

Research Report

2006 – 2010





Welcome to Thames Valley Children's Centre's Research Report!

This report illustrates some of the scientific inquiry that has taken place here at Thames Valley Children's Centre (TVCC). Summarizing years of work done by hundreds of researchers, clients, families, and clinicians is a formidable challenge. Capturing the vision of TVCC and its Research Program is simpler: Our Clients At Their Best.

At Thames Valley Children's Centre, we seek to bring understanding, inquiry, and innovation to the work we do with children and youth across Southwestern Ontario. And we 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 evidence 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. Their contributions are not always as obvious as when they are a named investigator or author – their enthusiasm may be the spark that ignites others' passion for research, and their expertise is behind many, many internal evaluation activities. At the same time, we were recently awarded a large, multi-year grant from the Canadian Institute for Health Research (CIHR) to do groundbreaking research into Quality of Life for youth with chronic conditions. We take great pride in this balance between supporting the day-to-day work of TVCC and producing original research of the highest academic standards.

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



Thames Valley Children's Centre 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 6,900 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, and
- adding to knowledge.

RESEARCH AT TVCC

According to Thames Valley Children's Centre's (TVCC) 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.

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 paediatric rehabilitation research that is an integral part of pediatric services.

RESEARCH PROGRAM FUNCTIONS

The Research Program assists staff with research-related activities through direct involvement, consultation, education, and the provision of resources.

Direct and Consultation Services

Services include providing advice on and carrying out all aspects of the research/evaluation process (e.g., formulating a research question, designing a questionnaire, analysing 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, many in-house quality assurance activities take place at the centre. TVCC researchers also provide support for these activities.

Examples of Quality Assurance Activities

- Assessing caregiver satisfaction with Autism Services
- Developing a Relationship-Centred Practice Tool
- Conducting a Parent Mentor Program assessment
- Conducting an assessment of "Getting Started at TVCC"
- Developing a client satisfaction survey

Education

Information sessions are arranged in which staff members share the results of TVCC 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 staff members to maximize the impact of findings on clinical practice by sharing findings with staff members from other TVCC programs.

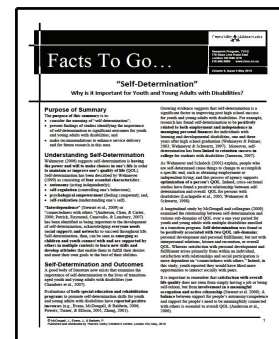
* Discovery

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



* Facts to Go

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.



Resources

The Research Program provides general information and resources on how to approach all aspects of the research/evaluation process.

RESEARCH PROGRAM TEAM

Staffing

The Research Program Team includes:

- A Director
- Centre Researchers
- A Research Officer

The Research Program is now 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. 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. Volunteers assist researchers with administrative tasks.

Team Members

Director

Karen Lowry, M.Cl.Sc. (2006-present)
Gillian King, Ph.D. (1988-2006)

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. candidate (2000-present)

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

Research Officer

Kathryn Hayman (2009-present)
Sara Farhan (2008-2009)
Linda Smith (1994-2008)

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 Coordinator

Megan Nichols, M.Sc. (2010-present)
Jonathan Schmidt, M.Sc. (2009-2010)

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 the writing of articles and presentations.

Volunteer

Susan Readings (2005-present)

The **Research Program Volunteer** is a valuable and dedicated resource to the department. The Volunteer completes requested tasks such as mass mailings of publications and maintaining databases.

Research Key Fact: Staff and Research



Since the creation of the Research Program **21 years** ago:

- ❖ **125 staff members** have been involved in research projects.
- ❖ TVCC staff members have been **principal investigators on 78 projects**.
- ❖ Members from **all of TVCC's programs and therapy disciplines** have been involved in research.
- ❖ **45 staff members** have been involved in **more than one research project**.

A LIFE NEEDS MODEL OF SERVICE

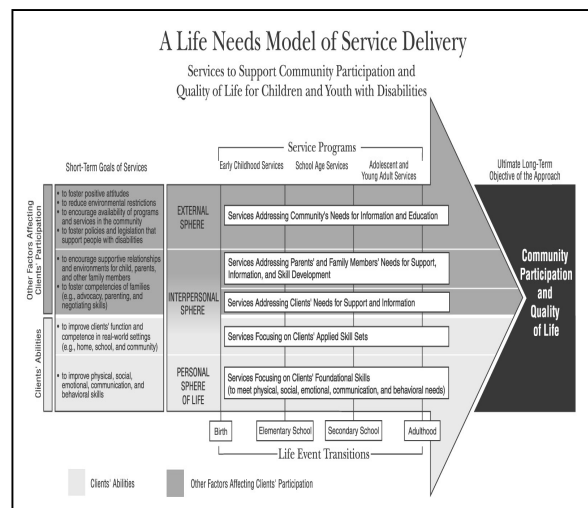
In conjunction with others at TVCC, the Research Program has played an instrumental role in the conceptualization of a model of services needed by children with disabilities, their families, and members of the community who play important roles in these children's lives.

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.



RESEARCH PROJECT APPROVAL PROCESS

At Thames Valley Children's Centre, all internal and external research and evaluation projects involving TVCC clients and/or their families and requiring informed consent must be approved by:

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

Informed consent is required if:

- The participants will be asked to complete any measures or questionnaires that they would not normally complete in the course of intervention or for quality assurance purposes;
- Participants will be randomly assigned to therapy conditions or waiting lists; and/or
- The researcher intends to present or publish the results.

Thames Valley Children's Centre 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 University of Western Ontario, and
- Members of a rehabilitation discipline.

Research Advisory Committee 2006-2010

Dr. Craig Campbell (*Member: 2007-present*)

Pediatric Neurologist
Children's Hospital, London Health Sciences Centre

Dr. Pamela Frid (*Member: 2003-present*)

Medical Director
Thames Valley Children's Centre

Dr. Robert Gardner (*Member: 1995-present*)

Department of Psychology
University of Western Ontario

Dr. Marilyn Kertoy (*Member: 1992-present*)

School of Communication Sciences and Disorders
University of Western Ontario

Jamie Kneale Fanning (*Member: 2003-present*)

Neonatal Intensive Care Unit
St. Joseph's Health Care London

Dr. Angela Mandich (*Member: 2007-present*)

Director, and Graduate Chair
School of Occupational Therapy
University of Western Ontario

Dr. Jan Miller Polgar (*Member: 1993-2007*)

School of Occupational Therapy
University of Western Ontario

Dr. Janette McDougall (*Chair: 2005-present*)

Centre Researcher, Research Program
Thames Valley Children's Centre

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** - who contribute time, energy, and commitment to finding the answers.
- ❖ The **clients and families** - who share their experiences and provide their valuable time and insights.
- ❖ Our **collaborators** - who contribute their expertise and important new perspectives.
- ❖ The **TVCC Board of Directors, Chief Executive Officer, and Program Directors** - who provide their support to research.
- ❖ The **Research Advisory Committee** - who ensure that our research is of the highest quality.

PROJECTS APPROVED BY RAC

The following **29 studies** were reviewed by the Research Advisory Committee between **1 April 2006 and 31 March 2010**, and approved to proceed. The names of current TVCC staff members are italicized and bolded. Names of former TVCC staff are italicized only.

June 2006

Focus on function study (Mary Law, Johanna Darrah, Peter Rosenbaum, Dianne Russell, Stephen Walter, Brenda Wilson, & Terry Petrenchik).

Functional change in occupations of children with hemiplegia after a modified constraint induced therapy program (*Teresa Mulligan*, & Julie South).

September 2006

Evaluating the role of 7q11.23 duplications in the pathogenesis of severe speech and language disorder (Lucy Osborne, & Janis Cardy).

November 2006

The social context, challenges, and strengths in the everyday lives of girls (Helene Berman).

Identification and development of common outcome indicators for Ontario's Children's Treatment Centres (CTCs) (Virginia Wright).

Effects of an exercise program for children with spastic diplegic cerebral palsy (*Flora Stephenson*, Sandi Spaulding, ***Cheryl Scholtes***, Mary Jenkins, & Andrew Johnson).

January 2007

A retrospective review of otologic and speech outcomes amongst children with cleft palate treated with and without intravelar veloplasty (Michael Brandt, Murad Husein, Damir Matic, & ***Anne Dworschak-Stokan***).

March 2007

Study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy (DMD) (Shannon Venance, Ricardo Viana, Kori LaDonna, Craig Campbell, & Valerie Schulz).

Cohort study of children age 3-6 years with cerebral palsy at high risk for bone morbidity (Pilot study) (Craig Campbell).

October 2007

Exploration of factors affecting changes in clients' performance in written communication (*Nadia Browning*, *Beata Batorowicz*, Micaela Gualtieri, *Laura Munoz*, & Megan Vereecken).

January 2008

Validity, reliability and responsiveness to change of two abbreviated versions of the Gross Motor Function Measure in children with cerebral palsy (Doreen Bartlett, & Laura Brunton).

March 2008

Parent involvement in IBI (Abbie Solish, & Adrienne Perry).

An evaluation of the long-term effectiveness of Botulinum toxin in children with spastic cerebral palsy (Tim Carey, Darcy Fehlings, Peter Rosenbaum, Virginia Wright, Unni Narayanan, & Charles Goldsmith).

Evaluation of communication apprehension in adolescents with velopharyngeal insufficiency (Philip Doyle, Murad Husein, Agnieszka Dzioba, & ***Anne Dworschak-Stokan***).

A phase 2b efficacy and safety study of PTC124 in subjects with nonsense-mutation-mediated Duchenne and Becker muscular dystrophy (Craig Campbell).

June 2008

Mechanostat theory used to understand bone complications in children with Duchenne muscular dystrophy (Craig Campbell, & Natasha Seeman).

Examining medical and psychosocial morbidity in children with Myotonic dystrophy (Craig Campbell, Rhiannon Taranik, & Ada Ho).

September 2008

Pilot study for biomarkers for spinal muscular atrophy (Craig Campbell, Rhiannon Taranik, Victoria Siu, & ***Cheryl Scholtes***).

Understanding the impact of exercise participation for children with a disability (Angela Mandich, & ***Kim Simpson***).

March 2009

The impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions (***Janette McDougall***, Virginia Wright, & Linda Miller).

The validity of alternative response formats for the test of Aided-Communication Symbol Performance (TASP): symbol size and number subtest (***Stacy McDougall***, ***Brent Duncan***, & ***Kelli Vessoayan***).

Plasma B-type natriuretic peptide levels and cardiac function in children with Duchenne muscular dystrophy and Myotonic dystrophy (Craig Campbell, Mike Grattan, Kambiz Norozi, & Liz Burrill).

September 2009

School reintegration for children and youth with acquired brain injury (Dawn Good, Peter Rumney, ***Janette McDougall***, Carol DeMatteo, Patricia McKeever, Denise Guerriere, Sue Loyst, Rhonda Martinussen, Sheila Bennett, & John Kumpf).

January 2010

Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem (***Sara Somers***, & ***Janice Gray***).

Canadian Neuromuscular Disease Registry (Craig Campbell, Shannon Venance, Rhiannon Taranik, & Ashrafunissa Janmohammad).

