed the FIATS-AAC questionnaire twice before and twice after their child received a new communication device. Children and youth were aged 3 to 16 years (76% were male) and mostly context-dependent communicators. Primary diagnoses included autism spectrum disorder, cerebral palsy, developmental delay, other genetic syndromes, and acquired

brain injury. Eighty percent of the children received their first high-tech device; whereas, the others received a replacement high-tech device for the study intervention. Most children (78%) were context-dependent communicators and most (93%) accessed their device by direct selection. The study showed that the FIATS-AAC questionnaire is reliable and can detect functional changes in children and youth and their families after receiving a graphic-based speech-generating device.

11. Childhood cerebral palsy integrated neuroscience discovery network CP-NET

Investigators: Craig Campbell¹, *Pamela Frid*², & Jennifer McLean¹
 Affiliation: Children's Hospital London Health Sciences Centre¹, Thames Valley Children's Centre²
 Status: Underway, Started-2012
 Funding: Ontario Brain Institute (\$384,615)

CP-NET is creating a population-based database of cerebral palsy (CP) that integrates detailed information about risk factors, neuropathology, neurodevelopmental and psychosocial status and genomics. CP-NET is recruiting a population-based cohort of children with CP born after Jan. 1, 2009 from 8 children's treatment centres across Ontario. Data is being gathered initially at baseline, confirmed at 5 years of age, and additional data is being collected again when the child is 7 years of age (if applicable). The core element of CP-NET is the Clinical Database Platform consisting of five clinical database platforms. Neuroimaging exams that have previously been done for clinical purposes are being obtained, read, coded, and analyzed to create the Neuroimaging Platform. Saliva samples are being obtained and DNA stored for the creation of the Genomic Platform. Standardized developmental outcome measures including a neurological exam, identification of co-morbidities, cognitive profile, pain assessment, and gross motor, fine motor, and communication classifications are being administered to create the Neurodevelopmental Platform. Finally, assessment of mental health, sleep, quality of life and participation comprises the Psychosocial & Participation Platform.

12. Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families and rehabilitation practitioners

 Investigators: Gillian King^{1,2,3}, Heidi Schwellnus¹, Michelle Servais^{4,5}, & Patricia Baldwin⁴
 Affiliations: Holland Bloorview Kids Rehabilitation Hospital¹, Bloorview Research Institute², University of Toronto³, Thames Valley Children's Centre⁴, Western University⁵

Status: Completed, 2014-2017

Funding: Institute of Coaching at McLean Hospital, Harvard Medical School Affiliate (\$26,930); and Holland Bloorview Centre for Leadership, Participation & Inclusion (\$18,000)

The use of coaching within pediatric rehabilitation is growing. Coaching is a goaloriented way to work with families. Solution-Focused Coaching (SFC) is a form of coaching that highlights family's strengths and their solutions for their situation. There is

little research on how SFC works with families and clinicians in pediatric rehabilitation. In the first part of this qualitative study, we investigated the benefits and impacts of using a Solution-Focused Coaching in pediatric rehabilitation (SFC-peds) approach from a therapists' perspective. We conducted interviews with 6 experienced clinicians who used the SFC-peds approach in their clinical practice (these service providers had a minimum of 20 hours of SFC-peds training and had used SFC-peds approach for a minimum of 3 years). The key themes that emerged from this study, focusing on clinicians' perceived impacts on their: a) clinical practice, b) attitudes, and c) clients and families. Clinicians reported that their practice was more responsive to clients/families (e.g., followed families' priorities, changed their pacing, and improved collaboration, communication, and quality of interactions). Clinicians said they had developed greater trust in the clients'/familys' abilities and reported a greater sense of freedom in their role (e.g., not needing to be the expert/"liberating"). Finally, clinicians described families as less-stressed and more engaged, empowered, and hopeful about their future. In the second part of this study, we asked youth and family who worked with the participating therapists about their experiences and outcomes of the SFC-peds Model. Semi-structured interviews were conducted at two time points (5 months apart) with 9 sets of families (11 participants included 7 mothers, 1 father, 2 youths, and 1 grandmother) who had received SFC-peds intervention within the past 6 months. There were 5 female and 4 male clients, ranging in age from 3 to 21 years, with 4 receiving physical therapy and 5 receiving occupational therapy. Clients had a range of disabilities, including developmental delay, epilepsy, Autism, Cerebral Palsy, and Fetal Alcohol Spectrum Disorder. A thematic analysis was conducted on the interview transcripts. Families confirmed that SFC-peds was a very positive therapy experience for families. Families felt supported emotionally, cognitively, and instrumentally by the therapist. Families reported that the strength-based and solution-focused approached enhanced: child and parent skill development, parent knowledge of their child and options going forward, capacity, community participation, and led to empowered mindsets. The SFCpeds intervention was experienced as client-driven and highly responsive to youths' and families' experiences in real-life situations. The co-construction of meaningful and realistic plans and goals, where goal attainment was celebrated, was experienced as a highly collaborative and goal-oriented process, that led to high levels of client engagement in therapy.

We help kids be kids!

TVCC Research Program Report 2014-2018 Research Program | 519-685-8700 ext. 53405 TVCC 2018 © | This document may be copied with credit and without changes 13. Can eye-tracking technology help girls with Rett syndrome meet individualized goals for communication?

Investigators: Janette McDougall^{1,2}, Victoria Mok^{2,3}, Barb Easton¹, Gill Steckle¹, Kelli Vessoyan¹, & Carrie Laskey¹

Affiliations: Thames Valley Children's Centre London¹, Western University², Children's Hospital London Health Sciences Centre³

Status: Completed, 2014-2017

Studies have investigated the use of eye-tracking technology to assess cognition in individuals with Rett syndrome, but few have looked at this access method for communication for this group. Loss of speech, decreased hand use, and severe motor apraxia significantly impact functional communication for this population. Eye gaze is one modality that may be used successfully by individuals with Rett syndrome. This multiple case study explored whether using eye-tracking technology, with ongoing support from a team of augmentative and alternative communication (AAC) therapists, could help four participants with Rett syndrome meet individualized communication goals. Two secondary objectives were to examine parents' perspectives on (a) the psychosocial impact of their child's use of the technology, and (b) satisfaction with using the technology. All four participants were rated by the treating therapists to have made improvement on their goals. According to both quantitative findings and descriptive information, eye-tracking technology was viewed by parents as contributing to participants' improved psychosocial functioning. Parents reported being highly satisfied with both the device and the clinical services received. This study provides initial evidence that eye-tracking may be perceived as a worthwhile and potentially satisfactory technology to support individuals with Rett syndrome to meet individualized communication goals. Future, more rigorous research that addresses the limitations of a case study design is required to substantiate study findings.

14. Numerical cognition in children with and without cerebral palsy

Investigators: Pamela Frid^{1,3}, Craig Campbell², & Celia Goffin³
 Affiliations: Thames Valley Children's Centre¹, Children's Hospital London Health Sciences Centre², Western University³
 Status: Closed, 2015-2017
 Funding: Ontario Brain Institute (\$48,106)

This study was to investigate the numerical and mathematical skills of children diagnosed with cerebral palsy (CP), and how differences in these constructs related to brain structure and function. A group of children ages 10-16 diagnosed with CP and an age-matched non-CP control group were to take part in several sessions. In session one, a physician was to assess various aspects of functioning in the children diagnosed with CP. Session two was to include the behavioural testing of the cognitive skills of both groups, an MRI was to be done at the final session where anatomical and functional data was to be collected. It was closed due to the fact of the inability to establish a transparent and efficient recruiting strategy with TVCC, making it apparent that the project would not be concluded in the time remaining.

15. The teen quality of life survey (T-QOL): Developing a brief questionnaire for adolescents

Investigator: Janette McDougall

Affiliation: Thames Valley Children's Centre, Western University Status: Completed, 2016-2017 Funding: Thames Valley Children's Centre (\$2,000)

The purpose of this pilot study was to develop a brief quality of life (QOL) questionnaire for use with adolescents with chronic health conditions aged 13 to 19 years. This pilot study was the initial stage in the development of this tool. The face and content validity of a draft questionnaire was assessed, and recommendations for improving the draft were obtained. The draft questionnaire was developed based on a body of research conducted by the Principal Investigator and others. Face and content validity were assessed in two ways: 1) through two focus groups, one with youth with chronic conditions and one with rehabilitation clinicians; and 2) through a mail-out process to youth with chronic conditions. Through both the focus groups and the mail-out, participants provided feedback on survey content. The pilot study developed the questionnaire to the point that a follow-up study can take place where the test-retest reliability, internal consistency, construct validity, and factor structure of the measure can be assessed.



Did You Know that the TVCC Research Program...



has done studies to understand the factors that influence social participation, life satisfaction, and quality of life for children and youth who receive rehabilitation services?

16. Children's outdoor play experiences: Why they play and how they benefit

Investigators: Tara Elton-Marshall^{1, 2, 3, 4}, Sharon Bernard¹, Janet Loebach¹, Jason Gilliland³, Julie George¹, Guy Faulkner⁵, Sarah Folino⁶, Caroline Fusco⁴, Scott Leatherdale², *Janette McDougall*^{3, 7}, Catherine O'Brien⁸, Terry Spencer⁹, Meghan Lynch⁴, & Samantha Wells¹

Affiliations: Centre for Addiction and Mental Health¹, University of Waterloo², Western University³, University of Toronto⁴, University of British Columbia⁵, Thames Valley District School Board⁶, Thames Valley Children's Centre⁷, Cape Breton University⁸, London District Catholic School Board⁹

Status: Underway, Started-2016 Funding: Lawson Foundation (\$100,000)

Canada and other western nations have experienced a steady decline in children's outdoor play. This decline has been attributed to broad societal changes including fewer pedestrian-friendly urban environments supporting children's outdoor activities (e.g., green spaces), technological advancements (e.g., computers) encouraging greater indoor sedentary activity, growing concerns over children's safety, and a shift toward increased participation in structured adult-supervised activities. Scientists are discovering that children who engage in outdoor play are more physically active, have fewer physical health problems (e.g., obesity), and enjoy better mental health. However, evidence to support effective interventions may be incomplete due to a failure to examine multiple determinants of children's outdoor play, over- reliance on adult opinion to define outdoor play and the factors that shape it, an absence of research clarifying how outdoor play leads to better health, and lack of knowledge of the factors influencing outdoor play for ethnic minority children whose access to play may be most restricted. To address these shortfalls, this study will adopt a mixed methods approach combining qualitative and quantitative data from community stakeholders and 6-8th grade children in London, Ontario schools. Objectives will: 1) identify key determinants of outdoor play based on child, parent, and community expert reports and objective environmental indicators; 2) explore mechanisms linking increased outdoor play to children's health; and 3) assess factors shaping outdoor play and its possible health benefits for ethnic minority children. Results will be shared with community stakeholders and scientists and ultimately guide the development of effective interventions.

17. On with the show: Exploring participation experiences of young people with and without disabilities

Investigators: Beata Batorowicz, Gill Steckle, & Kelli Vessoyan Affiliation: Thames Valley Children's Centre Status: Completed, 2016-2018 Funding: Thames Valley Children's Centre (\$3,000)

The importance of inclusive community-based programs for children with disabilities has been widely recognized, yet we still know little about the experiences of children who participate in such programs. The purpose of this study was to explore the experiences of children who participate in a week long community-based theatre camp and to link those experiences to opportunities offered by this setting. Experiences were evaluated using the Self-reported Experiences of Activity Setting (SEAS) and opportunities using the Measure of Environmental Qualities of Activity Settings (MEQAS). This study provided insights into designing programs geared towards particular developmental and health benefits.

18. The facilitators and barriers of physical activity engagement for youth and young adults with childhood-onset physical disabilities

Investigators: Joy MacDermid^{1,3}, Janette McDougall^{2,3}, & Matt Downs³
Affiliations: St. Joseph's Health Care¹, Thames Valley Children's Centre², Western University³

Status: Underway, Started-2018

This research project will attempt to identify the motivators, experiences and challenges of participation in physical activity for youth and young adults with childhood-onset physical disabilities. By conducting focus groups with both participants of recreational and exercise programs at Thames Valley Children's Centre (TVCC) and a group of clinicians from TVCC, this study seeks to identify the facilitators and the potential barriers youth and young adults (aged 12-25 years) with childhood-onset physical disabilities may experience when attempting to engage in physical activity. This study is also interested in determining if participants enrolled in physical activity programs at TVCC are motivated to continue with an active lifestyle after they are no longer eligible to participants think that ongoing physical activity will benefit youth and young adults with childhood-onset physical disabilities in the future. Findings can help improve the development of inclusive physical activity programs for individuals with childhood-onset physical disabilities both before and after transition to adult health services.

19. Managing persistent concussion symptoms in children and youth: A multidisciplinary approach to a multifaceted problem: revisiting a chart review

Investigators: Sara Somers¹, Janice Gray¹, Mary Ellen Kendall¹, Janette McDougall^{1,2}, Pamela Frid^{1,2}, & Stacy McDougall¹

Affiliation: Thames Valley Children's Centre¹, Western University² **Status**: Underway, Started-2016

The Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) implements a multidisciplinary approach to support the physical, educational, and psychosocial needs of children and their families. With increased awareness of the complexity of concussion management particularly in those with persistent symptoms, PABICOP has tracked referral trends over six years. A six-year retrospective chart review is being conducted to explore the trends in concussion referrals to the PABICOP. Of particular interest is the prevalence of recovery modifiers (e.g., gender, pre-existing mental health, family stress, anxiety, learning and developmental issues, and migraines/headaches). Data will be extracted from patient files. The results of this study will be used to enhance service delivery to this client group and to increase awareness and education regarding the sequelae of acquired brain injury in children and youth.