Myoblast transplantation in Duchenne and Becker muscular dystrophy patients (Craig Campbell, Shannon Venance, Guido Filler, Daniel Skuk, ***Cheryl Scholtes***, Rhiannon Taranik, Ashrafunissa Janmohammad, ***Linda Bolack***, Jacques Tremblay, & Jack Puymirat).

March 2010

Development of an indicator of the impact of assistive devices on children with disabilities and their families (Stephen Ryan, Bonita Sawatzky, & Kent Campbell).

Understanding the bodily experience of cerebral palsy: A phenomenology (Laura Brunton).

A randomized, double-blind, placebo-controlled, multiple ascending-dose study to evaluate the safety, tolerability, pharmacokinetics, and pharmacodynamics of Ace-031 (ActRIIB-IgG1) in subjects with Duchenne muscular dystrophy (Craig Campbell, & Shannon Venance).

PROJECTS

There were **36 research projects** that involved TVCC clients, their families, and TVCC staff members as participants underway between **1 April 2006 and 31 March 2010** 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.

Project information is located on the listed pages. Names of current TVCC staff members are bolded and italicized. Names of former TVCC staff members are italicized only.

INTERNAL PROJECTS

The following is a list of the 20 Internal research projects underway between 1 April 2006 and 31 March 2010 that involved TVCC staff members as named investigators.

Evaluation Projects

Program Evaluation

1. An evaluation of the School Support Program-Autism Spectrum Disorder
2. Peer-mediated social skills for students with autism spectrum disorder: Promoting generalization through a school-wide approach (A program evaluation of the Peers Establishing Effective Relationships Program [P.E.E.R. Pals Program])

Service Delivery

3. Effective listening and interactive communication skills in the delivery of services to children and families
4. Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem

Test and Measures

5. Keeping Information Together: Development and testing of a resource kit for parents of young adults who receive individualized funding for support
6. The validity of alternative response formats for the Test of Aided-Communication symbol Performance (TASP)

Therapy

7. A retrospective review of otologic and speech outcomes amongst children with cleft palate treated with and without intravelar veloplasty
8. Augmentative and alternative communication prescription review: Examining clinicians' perceptions, Study II
9. Does a custom dynamic seating system maintain pelvis position and what do client's think of it?
10. Effects of an exercise program for children with spastic diplegic cerebral palsy
11. Effects of serial casting with and without Botulinum toxin injections as interventions for spastic ankle equinus

12. Evaluation of communication apprehension in adolescents with velopharyngeal insufficiency
13. Exploration of factors affecting changes in clients' performance in written communication
14. Functional change in occupations of children with hemiplegia after a modified constraint induced therapy program
15. Pilot study for biomarkers for spinal muscular atrophy
16. The effectiveness of a Wilbarger based protocol on grooming occupations of preschoolers with autism spectrum disorder: A pilot single case design

Psychosocial Projects

17. School reintegration for children and youth with acquired brain injury
18. School role participation: Perspectives of the child, the parents, and the teachers
19. The impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions-Quality of Life
20. Understanding the impact of exercise participation for children with a disability

Evaluation Projects

Program Evaluation

1. **An evaluation of the School Support Program – Autism Spectrum Disorder**

Investigators: *Kathy Meyer, Janette McDougall, Michelle Servais, Sheila Case, Karen Dannenhold, Susan Johnson, & Colleen Riffin*

Status: Completed, 2005-2006

Increasing numbers of children are now diagnosed with an autism spectrum disorder (ASD) in the preschool years. Early intervention and preschool programs have become increasingly available, and have brought a corresponding demand for school-based services. In March of 2004, the Ontario Ministry of Children and Youth Services introduced a new program targeting school-aged children with ASD: the School Support Program - Autism Spectrum Disorder (SSP-ASD). This program provides consultation services to enhance supports for publicly funded school board staff in the provision of educational services for students with ASD. The SSP-ASD program draws upon a whole-school approach to provide a framework for enhancing school supports for students with ASD. Services are provided at the board, school, and classroom level. The program aims to modify aspects of the environment that may result in students' challenging behaviours. The program has four components: planning, training, consultation, and resource development and sharing. ASD consultants, trained in a relevant field, provide services. This study examined the utility of the



SSP-ASD Program for enhancing school-level outcomes over the period of one school year. One hundred and ninety-two educators completed study measures in late fall and late spring. Seventy of those educators who reported receiving no services from the program were compared to 45 educators who had one to four contacts with the program and 77 educators who had five or more contacts with the program.

Statistically significant main effects of program condition in favour of beneficial effects of the school support program were found for two school-level outcomes: 'supports' and 'teaming and collaboration.' Receiving services from the school support program over a period of one school year was indicated to be more useful for enhancing: (1) supports to educators to accommodate the needs of students, and (2) teaming and collaboration among relevant parties, than not receiving services from the program. Amount of service received appeared to influence outcomes. On average, educators were mostly to highly satisfied with the consultation process and the overall program. Educators reported all aspects of the program were useful, particularly professional development day sessions, and individual consultation and support. Study findings were used to enhance services provided by the SSP-ASD program.

Publications:

McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggan, C. (2006). An evaluation of the School Support Program - Autism Spectrum Disorder (SSP-ASD) (Facts To Go, Volume 2 Issue 2). London, ON: Thames Valley Children's Centre.

McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggan, C. (2009). A preliminary evaluation of a school support program for children with autism spectrum disorders. *Exceptionality Education International*, 19(1), 32-50.

Presentation:

McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggan, C. (2009, April). A preliminary evaluation of a school support program for children with autism spectrum disorders. Presented at the 17th Annual Research Day of the Ontario Association for Developmental Disabilities Research Special Interest Group, Barrie, ON.

2. Peer-mediated social skills for students with autism spectrum disorder: Promoting generalization through a school-wide approach (A program evaluation of the peers establishing effective relationships program [P.E.E.R. Pals Program])

Investigators: *Michelle Servais, Charmaine Chadwick, & Carmen Hall*

Status: Completed, 2007-2008

Students with Autism Spectrum Disorder (ASD) often have difficulties with social situations and peer interactions. These students need to be taught social skills directly as they do not naturally pick these skills up from their environment. Peer-mediated strategies have proven to be very effective in enhancing social skills in students with ASD. As part of service delivery to schools, the School Support Program—Autism Spectrum Disorder, Southwest Region created a Program to teach social skills to students with ASD: Peers Establishing Effective Relationships (PEER Pals Program). As part of the PEER Pals Program, social communication skills are taught in the classroom,

student leaders run structured games at recess for trained peers to participate in, and diversity training is provided for the entire school. A total of 68 key informants (principals, teachers, educational assistants, and parents) participated in focus groups and 63 school staff returned mailed questionnaires on the perceived usefulness of the Program, their satisfaction with the Program, and the features that participants liked most and least about the Program. Study findings indicated program benefits for all students, including those with ASD, as well as teachers and other school staff.

Publication:

Servais, M., Hall, C., Chadwick, C., & Lombardi, J. (2009). Peer-mediated school-based program proves successful in promoting positive social skills. (Facts To Go, Volume 5 Issue 3). London, ON: Thames Valley Children's Centre.

Presentations:

Hall, C., Servais, M., & Chadwick, C. (2008, November). Effectiveness of peer-mediated social skills training: Prerequisites for generalization for students with autism. Presented at the Ontario Association for Behaviour Analysis (ONTABA) Annual Provincial Conference, Toronto, ON.

Hall, C., Chadwick, C., & Servais, M. (2008, November). Reaching beyond the student with autism: A school-wide, peer-mediated approach to social skill teaching. Presented at the 52nd Ontario Provincial Conference of the Council for Exceptional Children, London, ON.

Service Delivery

3. Effective listening and interactive communication skills in the delivery of services to children and families

Investigators: *Gillian King, Linda Bolack, Colleen Willoughby, Tracy Shepherd, & Michelle Servais*

Affiliation: Holland Bloorview Kids Rehabilitation Hospital

Status: Completed, 2007-2010

The intent of this project was to study the nature of effective listening and interactive communication skills of paediatric rehabilitation therapists. The project has provided useful information that can raise therapists' self-awareness, encourage insight, and motivate therapists to improve their listening and communication skills.

The project summarized the literature on what is known about effective listening and communication skills in the health and social service field, (b) proposed an innovative framework outlining the nature of six core listening and interactive communication skills that underpin the effective delivery of services to children and families, and (c) provided a qualitative analysis of focus group data from two groups of therapists: a group selected based on the nomination of their peers as "expert listener-communicators" and a self-selected group with interest in the topic area. The project also provided data on the utility and validity of a preliminary version of a self-report measure of effective listening and communication skills.

This work can inform the delivery of clinical services to children and families.

Presentation:

Bolack, L., Shepherd, T., Servais, M., King, G., & Willoughby, C. (2009, November). Reflecting on effective communication and listening skills in therapeutic practice. Presented at the 2009 Children's Rehabilitation Services Conference, Toronto, ON.

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

Investigators: Sara Somers & Janice Gray
Status: Underway, 2010-2012

Recent research has highlighted the impact of concussion in high school aged athletes. In addition, research has also shown concussion rates for female athletes to be higher than male athletes and for their symptoms to take longer to resolve. The present study will investigate the incidence of concussion and duration of symptoms for referrals to the Paediatric Brain Injury Community Outreach Program (PABICOP) over time. This population is not restricted to high school aged athletes. By identifying possible trends in referrals, the hope is to be able to provide a more proactive targeted approach to supporting children and youth in their recovery from concussion.

Publication:

Somers, S., Gray, J., & McDougall, J. (2010). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. [Abstract] *Brain Injury* 24(3), 51-52.

Presentation:

Somers, S., Gray, J., & McDougall, J. (2010, March). Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. Presented at the 8th World Congress on Brain Injury, Washington, DC.

Test and Measures

5. Keeping Information Together: Development and testing of a resource kit for parents of young adults who receive individualized funding for support

Investigators: Debra Stewart, Mary Law, Cheryl Missiuna, Gillian King, & Peter Rosenbaum

Affiliation: CanChild Centre for Childhood Disability Research

Funding: Ministry of Community and Social Services, 2002-2007, \$43,500

Status: Completed, 2002-2006

The goal of this project was to develop a Resource Kit that could be broadly circulated to families who receive individualized funding. The goal was to enhance the quality of life and community participation of young adults with disabilities. The Resource Kit was developed with 10 families. Researchers sought input from all families as to the content and format of the kit. Another goal was to evaluate the Resource Kit as to its use, utility and impact.

Publication:

Stewart, D., Law, M., Burke-Gaffney, J., Missiuna, C., Rosenbaum, P., King, G., Moning, T., & King, S. (2006). Keeping It Together™: An information KIT for parents of children and youth with special needs. *Child: Care, Health, and Development*, 32, 493-500.

6. The validity of alternative response formats for the Test of Aided-Communication symbol Performance (TASP)

Investigators: Stacy McDougall, Brent Duncan, & Kelli Vessoyan

Status: Completed, 2009-2010

Individuals who use augmentative and alternative communication (AAC) often have physical difficulties accessing standardized assessment materials. The Test of Aided-Communication symbol Performance (TASP) assesses use of Picture Communication Symbols by individuals who directly access their AAC systems. Using computerized presentation, equivalency between adapted access response methods for the TASP Symbol Size and Number Subtest and a traditional response method was examined, using a Repeated Measures Experimental Design. Participants included children who use AAC and have direct access.