20. Capturing the experiences of sport-related concussions

Investigators: Andrew Johnson¹, *Janette McDougall*^{1,2}, & Annalise Tichenoff¹ Affiliations: Western University¹, Thames Valley Children's Centre² Status: Underway, Started-2014

Clinical treatments for concussion typically focus on "waiting" for symptoms to subside before resuming athletic (return to play; RTP) or academic (return to learn; RTL) activity. The goal of RTP and RTL protocols is to facilitate recovery by avoiding cognitive, physical, or sensory stimulation. At present, there is little effort paid to methods for improving adherence to RTP and RTL protocols and related obstacles faced by the adolescent population. This is a significant gap in the literature, given that there are unique social, emotional, and physical factors that may contribute to the ability of this population to adhere to these protocols. The main aims of this collective case study are: 1) to address how adolescents describe post-concussion lived experience after having sustained a concussion during sport participation; 2) how these life experiences are influenced by clinical treatment protocols (i.e., RTP and/or RTL); and 3) how adolescents interpret the sensory, cognitive, and physical withdrawal suggested with these protocols. Adolescents between the ages of 14 and 17 years who participate in the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) will be invited to take part in this project. Participants will be asked to attend three separate meetings. During these meetings, participants will take part in two semi-structured interviews and one focus group. Study findings can be used to inform PABICOP program planning and provide insight for caregivers and peers regarding the experiences youth face during concussion treatment and management.

21. Factors predicting functional communication in school-age children who use augmentative and alternative communication

Investigators: Mohammad Almudallal¹, Steve Ryan^{1,2}, *Michelle Servais*^{3,4}, *Tracy Shepherd*^{3,5} & Anne Marie Renzoni⁵

Affiliations: University of Toronto¹, Bloorview Research Institute², Thames Valley Children's Centre³, Western University⁴, Holland Bloorview Kids Rehabilitation Hospital⁵

Status: Completed, 2017-2018

Funding: Canadian Institutes of Health Research (\$2,080)

Functional communication, language, and literacy skills are fundamental for children to participate in all aspects of life. However, children with developmental disabilities such as an autism spectrum disorder, cerebral palsy, or Down syndrome may face challenges due to difficulties they experience during face-to-face communication. Those whose daily communication needs are not met by natural speech need augmentative and alternative communication (AAC) systems to support and improve their everyday communication in home, school, and community settings. There is a substantial body of research that demonstrates convincingly that children with complex communication needs derive substantial benefits from aided AAC. Research demonstrates that appropriate aided AAC interventions result in positive gains in skills such as turn taking, requesting, commenting, receptive and expressive vocabulary, mean length of message, morphology, phonological awareness, and reading and writing skills. Strong evidence also shows that aided AAC significantly may decrease challenging behaviors and increase compliance and on-task behaviors. Despite the availability of specialized devices and services, some 70% of young Canadians with speech-related disabilities-an estimated 13,000 under the age of 15 years-continue to have unmet needs for AAC devices for reasons that are not fully understood. It is essential to understand these predictive factors to inform decisions about how to structure AAC services and provide AAC systems/training that make judicious use of scarce healthcare resources. Identifying and understanding factors that predict everyday use of aided AAC in different settings may help services to be more sensitive to specific needs of each family and child who experiences communication challenges. This exploratory study used a cross-sectional research design (mailed survey) to examine the factors that predict everyday communication in school-age children (ages 6 to 14 years) with complex communication needs. Forty-two parents/caregivers whose children use AAC completed the survey which included background questions developed for this study and two parent-report questionnaires: the abbreviated Family Impact of Assistive Technology Scale for AAC (FIATS-AAC) and the Quebec User Satisfaction of Assistive Technology Scale (QUEST). We learned more about the factors that facilitated the use of AAC devices and the barriers that hindered the use of AAC devices. The findings from this study will help AAC clinicians to better plan ways to support children who have AAC needs. This may help make their services better in the future.

EXTERNAL PROJECTS

External projects are projects that do not have any TVCC staff members named as investigators. These projects, however, do involve TVCC clients, their families, and/or TVCC staff members as participants.

All external projects are reviewed and approved by the Research Advisory Committee before being allowed to approach TVCC clients or their families as potential participants. A TVCC staff member is assigned as a Research Contact to liaise with the external research and make the first contact inviting potential participants to take part in the research.

The following is a list of the **25 external research projects** underway between **1 April 2014** and **30 September 2018**. Abstracts of the projects are located on the listed pages. The names of the TVCC Research Contact are *italicized* and **bolded**. Names of former TVCC staff are italicized only.

- 1. An evaluation of the long-term effectiveness of Botulinum toxin in children with spastic cerebral palsy
 - **Investigators:** Darcy Fehlings¹, Tim Carey², Peter Rosenbaum³, Virginia Wright¹, Unni Narayanan⁴, & Charles Goldsmith³
 - **Affiliations:** Holland Bloorview Kids Rehabilitation Hospital¹, Children's Hospital London Health Sciences Centre², McMaster University³, Hospital for Sick Children⁴

TVCC Research Contact: Linda Bolack Status: Completed, 2008-2015

Spastic Cerebral Palsy is defined as the presence of persisting increased muscle tone and is further classified into a topography defined according to the type of limb involvement. The presence of spasticity, in addition to impacting on the motor impairment, is associated with poor muscle growth, and the development of joint contractures and orthopedic complications such as painful hip dislocation. Intramuscular injections of Botulinum Toxin A (BTA) cause both a reduction in spasticity and weakness of the muscle. In the last decade BTA has become a standard of treatment for appropriately selected children with spastic CP. However, evidence is lacking for the impact of BTA on long-term gross motor function, community mobility, and improved ease of care and comfort. This study examined the long-term effectiveness of BTA on the gross motor function, community mobility and participation of young ambulatory children (aged 2.5 - 5 years) with spastic CP over a three-year period. It is hypothesized that children who receive regular BTA injections will have greater improvements in gross motor function, community mobility and participation. The children were assessed at 12 month intervals on a variety of outcome measures which will fully characterize the nature and extent of impairment, activity, and participation.

2. Canadian Neuromuscular Disease Registry

Investigators: Craig Campbell, Shannon Venance, Rhiannon Taranik, & Ashrafunissa Janmohammad

Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2010

Neuromuscular disorders (NMD) are present in all populations and affect people of all ages. Individual NMDs are often referred to as rare or orphan diseases. A challenge is often the inability to identify and recruit the number of participants needed to complete clinical trials. The Canadian Neuromuscular Disease Registry (CNDR) will provide a tool to connect researchers with potential participants to increase the success of participant recruitment for clinical trials. The CNDR will also provide the ability to collect important information about the distribution of NMDs in Canada.

3. Monitoring development of children with cerebral palsy or gross motor delay

Investigators: Doreen Bartlett¹, Lisa Chiarello², Robert Palisano², Sally Westcott McCoy³, Lynn Jeffries⁴, Alyssa Laforme Fiss⁵, Steve Hanna⁶, & Jan Willem Gorter⁶

Affiliations: Western University¹, Drexel University², University of Washington³, University of Oklahoma Health Sciences Centre⁴, Mercer University⁵, McMaster University⁶

TVCC Research Contact: Michelle Truppe

Status: Completed, 2012-2018

The aim of this research study was to describe the changes in balance (a primary impairment), range of motion limitations, strength, and endurance (secondary impairments), number and impact of health conditions, and participation in self-care and recreation and leisure activities over a one-year period in young children with cerebral palsy(CP) aged 18 months to 10 years. One hundred and seventy-five children with CP, aged 18 months to 10 years, in each of the 5 levels of the Gross Motor Function classification System (GMFCS) were recruited. Trained therapist assessors measured the primary and secondary impairments (i.e. balance, range of motion limitations and strength) on two occasions (12-months apart). Through parental interview, changes were tracked in endurance, health conditions, and participation in self-care and recreation activities, at the same data collection points. These two data collection points were used to develop reference percentiles and present the data so that therapists can assist families to determine if other children with CP are developing as expected, better than expected, or more poorly than expected, depending on their functional ability levels. Rehabilitation services can be altered to ensure optimal motor development, health, self-care abilities and participation in life activities.

4. Stacking exercises aid the decline in forced vital capacity (FVC) and sick time (STEADFAST) in boys 6-16 years with Duchenne muscular dystrophy

Investigator: Craig Campbell Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: Cheryl Scholtes Status: Underway, Started-2014

Duchenne muscular dystrophy (DMD) is complicated by weak breathing muscles and lung infections. Lung volume recruitment (LVR), is a method for preserving lung function. The hypothesis is LVR will slow down the steady loss of lung function, prevent lung infection, and improve quality of life. The aim of this study is to compare standard care to LVR plus standard of care thus improving lung functions, quality of life and reduce sick time. 254 existing 6-16 year boys in 14 Canadian tertiary care hospitals will be contacted.

5. Health endpoints and longitudinal progression in congenital myotonic dystrophy (HELP-CDM)

Investigators: Craig Campbell Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Cheryl Scholtes* Status: Underway, Started-2014

Congenital myotonic dystrophy (CDM) is the result of a dominantly inherited disorder caused by a trinucleotide repeat expansion (CTGn) in the DMPK gene. Patients with CDM present at birth with respiratory insufficiency and hypotonia and later have intellectual impairment and motor delay. Currently, there are no published longitudinal or large group cross sectional studies evaluating children with CDM during infancy and childhood. This information is needed to document the rate and variation of progression, identify potential biomarkers, spectrum of manifestations, and individual trends and variation in functional abilities, and quality of life. Such information will allow proper design of treatment trials in children to assess promising new therapies, such as anti-sense oligonucleotides (ASO's). The recently described successful use of ASO treatment to reverse symptoms in the transgenic mouse model of myotonic dystrophy type-1 (DM1) offers promise that in the near future therapies for adult onset myotonic dystrophy will become available. If such treatment proves safe and appears beneficial, there will be great urgency to extend this therapy to children, especially those with the most severe form of disease. It is proposed to longitudinally characterize the symptoms and functional outcomes associated with CDM disease progression in early and late childhood to develop a model for symptom development and progression. This study will enroll 60 children with CDM and 30 control subjects with stratified recruitment into four cohorts.

6. Parents' experiences and perceptions when classifying their children with cerebral palsy: Advice for service providers

Investigators: Natalie Scime¹, Doreen Bartlett¹, Robert Palisano², & Laura Brunton¹ **Affiliations:** Western University¹, Drexel University² **TVCC Research Contact:** *Liz Lusk* **Status:** Completed, 2014-2016

This study explored parents' experiences using standardized classification systems to describe the motor, manual and communicative function of their children with cerebral palsy (CP). It also aimed to understand how useful parents find these classification systems and their ability to predict future function. Parents were encouraged to offer advice for service providers that represented the caregiver's perspective of what a positive family-provider interaction looks like. This advice was developed into communication guidelines for providers. The project hoped to better inform providers' approaches to conversations surrounding a CP diagnosis and prognosis and help facilitate supportive, family-centred interactions.

7. A Phase 3, randomized, double-blind, sham-procedure controlled study to assess the clinical efficacy and safety of ISIS 396443 administered intrathecally in patients with later-onset spinal muscular atrophy

Investigators: Craig Campbell, & Sharan Goobie Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Cheryl Scholtes* Status: Underway, Started-2014

This is a randomized, double-blind, sham-procedure controlled study for patients with spinal muscular atrophy (SMA). The treatment group will receive an intrathecal dose of ISIS-396443 via lumbar puncture 4 times over 15 months to test the clinical efficacy, safety, tolerability, and pharmacokinetics of the study drug. The primary goal of the study is to determine if four injections of the study drug, over a 15 month period, would improve muscle function, coordination and strength. This will primarily be evaluated using the Hammersmith Functional Motor Scale, The WHO Motor Milestone, and the Upper Limb Module Test.

8. A Phase 2 randomized, double-blind, placebo-controlled, multiple ascending dose study to evaluate the safety, efficacy, pharmacokinetics and pharmacodynamics of PF-06252616 in ambulatory boys with Duchenne muscular dystrophy

Investigators: Craig Campbell, & Cam-Tu Nguyen Affiliation: Children's Hospital London Health Sciences Centre Status: Cancelled, 2014-2018 TVCC Research Contact: *Cheryl, Scholtes*

This study focused on boys between the ages of 6-10 years with Duchenne muscular dystrophy. The study drug PF-06252616 was to be tested for efficacy, safety, pharmacokinetics and pharmacodynamics to determine if it would aid in muscle

strength and decrease the decline in ambulation. PF-06252616 is an engineered protein, called a monoclonal antibody that was designed to bind to and inhibit a naturally occurring protein called myostatin. Monoclonal antibodies are usually produced by the body's immune system to identify and fight foreign objects in your body, but can be made in the lab to target specific proteins that are affecting normal function. This study was cancelled by the sponsor.

9. The electronic monitoring of environmental triggers of unwanted behaviours

Investigators: Cathy Chovaz¹, Ken McIsaac², Robert Nowosielski¹, & Katie Hart¹ **Affiliations:** King's University College¹, Western University² **TVCC Research Contact:** *Veronica Vanderborght* **Status:** Discontinued, 2015-2015

The aim of this study was to test the effectiveness of an improved electronic monitoring system to identify environments triggers for disruptive behavior in deaf children who have an autism spectrum disorder diagnosis. The hypothesis was that unidentified environmental stimuli may be triggering disruptive behavior and that the co-morbid diagnoses of deafness and autism would make it very difficult for the child to expressively describe these hypo or hypersensitivities. The goal was to identify these potential triggers followed by modification of the environment to facilitate improved adaptive behaviours. Discontinued due to lack of specific recruitment.