Presentation:

McDougall, S., Duncan, B., & Vessoyan, K. (2010). Alternative presentation and response formats for the Test of Aided-Communication Symbol Performance (TASP). Presented at the 14th biennial conference of the International Society for Augmentative and Alternative Communication, Barcelona, Spain.

Therapy

7. A retrospective review of otologic and speech outcomes amongst children with cleft palate treated with and without intravelar veloplasty

Investigators: Michael Brandt, Murad Husein, Damir Matic, & Anne Dworschak-Stokan

Affiliation: London Health Sciences Centre

Funding: Paediatric Surgery Internal Grant Competition, 2007, \$2000

Status: Discontinued

Cleft lip and palate is a common congenital deformity. A feature of the cleft palate is a disorientation of the muscles that act together to move the soft palate and open up the eustachian tube. It has been hypothesized that the surgical repositioning of these disoriented muscles towards their natural course should improve the function of the soft palate and thus remedy the common speech and ear problems affecting children with this condition. The study had hoped to determine the otologic and speech benefits of this procedure and provide evidence to support its role in the care of children with cleft palate.

8. Augmentative and alternative communication prescription review: Examining clinicians' perceptions (Study II)

Investigators: Beata Batorowicz, & Tracy Shepherd

Funding: RACSN 2004 Service Provider Award, 2004-2006, \$3,000

Status: Completed, 2004-2006

Prescription review (PR) includes a discussion of the rationale for recommending specific Augmentative and Alternative Communication (AAC) equipment within a transdisciplinary team. PR is mandatory in Assistive Devices Program (ADP) AAC designated centres in Ontario. It allows professionals practicing in AAC to authorize government funding towards communication equipment for clients. PR has been practiced for over a decade and has never been evaluated. This study examined clinical staff's perceptions of advantages and disadvantages of PR. Relationships among these perceptions and professional

background, years of practice, size of team, range of experience, and team processes was examined.

Publication:

Batorowicz, B., & Shepherd, T. (2006). Team decision-making in AAC: Examining clinical perceptions. Proceedings of the 12th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC).

Presentation:

Batorowicz, B., & Shepherd, T. (2006, August). Team Decision-Making in AAC: Examining Clinical Perceptions. Presented at the 12th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC), Düsseldorf, Germany.

9. Does a custom dynamic seating system maintain pelvis position and what do client's think of it?

Investigators: *Sue Kirkpatrick, Jim Wighton, Sandi Spaulding, Thelma Sumsion, Lucine Truscott, Joy Sommerfreund, & Beata Batorowicz*

Affiliation: The University of Western Ontario School of Occupational Therapy

Funding: TVCC Research Award, 2004-2006, \$5,000

Status: Completed, 2004-2006

One goal of seating intervention for individuals who use wheelchairs is to optimize seating posture in relation to the performance of each individual to ensure maximal independence and function. It is possible, however, that a wheelchair and seating system may limit and affect the independence of the person using this equipment.

In clinical practice, the objective of providing optimal stability with minimal restraint is becoming accepted in the field of adapted seating. Maintaining static posture for a prolonged time can result in stress, fatigue, increased discomfort, pain, and tension. It can also increase spasticity and muscle contractures over time. For the purpose of this research project, a dynamic seating system was defined as a system that allows independent movement of a body part, while providing support, direction and control to that movement and then returning (or assisting to return) to the initial posture. It is thought that individuals who require supportive seating in a wheelchair may benefit both physiologically and psychologically from a seating system that balances support with freedom of movement.

The Seating and Mobility Team at TVCC designed and developed a customized dynamic seating system composed of an articulating back support and sliding footrest. The backrest allows for spinal extension while maintaining pelvic positioning and providing trunk support, and the sliding footplate allows for knee and ankle extension while supporting the feet. This system allows movement while maintaining support and facilitating individuals returning to their original seated position.

The research project compared the participants' movements in the dynamic seating system and in a static system. Participants and their parents/caregivers were asked their views about their experiences using both systems, the participants' ability to perform tasks, what they liked and disliked about the systems, and the participants'

social, physiological, and physical functioning while using the systems.

Publication:

Wighton, J., Smith, L., & Stephenson, F. (2008). A dynamic wheelchair seating system: Design and technical development. (Facts To Go, Volume 4 Issue 1). London, ON: Thames Valley Children's Centre.

10. Effects of an exercise program for children with spastic diplegic cerebral palsy

Investigators: *Flora Stephenson, Sandi Spaulding¹, Cheryl Scholtes, Mary Jenkins², & Andrew Johnson³*

Affiliation: The University of Western Ontario School of Occupational Therapy¹, London Health Sciences Centre², & The University of Western Ontario Faculty of Health Sciences³

Status: Discontinued

People with disabilities are a group that is at a high risk of being physically inactive. Children with physical disabilities participate in fewer physical activities and in lower intensities compared to their peers. The inactive lifestyle will put people with disabilities at further risk of developing additional health conditions. Therefore, it becomes apparent that physical activity opportunities should be provided to children with disabilities in order to help them adopt and maintain a physically active lifestyle.

Based on the gap identified in the literature, this study was to examine the effects of a complete exercise program, that is, a program that consists of strength, cardiovascular, and flexibility training designed for primary school children with CP. Since the children with CP typically have decreased balance, a balance-training component was to also be included in this exercise program. This study also wanted to examine the potential psychological changes through examining health related quality of life. Physical activities is vital to maintaining healthy body mass, body composition and psychological well-being.

11. Effects of serial casting with and without Botulinum toxin injections as interventions for spastic ankle equinus

Investigators: *Flora Stephenson, Cheryl Scholtes, Tim Carey, & Kellie Leitch*

Affiliation: Children's Hospital of Western Ontario

Funding: TVCC Research Award, 2005-2007, \$1,646

Status: Completed, 2005-2007

The goal of this study was to obtain more outcome information associated with the effects of serial casting with and without botulinum toxin, since results in the literature shows different trends for the outcomes from these two treatments. The objective of the study was is to examine passive range of motion at the ankle and gait characteristics in children at Thames Valley Children's Centre who have undergone serial casting treatment for spastic ankle equinus either with or without Botox injections to the plantar flexor muscles. Fifty-seven clients and/or their caregivers participated. No differences

were found between the treatment results of serial casting alone and Botox and serial casting.

Publication:

Stephenson, F., **Scholtes, C.**, Carey, T., & Leitch, K. (2007). Evaluation of two treatments for Toe-Walking for children with cerebral palsy (Facts To go, Volume 3 Issue 2). London, ON: Thames Valley Children's Centre.

Presentations:

Stephenson, F., **Scholtes, C.**, Carey, T., & Leitch, K. (2006, November). Effects of serial casting with and without Botulinum Toxin injections as interventions for Spastic Ankle Equinus. Presented at the Paediatric Interest Day, London, ON.

Carey, T., Leitch, K., **Scholtes, C.**, & Stephenson, F. (2007, June). Effects of serial casting with and without Botulinum Toxin injections as interventions for Spastic Ankle Equinus. Presented at the Canadian Orthopaedic Association Conference, Halifax, NS.

interviews were conducted with the participants (or their parents/caregivers if the child was under the age of 10) to gain a better understanding of their individual perceptions of factors that contributed to the change in their performance scores.

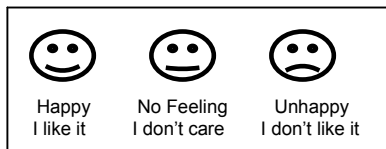
12. Evaluation of communication apprehension in adolescents with velopharyngeal insufficiency

Investigators: Philip Doyle¹, Murad Husein², Agnieszka Dzioba¹, & **Anne Dworschak-Stokan**

Affiliation: The University of Western Ontario¹, and London Health Sciences Centre²

Status: Completed, 2008-2008

The purpose of this study was to gain a better understanding of the impact of living with velopharyngeal insufficiency (VPI) from the perspective of the individual by measuring the level of communication apprehensive (CA) that these individuals experienced. Specifically, the objectives of the study were: 1) to evaluate the CA of adolescents with VPI using the Measure of Elementary Communication Apprehension and compare scores of this clinical population with those of a control group of age and gender matched normally speaking children; and 2) to evaluate the association between CA scores and scores on a standard auditory-perceptual assessment of voice quality (the American Cleft Palate Association speech Pathology Data Entry Form) in the VPI population.



13. Exploration of factors affecting changes in clients' performance in written communication

Investigators: **Nadia Browning, Beata Batorowicz, Micaela Gualtieri, Laura Munoz,** & Megan Vereecken

Affiliation: The University of Western Ontario

Status: Completed, 2007-2008

This project explored changes in children's performance of writing tasks following provision of written communication devices. Augmentative Communication Service (ACS) at the Thames Valley Children's Centre has begun to incorporate pre and post measures of children's performance and satisfaction according to their self-report using the Canadian Occupational Performance Measure. Changes in these performance scores were analyzed by chart review. Face-to-face qualitative

14. Functional change in occupations of children with hemiplegia after a modified constraint induced therapy program

Investigators: **Teresa Mulligan,** & Julie South

Affiliation: The University of Western Ontario
School of Occupational Therapy

Status: Completed, 2006-2008

The purpose of this pilot study was to measure functional changes in children with hemiplegia after a modified constraint induced therapy (CIT) protocol. The specific purpose was to determine the effectiveness of proposed modifications to protocols previously validated in the literature in order to promote best practice within the Thames Valley Children's Centre service delivery models. These modifications included decreased frequency and intensity of intervention and also increased emphasis on functional change and client-selected goals. Through single case A/B/A design, subjects were used as their own controls for comparison and functional, client centred outcome measures that were used before, during and after the six week protocol was implemented.

15. Pilot study of biomarkers for spinal muscular atrophy

Investigators: Craig Campbell¹, Rhiannon

Taranik², Victoria Siu¹, & **Cheryl Scholtes**

Affiliation: London Health Sciences Centre¹,
The University of Western Ontario²

Funding: Spinal Muscular Atrophy Foundation,
2008-2009, \$11,991

Status: Completed, 2008-2009

Spinal Muscular Atrophy (SMA) is a genetic disease affecting the nerves that bring information about movement from the spinal cord to the muscles.

The aim of this study was to identify a biomarker or panel of biomarkers from a wide range of SMA patients. The hypothesis was that using proteomic and metabolomic techniques there would be, as yet unrecognized, biomarkers that would provide insight into potential therapeutic targets for this condition.

16. The effectiveness of a Wilbarger based protocol on grooming occupations of preschoolers with autism spectrum disorder: A pilot single case design

Investigators: **Teresa Mulligan,** & Kelly Roberts

Affiliation: The University of Western Ontario
School of Occupational Therapy

Status: Discontinued

This study hoped to evaluate the functional outcomes of four preschool-aged child with autism spectrum disorder (ASD) who were having problems completing self care activities. Using a single case design method with an A/B/A format, the children would be assessed after receiving the Wilbarger based Protocol (WP) for three weeks. The WP is a sensory stimulation technique developed by occupational therapists and used to help clients with tactile and other sensory sensitivities contributing to function difficulties, such as difficulties brushing hair

or tolerating teeth brushing. The primary objectives of the study were to: use standardized measures to evaluate functional outcomes as a result of intervention using the WP, measure parent satisfaction with and importance of grooming occupations in their child, gather information about the sensory processing characteristics of the child that respond to the WP, and utilize information to direct further research on sensory processing interventions.