10. Optimizing life success through residential immersive life skills programs for youth with disabilities

Investigators: Gillian King¹, Amy McPherson², Shauna Kingsnorth², Jan Willem Gorter³, & Tanya Glencross-Eimantas⁴

Affiliations: Bloorview Research Institute¹, Holland Bloorview Kids Rehabilitation Hospital², CanChild Centre for Childhood Disability Research, McMaster University³, ErinOak Kids Centre for Treatment and Development⁴

TVCC Research Contact: Michelle Truppe

Status: Underway, Started-2015

Young people with disabilities often lag behind their typically developing peers in the achievement of adult roles, which has been attributed to a lack of opportunities to develop critical life skills. Residential Immersive Life Skills (RILS) programs provide situated learning opportunities to develop life skills alongside peers and away from home in real-world settings. Retrospective research suggests that attending RILS programs is a transformative experience that empowers youth, provides parental hope, and increases service provider expertise. However, prospective, comparative research is needed to determine longer term benefits of these programs on youth life trajectories, in addition to exploring the program features and participant experiences that optimize program success. While RILS programs provide youth with disabilities the chance to develop life skills for adulthood, it is not known yet whether RILS programs build skills that last in the long-term. This study examined the life skills outcomes for youth in RILS programs and how well outcomes lasted over time. The intervention RILS group was

compared to three control groups: (a) youth who took part in a RILS program in a future year; (b) matched youth in a non-residential life skills program, and (c) matched youth not in any life skills program. Qualitative interviews were conducted with alumni of three RILS programs. Data were thematically analyzed using a phenomenological approach. Themes identified from fourteen interviews were: (1) enhancing higher-order skills; (2) new notions of independence; and (3) identity change, empowerment, and advocacy. Opportunities to learn and practise a variety of skills in a structured, facilitative environment led to increased competence and motivation to engage in independent activities. Engaging with peers undergoing similar experiences also helped some youth integrate disability into their identity. Providing youth with physical disabilities opportunities to engage with others sharing similar experiences and challenges is essential. The study contributes toward the development of evidence-based best practices for life skills programs.

11. Infant and child feeding resource needs assessment

Investigators: Colleen O'Connor¹, Janet Madill¹, Cathy Verkley², & Susan Bird¹ **Affiliations:** Brescia University College¹, Revera Home Health Services² **TVCC Research Contact:** *Michelle Truppe* **Status:** Completed, 2015-2016

A discussion among community members revealed that referrals being made to community dietitians were not always being met; revealing disconnection between pediatric patients requiring nutrition care and the accessibility of the community resources available to them. Results from this study began to quantify the issue and were presented to the Southwest Local Health Integration Network (LHIN). As fitting with the LHIN's objectives, the results alerted them to accessibility gaps which affected this high risk pediatric population; allowing them to develop appropriate solutions to ensure the needs of this group were being met.

12. How do individuals with cerebral palsy and their families prefer to receive and use evidence-based information to individualize services to optimize outcomes?

Investigators: Tianna Deluzio, Doreen Bartlett, Alisiyay Daya, & Deb Lucy Affiliation: Western University-School of Physical Therapy TVCC Research Contact: *Liz Lusk* Status: Completed, 2016-2017

This study's goals were to describe the format in which children with cerebral palsy (CP) and their parents prefer to receive evidence-based information about their children's development and to understand how they intend to use this information. Participants consisted of 122 pairs of children with CP and their parent(s)/guardian(s). Participants were sent a questionnaire to gauge information preferences and to guide subsequent in-depth interviews. Additional interviews took place to present "mock-ups" of suggested information formats. Interviews were audio-taped and transcribed for analysis. Member reflection took place to ensure the results are meaningful for participants.
13. Trial readiness and endpoints assessment in congenital myotonic dystrophy (TREAT-CDM)

Investigators: Craig Campbell, Eugenio Zapata, & Delia Ceballos Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2016

Congenital myotonic dystrophy (CDM) is a multi-systemic, dominantly inherited disorder caused by a trinucleotide repeat expansion (CTGn) in the DMPK gene. Currently there are no therapeutic trials for CDM, however there are ongoing therapeutic trials in adults with DM1 using an antisense oligonucleotide to target the destruction of the CTG repeat. In order for a potential therapy to be tested in the CDM population, there needs to be an established set of outcome measures to be used in the clinical trial. Participants with CDM will participate in this longitudinal natural history study to establish the normal values for various outcome measures for this disease.

14. A double-blind, placebo-controlled, multicentre study with an open-label extension to evaluate the efficacy and safety of SRP-4045 and SRP-4053 in patients with Duchenne muscular dystrophy

Investigators: Craig Campbell & Eugenio Zapata Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2016

Participants with Duchenne muscular dystrophy with a confirmed mutation that is amenable to correction by skipping exon 45 or 53 will receive SRP-4045 or SRP-4053 intravenously over a 96 week double blind period and a 96 week open-label period. SRP-4045 and SRP-4054 are phosphorodiamidate morpholino oligomers that alter the splicing of pre-mRNA transcript to produce functional dystrophin. Drug efficacy will be measured using change from baseline to week 96 in the 6-Minute Walk Distance.

15. A phase 1b/2 randomized, double-blind, placebo-controlled study of ACE-083 in patients with facioscapulohumeral muscular dystrophy (FSHD)

Investigators: Craig Campbell, Eugenio Zapata, & Delia Ceballos Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2016

Patients with Facioscapulohumeral muscular dystrophy with participate in a two part dose finding study receiving ACE-083, a myostatin inhibitor, via intramuscular injections in one leg and one arm muscle every three weeks for a period of months. Myostatin is a chemical that blocks muscle development and by inhibiting myostatin the goal is to create stronger, healthier muscles.

16. A two part seamless, open-label, multicentre study to investigate the safety, tolerability, pharmacokinetics, pharmacodynamics and efficacy of Ro7034067 in infants with type1 spinal muscular atrophy

Investigators: Craig Campbell & Eugenio Zapata Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Closed, 2016-2018

Participants with Spinal muscular atrophy were to participate in a two part dose finding study receiving a once daily oral solution of RO7034067 a SMN2 mRNA splicing compound to increase the expression of functional SMN protein. The study did not enroll any patients therefore the study was closed.

17. A two-part seamless, multi-centre randomized, placebo-controlled, double-blind study to investigate the safety, tolerability, pharmacokinetics, pharmacodynamics and efficacy of Ro7034067 in type2 and 3 spinal muscular atrophy patients

Investigators: Craig Campbell & Eugenio Zapata Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: Colleen Willoughby Status: Underway, Started-2016

Participants with Spinal muscular atrophy will participate in a two part dose finding study receiving a once daily oral solution of RO7034067 a SMN2 mRNA splicing compound to increase the expression of functional SMN protein.

18. A phase 2, double-blind, randomized, placebo-controlled, multiple dose study of CK-2127107 in two ascending dose cohorts of patients with spinal muscular atrophy (SMA)

Investigators: Craig Campbell, Eugenio Zapata, & Christine Shoesmith Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2016

CK-2127107 is being investigated as a potential new therapy for improving muscular weakness and muscle fatigue in patients with Spinal muscular dystrophy (SMA). This is the first study with this molecule being conducted in SMA patients and is designed to assess the effect of 8 weeks of dosing of CK-2127107 on measures of muscle function in both ambulatory and non-ambulatory patients. The study drug is not a disease modifying agent but acts to cause calcium adherence to the contractile elements of the muscle fibre, with the goal to improve muscle contractility in weak muscles.

19. A randomized, double blind, placebo-controlled study to assess the efficacy, safety, and tolerability of BMS-986089 in ambulatory boys with Duchenne muscular dystrophy

Investigators: Craig Campbell & Eugenio Zapata Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Colleen Willoughby* Status: Underway, Started-2017

The purpose of this study is to evaluate the efficacy, safety and tolerability of weekly subcutaneous (SC) doses of BMS-986089 compared to placebo in ambulatory boys with Duchenne muscular dystrophy (DMD). BMS-986089 is being developed as a once weekly, subcutaneously administered therapeutic to increase muscle mass and strength.

20. Engagement in the pediatric rehabilitation intervention process: Its nature, measurement, and role in the determination of outcomes

Investigators: *Gillian King*¹, Virginia Wright¹, Jenny Ziviani², Lisa Chiarello³, Heidi Schwellnus⁴, Roger Ideishi⁵, & Matthew McLarnon⁶

Affiliations: Bloorview Research Institute¹, The University of Queensland², Drexel University³, Holland Bloorview Kids Rehabilitation Hospital⁴, Temple University⁵, Oakland University⁶

TVCC Research Contact: *Michelle Servais* Status: Underway, Started-2020

When children with disabilities and their parents/caregivers take part in therapy, their outcomes are considered to be better. The research team are looking at the ways in which parents/caregivers feel involved and not involved at their appointments. Researchers think families can help us understand what being involved means and how to make therapy appointments be the best they can be. The researchers developed questionnaires to measure engagement in therapy. This project tries out these questionnaires in real-life therapy sessions. Parents/caregivers attending therapy sessions of their children are being invited to answer questions over the phone, by email, or by mail, so that they can tell us about their involvement in their child's appointments.

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21. Children and teens in charge of their health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities

Investigators: Amy McPherson¹, Elaine Biddiss¹, Paige Church², *Gillian King*¹, Desiree Maltais³, Chantal Merette³, Helene Moffet³, Fiona Moola¹, & Heidi Schwellnus²

Affiliations: Bloorview Research Institute¹, Holland Bloorview Kids Rehabilitation Hospital², Laval University³

TVCC Research Contact: Liz Lusk

Status: Underway, Started-2017

This feasibility study focuses on a promising coaching approach called solution-focused coaching for children with physical disabilities to help them improve and sustain physical activity and healthy eating habits. Thirty children will participate in the study for 12 months. All will receive usual care and basic printed information about healthy lifestyles. In addition, 15 will receive coaching for the first six months. All children will be assessed at 4 times points during the study. Findings will inform the feasibility and acceptability of a large study of solution-focused coaching and sensitivity of chosen outcome measures to coaching over 12 months.

22. Constructing and validating the interRAI 0-3 for the developmental and mental health needs of children and families

Investigators: Shannon Stewart, Sarah Coulter, & Jo Ann Iantosca Affiliation: Western University TVCC Research Contact: *Michelle Truppe* Status: Underway, Started-2017

Early childhood is a period of significant developmental gain, with researchers and policy makers identifying the importance of the formative years. Collaborating with a panel of local specialists and international researchers, the interRAI 0-3 assessment-to-intervention system has been developed to address early life indicators such as developmental differences, child temperament, behavior, medical needs, stress and trauma, family and social relations, and prevention and service utilization. Validation efforts are underway to establish the clinical utility of the interRAI 0-3, as there is recognized need to become evidence-informed in decision making regarding service provision, particularly in supporting young children.

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23. Determining the natural course of fatigue in children and adolescents with cerebral palsy

Investigators: Laura Brunton¹ & Elizabeth Condliffe² **Affiliations:** Western University¹, University of Calgary² **TVCC Research Contact:** *Michelle Truppe* **Status:** Underway, Started-2018

Some children and youth with cerebral palsy experience fatigue (or tiredness) that impacts their health and day-to-day life activities. At this time, it is hard to predict who might be affected by fatigue, and how it will affect their lives. It is also unknown when fatigue becomes a problem which makes it hard to provide treatment or prevent it from happening. This study will survey 600 children and youth with cerebral palsy from age 7 to 18 years, of all ability levels, to understand when fatigue becomes a significant problem and to demonstrate the impact it has on their daily life.

24. Health concerns of adolescents and adults with childhood-onset physical disability

Investigators: Caitlin Cassidy & Laura Brunton Affiliations: Western University TVCC Research Contact: Colleen Willoughby Status: Underway, Started-2018

The purpose of this study is to understand the most common health care challenges being faced by adolescent and adult patients with childhood-onset disability. A secondary purpose is to determine what additional factors are related to the concerns raised by patients (e.g., age, additional diagnoses, etc.). Patients in the Transitional and Lifelong Care (TLC) program at Parkwood Institute will be invited to participate. Information about the concerns they raise in their medical appointments (and/or concerns raised by their parents/caregivers) will be gathered. It is hoped that this information will eventually guide improvements in this new clinical program.

25. A randomized, double-blind study to evaluate the efficacy and safety to Tideglusib versus placebo for the treatment of children and adolescents with congenital myotonic dystrophy

Investigators: Craig Campbell, Eugenio Zapata, & Salma Remtulla Affiliation: Children's Hospital London Health Sciences Centre TVCC Research Contact: *Carrie Laskey* Status: Underway, Started-2018

Myotonic dystrophy type 1 (DM1) is a monogenetic disorder caused by non-coding expansion repeats in the DMPK gene. DM1 may be present at birth as congenital myotonic dystrophy (CDM). CDM is a life threatening disorder associated with significant morbidity and mortality. Tideglusib is a new chemical entity from the thiadiazolidindiones chemical family. It is an irreversible inhibitor of Glycogen synthase kinase 3 beta, which is implicated in neuromuscular and neurodevelopmental disorders and mediates the muscle pathology in DM1. This study seeks to investigate the efficacy and safety of Tideglusib in children and adolescents age 6-16 years, affected by CDM.

QUALITY ASSURANCE PROJECTS

Quality Assurance activities are an integral part of providing quality services and interventions to clients and families. At TVCC, staff members evaluate their practices, programs and services to learn about what works best, and to enhance service delivery and research practices. Selected quality assurance activities that took place between **1 April**, **2014** and **30 September**, **2018** are listed below.

1. Developmental Resources for Infants (DRI): Examining families' experiences transitioning to a new agency

Investigators: *Michelle Servais*^{1,2}, *Sue O'Grady*¹, Michelle Tucker³, & Developmental Resources for Infants Team

Affiliations: Thames Valley Children's Centre¹, Western University², Child & Parent Resource Institute³

Status: Underway, Started-2018

The Home Visiting Program for Infants (HVPI) at the Child and Parent Resource Institute (CPRI), the Thames Valley Children's Centre (TVCC), the and tykeTALK (Middlesex London Health Unit) work collaboratively to provide a seamless transition of service when children require further services beyond two years of age. We are currently examining the transition processes (when families finish services from HPVI and then receive services from TVCC and tykeTALK) from the perspective of clients/families by asking families to complete a survey 3 months after their transition meeting. We hope that this feedback will provide information about what parts of the transition process are most valuable for parents. Our hope is that the processes that we currently have in place are making this transition personalized, relevant, and supportive for families. This feedback will help the programs to enhance their services for clients/families.