Psychosocial Projects

17. School reintegration for children and youth with acquired brain injury

Investigators: Dawn Good¹, Peter Rumney², **Janette McDougall**, Carol DeMatteo³, Patricia McKeever², Denise Guerriere⁴, Sue Loyst⁵, Rhonda Martinussen⁴, Sheila Bennett¹, & John Kumpf⁶

Affiliations: Brock University¹, Bloorview Kids Rehabilitation², McMaster University³, University of Toronto⁴, Georgian College⁵, Ontario Brain Injury Association⁶

Funding: Ontario Neurotrauma Foundation, 2009-2011, \$360,000

Status: Underway, 2007-2011

Partnering with Children's Centres and schools across Ontario, this study will investigate individual, academic, and system-related factors that relate to the successful return to school of children and youth with Acquired Brain Injury (ABI).

Using questionnaires and standardized testing, this study proposes to identify and examine the impact of the important factors involved in returning to school and how those factors are related to outcomes.

The results of this study will contribute to the understanding and advancement of the academic, social, and environmental features supporting successful school reintegration for students with ABI.

Publication:

Good, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N. (2009) School reintegration for children and youth with Acquired Brain Injury. [Abstract] *Journal of Head Trauma Rehabilitation*, 24(5), 399.

Presentations:

McDougall, J., Good, D., Rumney, P., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, November). School reintegration for children and youth with Acquired Brain Injury. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON.\nGood, D., Rumney, P., **McDougall, J.**, Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & Decourville, N. (2009, October). School reintegration for children and youth with Acquired Brain Injury. Presented at the North American Brain Injury Society 7th Annual conference on Brain Injury, Austin, TX.

Good, D., Rumney, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, May). School reintegration for children and youth with Acquired Brain Injury. Presented at the 16th

Annual Conference on Neurobehavioural Rehabilitation in Acquired Brain Injury, Hamilton Health Sciences, Hamilton, ON.

Good, D., Rumney, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, April). *School reintegration for children and youth with Acquired Brain Injury*. Presented at the 17th Annual Research Day of the Ontario Association for Developmental Disabilities Research Special Interest Group, Barrie, ON.

18. School role participation: Perspectives of the child, the parents, and the teachers

Investigators: Jacqueline Specht¹, **Gillian King**, **Michelle Servais**, Marilyn Kertoy², & Terry Spencer³

Affiliation: The University of Western Ontario, Faculty of Education¹, School of Communication Sciences and Disorders²; London District Catholic School Board³

Funding: Provincial Centre of Excellence for Child and Youth Mental Health, Grant in Aid, 2005-2006, \$7,065; Social Sciences and Humanities Research Council of Canada, 2006-2009, \$109,563

Status: Completed, 2006-2009

Repeatedly, participation has been shown as key to the healthy adjustment of individuals. Unfortunately, children with disabilities have been found to participate less than children without disabilities and these differences increase through middle and late childhood, thus putting them at risk for negative life outcomes such as low self-esteem, depression, and anxiety. Promoting children's active engagement in school through opportunities such as involvement in classroom lessons, games, sports, and social events, leads to a greater likelihood of successful experiences. This may be especially true during the transition to secondary school when the emphasis on social comparison is heightened. The potential worries and vulnerabilities of children with respect to social comparison may interfere with participation.

The project examined children's participation in school roles (e.g., leader, friend, athlete, helper), which is a novel and conceptually meaningful approach to understanding the complexities of participation. Using mixed methods, the child, his/her parent(s), and his/her teacher(s) were interviewed about the roles in which children participate during the school day. Researchers used measures to assess (a) the cognitive, communicative, and physical functioning of the children, (b) the child's self-concept, (c) child's participation in activities outside of school, (d) the school culture, and (e) the classroom environment in order to assess how these characteristics relate to school role participation. Interviews were carried out with students in Grades 7, 8, and 9 who were followed for a period of 2 years. This sequential approach allowed researchers to see the development of roles at the end of elementary school through to the middle of secondary school. By involving children with and without disabilities as well as their teachers and parents, researchers were able to (a) compare the roles between children, (b) examine the perspectives of the children, parents and teachers, and (c) compare these perspectives to determine if and where the gaps in promoting participation exist.

This program of research provided important information to help teachers, service providers, and

parents understand the experiences of children in the school setting.

Presentations:

- Specht, J. A., **Servais, M.**, Kertoy, M., Spencer, T., King, G., Cressman, C., Pompeo, M., & Young, G. (2008, March). School role participation: Perspectives of the child, parent, and the teacher. Presented at the 2008 Eighth Annual Second City Conference on Disability Studies in Education, New York, NY.
- Specht, J. A., **Servais, M.**, Kertoy, M., Spencer, T., King, G. A., Cressman, C., Pompeo, M., & Young, G. (2008, August). School participation: Opportunities, enhancers, and limiters. Presented at the Annual Meeting of the American Psychological Association. Boston, MA.
- Specht, J. A., Spencer, T., **Servais, M.**, Kertoy, M., Young, G., Pompeo, M., Cressman, C., & Puskarich, M. (2008, November). School participation: How educators can help. Presented at the 52nd Ontario Provincial Conference of the Council for Exceptional Children, London, ON.
- Specht, J. A., **Servais, M.**, Kertoy, M., Spencer, T., King, G., Young, G., Pompeo, M., Young, G., & Puskarich, M. (2009, August). School roles: Opportunities to participate. Presented at the American Psychological Association Annual Conference, Toronto, ON.
- Spencer, T., Specht, J., **Servais, M.**, Kertoy, M., King, G., Pompeo, M., Young, G., & Puskarich, M. (2010, February). *Elementary school roles: Making sure all participate*. Presented at the 5th Annual Ontario Education Research Symposium, Toronto, ON.

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

Investigators: *Janette McDougall*, Virginia Wright¹, & Linda Miller²

Affiliation: Holland Bloorview Kids Rehabilitation Hospital/Bloorview Research Institute¹, University of Western Ontario School of Graduate and Postdoctoral Studies²

Funding: Canadian Institutes of Health Research, 2009-2014, \$742,340

Status: Underway, 2009-2014

Optimizing quality of life for children and youth is a key goal of the Ontario Association of Children's Rehabilitation Services (OACRS) centres. Many supports and interventions are directed toward this goal. It is important for clients, families, service providers, and policy makers to understand the key factors that influence changes in life quality throughout childhood and adolescence for children and youth with chronic conditions.



To this end, researchers will examine the impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions.

This research endeavour includes a five-year survey-based study and a qualitative study. The survey-based study will address two unexplored research areas: 1) the changing nature of quality of life for youth with chronic conditions over a three-year period, and 2) the factors that influence change in quality of life for youth. Approximately 575 youth aged 11 to 17 years (and one of their parents) who receive services from eight OACRS centres across Ontario will participate. Youth and parents will each

complete a brief questionnaire at four time points that include questions about quality of life and the factors that research and conceptual thinking suggest influence changes in life quality for youth with chronic conditions. Some of the factors to be explored are: youths' physical and emotional functioning, self-determination, social participation, and family and environmental supports. Advanced statistical analysis procedures will be used to evaluate changes in quality of life and to determine the factors related to change.

Twenty to thirty youth from TVCC will be involved in the qualitative study. The youth will take part in individual interviews and focus groups to consider what "quality of life" means to them and what aspects of life they feel are most important for enhancing their life quality. These findings will be examined alongside those of the survey-based study.

Findings from this research will help us to understand more about quality of life from the perspectives of youth and their families, and can help guide program and policy development toward optimizing life quality for youth with chronic conditions!

Publication:

McDougall, J., Wright, V., & Miller, L. (2009). What is "quality of life" and how can research identify the factors that optimize life quality for children and youth with chronic conditions? (Facts to Go, Volume 5 Issue 1). London, ON: Thames Valley Children's Centre.

Presentation:

McDougall, J., Wright, V., & Miller, L. (2009, November). Changes in quality of life for youth with chronic conditions: The impact of personal, interpersonal and environmental factors. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Toronto, ON.

20. Understanding the impact of exercise participation for children with a disability

Investigators: Angela Mandich, & *Kim Simpson*

Affiliation: The University of Western Ontario/School of Occupational Therapy

Status: Underway, 2009-2010

This study aims to explore the impact of participation in a fitness program for youth with a physical disability. Due to the individualized nature of childhood disability and participation, semi-structured parent and youth interviews will be used to understand health impact of participating in a fitness program for youth with a disability using a qualitative interview guide created by the researcher. This study will also include two other phases of research; following the interviews, participants and therapists will use Goal Attainment Scaling to evaluate the impact of fitness participation on motor skills and video analysis using the Performance Quality Rating Scale to evaluate the quality of motor improvement of client fitness goals.

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 potential participants. A TVCC staff member is assigned as a Research Contact to liaise with the external researcher and make the first contact inviting potential participants to take part in the research.

The following is an alphabetical list of the **16 external research projects** underway between **1 April 2006 and 31 March 2010**. Abstracts of the projects are located on the listed pages. The names of the TVCC Research Contact are bolded and italicized. Names of former TVCC staff are italicized only.

21. A phase 2b efficacy and safety study of PTC124 in subjects with nonsense-mutation-mediated Duchenne and Becker muscular dystrophy
22. Adolescents with CP: What happens to mobility and self-care?
23. An evaluation of the long-term effectiveness of Botulinum toxin in children with spastic cerebral palsy
24. Canadian Neuromuscular Disease Registry
25. Cohort study of children age 3-6 years with cerebral palsy at high risk for bone morbidity (pilot study)
26. Evaluating the role of 7q11.23 duplications in the pathogenesis of severe speech and language disorder
27. Examining medical and psychosocial morbidity in children with Myotonic dystrophy
28. Focus on function study
29. Identification and development of common outcome indicators for Ontario's Children's Treatment Centres
30. Mechanostat theory used to understand bone complications in children with Duchenne muscular dystrophy
31. Parental involvement in intensive behavioural intervention
32. Plasma B-type natriuretic peptide levels and cardiac function in children with Duchenne muscular dystrophy and Myotonic dystrophy
33. Study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy
34. The social context, challenges, and strengths in the everyday lives of girls
35. The transition of children with autism from intensive behavioural intervention programs into the school system
36. Validity, reliability and responsiveness to change of two abbreviated versions of the Gross Motor Function Measure in children with cerebral palsy

21. A phase 2b efficacy and safety study of PTC124 in subjects with nonsense-mutation-mediated Duchenne and Becker muscular dystrophy

Investigators: Craig Campbell

Affiliation: Children's Hospital of Western Ontario, London Health Sciences Centre

TVCC Research Contacts: *Linda Bolack*, & *Cheryl Scholtes*

Status: Active phase of study discontinued, follow-up with clients ending 2011

This study was planned as a multicentre, double blind, placebo controlled, phase 2b Efficacy and Safety Study of the pharmaceutical PTC124 among boys of the age ≥ 5 years with Nonsense-Mutation-Mediated Duchenne and Becker muscular dystrophy (DMD and BMD). 165 boys from 25 centers of North America and Europe were to be randomized to 1:1:1 of PTC124 10, 10 and 20 mg/kg (low dose) or 20, 20 and 40 mg/kg (high dose) or placebo, for a period of 48 weeks.