2. An evaluation of Autism Service's transitions to the new Ontario Autism Program

Investigators: Michelle Servais^{1,2}, Sarena Renaud¹, Megan Byron-Palenchuk¹, Norman Conkey¹, Bethany Dinsmore¹, Denise Holloway¹, Leanne McQueen¹, Meghan McTavish¹, Rebecca Parker¹, Laura Poustie¹, Liz Salgado¹, LeeAnn Sneddon¹, Veronica Vanderborght¹, & Mallory Young¹

Affiliation: Thames Valley Children's Centre¹, Western University² **Status:** Completed, 2017-2018

The change to the new Ontario Autism Program (OAP) necessitated revisions and new approaches to service delivery models. This evaluation focused on some of the key elements that a children's treatment centre used to drive the change process, support staff through these changes, and facilitate the transformation of services. Kotter's Eight-Step Process Model for Leading Change (1996) was used to guide change management (e.g., creating a climate for change, engaging and enabling staff, and implementing and sustaining change). A transition team was created to support change efforts and create buy-in. The team used one-hour focus group interviews with all staff to gather staff input, provide an opportunity for staff to design services, and gain commitment to change. Focus group questions: a) captured team members' experience, knowledge, insight, ideas and perceptions about best practices for service delivery and familycentred service; b) engaged staff in development of the OAP; c) gathered staff feedback about the plans for OAP service changes; d) checked staff understanding and identified further training needs; and e) helped staff to cope with change. Responses were collated and transition team members used a thematic analysis to analyze the data. Key themes that emerged from the focus group data included: designing family-centred services that engaged clients and families, staff responses to new service plans, the wide spectrum of staff members' feelings related to change, and strategies to cope with change. Based on staff members' knowledge and understanding of the OAP service plan, information, communication, and training needs were identified and addressed.

3. Evaluation of the Autism Service's IBI Pilot Program: An examination of interprofessional collaboration

Investigators: Michelle Servais^{1,2}, Janet Gritzan¹, Michelle Truppe¹, Laura Pritchard¹, Veronica Vanderborght¹, Lisa Widdifield¹, & Debbie Shugar³

Affiliations: Thames Valley Children's Centre¹, Western University², Middlesex London Health Unit³

Status: Completed, 2016-2018

This project was an evaluation of an innovative pilot program designed to enhance services: pediatric rehabilitation and autism professionals provided integrated services within 5 IBI Classrooms for 6 months (1 OT and 1 SLP were assigned to each classroom for up to a half day per week). Focus groups were held at the end of the pilot to capture team members' experiences and perceptions of this approach and team members completed 2 questionnaires that explored interdisciplinary collaboration (at 2 and 6 months). Key themes that emerged from the focus group data included the benefits, challenges, and suggestions for moving forward. Team members noted that this was a

truly integrated approach: shared information and feedback led to having joint expectations. Staff felt that having a consistent rehabilitation professional in the classroom led to enhanced communication, connection, rapport, and relationships. This model resulted in immense shared learning and increased knowledge and awareness: "I wouldn't necessarily seek out information, as I don't know what I don't know." Staff liked learning from other disciplines (learned about others' roles and approaches, and new strategies). Time was a key challenge for therapists, given only one half day per week of dedicated time. To improve efficiencies, such programs should have more dedicated time for therapists. Moving forward staff would like some front-end education/training (to better understand assessments, goals, processes: why disciplines do things that way) and more joint meetings. Both the focus group and questionnaire data also revealed that clinicians highly valued interdisciplinary collaboration and desired continued opportunities to work together.

4. What early years families tell us about important elements of documentation

Investigators: Michelle Servais^{1,2}, Patricia Baldwin¹, Michelle Truppe¹, Mary Ellen McLean¹, & Janet Gritzan¹

Affiliations: Thames Valley Children's Centre¹, Western University² **Status:** Completed, 2012-2015

This program evaluation examined the value of written reports for early years families. Getting Started at Thames Valley Children's Centre (GSAT) is an entry to service program where clinicians provide comprehensive documentation for families new to service. Often GSAT reports are jointly written and take time to compose. Clinicians wanted to know whether they were creating reports that were useful and responsive to families' needs. Thirteen Early Childhood Services therapists interviewed 20 families on what parts of the GSAT report they found most useful and less useful, and liked most and least. Participants' feedback was collated and analyzed for the key elements that early years' families valued about reports. We found that customization and comprehensiveness of documentation seems to be important for early years' families. Documentation is a valued part of intervention in supporting parents and other service providers in their continued work. It also supported families with trying out therapeutic strategies at home. This evaluation involved families that were new to TVCC, and their information needs may be different than other families (e.g., families who have been in services for a longer time). We learned from this evaluation that clinicians may benefit from resources that support their thinking about documentation. "A Resource Tool for Clinical Documentation—Guiding Questions and Tips for Clinicians" was developed to support clinicians in their conversations with families. This evaluation contributed to the development of best practices for documentation.

5. Enhancing Strength-Based Clinical Practices in Pediatric Rehabilitation

Investigators: Michelle Servais^{1,2} & Patricia Baldwin¹ Affiliations: Thames Valley Children's Centre¹, Western University² Status: Completed, 2014-2016

In this knowledge translation project, we identified key findings from the research literature that supported the importance of using a strengths-based approach in pediatric rehabilitation and linked this evidence to specific strategies for strengthsbased practice. We described the values and principles associated with a strengthsbased approach, provided examples of tools and resources to identify strengths, and shared specific strengths-based strategies that could be used in pediatric rehabilitation practice. Using a strengths-based approach can enhance parental engagement and improve effectiveness of services (Tehan & McDonald, 2010). However, in a study of strengths-based services, Lietz (2011) found that only half of families described services that were indicative of strengths-based principles (in Scerra, 2011). Clearly, there is a need to translate strengths-based evidence and principles into strategies that therapists can use in their practice. In this project we highlighted evidence-based principles of a strengths-based approach and illustrated what this might look like in pediatric rehabilitation practice in terms of therapists' knowledge, attitudes, and behaviours. Using a strengths-based approach shifts how therapists work with families. Rather than a deficit-based paradigm or focus on fixing problems, in a strength-focus approach therapists work with clients/families to explore what can be, and identify and use client/family strengths to support change and work on meaningful goals. In a strengthsbased approach, therapists: develop collaborative relationships with families; emphasize strengths, capabilities, solutions, and resources; are mindful of the language they use; acknowledge and reframe for the positive, and ask qualitatively different questions (e.g., from an exploratory, curious stance: 'What's working well?').

6. A program evaluation of the Getting Started at Thames Valley Children's Centre (GSAT) Service

Investigators: Michelle Servais^{1,2}, Patricia Baldwin¹, Michelle Truppe¹, Linda Bolack¹, Karen Tjosvold¹, Brent Duncan¹, Melissa Heeney¹, Stacy McDougall¹, Janet Gritzan¹, Mary Ellen McLean¹, Carolyn Nicholson¹, & Gill Stapleton¹ Affiliation: Thames Valley Children's Centre¹, Western University²

Status: Completed, 2011-2015

Getting Started at Thames Valley Children's Centre (GSAT) service is a centre-wide, multi-disciplinary program for welcoming newly referred families to Thames Valley Children's Centre (TVCC) services. GSAT was created in response to lengthy wait times for newly referred clients and families at TVCC. Getting Started at Thames Valley Children's Centre (GSAT) used a quality improvement process that was a strengthsbased, solution-focused approach to realign the front end of service delivery. This service was designed to welcome new families in a timely manner, address their priority needs, respond to their questions, and connect families to resources in their communities. Together, a plan is co-created to determine next steps. The GSAT team

recognizes that, for families, 'getting it right at the beginning' has a positive impact on their journey. An evaluation was conducted to examine the GSAT processes to determine what was working well and how this service could be enhanced. Key organizational learnings included: (a) a positive process of inquiry is important to help families explore possibilities and what is needed; (b) timely service responsiveness that is matched to families'/childrens' priority needs is extremely critical; (c) starting more quickly with families' goals helps to decrease families' worries and increase families' engagement in the therapy process; (d) the importance of acknowledging families' readiness for change, and (e) front-loading services allows everyone to "get it right in the beginning", so that everyone is more prepared for their next steps.

7. Healthcare professionals' perspectives on collecting research data over time

Investigators: Janette McDougall^{1,2}, Megan Nichols¹ Affiliation: Thames Valley Children's Centre¹, Western University² Status: Completed, 2014-2015

This guality assurance project explored the perspectives of health professionals about administering study questionnaires over time with youth who have chronic health conditions. The 'Quality of Life' (QOL) study explored the changing nature of QOL in youth with chronic conditions and the factors that predict change in QOL for these adolescents. Four hundred and thirty-nine youth aged 11 to 17 from eight Ontario children's treatment centres enrolled in the study. Questionnaires were administered to youth and parents shortly after admission to the study and then again every 12 months for 3 years. Youth completed their questionnaires through face-to-face interviews with trained study interviewers. Interviewers were healthcare professionals with clinical experience working with youth (e.g., occupational therapists, physiotherapists, speech and language pathologists, social workers, recreation therapists). At the end of data collection, the project coordinator facilitated a focus group with five study interviewers at Thames Valley Children's Centre to learn about their experiences administering research questionnaires with youth across time. The focus group was transcribed, a content analysis was conducted, data was coded, and themes were identified. The following lessons learned were identified: 1) consistency is important; 2) understanding research is different from clinical work; 3) respect participants' choice not to respond to all questions; 4) support the participation of youth with complex disabilities; 5) families and clinicians enjoy participating in research. Interviewers' perspectives will be used to inform data collection procedures for future research studies involving youth with chronic conditions and their families.





Did You Know that the TVCC Research Program...

has contributed to studies that are developing new ways of sharing knowledge and providing services, such as:

- creating training videos for clinicians
- understanding the use of solution-focused coaching in pediatric rehabilitation

RESEARCH PROGRAM KEY FACTS

Since the creation of the TVCC Research Program 30 Years ago:

- Total number of TVCC staff members involved in research: 185
- Projects on which staff members were principal investigators: 88
- Completed projects with TVCC staff members as named investigators: 117
- Completed projects by external researchers: 57
- Total number of projects completed: 174

RESEARCH FUNDING

Between **1 April**, **2014** and **30 September**, **2018** a total of **\$200,116** in funding from granting agencies was awarded to **7** research projects with TVCC staff members as investigators. The names of TVCC staff members who were investigators on the grants are **bolded and italicized**. Names of former TVCC staff are *italicized* only.

Canadian Institutes of Health Research-\$2,080

Factors predicting functional communication in school-age children who use augmentative and alternative communication.

Investigators: Steve Ryan^{1,2,3}, Mohammad Almudallal³, *Michelle Servais*^{4,5}, *Tracy Shepherd*⁴, & Anne Marie Renzoni² Affiliations: Bloorview Research Institute¹, Holland Bloorview Kids Rehabilitation Centre², University of Toronto³, Thames Valley Children's Centre⁴, Western University⁵ Status: Completed, 2017-2018

Holland Bloorview Centre for Leadership, Participation and Inclusion-\$18,000

Solution-focused coaching in pediatric rehabilitation: A qualitative study of transformative experiences for service providers.

Investigators: Heidi Schwellnus¹, *Gillian King*^{1,2,3}, *Michelle Servais*^{4,5}, & *Patricia Baldwin*⁴ Affiliations: Holland Bloorview Kids Rehabilitation Centre¹, Bloorview Research Institute², University of Toronto³, Thames Valley Children's Centre⁴, Western University⁵ Status: Completed, 2014-2017

Institute of Coaching at McLean Hospital, Havard Medical School Affiliate-\$26,930

Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families.

Investigators: Heidi Schwellnus¹, *Gillian King*^{1,2,3}, *Michelle Servais*^{4,5}, & *Patricia Baldwin*⁴ Affiliations: Holland Bloorview Kids Rehabilitation Centre¹, Bloorview Research Institute², University of Toronto³, Thames Valley Children's Centre⁴, Western University⁵ Status: Completed, 2014-2017

Lawson Foundation-\$100,000

Children's outdoor play experiences: Why they play and how they benefit Investigators: Tara Elton-Marshall^{1, 2, 3, 4}, Sharon Bernard¹, Janet Loebach¹, Jason Gilliland³, Julie George¹, Guy Faulkner⁵, Sarah Folino⁶, Caroline Fusco⁴, Scott Leatherdale², *Janette McDougall*^{3, 7}, Catherine O'Brien⁸, Terry Spencer⁹, Meghan Lynch⁴, & Samantha Wells¹ Affiliations: Centre for Addiction and Mental Health¹, University of Waterloo², Western University³, University of Toronto⁴, University of British Columbia⁵, Thames Valley District School Board⁶, Thames Valley Children's Centre⁷, Cape Breton University⁸, London District Catholic School Board⁹ Status: Underway, Started-2016

Ontario Brain Institute-\$48,106

Numerical cognition in children with and without cerebral palsy **Investigators:** Daniel Ansari³, **Pamela Frid**^{1,3}, Craig Campbell², & Celia Goffin³ **Affiliations:** Thames Valley Children's Centre¹, Children's Hospital London Health Sciences Centre², Western University³ **Status:** Closed, 2015-2017

Thames Valley Children's Centre-\$3,000

On with the show: Exploring participation experiences of young people with and without disabilities

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Investigators: Beata Batorowicz, Gill Steckle, & Kelli Vessoyan
Affiliation: Thames Valley Children's Centre
Status: Completed, 2016-2018
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Thames Valley Children's Centre-\$2,000

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    The teen quality of life survey (T-QOL): Developing a brief questionnaire for adolescents
        Investigator: Janette McDougall
        Affiliation: Thames Valley Children's Centre, Western University
        Status: Completed, 2016-2017
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PROJECT FUNDING KEY FACTS

Since 1989 the total amount of funding received is **\$8,158,498** for **127** grants with TVCC staff as named investigators on the study submission.

FUNDING SOURCES

Since 1989, funding for research endeavours taking place at TVCC has been received from the following agencies:

- Apple Canada Incorporated
- Bloorview Kids Foundation
- Canadian Institutes of Health Research
- Canadian Occupational Therapy Foundation
- CanChild, Centre for Childhood Disability Research
- Chedoke-McMaster Hospitals
- Child and Parent Resource Institute
- Children's Hospital of Western ON Foundation
- Easter Seal Association
- Easter Seal Research Institute
- Education Quality and Accountability Office
- Eli Lilly
- Harvard Medical School
- Health Canada, Health Policy Research Program
- Holland Bloorview Centre for Leadership
- Hospital for Sick Children Foundation
- Institute of Coaching
- Jesse's Journey
- Lawson Foundation
- National Crime Prevention Centre
- National Institutes of Health
- Ontario Brain Institute
- Ontario Health Care Evaluation Network
- Ontario Mental Health Foundation
- Ontario Ministry of Community and Social Services
- Ontario Ministry of Health
- Ontario Neurotrauma Foundation
- Ontario Rehabilitation Research Network
- Ontario Rehabilitation Technology Consortium
- PTC Therapeutics
- Reseau Provincial de Recherche en Adaptation-Readaptation
- Research Alliance for Children with Special Needs
- SIMone Ontario Simulation Network
- Social Sciences and Humanities Research Council of Canada
- St. Mary's Fund from St. Joseph's Health Centre
- Thames Valley Children's Centre
- The Jack and Ina Pollock Foundation

- The Richard and Jean Ivey Fund
- United Cerebral Palsy Foundation
- United States National Institute of Health
- Western University

PUBLICATIONS

TVCC produces and transfers knowledge about children with special needs and our research findings through professional publications. Findings have clear implications for enhancing services and therapeutic interventions. The following is a list of articles and resources that were published between **1 April**, **2014** and **30 September**, **2018**. Names of TVCC staff members are bolded and italicized. Former TVCC staff member's names are italicized only.

CHAPTERS PUBLISHED IN BOOKS

 King, G., & Servais, M. (2018). Effective Listening and Interactive Communication Scale (ELICS).
 In D. L. Worthington & G. Bodie, The Sourcebook of Listening Research: Methodology and Measures (pp. 252-258). Hoboken, NJ: John Wiley & Sons, Inc.



Note: The Sourcebook of Listening Research: Methodology & Measures won the 2018 Distinguished Book Award from the Communication and Social Cognition Division of the National Communication Association.

PUBLISHED ABSTRACTS

McDougall, J., & Wright, V. (2017). Factors related to symptoms of social anxiety in youth with cerebral palsy. [Abstract] *Developmental Medicine & Child Neurology, 59*(S3): 36 (Suppl.).

- *McDougall, J.,* & Wright, V. (2017). Subjective quality of life for youth with spina bifida. [Abstract] *Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 10*(S1): S56.
- Good, D., Rumney, P., Bennett, S., *McDougall, J.*, DeMatteo, C., & Martinussen, R. (2014). An investigation of factors that influence socioemotional and academic gains in the classroom for students living with the effects of ABI. [Abstract] *Brain Injury, 28*(5-6): 828-828.
- *McDougall*, *J*., & Wright, V. (2014). Perceived quality of life for youth with chronic conditions: Exploring related factors. [Abstract] *Archives of Physical Medicine and Rehabilitation*, *95*: E6.
- Servais, M., Shepherd, T., Bolack, L., Willoughby, C., Strachan, D., Baldwin, P., Moodie, S., Parker, K., Savage, D., Knickle, K., McNaughton, N., & King, G. (2014). Developing authentic clinical simulations for effective listening and communication. [Abstract]. In 2013 Ontario Simulation Exposition Presentation Abstracts. Toronto, ON: SIMone Ontario Simulation Network.

JOURNAL PUBLICATIONS

- *McDougall, J.* & Wright, V. (2018). Domain-based and overall life satisfaction for youth with chronic conditions: The role of personal, interpersonal, and environmental factors over a one-year period. *Applied Research In Quality of Life*,13(4), 1097-1115. doi: 10.1007/s11482-017-9577-9
- Ryan, S. E., Shepherd, T., Renzoni, A. M., Servais, M., Kingsnorth, S., Laskey, C., Ward, K., & Bradley, K. (2018). Responsiveness of a parent-reported outcome measure to evaluate AAC interventions for children and youth with complex communication needs. Augmentative and Alternative Communication, 34(4), 348-358. doi. 10.1080/07434618.2018.1520296
- Vessoyan, K., Steckle, G., Easton, B., Nichols, M., Mok Siu, V., & McDougall, J. (2018, in press). Using eye-tracking technology for communication in Rett syndrome: Perceptions of impact. Augmentative and Alternative Communication. (EPrint Link: www.tandfonline.com/eprint/I2q3Y26D2fjc6jUiGcse/full).
- Zarrei, M., Fehlings, D., Mawjee, K., Switzer, L., Thiruvahindrapuram B., *Frid, P.,...*Scherer S.W. (2018). De novo and rare inherited copy number variations in the hemiplegic form of cerebral palsy. *Genetics in Medicine, 20*(2), 172-180. doi: 10.1038/gim.2017.83
- *King, G.,* Schwellnus, H., *Servais, M.,* & *Baldwin, P.* (2017, in press). Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences and outcomes for families. *Physical and Occupational Therapy in Pediatrics.*

- King, G., Servais, M., Shepherd, T., Willoughby, C., Bolack, L., Moodie, S., Baldwin, P., Strachan, D., Knickle, K., Pinto, M., Parker, K., & McNaughton, N. (2017). A listening skill educational intervention for pediatric rehabilitation clinicians: A mixed-methods pilot study. Developmental Neurorehabilitation, 20(1), 20-52. doi: 10.3109/17518423.2015.1063731
- *Etherington, N., McDougall, J.,* DeWit, D., & Wright, V. (2016). Maternal factors and the emotional and behavioural functioning of adolescents with chronic health conditions. *Disability and Rehabilitation, 38*(14), 1359-1369. doi: 10.3109/09638288.2015.1099055
- King, G., Shepherd, T. A., Servais, M., Willoughby, C., Bolack, L., Strachan, D., Moodie, S., Baldwin, P., Knickle, K., Parker, K., Savage, D., & McNaughton, N. (2016). Developing authentic clinical simulations for effective listening and communication in pediatric rehabilitation service delivery. Developmental Neurorehabilitation 19(5), 284-294. doi: 10.3109/17518423.2014.989461
- *McDougall, J.,* DeWit, D., *Nichols, M.,* Miller, L., & Wright, F.V (2016). Three-year trajectories of global perceived quality of life for youth with chronic health conditions. *Quality of Life Research, 25*(12), 3157-3171. doi: 10.1007/s11136-016-1353-z
- *McDougall, J., Baldwin, P., Evans, J., Nichols, M., Etherington, N.,* & Wright, V. (2016). Quality of life and self-determination: Youth with chronic health conditions make the connection. *Applied Research in Quality of Life, 11*, 571-599. doi: 10.1007/s11482-014-9382-7
- Baldwin, P. J., Evans, J., Etherington, N., Nichols, M., Wright, V., & McDougall, J. (2015). Youth with disabilities talk about spirituality: A qualitative descriptive study. *The Qualitative Report, 20*(7), 941-958. https://nsuworks.nova.edu/tqr/vol20/iss7/1/
- Bedell, G., & *McDougall, J.* (2015). The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic conditions. *Developmental Neurorehabilitation, 18*(6), 375-382. doi: 10.3109/17518423.2013.855273
- King, G., Specht, J., Petersen, P., Servais, M., Bartlett, D., 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. doi: 10.1080/00131881.2014.934
- *McDougall, J.,* Wright, V., DeWit, D., & Miller, L. (2014). ICF-based functional components and contextual factors as correlates of perceived quality of life for youth with chronic conditions. *Disability and Rehabilitation, 36*(25), 2143-2151 doi: 10.3109/09638288.2014.892642
- 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, 47-63. doi: 10.1080/10904018.2014.861295

NON PEER-REVIEWED PUBLICATIONS

McDougall, J., Nichols, M., & Wright, V. (2016). How can perceived quality of life be optimized for youth with chronic health conditions throughout adolescence? *Rehab & Community Care Medicine, 25* (3). Toronto, ON: BSC Communications Ltd.

NEWSLETTERS

McDougall, J., & Wright, V. (2015). Exploring ICF-based correlates of perceived quality of life for youth with chronic health conditions. *World Health Organization Family of International Classifications Newsletter,* 13(1).

REPORTS

- Schwellnus, H., *King, G.*, **Servais**, **M**., & Baldwin, P. (2017, April). Final report. Solution-focused coaching in pediatric rehabilitation: Investigating transformative experiences for families. Toronto, ON: Bloorview Research Institute.
- *McDougall, J.,* & Wright, V. (2014, October). *The "quality of life" study: Baseline report to families and stakeholders.* London, ON: Thames Valley Children's Centre.

TOOLS/MEASURES

DD-Accessibility and Mobility CAP

Palisano, R.J., Theall, L.A., Stewart, S.L., Desserud, S., & Willoughby, C. (2016). Accessibility and Mobility CAP. In S.L. Stewart, L.A. Theall, J.N. Morris, K. Berg, M. Björkgren, A. Declercq, et al. interRAI Child and Youth Mental Health and Developmental Disability Collaborative Action Plans (CAPs): For use with the ChYMH-DD Assessment Instrument, Version 9.3 (pp. 83-88). Washington, DC: interRAI. ISBN 978-1-62255-061-6.

DD-Life Skills CAP

Theall, L.A., Stewart, S.L., McLean, J., Mathias, K., Swart, G.T., & Willoughby, C. (2016). Life Skills CAP. In S.L. Stewart, L.A. Theall, J.N. Morris, K. Berg, M. Björkgren, A. Declercq, et al. interRAI Child and Youth Mental Health and Developmental Disability Collaborative Action Plans (CAPs): For use with the ChYMH-DD Assessment Instrument, Version 9.3 (pp. 97-104). Washington, DC: interRAI. ISBN 978-1-62255-061-6.

Clinical Documentation Resource: Guiding Questions and Tips for Clinicians

Baldwin, P., (2015). A resource for clinical documentation: Guiding questions and tips for clinicians. *Thames Valley Children's Centre.*

Effective Listening and Interactive Communication Scale-Assessment Rubric (ELICS-AR)

King, G., Servais, M., Bolack, L., Shepherd, T. A., & Willoughby, C. (2014). In G. King, , T. Shepherd, M. Servais, C. Willoughby, L. Bolack, D. Strachan, S. Moodie, P. Baldwin, K. Knickle, K. Parker, D. Savage, & N. McNaughton (2016). Developing authentic clinical simulations for effective listening and communication in pediatric rehabilitation service delivery. Developmental Neurorehabilitation 19(5), 284-294. doi: 10.3109/17518423.2014.989461

Complexity Rating Scale for Clinical Simulations

Servais, M., Moodie, S., Strachan, D., King, G., Shepherd, T., Willoughby, C., Bolack, L., Baldwin, P., Knickle, K., Parker, K., Savage, D., & McNaughton, N. (2014). In G. King, , T. Shepherd, M. Servais, C. Willoughby, L. Bolack, D. Strachan, S. Moodie, P. Baldwin, K. Knickle, K. Parker, D. Savage, & N. McNaughton (2016). Developing authentic clinical simulations for effective listening and communication in pediatric rehabilitation service delivery. Developmental Neurorehabilitation 19(5), 284-294. doi: 10.3109/17518423.2014.989461

EASY-TO-READ SUMMARIES

Facts to Go Publication

Facts to Go publications are brief information summaries on research topics written by staff members and community researchers and published and distributed by the Research Program. Copies of the *Facts to Go* publication can be requested from the website: www.tvcc.on.ca

	Russer Valley - Diskisser Out
Facts To G	assifying their Children with
Introduction Three classification systems are routinely used or provide a "unclinal profile of children with "terebrail palsy (CP). The Gross Motor Function material and the system (Carlow Schwarz Mathematical material and the system (Carlow Schwarz Mathematical material and Schwarz Mathematical material system (Carlow Schwarz Mathematical material system) (Carlow Schwarz Mathematical material Schwarz Mathematical material Schwarz Mathematical Carlow Schwarz Mathematical Schwarz Mathematical Schwa	child's function throughout the day can be obtained by involving parents in the dasification process, as parents are most familiar with their child's usual performances as opposed to their child's usual performances as process allow reformances as process and with motor function as variety of environmental settings ² involvement in the classification process allow rifermation to be more accessible and may addiness family needs. Involvement and the classification process allow refers of function and how they understand and utilize the information. Further, in studies to dark have assembled parents' perspectives about having progradual decisions with thereas the information. Further, in studies to dark have assembled decisions with thereas the information. Purpose of this summary applicities and the carbit places applicities of perspectives and thermation applicities of more provided thermation applicities of more provided thermation applicities of the carbit places. This summary outlines the findings of a published more carbit places. The summary outlines the findings of a published more reparation and classifying the children strip perceptions card strip water the carbit places. This summary outlines the findings of a published more carbit places and the carbit applicities of more the parents' application the children that perceptions card strip decrifted in hits paper where to a longing the on future function, and to calbit place the carbit perceptions and the commencies of classifying theory of the commencies of classifying theory of the commencies of the carbit perceptions card strip water the commencies of classifying theory of the commencies of the carbit perceptions card strip and theory perceptions carbit perceptions card strip and theory perceptions carbit perceptions card strip and theory perceptions carbit percept

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- *McDougall, J.,* & Wright, V. (2018). What contributes to multidimensional life satisfaction for youth with chronic health conditions? (*Facts to Go, Volume 14, Issue 1*). London, ON: Thames Valley Children's Centre.
- Lagosky, S., & Bartlett, D. (2016). Understanding knowledge use in parents of young children with cerebral palsy: An embedded case study. (*Facts to Go, Volume 12, Issue 2*). London, ON: Thames Valley Children's Centre.
- *McDougall, J., Nichols, M.,* & Wright, V. (2016). How can perceived quality of life be optimized for youth with chronic health conditions throughout adolescence? (*Facts to Go, Volume 12, Issue 3*). London, ON: Thames Valley Children's Centre.
- Nichols, M., McDougall, J., Baldwin, P., & Wright, V. (2016). Quality of life, self-determination, and spirituality: What youth with chronic conditions have to say. (Facts to Go, Volume 12, *Issue 1*). London, ON: Thames Valley Children's Centre.
- Scime, N., Bartlett, D., Brunton, L., & Palisano, R. (2016). Parents' experiences of classifying their children with cerebral palsy & recommendations for family-centred care. (*Facts to Go, Volume 12, Issue 4*). London, ON: Thames Valley Children's Centre.
- *McDougall, J.* (2015). Learning about quality of life for young people with severe or profound disabilities. (*Facts to Go, Volume 11, Issue 1*). London, ON: Thames Valley Children's Centre.
- *Turner, N.,* & *McDougall, J.* (2015). Implications of substance use for young people living with developmental disabilities. (*Facts to Go, Volume 11, Issue 2*). London, ON: Thames Valley Children's Centre.
- *Etherington, N.,* & *McDougall, J.* (2014). Understanding the mental health needs of children and youth with chronic conditions. (*Facts to Go, Volume 10, Issue 2*). London, ON: Thames Valley Children's Centre.
- Phelan, S., & Kinsella, E., A. (2014). Understanding disability and identity in childhood:
 Perspectives of children and their parents. (*Facts to Go, Volume 10, Issue 1*). London, ON:
 Thames Valley Children's Centre.