The study was to compare two doses of the drug, thereby addressing the dose response relationship aspects of a phase 2 study.

22. Adolescents with CP: What happens to mobility and self-care?

Investigators: Peter Rosenbaum, Robert Palisano, Doreen Bartlett, Steven Hanna, Maureen O'Donnell, Dianne Russell, Stephen Walter, & Ellen Wood

Affiliation: CanChild Centre for Childhood Disability Research

TVCC Research Contact: *Ann MacPhail*

Status: Completed, 2002-2008

Although it has been suggested that adolescents with cerebral palsy (CP) may experience loss of function following puberty, little research evidence exists to support this claim. Over 300 adolescents and their parents were invited to participate in annual assessments for four years, providing unique information on maturation in one of the more prevalent developmental disabilities of childhood. This study paved the way for a new generation of studies directed at secondary prevention and health promotion.

Publications:

Palisano, R. J., Copeland, W. P., & Galuppi, B. E.

(2007). Performance of physical activities by adolescents with cerebral palsy. *American Physical Therapy Association*, 87(1), 77-87.

Livingston, M. H., Rosenbaum, P. L., Russell, D. J., & Palisano, R. J. (2007). Quality of life among adolescents with cerebral palsy: What does the literature tell us? *Developmental Medicine & Child Neurology*, 49, 225-231.

Rosenbaum, P. L., Livingston, M. H., Palisano, R. J., Galuppi, B. E., & Russell, D. J. (2007). Quality of life and health-related quality of life of adolescents with cerebral palsy. *Developmental Medicine & Child Neurology*, 49, 516-521.

Tieman, B., Palisano, R., J., Gracely, E., J., & Rosenbaum, P., L. (2007). Variability in mobility of children with cerebral palsy. *Pediatric Physical Therapy*, 19, 180-187.

23. 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

Affiliation: Holland Bloorview Kids Rehabilitation Hospital¹, Children's Hospital of Western Ontario, London Health Sciences Centre², McMaster University³, Hospital for Sick Children⁴

TVCC Research Contact: *Linda Bolack*

Status: Underway, 2008-2012

Cerebral palsy is defined as a "group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain". Spastic CP 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 will examine 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 will be assessed at 12 month intervals on a variety of outcome measures which will fully characterize the nature and extent of impairment, activity, and participation.

24. Canadian Neuromuscular Disease Registry

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

Affiliation: Children's Hospital of Western Ontario, London Health Sciences Centre

TVCC Research Contact: *Linda Bolack*

Status: Underway, 2010-2012

Neuromuscular Diseases (NMDs) are a group of disorders involving the central and peripheral nervous systems. Although principally disorders of the nervous system they may be associated with symptoms and signs that can impact nearly every body system either as a component of the disorder itself or as a secondary phenomenon. Amongst the various disorders, examples of cognitive impairment, gastrointestinal dysfunction, ocular abnormalities, endocrine dysfunction, musculoskeletal deformity, incoordination, pain, and systemic organ dysfunction or failure can all be found.

Neuromuscular disorders are present in all populations and affect people of all ages. Because individual NMDs are often referred to as rare or orphan diseases, they do not attract the interest and investment in therapy from the pharmaceutical industry. The 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.

25. Cohort study of children age 3-6 years with cerebral palsy at high risk for bone morbidity (Pilot study)

Investigators: Craig Campbell

Affiliation: Children's Hospital of Western Ontario, London Health Sciences Centre

TVCC Research Contact: *Cheryl Scholtes*

Status: Underway, 2007-2012

Cerebral palsy (CP) is a common disorder caused by brain damage during early development

that affects a child's strength and movement. Many children with CP have other problems including learning difficulties, seizures and bone problems. Bone problems include broken bones, scoliosis (curvature of the spine) and joint dislocations. These problems all cause significant suffering for affected children and their families when they occur. Also, a great deal of health care resources is frequently required to diagnose and treat these problems. The causes of the bone problems in children with CP are due partly to abnormal muscle tension but may also be due to low bone strength as well.

Researchers in previous studies have felt that poor nutrition, inability to walk and the use of epilepsy medication are all factors that may make bones weaker. These studies on bone strength in children with CP have been done on small groups of children and so a clear picture of the extent of the problem and the risk factors that may cause low bone density are similarly not fully known. As well, the potential impact of low bone strength on pain and on quality of life in children with CP has never been examined in a cohort study.

The purpose of this study is to find out risks for low bone strength and the relationship to bone complications in children with CP. The aim is to establish temporal relationships between risk factor and outcome. By interviewing the families and reviewing medical histories of children with CP, testing bone strength using a bone densitometer, X-rays and laboratory tests and then following children for the period of five years for their bone health, these questions will be better understood. The result from this study will help the scientific community to understand more of the child's bone health in CP and assist neurologist, orthopaedic surgeons and the endocrinologists to be the case of children with the disease.

26. Evaluating the role of 7q11.23 duplications in the pathogenesis of severe speech and language disorder

Investigators: Lucy Osborne¹, & Janis Cardy²

Affiliation: Department of Medicine and Medical Genetics & Microbiology, University of Toronto¹, School of Communication Sciences and Disorders, The University of Western Ontario²

TVCC Research Contact: *Alison McVittie*

Status: Completed, 2006-2007

Recently, it was found that duplication of a region of chromosome 7 (dup7q11.23) is associated with severe speech and expressive language delay. Although speech/language impairment (S/LI) has a strong genetic basis, only one gene has previously been implicated, and only in a few families.

The aim of this study was to i) test 500 children with S/LI to determine if dup7q11.23 is a common cause of S/LI, ii) characterize the specific speech/language deficits of those with dup7q11.23, and iii) identify the causative gene(s).

In the Fall of 2007, preliminary analyses of 180 saliva samples that were collected from children with speech/language delay (predominantly recruited through parent websites) was conducted. Contrary to predictions, none of the children showed duplication of 7q11.23. It was concluded that speech/expressive language delay was too broad a phenotype to easily allow identification of dup7q11.23, so recruitment in this population was suspended.

Presentation:

Oram Cardy, J., Somerville, M.J., Young, E.J., Bamforth, S., Lilley, M., & Osborne, L.R. (2007, October). Screening for dup7q11.23 in children with expressive language delay. Presented at the Annual Meeting of the American Society of Human Genetics, San Diego, CA.

27. Examining medical and psychosocial morbidity in children with myotonic dystrophy

Investigators: Craig Campbell¹, Rhiannon Taranik², & Ada Ho²

Affiliations: Children's Hospital of Western Ontario, London Health Sciences Centre¹, The University of Western Ontario²

TVCC Research Contact: *Linda Bolack*

Status: Underway, 2008-2011

Myotonic dystrophy type 1 (DM1) is an autosomal dominant disease of unstable trinucleotide repeat expansion. Classic adult onset disease is typically associated with a repeat size of 100-1000, whereas those with childhood or congenital onset (CDM) usually have over 1000 repeats. CDM only occurs in DM1 and has an estimated incidence of 0.08 per 1000 live births. CDM constitutes the third largest group of children in the pediatric neuromuscular clinic at Children's Hospital of Western Ontario. CDM is a disease characterized by progressive muscular weakness and multisystem manifestations.

Various studies report muscle weakness and myotonia, respiratory, cardiovascular, gastrointestinal, orthopaedic, and ocular complication in DM1 patients. However, no studies have examined the broad spectrum of medical morbidities involved with the congenital form, which would be useful in determining any differences from adult-onset DM1, establishing practice guidelines and establishing relevant outcomes for clinical trials.

This study will recruit subjects ages 5 to 18 years of age. Psychosocial variable will be measured with the Pediatric Quality of Life Inventory (PedsQL), Child Behaviour Checklist (CBCL), Pediatric Daytime Sleepiness Scale (PDSS), Pediatric Sleep Questionnaire (PSQ), and school and family functioning questionnaires. Functional measures including myometry, the Six minute walk test (6MWT), and Stepwatch activity monitoring (SAM) will be examined as potential outcome measures for childhood DM1.

28. Focus on function study

Investigators: Mary Law¹, Johanna Darrah², Peter Rosenbaum¹, Dianne Russell¹, Stephen Walter³, Brenda Wilson⁴, & Terry Petrenchik¹

Affiliation: McMaster University, CanChild Centre for Childhood Disability Research¹, Department of Physical Therapy, University of Alberta², McMaster University³, Calgary Health Region⁴

TVCC Research Contact: *Kathy O'Connor*

Status: Completed, 2006-2010

The primary objective of this study was to conduct a multi-site trial to evaluate the efficacy of a context-focused therapy approach in improving performance of functional tasks, mobility, participation in everyday activities, and quality of life in 220 children 12 months to 5 years and 11 months of age who have cerebral palsy.

A randomized clinical trial research design was used to examine the efficacy of the context-focused approach compared to a child-focused approach.

Publication:

Law, M., Darrah, J., Pollock, N., Rosenbaum, P., Russell, D., Walter, S., Petrenchik, T., Wilson, B., & Wright, V. (2007). Focus on Function – a randomized controlled trial comparing two rehabilitation interventions for young children with cerebral palsy. *BMC Pediatrics*, 7, 31-43.

Presentations:

Darrah, J., & Law, M. (2009, September). An intervention approach for children with cerebral palsy focusing on task and environmental demands. Presented at the American Academy for Developmental Medicine and Child Neurology (AAPDM), Scottsdale, AZ.

Wilson, B. (2009, October). Focus on function for children with cerebral palsy: The family-centred functional therapy study. Presented at the Alberta Centre for Child, Family & Community Research (ACFCR), Edmonton, AB.

29. Identification and development of common outcome indicator for Ontario's Children's Treatment Centres

Investigators: Virginia Wright

Affiliation: Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

TVCC Research Contact: *Karla LaFayette*

Status: Completed, 2006-2007

There is a growing interest internationally on establishment of meaningful and standardized processes for measurement of change with our clients across the broad domains of the International Classification of Functioning. Ontario Association of Children's Rehabilitation Centres (OACRS), was funded by the Ministry of Children and Youth Services (MCYS) to investigate measurement of change practices across Ontario in OACRS Children's Treatment Centres.

This study used clinician interviews to obtain information about present day clinical outcome measurement practice. The purpose of this 'front-line' work was to obtain information that will guide in determination of recommended approaches and tools for evaluation of change of clients who are connected with OACRS treatment centres.

Presentations:

Wright, V. (2007, October). From clinical observation to outcome measurement. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Waterloo, ON.
Wright, V. (2007, October). Results from the OACRS outcome indicators study. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Waterloo, ON.
Wright, V. (2007, October). Results from the OACRS outcome indicators study. Canadian Presented at the Annual conference of the Network for Child and Youth Rehabilitation (CN-CYR), Montreal, QC.