Lessons Learned Publication

At TVCC, staff members evaluate their practices, programs, and services to learn about what works best, and to enhance service delivery. As part of TVCC's knowledge transfer strategy, the *Lessons Learned* publication series provides staff an opportunity to communicate their findings, and share their lessons learned. These summaries can be accessed through our website at www.tvcc.on.ca

- Baldwin, P., Servais, M., Truppe, M., & McDougall, S. (2016). Getting Started at Thames Valley Children's Centre (GSAT, Part 2): Development of an organization best practice for entry to services. Lessons Learned, 4(1). London, ON: Thames Valley Children's Centre.
- Nichols, M., & McDougall, J. (2015). Healthcare professionals' perspectives on collecting research data over time: Interviewing youth for the 'Quality of Life' study. Lessons Learned, 3(1). London, ON: Thames Valley Children's Centre.
- Servais, M., Baldwin, P., Truppe, M., Bolack, L., Tjosvold, K., & Duncan, B. (2014). An evaluation of the Getting Started at Thames Valley Children's Centre Program (GSAT, Part 1). Lessons Learned, 2(1). London, ON: Thames Valley Children's Centre.



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EDUCATIONAL RESOURCES

The Integrated Clinical Education Research Team: Helping to Enhance Listening Practice (*King, G., Servais, M., Shepherd, T., Willoughby, C., Bolack, L.,* Moodie, S., & Strachan, D., 2017). *Learning to Listen: The Effective Listening and Interactive Communication Scales video.*

The Integrated Clinical Education Research Team: Helping to Enhance Listening Practice (*King, G., Servais, M., Shepherd, T., Willoughby, C., Bolack, L.,* Moodie, S., *Baldwin, P.,* Strachan, D., Knickle, K., Pinto, M., Parker, K., & McNaughton, N., 2015). *Listening skills simulations video series.*

RESEARCH PUBLICATIONS KEY FACTS

On average **8** journal articles are published or accepted for publication each year. Over the last 30 years, the following have been published.

- Peer-reviewed journal articles: 186
- Books: **2**
- Book chapters: 12
- Measurement tools: 6
- TVCC easy-to-read summaries: 40 Facts To Go/Focus On/Lessons Learned
- Articles in the TVCC's Family Link: 23



has shared knowledge in scientific journals and at conferences to make a difference in the lives of children and youth worldwide?



PRESENTATIONS

Our research findings have been communicated through presentations at international, national, provincial and regional conferences, and meetings. TVCC staff members made the following **external presentations** between **1 April**, **2014** and **30 September**, **2018**. Names of TVCC staff members are **bolded** and *italicized*. Names of former TVCC staff are *italicized* only.

INTERNATIONAL

American Academy for Cerebral Palsy and Developmental Medicine, Montreal, QC.

McDougall, J., & Wright, V. (2017, September). *Factors related to symptoms of social anxiety in youth with cerebral palsy.* Presented at the 71st Annual American Academy for Cerebral Palsy and Developmental Medicine, Montreal, QC.

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American Congress of Rehabilitation Medicine Conference, Toronto, ON.

McDougall, J., & Wright, V. (2014, October). *Perceived quality of life for youth with chronic conditions: Exploring related factors.* The 91st Annual American Congress of Rehabilitation Medicine Conference, Toronto, ON.

American Occupational Therapy Association Annual Conference, Baltimore, MD.

Bedell, G., & *McDougall, J.* (2014, April). *Further validation of the Child and Adolescent Scale of Environment (CASE)*. Presented at the American Occupational Therapy Association Annual Conference, Baltimore, MD.

Coaching in Leadership and Healthcare Conference, Boston, MA.

Schwellnus, H., King, G., Baldwin, P., & Servais, M. (2016, September). Solution-focused coaching in pediatric rehabilitation: Transformative experiences of service providers.
 Presented at the 2016 Coaching in Leadership and Healthcare Conference, Boston, MA.

International Positive Psychology Conference, Montreal, QC.

Servais, M., Schwellnus, H., *King, G., & Baldwin, P.* (2017, July). *The impacts and transformative experiences of solution-focused coaching: Clients' and clinicians' perspectives*. Presented at the 2017 International Positive Psychology Conference, Montreal, QC.

International Society for Augmentative and Alternative Communication, Broadbeach, Queensland, Australia.

Ryan, S., Shepherd, T., Renzoni, A.M., Servais, M., Bradley, K., Kingsnorth, S., Laskey, C., Oh, A., & Ward, K. (2018, July). Responsiveness of the Family Impact of Assistive Technology Scale for AAC interventions. Presented at the 2018 International Society for Augmentative and Alternative Communication, Broadbeach, Queensland, Australia.

International Society of Augmentative and Alternative Communication, Lisbon, Portugal.

Shepherd, T., Renzoni, A.M., Viegas, C., Kalp, F., & Ryan, S.E. (2014, June). Understanding factors that predict functional communication in children and youth with complex communication needs. Presented at the International Society of Augmentative and Alternative Communcation, Lisbon, Portugal.

International Society for Augmentative and Alternative Communication, Toronto, ON.

Vessoyan, K., Easton, B., Steckle, G., McDougall, J., & Mok, V. (2016, August). *Look what eye can communicate! Eye tracking technology for girls with Rett Syndrome.* Presented at the International Society for Augmentative and Alternative Communication, Toronto, ON.

International Society for Quality of Life Studies, Innsbruck, Austria.

McDougall, J., & Wright, V. (2017, September). *Trajectories of perceived quality of life for youth with chronic conditions.* Presented at the 15th Annual Conference of the International Society for Quality of Life Studies, Innsbruck, Austria.

World Congress on Brain Injury, Washington, DC.

Somers, S., Gray, J., & McDougall, J. (2010, March). *Managing complex concussions: A multidisciplinary approach to a multifaceted problem.* Presented at the World Congress on Brain Injury, Washington, DC.

World Congress on Spina Bifida Research and Care, San Diego, CA.

Lowry, K. (*for McDougall, J.,* & Wright, V.) (2017, March). *Subjective quality of life for youth with spina bifida*. Presented at the Third World Congress on Spina Bifida Research and Care, San Diego, CA.

World Federation of Occupational Therapy Congress, Yokohama, Japan.

Bedell, G. & McDougall, J. (2014, June). Further validation of the Child and Adolescent Scale of Environment (CASE). Presented at the World Federation of Occupational Therapy Congress, Yokohama, Japan.

Young Adult Institute Network Conference, New York, NY.

McDougall, J. (2015, May). Perceived quality of life for youth with disabilities: Exploring related factors using a mixed-methods approach. Presented at the 36th Annual Young Adult Institute Network Conference, New York, NY.

NATIONAL

Canadian Association of Occupational Therapists Conference, Vancouver, BC.

Baron, H., Hawrylyshyn, N., Hunt, S., & *McDougall, J.* (2018, June). Understanding quality of life in occupational therapy: A scoping review. Presented at the 2018 Canadian Association of Occupational Therapists Conference, Vancouver, BC.

Canadian Association of Pediatric Health Centres, Halifax, NS.

McDougall, *J.*, & Wright, V. (2016, October). *Perceived quality of life for youth with chronic conditions: A longitudinal study*. Presented at the Annual meeting of the Canadian Association of Pediatric Health Centres, Halifax, NS.

Canadian Positive Psychology Association Conference, Niagara-on-the-Lake, ON.

- *McDougall, J.* (2016, June). *Quality of life for youth with chronic conditions: A longitudinal study.* Presented at the 3rd Canadian Positive Psychology Association Conference. Niagara-on-the-Lake, ON.
- Servais, M., Schwellnus, H., King, G., Baldwin, P. (2016, June). Transforming clinical practice: Service providers' experiences of using solution-focused coaching in pediatric rehabilitation. Presented at the 3rd Canadian Positive Psychology Association Conference, Niagara-on-the-Lake, ON.

Canadian Positive Psychology Association Conference, Ottawa, ON.

McDougall, J. (2014, July). A 'positive' focus for pediatric rehabilitation. Presented at the 2nd Canadian Positive Psychology Association Conference. Ottawa, ON.

Canadian Positive Psychology Association Conference, Toronto, ON.

Servais, M., Shepherd, T., Bolack, L., Knickle, K., King, G., Moodie, S., Willoughby, C., Strachan, D., & Pinto, M. (2018, May). Strength-based listening: Enhancing clinician's listening and communication skills. Presented at the 4th Canadian Positive Psychology Association Conference, Toronto, ON.

Canadian Sociological Association Annual Meeting, St. Catharines, ON.

Etherington, N., **McDougall**, J., DeWit, D., & Wright, V. (2014, May). Emotional and behavioural difficulties among children and youth with chronic conditions: What role for mothers' mental health? Presented at the 2014 Canadian Sociological Association Annual Meeting, St. Catharines, ON.

PROVINCIAL

Bloorview Research Institute Symposium, Toronto, ON.

- *McDougall, J.,* & Wright, V. (2017, November). *Factors related to symptoms of social anxiety in youth with cerebral palsy.* Presented at the 12th Annual Bloorview Research Institute Symposium, Toronto, ON.
- Swett, C., Welton, C., *Shepherd, T.A.*, Renzoni, A.M., Ryan, S.E. (2017, November). *Reliability* and validity of the youth evaluation of products scale for augmentative and alternative communication (AAC) devices. Presented at the Annual Bloorview Research Institute Symposium, Toronto, ON.
- **McDougall**, J., & Wright, V. (2014, November). *Perceived quality of life for youth with chronic conditions: Exploring related factors.* Presented at the 9th Annual Bloorview Research Institute Symposium, Toronto, ON.

Shepherd, *T.A.*, Renzoni, A.M., Viegas C, Kalp F, & Ryan, S.E. (2014, November). *Understanding factors that predict functional communication in children and youth with complex communication needs*. Presented at the Annual Bloorview Research Institute Symposium. Toronto, ON.

Children's Health and Environment Workshop & Symposium, London, ON.

Elton-Marshall, T., Bernard, S., Loebach, J., Gilliland, J., George, J., Faulkner, G., Folino, S., Fusco, C., Leatherdale, S., *McDougall, J.*, O'Brien, C., Spencer, T., Lynch, M., & Wells, S. (2017, June). *"They are having fun but they are still inside the house and not together": A qualitative study of barriers and facilitators of active outdoor play among youth in Grades 6 to 8.* Presented at the Children's Health and Environment Workshop & Symposium: Moving Research to Action for Healthy Kids, London, ON.

Empowered Kids Ontario Conference, Toronto, ON.

- **McDougall**, J. & Wright, V. (2018, November). What contributes to multidimensional life satisfaction for youth with chronic conditions? Presented at the 2018 Empowered Kids Ontario Conference, Toronto, ON.
- Servais, M., Renaud, S., Dinsmore, B., Holloway, D., Poustie, L., McQueen, L., Sneddon, L., Salgado, L., Young, M., Byron-Palenchuk, M., McTavish, M., Conkey, N., Parker, R., & Vanderborght, V. (2018, November). Transforming services: Staff perspectives on changing and developing autism services. Presented at the 2018 Empowered Kids Ontario Conference, Toronto, ON.

Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.