30. Mechanostat theory used to understand bone complications in children with Duchenne muscular dystrophy

Investigators: Craig Campbell¹, & Natasha Seemann²

Affiliations: Children's Hospital of Western Ontario, London Health Sciences Centre¹, Schulich School of Medicine and Dentistry, The University of Western Ontario²

TVCC Research Contact: *Linda Bolack*

Status: Underway, 2008-2010

This study will be investigating the relationship between bone density and bone complications in children with Duchenne muscular dystrophy (DMD). In the past, it has been difficult to define osteopenia, or weak bones in children, especially those with chronic diseases, since there is not yet an adequate way to use bone density measurements in children.

The Mechanostat theory views bone strength as principally driven by the muscle forces acting on the bone. Using this theory one does not compare children with DMD to age-matched controls without DMD but to those of similar muscle mass.

This study will be using bone content and muscle mass measurements from dual x-ray absorptiometry, which is a commonly used clinical test but typically analyzed differently, to classify DMD children as having osteopenia and then determining if bone complications occur more commonly in those with osteopenia.

31. Parental involvement in intensive behavioural intervention

Investigators: Abbie Solish, & Adrienne Perry

Affiliation: York University Department of Psychology

TVCC Research Contact: Louise LaRose

Status: Completed, 2008-2010

This project was part of a larger program of study examining potential factors predictive of outcome of early intensive behavioural intervention (IBI) for children with autism. A significant number of studies show that early intensive instruction, using the methods of IBI can result in significant improvements for at least some children with autism. Many professionals in the field emphasize the importance of parent involvement in IBI, however almost no research to date has shown whether parent involvement actually has an impact on children's progress in therapy. Before future research can confirm whether parent involvement in IBI affects children's outcome in therapy, it is essential to understand what "involvement" really means and how it can be measured.

This part of the study focused on parents' roles in the child's IBI therapy, with the ultimate goal to identify specific parental features related to successful child outcome. This study operationalized and explored parental involvement in IBI. Based on findings and suggestions from the limited research in this area, as well as observations from clinical experience and input from IBI therapists, we believed that parent involvement in IBI may be influenced by a number of factors.

The findings demonstrated that parents with higher self-efficacy or confidence about their ability to participate in their children's programs, greater knowledge of autism and IBI, and stronger general belief in IBI, were more likely to have higher levels of involvement in their children's IBI programs and agencies. Further analyses showed that of all the variables, parents' self-efficacy had the strongest relationship with parent involvement. This finding held true after ensuring that the children's age at the time of the study and their development level when their IBI began were taken into account.

These findings suggest that working with parents to help them become more self-confident, more knowledgeable, and have strong beliefs in IBI, may lead to their increased involvement in their children's IBI program. The hope is that involvement may, in turn, result in the child making greater progress in therapy. Therefore, results add support to the notion of providing supportive services to parents with children in IBI programs.

Publication:

Solish, A., & Perry, A. Parents' involvement in their children's behavioural intervention programs: parent and therapist perspectives. *Research in Autism Spectrum Disorders*. 2(4), 728-738.

Presentation:

Solish, A. (2006, November). Factors predicting parents' involvement in IBI. Presented at the 2006 Conference of The Ontario Association for Applied Behaviour Analysis, Markham, ON.

32. Plasma B-type natriuretic peptide levels and cardiac function in children with Duchenne muscular dystrophy and Myotonic dystrophy

Investigators: Craig Campbell¹, Mike Grattan², Kambiz Norozi³, & Liz Burrill³

Affiliation: Children's Hospital of Western Ontario, London Health Sciences Centre¹, The University of Western Ontario², Department of Pediatrics, London Health Sciences Centre³

TVCC Research Contact: Linda Bolack

Status: Underway, 2009-2012

The term muscular dystrophy defines a group of disorders characterized by muscle wasting and weakness. The most common form of muscular dystrophy is Duchenne Muscular Dystrophy (DMD). The next most common muscular dystrophy and most common adult onset muscular dystrophy is Myotonic Dystrophy (MD).

B-type natriuretic peptide (BNP) is a cardiac hormone, which is released in response to ventricular myocyte stretch. BNP lowers the peripheral vascular resistance, through down-regulation of the rennin-angiotensin-aldosterone system (causing increased sodium and urine excretion) and smooth muscle relaxation.

Children diagnosed with DMD and MD, being followed at the Thames Valley Children's Centre, will be asked to participate in this study. Clinical, echocardiographic and BNP levels will be followed and compared with normative plasma BNP levels. The objective of the study is to determine if BNP levels can be used to predict the stage of left ventricular dysfunction.

33. Study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy (DMD)

Investigators: Shannon Venance¹, Ricardo Viana², Kori LaDonna¹, Wilma J. Koopman¹, Craig Campbell¹, & Valerie Schulz¹

Affiliation: Children's Hospital of Western Ontario, London Health Sciences Centre¹, The University of Western Ontario²

TVCC Research Contact: Linda Bolack

Status: Completed, 2007-2010

The last 20 to 30 years has seen significant advancement in the management of Cystic Fibrosis and Duchenne Muscular Dystrophy (DMD) as they enter adulthood, these individuals have evolving needs, which may not be fully addressed in a child centred program. In addition, the disease specific management may be unfamiliar to adult oriented health care professionals, who are most comfortable managing adult diseases. These are a few reasons that the transition to adult oriented care can be difficult for the individual, his or her family, and the health care teams involved.

The main objective of this study was to explore care transition from Thames Valley Children's Centre (Pediatric Neuromuscular Clinic) to the London Health Sciences Centre-Adult

Neuromuscular Clinic in the Duchenne Muscular Dystrophy population. A pilot study involving a needs assessment and gap analysis was performed. The services offered and goals and objectives from the perspective of the young men with DMD and their caregivers was explored. The study also incorporated a neuromuscular specific quality of life instrument.

Presentations:

Viana, R., LaDonna, K., Koopman, W., Campbell, C., Schulz, V., & Venance, S. (2007, October).

Pilot study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy. Presented at the 12th International Meeting of World Muscle Society, Italy.

LaDonna, K., Koopman, W., Viana, R., Campbell, C., Schulz, V., & Venance, S. (2008, June). Pilot study to determine the transition needs of adolescents and adults with Duchenne muscular dystrophy. Presented at the 39th Annual Scientific Sessions of the Canadian Association of Neuroscience Nurses, Victoria, BC.

with autism should include and their general experiences of this process and describe the similarities and/or differences between groups. A total of 26 IBI staff participated in the study from four regional programs. This group consisted of senior therapists, transition coordinators, clinical supervisors/psychologists, and ASD consultants from the school support program. A total of 11 school staff participated in the study from three Ontario school boards. This group consisted of educational assistants, behaviour consultants, members of the school board autism team, senior school board personnel, principals and speech and language pathologists.

This study demonstrated that there are barriers to effective transition planning and some discrepancies between the hypothetical views and actual experiences of IBI and school staff. However, on a positive note, there is also a great deal of similarity between the two groups, particularly in their "ideal" view of transition, which is very hopeful. Overall, both groups agree on the importance of inclusion, the importance of individualizing the transition process, and the importance of involving families in transition planning. Sharing a similar view of what transition should ideally be for these children is the first step to creating a unified experience of transition. Future research must further address ways to make this idea process a reality.

Presentation:

Levy, A. (2006, November). The transition of children with autism from IBI into the school system. Presented at the 2006 annual conference of The Ontario Association for Applied Behaviour Analysis, Markham, ON.

34. The social context, challenges, and strengths in the everyday lives of girls

Investigators: Helene Berman

Affiliation: The University of Western Ontario, School of Nursing

TVCC Research Contact: Jan Evans

Status: Discontinued

This study was part of a national participatory action research (PAR) project designed to engage girls in the design and conduct of research on violence in the lives of girls. The research was to involve five Family Violence Research Centres across Canada. The primary objectives of this research were: 1) to engage a diverse group of girls in a PAR study where they can learn how knowledge can be used to bring about change; and 2) to examine how social inequalities based on race, gender, class, ability, and sexual orientation shape the lives of girls.

36. Validity, reliability and responsiveness to change of two abbreviated versions of the Gross Motor Function Measure in children with cerebral palsy

Investigators: Doreen Bartlett, & Laura Brunton

Affiliation: The University of Western Ontario, School of Physical Therapy

TVCC Research Contact: Cheryl Scholtes

Status: Completed, 2008-2009

The current "gold standard" measure to obtain an estimate of gross motor function in children with cerebral palsy is the 66-item version of the Gross Motor Function Measure (GMFM-66). A considerable amount of time is required of therapists, as well as children and their families, in order to provide the estimate of motor ability. Reducing the time required for assessment by reducing the number of items needed to produce an accurate depiction of these functional limitations experienced by the children would be beneficial.

This study measured the motor function in children with cerebral palsy to determine which of two shortened forms of a standard scale would still have the ability to see change and stay stable and accurate in measuring motor abilities in children with cerebral palsy. Shortening this tool would reduce the time needed to get an idea of the child's motor function. A shorter tool would allow for it to be used more in both practice and in research.

Presentation:

Bartlett, D., & Brunton, L. (2009, November).

Validity, reliability and responsiveness to change of two abbreviated versions of the Gross Motor Function Measure in children with cerebral palsy. Presented at Ontario Association of Children's Rehabilitation Centres conference, Toronto, ON.

35. The transition of children with autism from intensive behavioural intervention programs into the school system

Investigators: Alissa Levy, & Adrienne Perry

Affiliation: York University Department of Psychology

TVCC Research Contact: Louise LaRose

Status: Completed, 2005-2006

The transition of young children with autism into the school system is a unique process. The majority of these children will transition from Intensive Behaviour Intervention (IBI) programs into the school system. IBI programs are geared specifically to improve the skill deficits of these children. The programs are highly structured, intense, and utilize behavioural techniques. IBI programs are substantially different from most programs offered in the school system. Therefore, this transition path is fraught with its own unique challenges, facing both IBI programs and the school system, to ensure learning, maintenance of learned skills, and continued successful education. However, little or no empirical work has been done on the transition from IBI programs to the school system. The purpose of this study was to begin to clarify what the process of transition is for children with autism and what the strengths and weaknesses of this process are, from multiple perspectives. This study examined the perception of both IBI program and school staff. It compared these individual's views of what, hypothetically, the process of transition for children

GRANTS RECEIVED FOR TVCC PROJECTS

Between 1 April 2006 and 31 March 2010 a total of **\$1,116,331** in funding from granting agencies was awarded to **4** 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.....\$742,340

The impact of personal, interpersonal, and environmental factors on changes in quality of life for youth with chronic conditions-Quality of Life (QOL) Study, 2009-2014 (***Janette McDougall***, Virginia Wright, & Linda Miller).

Ontario Neurotrauma Foundation.....\$360,000

School reintegration for children and youth with acquired brain injury, 2008-2010 (Dawn Good, Peter Rumney, ***Janette McDougall***, Carol DeMatteo, Patricia McKeever, Denise Guerriere, Sue Loyst, Rhonda Martinussen, Sheila Bennett, & John Kumpf).

Pediatric Surgery Internal Grant Competition.\$2,000

A retrospective review of otologic and speech outcomes amongst children with cleft palate treated with and without intravelar veloplasty, 2007 (Michael Brandt, Murad Husein, Damir Matic, & ***Anne Dworschak-Stokan***).

Spinal Muscular Atrophy Foundation.....\$11,991

Pilot study of biomarkers for spinal muscular atrophy, 2008-2009 (Craig Campbell, Rhiannon Taranik, Victoria Siu, & ***Cheryl Scholtes***).

Funding Sources

Since 1989, funding for TVCC research endeavours 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 Ontario Foundation
- Easter Seal Association
- Easter Seal Research Institute
- Education Quality and Accountability Office
- Health Canada, Health Policy Research Program
- Hospital for Sick Children Foundation
- National Crime Prevention Centre
- National Institutes of Health
- 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

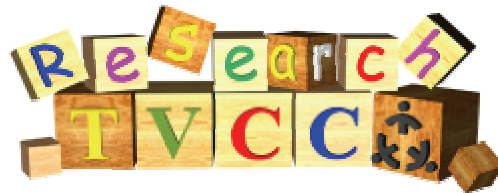
- Reseau Provincial de Recherche en Adaptation-Readaptation
- Research Alliance for Children with Special Needs
- Social Sciences and Humanities Research Council St. Mary's Fund from St. Joseph's Health Centre
- Thames Valley Children's Centre
- The Jack and Ina Pollock Foundation
- The Richard and Jean Ivey Fund
- The University of Western Ontario
- United Cerebral Palsy Foundation

Research Key Fact: Project Grants/Funding

Since 1989 the total amount of funding - **\$7,729,070** for **118** grants



- ❖ Projects awarded funding – 97
- ❖ Projects receiving more than one grant – 17
- ❖ Funding sources – 36
- ❖ Projects under \$5,000 – 39
- ❖ Projects of \$5,000 – 18
- ❖ Projects with funding between \$5,001 and \$9,999 – 8
- ❖ Projects with funding between \$10,000 and \$50,000 – 26
- ❖ Projects with funding of \$51,000 and \$250,000 – 20
- ❖ Projects with funding over \$250,000 - 7



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 2006 and 31 March 2010**. Names of TVCC staff members are bolded and italicized. Former TVCC staff member's names are italicized only.

BOOK CHAPTER

Participation of children in school and community. Law, M., Petrenchik, T., Ziviani, J., & King, G. (2006). In S. Rodger and J. Ziviani (Eds.), *Occupational therapy with children: Understanding children's occupations and enabling participation* (pp. 67-90). Oxford: Blackwell.

TRAINING MANUAL

Goal Attainment Scaling: Description, Utility, and Applications in Pediatric Therapy Services, Second Edition. A Resource Book/Training Manual. **McDougall, J.** & King, G. (2007). London, ON: Thames Valley Children's Centre.

A resource book/training manual about using Goal Attainment Scaling (GAS) in pediatric therapy services was developed as part of a larger study that used GAS to evaluate school health support services for children with special needs. GAS is an individualized, criterion-referenced measure of change. Using GAS involves defining a set of unique goals for a client, and then specifying a range of outcomes on a scale recommended to contain five levels, which reflect concrete functional activities.

A first edition of the resource book/training manual was developed as a resource to assist clinicians, administrators, and researchers when using GAS to monitor change over time for individual clients and/or to evaluate the effectiveness of programs and services. The second edition has been updated to include current literature and to explain and provide examples of how goals can be written for all functional levels identified in the International Classification of Functioning, Disability, and Health (i.e., impairments, activity limitations, and participation restrictions).

The authors of this manual have provided training to small and large groups of clinicians at Thames Valley Children's Centre and other children's treatment centres in Ontario, in addition to using GAS to evaluate pediatric therapy programs.

Visit the Thames Valley Children's Centre's website at www.tvcc.on.ca/measures-tools-ndresources.htm#gas to download a copy of this training manual.

PUBLISHED ABSTRACTS

Chronic conditions and disability among Canadian school-aged children: A national profile. **McDougall, J., King, G., DeWit, D., Miller, L., Hong, S., Offord, D., LaPorta, J., & Meyer, K.** (2008, October). *Neurorehabilitation and Neural Repair*, 22 (5), 514.

Chronic conditions and disability among Canadian school-aged children: A national profile. **McDougall, J., King,**

G., DeWit, D., Miller, L., Hong, S., Offord, D., LaPorta, J., & Meyer, K. (2008, October). *Archives of Physical Medicine and Rehabilitation*, 89, E1-55 (10), E44.
Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. **Somers, S., Gray, J., & McDougall, J.** (2010). *Brain Injury*, 24(3), 51-52.
School reintegration for children and youth with Acquired Brain Injury. Good, D., Rumney, P., **McDougall, J., Bennett, S., Martinussen, R., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Kumpf, J., & DeCourville, N.** (2009). *Journal of Head Trauma Rehabilitation*, 24(5), 399.

JOURNALS

Augmentative and Alternative Communication

- AAC and community partnerships: The participation path to community inclusion. **Batorowicz, B., McDougall, S., & Shepherd, T. A.** (2006). *Augmentative and Alternative Communication*, 22(3), 178-195.
- Beyond physical accessibility: Participation and communication in the library. **Shepherd, T., & McDougall, S.** (2008). *Augmentative and Alternative Communication*, 24(4), 313-322.
- Communication access for the library for individuals who use augmentative and alternative communication. **Shepherd, T., & McDougall, S.** (2008). *Augmentative and Alternative Communication*, 24, 313-322.
- Reliability of speech generating devices: A 5-year review. **Shepherd, T., Campbell, K., Renzoni, A., & Sloan, N.** (2009). *Augmentative and Alternative Communication*, 25(3), 145-153.

Australian Occupational Therapy Journal

The development of expertise in paediatric rehabilitation therapists: the roles of motivation, openness to experience, and types of caseload experience. **King, G., Currie, M., Bartlett, D., Strachan, D., Tucker, M. A., & Willoughby, C.** (2008). *Australian Occupational Therapy Journal*, 55, 108-122.

Brain Injury

An evaluation of the Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP). **McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gillett, J., Gray, J., Somers, S., Frid, P., DeWit, D., Pearlman, L., & Hicock, F.** (2006). *Brain Injury*, 20(11), 1189-1205.

Child: Care, Health and Development

- Keeping It Together™: An information KIT for parents of children and youth with special needs. Stewart, D., Law, M., Burke-Gaffney, J., Missiuna, C., Rosenbaum, P., King, G., Moning, T., & King, S. (2006). *Child: Care, Health and Development*, 32(4), 493-500.
- Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. **King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P.** (2007). *Child: Care, Health & Development*, 33(1), 28-39.

Service integration and coordination: A framework of approaches for the delivery of coordinated care to children with disabilities and their families. *King, G., & Meyer, K.* (2006). *Child: Care, Health and Development*, 32(4), 477-492.

Children's Health Care

Predictors of change over time in the activity participation of children and youth with physical disabilities. *King, G., McDougall, J., DeWit, D., Petrenchik, T., Hurley, P., & Law, M.* (2009). *Children's Health Care*, 38, 321-351.

Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis. *King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., Kertoy, M., & Petrenchik, T.* (2006). *Children's Health Care*, 35(3), 209-234.

The effectiveness of transition strategies for youth with disabilities. *King, G., Baldwin, P., Currie, M., & Evans, J.* (2006). *Children's Health Care*, 35(2), 155-178.

Developmental Medicine and Child Neurology

Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S.* (2006). *Development Medicine and Child Neurology*, 48(5), 337-342.

Developmental Neurorehabilitation

The development of expertise in pediatric rehabilitation therapists: Changes in approach, self-knowledge, and use of enabling and customizing strategies. *King, G., Currie, M., Bartlett, D. J., Gilpin, M., Willoughby, C., Tucker, M. A., Strachan, D., & Baxter, D.* (2007). *Developmental Neurorehabilitation*, 10(3), 223-240.

Disability and Rehabilitation

The ICF-CY and Goal Attainment Scaling: The benefits of their combined use in pediatric rehabilitation practice. *McDougall, J., & Wright, V.* (2009). *Disability and Rehabilitation*, 31(16), 1362-1372.

Evaluation and Program Planning

A framework of operating models for interdisciplinary research programs in clinical service organizations. *King, G., Currie, M., Smith, L., Servais, M., & McDougall, J.* (2008). *Evaluation and Program Planning*, 31, 160-173.

A measure of community members' perceptions of the impacts of research partnerships in Health and Social Services. *King, G., Servais, M., Kertoy, M., Specht, J., Currie, M., Rosenbaum, P., Law, M., Forchuk, C., Chalmers, H., & Willoughby, T.* (2009). *Evaluation and Program Planning*, 32, 289-299.

Evidence-Based Communication Assessment and Intervention

Expertise in research-informed clinical decision making: Working effectively with families of children with little or no functional speech. *King, G., Batorowicz, B., & Shepherd, T.* (2008). *Evidence-Based Communication Assessment and Intervention*, 2(2), 106-116.

Exceptionality Education International

A preliminary evaluation of a school support program for children with autism spectrum disorders. *McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggan, C.* (2009). *Exceptionality Education International*, 19(1), 32-50.

Health and Social Care in the Community

Features and impacts of five multi-disciplinary community-university research partnerships. *King, G., Servais, M., Forchuk, C., Chalmers, H., Currie, M., Law, M., Specht, J., Rosenbaum, P., Willoughby, T., & Kertoy, M.* (2010). *Health and Social Care in the Community*, 18(1), 59-69.

International Journal of Disability, Development, and Education

Measuring the expertise of paediatric rehabilitation therapists. *King, G., Bartlett, D. J., Currie, M., Gilpin, M., Baxter, D., Willoughby, C., Tucker, M. A., & Strachan, D.* (2008). *International Journal of Disability, Development and Education*, 55(1), 5-26.

International Journal of Spirituality and Health

An exploration of spirituality, spiritual beliefs, and pediatric rehabilitation. *Baldwin, P., McDougall, J., & Evans, J.* (2008). *International Journal of Spirituality and Health*, 9(4), 249-262.

International Society of Augmentative and Alternative Communication (ISAAC)

Team decision-making in AAC: Examining clinical perceptions. *Batorowicz, B., & Shepherd, T.* (2006). *Proceedings of the 12th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC).*

Journal of Interprofessional Care

Measuring the quality of transdisciplinary teams. *Batorowicz, B., & Shepherd, T.* (2008). *Journal of Interprofessional Care*, 22, 612-620.

Paediatrics & Child Health

Employing the International Classification of Functioning, Disability and Health to enhance services for children and youth with chronic physical health conditions and disabilities. *McDougall, J., Horgan, K., Baldwin, P., Tucker, M. A., & Frid, P.* (2008). *Paediatrics & Child Health*, 13(3), 173-178.

Physical and Health Education Journal

Canada's active schools: A review of school-based physical activity interventions in Canada. *Patton, I., & McDougall, J.* (2009). *Physical and Health Education Journal*, 75, 16-22.

Physical & Occupational Therapy in Pediatrics

A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Stewart, D., Stavness, C., King, G., Antle, B., & Law, M.* (2006). *Physical & Occupational Therapy in Pediatrics*, 26(4), 5-24.

A trajectory of troubles: Parents' impressions of the impact of developmental coordination disorder. *Missiuna, C., Moll, S., King, S., King, G., & Law, M.*

(2007). *Physical & Occupational Therapy in Pediatrics*, 27(1) 81-101.