- *McDougall, J., Vessoyan, K., Steckle, G., Easton, B., Nichols, M.,* & Mok Siu, V. (2017, November). *Look what 'Eye' Can Communicate.* Presented at the 2017 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., King, G., Schwellnus, H., & Baldwin, P. (2017, November). Families' experiences and outcomes with a Solution-Focused Coaching (SFC-peds) intervention. Presented at the 2017 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., Shepherd, T., Willoughby, C., Bolack, L., King, G., Moodie, S., & Strachan, D. (2017, November). Enhancing listening: How to listen in complex situations. Presented at the 2017 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., Truppe, M., Gritzan, J., Pritchard, L., Vanderborght, V., Widdifield, L. & Shugar, D. (2017, November). Collaborative integrated service: Rehabilitation and autism therapists inIBI classrooms. Presented at the 2017 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON

- *McDougall, J.* & Wright, V. (2016, November). *Quality of life for youth as they move through adolescence: People, purpose, and passion matter.* Presented at the 2016 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Renwick, C., Inkpen, J., *LaPorta, J.*, & Harvey, D. (2015, November). *Building a disability common research agenda*. Presented at the 2015 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., King, G., Shepherd, T., Moodie, S., Willoughby, C., Knickle, K., Bolack, L., Baldwin, P., Strachan, D., Pinto, M., Parker, K., McNaughton, N., & Savage, D. (2015, November). Enhancing the listening and communication skills of clinicians: Research findings and best practices from an inter-professional educational interventi. Presented at the 2015 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- *King, G., Shepherd, T., Servais, M., Willoughby, C.,* & Knickle, K. (2014, November). *Enhancing clinical listening skills: A collaborative partnership involving clinical practice, research, and education*. Presented at the 2014 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- *McDougall, J.*, Wright, V., Baldwin, P., Miller., L., Evans, J., *Nichols, M.*, & Etherington, N. (2014, November). *Perceived quality of life for youth with chronic health conditions: Exploring related factors using a mixed-methods approach*. Presented at the 2014 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., & Baldwin, P. (2014, November). Transforming practice: Key elements and strategies for using a strengths-based approach in pediatric rehabilitation. Presented at the 2014 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.
- Servais, M., Heeney, M., McDougall, S., Baldwin, P., Gritzan, J., McLean, M. E., Nicholson, C., Stapleton, G., & Truppe, M. (2014, November). Transforming and enhancing entry-toservice for families: An organization's experience with listening and responding to families' priority needs. Presented at the 2014 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.

Ontario Simulation Exposition, Toronto, ON.

Servais, M., King, G., Shepherd, T., Willoughby, C., Bolack, L., Moodie, S., Baldwin, P., Strachan, D., Knickle, K., Pinto, M., Parker, K., McNaughton, N., & Savage, D. (2015, December).
 Curriculum design: Findings and best practices from an educational intervention to enhance listening skill development of clinicians. Presented at the 2015 Ontario Simulation Exposition, Toronto, ON.

Paediatric Research Day, London Health Science Centre, London, ON.

- *McDougall, J., Vessoyan, K., Steckle, G., Easton, B., Nichols, M.,* & Mok Siu, V. (2018, May). *Look what 'Eye' Can Communicate*. Presented at the Thirteenth Annual Paediatric Research Day, London Health Science Centre, London, ON.
- *McDougall, J., & Servais, M.* (2017, May). *Thames Valley Children's Centre Research Program: Informing clinical practice and optimizing quality of life for children and families.* Presented at the Thirteenth Annual Paediatric Research Day, London Health Science Centre, London, ON.
- Servais, M., King, G., Schwellnus, H., & Baldwin, P. (2017, May). Client-centred approach: Clinician's experiences using solution-focused coaching in pediatric rehabilitation. Presented at the Thirteenth Annual Paediatric Research Day, London Health Science Centre, London, ON.

Society for Teaching and Learning in Higher Education (STLHE) Conference, London, ON.

- Servais, M., King, G., Shepherd, T., Willoughby, C., Bolack, L., Moodie, S., Baldwin, P., Strachan, D., Knickle, K., Pinto, M., Parker, K., McNaughton, N., & Savage, D. (2016, June). Curriculum design: Findings and best practices from an educational intervention to enhance listening skill development of clinicians. Presented at the 2016 Society for Teaching and Learning in Higher Education (STLHE) Conference, London, ON.Ward Summer Student Research Day at Holland Bloorview, Toronto, ON.
- Tsui, T., Kingsnorth, S., Bradley, K., Hilmer, M., Laskey, C., Renzoni, A. M., Ryan, S., Servais, M., Shepherd, T., & Ward, K. (2014, July). Profiling the Canadian scene: A scan of augmentative and alternative communication clinics. Presented at the 2014 Ward Summer Student Research Day at Holland Bloorview, Toronto, ON.

INVITED PRESENTATIONS

Community Services Coordination Network, London, ON.

Servais, M., Shepherd, T., Willoughby, C., King, G., Moodie, S., *Bolack, L.,* & Strachan, D. (2018, September). *Listening your way through complex communication situations.* Presented at the Community Services Coordination Network, London, ON.

Grandview Children's Centre, Oshawa, ON.

Shepherd, T., Moodie, S., *Willoughby, C.,* Knickle, K., *Servais, M.,* King, G., Bolack, L., & Strachan, D. (2017, February). *Effective listening and communication: Working on clinical teams and with families. How to listen in complex situations.* Presented at the Grandview Children's Centre, Oshawa, ON.

Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.

Ryan, S., *Laskey, C.*, Renzoni, A. M., *Shepherd, T.*, & *Servais, M*. (2014, November). *AAC Outcomes for Kids Research Alliance: Origins of an integrated knowledge translation network*. Presented at the 2014 Ontario Association of Children's Rehabilitation Services (OACRS) Conference, Toronto, ON.

Western University, London, ON.

- *Servais, M.*, Moodie, S., *Bolack, L., King, G., Shepherd, T., Willoughby, C.*, & Strachan, D. (2018, October). *Clinical listening in complex situations*. Presentation for the Speech Language Pathology and Audiology student clinicians, Faculty of Health Sciences, Western University, London, ON.
- Servais, M., & Bolack, L. Moodie, S., King, G., Shepherd, T., Willoughby, C., & Strachan, D. (2018, October). Learning to listen: Deepening clinical listening skills. Research findings and practical strategies. Presentation for the Speech Language Pathology and Audiology student clinicians, Faculty of Health Sciences, Western University, London, ON.
- **McDougall**, J. (2017, November). Applying the ICF/ICF-CY to enhance services and the quality of life of children and youth with chronic health conditions. Presentation for graduate students at Elborn College, Western University, London, ON.
- *Servais, M.* (2017, November). *Learning to listen: Deepening clinical listening skills.* Presentation for the Speech Language Pathology and Audiology student clinicians, Faculty of Health Sciences, Western University, London, ON.
- *Servais, M.*, Moodie, S., *Baldwin, P.* (2015, March). *Learning to listen: Deepening listening skills.* Presentation for Audiology student clinicians, Faculty of Health Sciences, Western University, London, ON.
- *McDougall*, *J*. (2015, October). *Perceived quality of life for youth with chronic health conditions: Exploring related factors using a mixed methods approach*. Presented at Elborn College, Western University, London, ON.
- *McDougall*, *J*. (2015, November). *Applying the ICF to enhance services and the quality of life of children and youth with chronic health conditions*. Presented at Elborn College, Western University, London, ON.
- **McDougall**, J. (2015, January). Applying the ICF to enhance services and the quality of life of children and youth with chronic health conditions. Presented at the Faculty of Health Sciences, Western University, London, ON.

EXTERNAL NON-PEER REVIEWED PRESENTATIONS

Western University, London, ON.

Baron, H., Hawrylyshyn, N., Hunt, S., & *McDougall, J.* (2018, April). *Understanding quality of life in occupational therapy: A scoping review.* Presented at the 2018 Evidence-based Practice Conference, Elborn College, Western University, London, ON.

INTERNAL RESEARCH PRESENTATIONS

The Thames Valley Children's Centre, London, ON.

- Servais, M., Shepherd, T., Willoughby, C., King, G., Moodie, S., Bolack, L., & Strachan, D. (2018, November). Listening your way through complex communication situations: Deepening listening skills. Presented for the Ontario Autism Program, Thames Valley Children's Centre, London, ON. (Invited presentation).
- *Servais*, *M*. (2017, November). *Wellness series: Exploring evidence-based practices for flourishing. Practicing self-compassion and other mindsets for personal growth and development*. Presented at the Thames Valley Children's Centre, London, ON.
- Servais, M. (2017, June). Wellness series: Exploring evidence-based practices for flourishing. Savouring life's joys and immersing in nature. Presented at the Thames Valley Children's Centre, London, ON.
- Shepherd, T., Servais, M., Moodie, S., Willoughby, C., Strachan, D., Bolack, L., King, G., & Knickle, K. (2017, May). Listening your way through complex situations: Research findings and practical strategies. Presentation for the Early Childhood, School Age, and Adolescent Programs, Thames Valley Children's Centre, London, ON.
- *Servais, M.* (2017, April). *Wellness series: Exploring evidence-based practices for flourishing. Finding purpose, meaning, and passion.* Presented at the Thames Valley Children's Centre, London, ON.
- Servais, M. (2017, March). Wellness series: Exploring evidence-based practices for flourishing. Cultivating optimism and positivity. Presented at the Thames Valley Children's Centre, London, ON.
- Shepherd, T., Moodie, S., Servais, M., Willoughby, C., Strachan, D., King, G., & Bolack, L. (2017, March). Listening your way through complex situations: Research findings and practical strategies. Presentation for the Clinical and Technical Specialty Services Team, Thames Valley Children's Centre, London, ON.
- *Servais, M.* (2017, February). *Wellness series: Exploring evidence-based practices for flourishing. Expressing gratitude and appreciation.* Presented at the Thames Valley Children's Centre, London, ON.

- *Servais, M.* (2017, January). *Wellness series: Exploring evidence-based practices for flourishing. Practicing mindfulness and meditation.* Presented at the Thames Valley Children's Centre, London, ON.
- **McDougall**, J. & Turner, N. (2016, June). The 'Quality of Life' study and the 'I Have Something to Say project'. Presented to Members of Provincial Parliament. Thames Valley Children's Centre: London, ON.
- **McDougall**, J. (2015, November). Presentation of Thames Valley Children's Centre's Research Report (2010-2014). Presented at the Operational Priorities Committee Meeting, Thames Valley Children's Centre,: London, ON.
- Servais, M., Heeney, M., McDougall, S., Baldwin, P., Gritzan, J., McLean, M. E., Nicholson, C., Stapleton, G., & Truppe, M. (2015, March). Transforming and enhancing entry-to-service for families: An organization's experience with listening and responding to families' priority needs. Presented at the Operational Priorities Committee, Thames Valley Children's Centre, London, ON.
- Servais, M., Baldwin, P., Gritzan, J., McLean, M. E., Truppe, M., McDougall, S. (2014, July). Highlights of the GSAT documentation evaluation results. Presentation for the Early Childhood Services and Family and Community Services Programs, Thames Valley Children's Centre, London, ON.
- Servais, M., Baldwin, P., Gritzan, J., McLean, M. E., Truppe, M., McDougall, S. (2014, May). Highlights of the GSAT documentation evaluation results. Presentation for the Documentation Committee, Thames Valley Children's Centre, London, ON.
- **McDougall**, J. (2014, April). The impact of personal, impersonal, and environmental factors on changes in quality of life for youth with chronic conditions: learning from families' perspectives. Presented at the Thames Valley Children's Centre's Leadership Team Meeting, Thames Valley Children's Centre, London, ON.

WEBINARS

- Ryan, S. E., *Shepherd, T.,* Renzoni, A. M., *Servais, M.,* Kingsnorth, S., *Laskey, C.,* Ward, K., Bradley, K. (2017, November). *Toward improving AAC services for young people with complex communication needs.* (Video webinar link: youtu.be/n_w62uF721U).
- Shepherd, T.A., Renzoni, A.M., & Ryan, S.E. (2016, June). *Measuring real-world outcomes of* AAC for children and youth in school activity settings. (Video webinar link: www.youtube.com/watch?v=DhOAbXnGaDM).
- *McDougall*, *J.*, & Baldwin P. (2015, March). Quality of life for youth with chronic conditions: Learning from Youths' and Parents' Perspectives. Canadian Association of Pediatric Health Centre. (Video webinar link: www.youtube.com/watch?time_continue=25&v=70ncstGz1f4).

Ryan, S. E., *Servais*, *M.*, *Shepherd*, *T.*, *Laskey*, *C.*, Renzoni, A. M., Kingsnorth, S., Ward, K., & Bradley, K. (2014, June). Introduction to the AAC Outcomes for Kids Alliance and introduction to the FIATS-AAC research study. Available at www.youtube.com/watch?v=ZtnQHp66dAY&feature=youtu.be

STAFF CHILD HEALTH SYMPOSIUM PRESENTATIONS

The 'P-Words': Play, Physical Activity, People, Participation, and Possibilities

- *Downs, M.,* MacDermid, J., & *McDougall, J.* (2018, May). *The facilitators and barriers of physical activity engagement for youth and young adults with childhood onset physical disabilities.* Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- Elton-Marshall, T., Bernard, S., Loebach, J., Gilliland, J., George, J., Faulkner, G., Folino, S., Fusco, C., Leatherdale, S., *McDougall, J.*, O'Brien, C., Spencer, T., Lynch, M., & Wells, S. (2018, May). A qualitative study of barriers and facilitators of active outdoor play among youth in grades six to eight. Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- *Faragher, K.,* Hall, C., *Machado, F.,* & Quinlan, L. (2018, May). *Camps on TRACKS-Creating meaningful interactions for children with disabilities and their peers.* Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- Love, D., Campbell, C., Andrade, A., *Teichrob, R.,* & Pearlman, L. (2018, May). *Shared decision making pilot in pediatric neurology and related clinics.* Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- **McDougall**, J., & Wright, V. (2018, May). What contributes to multidimensional life satisfaction for youth with chronic health conditions? Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- Servais, M., Flanagan, T., Truppe, M., Gritzan, J., Pritchard, L., Vanderborght, V., Widdifield, L., & Shugar, D. (2018, May). Evaluation of a collaborative, integrated approach to service delivery: Rehabilitation and autism therapists in IBI classrooms. Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- Servais, M., King, G., Schwellnus, H., & Baldwin, P. (2018, May). Impact of a strength-based intervention: Families' experiences and outcomes with solution-focused coaching (SFC-peds). Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.

- Servais, M., Ryan, S., Shepherd, T., Renzoni, A. M., Bradley, K., Kingsnorth, S., Laskey, C., Ward, K., & Oh, A., (2018, May). Developing meaningful outcome measures: The Family Impact of Assistive Technology Scale for AAC interventions (FIATS-AAC). Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.
- *Turner, N.* (2018, May). *The universality of music: Using creativity to increase access to the benefits of music!* Presented at the 5th Annual Child Health Symposium, Thames Valley Children's Centre, London, ON.

Optimizing Child Health: Address Stress for Success

- Bolack, L., Servais, M., King, G., Shepherd, T., Willoughby, C., Baldwin, P., Knickle, K., Pinto, M., Parker, K., McNaughton, N., & Savage, D. (2017, May). Findings and best practices from an educational intervention to enhance listening skill development of clinicians. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- Caryn, R. & **Scholtes**, *C*. (2017, May). Three-Dimensional gait analysis for cerebral palsy and its role in the clinical decision making process. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- **Corbeil**, L. (2017, May). A clinical perspective: Reciprocal crawling a foundational building block for motor control, coordination and balance. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- Faragher, K., Hall, C., Quinlan, L., Landowski, B., Morrison, A., Robertson, A., Machado, F., & Lusk, S. (2017, May). Peer-mediated social skills training in a city-wide, inclusive summer camp. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *McDougall, J., Nichols, M.,* & *Lowry, K.* (2017, May). *Subjective quality of life for youth with spina bifida*. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *McDougall*, *J.*, & *Servais*, *M*. (2017, May). *Thames Valley Children's Centre Research Program: Informing clinical practice and optimizing quality of life for children and families*. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- **McDougall**, J., & Wright, V. (2017, May). Factors related to symptoms of social anxiety in youth with cerebral palsy. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- Love, D., Mabaya, G., Katz, S., Lawson, M., Price, A., Radhakrishnan, D., Mah, J.K., Korngut, L., McMillan, H.J., *Scholtes, C.*, Shephard, A., Hoey, L., Heletea, M., & Campbell, C. (2017, May). Understanding decision needs for respiratory interventions in pediatric neuromuscular disorders. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.

- *Servais, M.,* Schwellnus, H., *King, G.,* & *Baldwin, P.* (2017, May). *Clinicians' experiences using solution-focused coaching in pediatric rehabilitation.* Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *Servais*, *M.*, Schwellnus, H., *King, G.*, & *Baldwin*, *P.* (2017, May). *Impacts on practice: Solution-focused coaching in pediatric rehabilitation*. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *Turner, N.* (2017, May). *Engaging in research as a young clinician: Lessons learned.* Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *Turner, N.* (2017, May). *Let's talk about sex: Supporting youth with disabilities in understanding, exploring, and discussing sexuality.* Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *Vessoyan, K., Batorowicz, B., & Steckle, G.* (2017, May). "On With The Show"- Exploring participation experiences of young people with and without disabilities. Presented at the 4th Annual Child Health Symposium. Western University, London, ON.
- *Vessoyan, K., Easton, B., Steckle, G., Nichols, M.,* Mok Siu, V., & *McDougall, J.* (2017, May). *Four girls with Rett syndrome using eye tracking technology for communication: Goal attainment, psychosocial impact, and device satisfaction.* Presented at the 4th Annual Child Health Symposium. Western University, London, ON.

Resilience Building in the Family and Community

- Batorowicz, B., Kulis, A., Chrabota, U., & Zychowicz, P. (2016, May). Why children do not participate in after-school activities: parents' perspectives. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Batorowicz, B., Stadskleiv, K., Von Tetzchner, S., & Missiuna, C. (2016, May). Including children with complex communication needs and severe motor impairments in Play with Peers. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **Bell**, J., & **Orsini**, **A**. (2016, May). Parent mentoring at Thames Valley Children's Centre. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Goffin, C., Ansari, D., Campbell, C., *Frid, P.,* & Mazza, E. (2016, May). *Numerical processing in children with cerebral palsy.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **Lynch**, K. (2016, May). Teaching is treating the role of pain education in helping paediatric patients with chronic pain. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.

- Mazza, E., Campbell, C., *Frid, P.*, Cassidy, C., & Hicks, R. (2016, May). *Childhood Cerebral Palsy Integrated Neuroscience Discovery Network "CP-NET"- clinical database platform at Thames Valley Children's Centre.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *McDougall, J.,* Marshall, T., Faulkner, G., Fusco, C., Gilliland, J., Loebach, J., O'Brien, C., Wells, S., Killip, S., Spencer, T., & Archer, J. (2016, May). *Children's outdoor play experiences: How they play and why they benefit.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *McDougall, J.,* Wright, V., Miller, L., & *Nichols, M.* (2016, May). *Perceived quality of life for youth with chronic health conditions: Exploring changes over time.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Nichols, M., McDougall, J., Benincasa, K., & Turner, N. (2016, May). Teen Quality of Life (T-QOL) survey: Developing a new measure of QOL for youth with chronic health conditions. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *Servais, M.*, (2016, May). A primer on using strengths-based approaches in practice. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Servais, M,. Schwellnus, H., King, G., & Baldwin, P. (2016, May). Transforming clinical practice: Clinicians' experiences of using solution-focused coaching in pediatric rehabilitation. Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **Shepherd**, **T**., Surins, H., Wojnowska, C., Renzoni, A., & Ryan, S. (2016, May). What do youth think about their communication devices? Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *Teichrob, R.* (2016, May). *Mindfulness practice from OM to Fight Song.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *Turner, N., & McDougall, J.* (2016, May). *The 'I Have Something to Say' Project: Young People and their Families Speak Out about Special Needs and Change.* Presented at the 3rd Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.

Connecting with Youth: Research and Best Practices in Child Health

- *Baldwin, P.,* & *Flanigan, A.* (2015, May). A conversation: Facilitating the use of personal strengths and resources during transitions. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- **Benincasa**, K., & **Stevens**, P. (2015, May). Youth mentor program learning as we go. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- **Burnett, M**., & **Stevens**, *P*. (2015, May). Youth for youth why youth led activities make a difference. Presented at the 2nd Annual Child Health Symposium. Western University. London, ON.
- **Dworschak-Stokan**, **A**. (2015, May). Speech and language in 22Q.11 deletion syndrome. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- **Faragher**, K. (2015, May). A conversation about using social media to engage recreation and *leisure participation*. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Evans, L.*, Lim, S., *Kraft, J.*, & *Baldwin, P.* (2015, May). *Solution-focused communication boards for client-directed care.* Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Fowles, L*. (2015, May). *A clinical perspective: Dealing with anxiety in children and adolescents.* Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Machado*, *F.*, *Faragher*, *K.*, *Hall*, *C.*, & Quinlan, L. (2015, May). *Camps on TRACKS-Creating meaningful interactions for children with disabilities and their peers*. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *McAllister*, *E.*, & *Johnson*, *S*. (2015, May). *Being a wise consumer: How to evaluate and select treatments for children and youth with autism spectrum disorders.* Presented at the 2ndAnnual Child Health Symposium. Western University, London, ON.
- **McDougall**, J. (2015, May). Learning about quality of life for young people with severe or profound disabilities. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *McDougall*, *J.*, Wright, V., *Baldwin*, *P.*, *Evans*, *J.*, *Nichols*, *M*., & *Etherington*, *N.* (2015, May). *Quality of life and self-determination: Youth with chronic health conditions make the connection*. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- **McDougall**, J., Wright, V., & Miller, L. (2015, May). *Perceived quality of life for youth with chronic conditions: Exploring related factors.* Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Nichols, M.*, & *McDougall, J.* (2015, May). *Healthcare professionals' perspectives on collecting data over time: Interviewing youth for the "Quality of Life" study.* Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- **Servais**, **M**., & Baldwin, P. (2015, May). Transforming practice: Key elements and strategies for using a strengths-based approach in pediatric rehabilitation. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- Servais, M., King, G., Moodie, S., Strachan, D., Shepherd, T., Bolack, L., Willoughby, C., Baldwin, P., Parker, K., Savage, D., Knickle, K., McNaughton, N., & Pinto, M. (2015, May). Developing authentic clinical simulations for effective listening and communication. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.

- Servais, M., King, G., Shepherd, T., Willoughby, C., Bolack, L., Moodie, S., Baldwin, P., Strachan, D., Knickle, K., Pinto, M., Parker, K., McNaughton, N., & Savage, D. (2015, May). Findings and best practices from an educational intervention to enhance listening skill development of clinicians. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Servais, M.* & *McDougall, S.* (2015, May). *Knowledge exchange: AAC and Autism service providers collaborating for communication*. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.
- *Servais, M., McLean, M. E., Baldwin, P., Truppe, M.* & *Gritzan, J.* (2015, May). *Important elements of clinical documentation: What matters to early years families and the creation of a resource tool for clinicians*. Presented at the 2nd Annual Child Health Symposium. Western University, London, ON.

<u>Collectively Creating Connections and Collaborations: Research and Best</u> <u>Practices in Child Health</u>

- *Baldwin, P.* (2014, May). *Is there therapeutic value In the use of telecommunications?* Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *Baldwin, P.* (2014, May). *Using strengths-based questions in evaluation and research.* Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Baldwin, P., Evans, J., Wright, V., Etherington, N., Nichols, M., & McDougall, J. (2014, May). Spirituality and quality of life: What youth with disabilities have to say. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Etherington, N., **McDougall**, J., & Wright, V. (2014, May). Does mom matter? Examining the link between maternal characteristics and the emotional and behavioral outcomes of children and youth with chronic conditions. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **Gray**, J., Somers, S., & Bailey, P. Concussion in children and youth: Tracking the trends in a pediatric ABI program. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **McDougall**, J. (2014, May). The ICF What's it worth to pediatric rehabilitation? Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **McDougall**, J. & Bartlett, D. (2014, May). *How many hoops do I have to jump through?* Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- **McDougall**, J. & Good, D. (2014, May). Successful school reintegration for students who have experienced an acquired brain injury. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.

- *McDougall, J.*, Wright, V., & Miller, L. (2014, May). *Quality of life for youth with chronic health conditions: Exploring related factors.* Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Servais, M., Ryan, S., Bradley, K., Hilmer, M., Kingsnorth, S., Laskey, C., Renzoni, A., Shepherd, T., Ward, K., Pinto, M., & Etherington, N. (2014, May). Toward improvement of augmentative and alternative communication services for young people with complex communication needs: Development of an outcome measure. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Shepherd, T., Baldwin, P., Bolack, L., Servais, M., Willoughby, C., Strachan, D., Moodie, S., Parker, K., Savage, D., Knickle, K., McNaughton, N., & King, G. (2014, May). Improving listening skills through simulation for pediatric rehabilitation therapists. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- Somers, S., Gray, J., Kendall, M., & Frid, P. (2014, May). Responding to changing needs: A support group model of care for female adolescents with persistent concussion symptoms. Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.
- *Vessoyan, K., Steckle, G., Easton, B., McDougall, J.*, Mok, V., *Laskey, C.* (2014, May). *Can eye-tracking technology help girls with Rett Syndrome meet their individualized goals for communication?* Presented at the 1ST Annual Child Health Symposium. Thames Valley Children's Centre, London, ON.

DISCOVERY SERIES SESSIONS

The "Discovery Series" sessions provide researchers with a forum to present the results of their research projects to the TVCC staff members. The following Discovery session was held between 2014 and 2018:

- Bartlett, D. (2017, November). *Monitoring development of children with cerebral palsy or gross motor delay.* Presented at the Thames Valley Children's Centre, London, ON.
- Scime, N. (2016, April). *Parents' experiences and perceptions when classifying their children with cerebral palsy: Advice for service providers.* Presented at the Thames Valley Children's Centre, London, ON.



RESEARCH PRESENTATION FACTS

Since 1988, TVCC staff members have made **350** external presentations.

Over the last 30 years, the following presentations have been made.

- International conferences: 98
- National conferences: 39
- Provincial conferences: 159
- Invited presentations: 30 (14 Internationally, 1 Nationally, and 15 Provincially)
- Non-peer reviewed presentations: 24

International presentations have been made at the following:

- American Academy for Cerebral Palsy and Developmental Medicine
- American Cleft Palate/Craniofacial
 Association
- American Congress of Rehabilitation Medicine
- American Educational Research Association
- American Occupational Therapy Association
- American Psychological Association
- American Society for Neurorehabilitation
- American Society for Surgery of the Hand
- American Speech-Language and Hearing Association
- Assistive Technology Industry Association
- Association for the Care of Children's Health
- Australian Academy of Cerebral Palsy and Developmental Medicine
- Australian Cerebral Palsy Association
- Child and Youth Health, Third World Congress
- Child Health Psychology
- College of Occupational Therapists United Kingdom
- Congress on Spina Bifida Research and Care
- Danish Resource Centre of Brain Injury
- Early Childhood Intervention Australia National
- European Congress on Psychology
- European Federation for Research in Rehabilitation
- European Speech Communication Association
- Interdisciplinary Advances in Qualitative Methods
- International Conference on Cerebral Palsy
- International Conference on the Scientific Basis of Health Sciences

- International First Conference on Family-Centered Care
- International Institute for Qualitative Methodology
- International Meeting for Autism Research
- International Paediatric Neuromuscular Rehabilitation
- International Positive Psychology Association Conference
- International Seating Symposium
- International Society for Applied Behaviour Analysis
- International Society of Augmentative and Alternative Communication
- International Society for Quality of Life Studies
- International Symposium of Adapted Physical Activity
- Joint Congress of the Canadian Physiotherapy Association and American Physical Therapy Association
- North American Brain Injury Society
- North American Collaborating Centre Conference on ICF
- North American ICIDH-2 Conference
- North Coast Regional Conference of the Society of Pediatric Psychology
- Second City Disabilities Studies in Education, New York
- Society for Research in Child Development
- Solution-Focus Brief Therapy Association Annual Conference
- University of California San Diego New Frontiers in Pediatric Traumatic Brain Injury
- World Congress on Brain Injury
- World Federation of Occupational Therapists Congress
- Young Adults Institute Network Conference

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