An evaluation of the Youth En Route program. **Evans, J., McDougall, J., & Baldwin, P.** (2006). *Physical & Occupational Therapy in Pediatrics*, 26(4), 63-87.

Bringing the Life Needs Model to life: Implementing a service delivery model for pediatric rehabilitation. **King, G., Tucker, M. A., Baldwin, P., & LaPorta, J.** (2006). *Physical & Occupational Therapy in Pediatrics*, 26(1/2), 43-70.

School-based occupational therapy for children with fine motor difficulties: Evaluating functional outcomes and fidelity of services. Bayona, C. L., **McDougall, J., Tucker, M. A., Nichols, M., & Mandich, A.** (2006). *Physical & Occupational Therapy in Pediatrics*, 26(3), 89-110.

Qualitative Health Research

Social support processes and the adaptation of individuals with chronic disabilities: A qualitative retrospective study. **King, G., Willoughby, C., Specht, J., & Brown, E.** (2006). *Qualitative Health Research*, 16(7), 902-925.

Rehab & Community Care Medicine

Enhancing social support: Helping youth with chronic conditions. **McDougall, J., & Willoughby, C.** (2007, Winter). *Rehab & Community Care Medicine*, 19(4), 19.

Remedial and Special Education

The importance of self-determination to perceived quality of life for youth and young adults with chronic conditions and disabilities. **McDougall, J., Evans, J., & Baldwin, P.** (2009). Remedial and Special Education. Prepublished December 10, 2009, DOI: 1177/0741932509355989.

Supportive Care in Cancer

Quality of life in survivors of childhood cancer: A systematic review of the literature (2001-2008). **McDougall, J., & Tsonis, T.** (2009). *Supportive Care in Cancer*, 17(10), 1231-1246.

- Evaluation of two treatments for toe-walking for children with cerebral palsy (Volume 3 Issue 2, September 2007), **Stephenson, F., Scholtes, C., Carey, T., & Leitch, K.**
- Enhancing social support for children and youth with chronic physical health conditions (Volume 3 Issue 3, September 2007), **McDougall, J., & Willoughby, C.**
- A dynamic wheelchair seating system: Design and technical development (Volume 4 Issue 1, June 2008), **Wightton, J., Smith, L., & Stephenson, F.**
- What is "quality of life" and how can research identify the factors that optimize life quality for children and youth with chronic conditions? (Volume 5 Issue 1, May 2009), **McDougall, J., Wright, V., & Miller, L.**
- Relationship-centered practice: A best practice in pediatric rehabilitation service delivery (Volume 5 Issue 2, May 2009), **Servais, M., Baldwin P., & Tucker, M. A.**
- Peer-mediated school-based program proves successful in promoting positive social skills (Volume 5 Issue 3, September 2009), **Servais, M., Hall, C., Chadwick, C., & Lombardi, J.**
- The developmental resources for infants partnership: Enhancing interdisciplinary collaboration to improve services for clients and families (Volume 5 Issue 4, September 2009), **Servais, M., Tucker, M. A., & Strachan, D.**
- Spirituality and rehabilitation (Volume 6 Issue 1, January 2010), **Baldwin, P.J., McDougall, J., & Evans, J.**



EASY-TO-READ SUMMARIES

"Facts to Go"

Facts to Go are one-page information sheets on research topics written by staff members and published and distributed by the Research Program.

Facts To Go can be requested from the website: www.tvcc.on.ca/

- An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) (Volume 2 Issue 1, August 2006), **McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gray, J., Somers, S., Gillett, J., & Frid, P.**
- An evaluation of the School Support Program-Autism Spectrum Disorder (SSP-ASD) (Volume 2 Issue 2, December 2006), **McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggan, C.**
- Team decision-making in augmentative communication: Clinical perceptions (Volume 3 Issue 1, January 2007), **Batorowicz, B., & Shepherd, T.**

Research Key Fact: Publication



On average, 8 articles are published or accepted for publication each year. Since 1989 there have been 189 Peer-Reviewed publications.

- ❖ Peer-reviewed articles – 144
- ❖ Book – 1
- ❖ Book chapters – 9
- ❖ Measurement Tool – 1
- ❖ Research reports - 21

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 2006 and 31 March 2010**. Names of TVCC staff members are bolded and italicized. Names of former TVCC staff are italicized only.

INTERNATIONAL

American Congress of Rehabilitation Medicine-American Society of Neurorehabilitation Joint Educational Conference, Toronto, ON.

Chronic conditions and disability among Canadian school-aged children: A national profile. **McDougall, J.** (2008, October).

American Psychological Association. Boston, MA, USA.

School participation: Opportunities, enhancers, and limiters. Specht, J. A., **Servais, M.**, Kertoy, M., Spencer, T., *King, G.* Cressman, C., Pompeo, M., & Young, G. (2008, August).

Assistive Technology Industry Association, Chicago, IL, USA.

Automatic and step scanning performance of 3 year olds. *Batorowicz, B.*, & **Shepherd, T.** (2009, October).

College of Occupational Therapists Specialist Section-Children, Young People, and Families Conference, University of Warwick, Coventry, United Kingdom.

Application and relevance of a combined "ICF(CY) & CMOP-E" framework to enhance occupational engagement in children. Hasselbusch, A., & **McDougall, J.** (2009, November).

Eighth Annual Conference of the ASHA Division on AAC, Atlanta, GA, USA.

A model of clinical decision making in AAC: Expert inquiry; evidence based decision making in AAC. *Batorowicz, B.*, & **Shepherd, T.** (2007, February).

International Conference of the International Society of Augmentative and Alternative Communication (ISAAC), Düsseldorf, Germany.

Beyond physical accessibility: Communication for all in the library. **McDougall, S.**, & **Shepherd, T.** (2006, July).
Team decision-making in AAC: Examining clinical perceptions. *Batorowicz, B.*, & **Shepherd, T.** (2006, July).
Voice output communication aid reliability: The shocking truth. **Shepherd, T.**, Renzoni, A., Sloan, N., & Campbell, K. (2006, July).

International Society for Applied Behaviour Analysis Annual Conference, Phoenix, AZ, USA.

Generalizing social skills outside the classroom: A peer-mediated approach for students with autism. *Hall, C.*, & *Chadwick, C.* (2009, May).

North American Brain Injury Society 7th Annual Conference on Brain Injury. Austin, TX, USA.

School reintegration for children and youth with Acquired Brain Injury. *Good, D.*, *Rumney, P.*, **McDougall, J.**, *Bennett, S.*, *Martinussen, R.*, *DeMatteo, C.*, *McKeever, P.*, *Guerriere, D.*, *Loyst, S.*, *Kumpf, J.*, & *DeCourville, N.* (2009, October).

Second City 8th Conference on Disability Studies in Education, New York, NY, USA.

School role participation: Perspectives of the child, parent, and the teacher. Specht, J. A., **Servais, M.**, Kertoy, M., Spencer, T., *King, G.*, Cressman, C., Pompeo, M., & Young, G. (2008, March).

Solution-Focus Brief Therapy Association Annual Conference, Austin, TX, USA.

Introducing a solution focused approach in a pediatric rehabilitation setting. **Baldwin, P.** (2008, November).

University of California San Diego (UCSD) Conference New Frontiers in Pediatric Traumatic Brain Injury, San Diego, CA, USA.

An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). **Gray, J.**, **McDougall, J.**, **Somers, S.**, **Servais, M.**, *Sommerfreund, J.*, *Rosen, E.*, *Gillett, J.*, *DeWit, D.*, & *Frid, P.* (2007, November).

World Congress on Brain Injury 8th Annual Conference, Washington, DC, USA.

Managing complex concussions in children and youth: A multidisciplinary approach to a multifaceted problem. **Somers, S.**, **Gray, J.**, & **McDougall, J.** (2010, March).

NATIONAL

Biennial International Meeting for Autism Research, Montreal, QC.

Belief systems of families of children with autism spectrum disorders. *King, G.*, *Zwaigenbaum, L.*, *Rosenbaum, P.*, *King, S.*, *Bates, A.*, & *Baxter, D.* (2006, June).

Biennial 13th Conference of the International Society for Augmentative and Alternative Communication in Montreal, Quebec.

The I Can Newsletter: Sharing information to increase participation. **Pallant, K.**, **Steckle, G.**, & **Vessoyan, K.** (2008, August).

Canadian Occupational Therapy Conference, Montreal, QC.

Participation of children with physical disabilities in out of school occupations. *Law, M.*, *King, G.*, *Kertoy, M.*, *Hurley, P.*, *Hanna, S.*, *Petrenchik, T.*, *Rosenbaum, P.*, & *Young, N.* (2006, June).
Young adults with developmental coordination disorder: From disability to resilience. *Moll, S.*, *Missiuna, C.*, *Stewart, D.*, *King, G.*, & *MacDonald, K.* (2006, June).

Canadian Pediatric Society 85th Annual Meeting. Victoria, BC.

Employing the International Classification of Functioning, Disability, and Health (ICF) to enhance services for children and youth with chronic conditions and disabilities. *Frid, P., McDougall, J., Horgan, K., Baldwin, P., & Tucker, M. A.* (2008, June).

4th International Multidisciplinary Conference on Spirituality and Health: Interweaving Science, Wisdom and Compassion, Vancouver, BC.

An exploration of spirituality, spiritual beliefs and pediatric rehabilitation. *Baldwin, P., & Evans, J.* (2006, November).

International Society for Augmentative and Alternative Communication, Montreal, QC.

Diversity awareness: A model for peer acceptance of students with disabilities. *McDougall, S., & Hall, C.* (2008, August).

North American Collaborating Center 14th Conference on ICF, Quebec City, QC.

Applying the ICF at a children's rehabilitation centre to enhance the participation of children and youth with chronic conditions and disabilities. *McDougall, J., Horgan, K., Baldwin, P., Tucker, M. A., & Frid, P.* (2008, August).

PROVINCIAL

American Psychological Association Annual Conference, Toronto, ON.

School roles: Opportunities to participate. Specht, J. A., *Servais, M.*, Spencer, T., *King, G.*, young, G., Pompeo, M., Young, G., & Puskarich, M. (2009, August).

Bloorview Research Institute Symposium, Toronto, ON.

Performance of 3 year olds using step and automatic scanning techniques: Preliminary results. *Batorowicz, B., & Shepherd, T.* (2008, November).
Speech generating device reliability. *Shepherd, T., Renzoni, A., Sloan, N., & Campbell, K.* (2006, November).
Speech generating device reliability: The shocking truth! *Shepherd, T., Renzoni, A., Sloan, N., & Campbell, K.* (2007, November).

Council for Exceptional Children Annual Conference, London, ON.

Autism disability awareness in schools. *Hall, C., & McDougall, S.* (2008, November).
Reaching beyond the student with autism: A school-wide peer-mediated approach to social skill teaching. *Hall, C., Chadwick, C., & Servais, M.* (2008, November).

Early Words, The Hamilton Preschool Speech and Language Service, Regional Systems Day, Hamilton, ON.

Providing family-centered service through relationship-centered practice. *Servais, M., Tucker, M. A., & Baldwin, P.* (2009, May).

Engaging Reflection in Health Professional Education and Practice 2009 Conference, London, ON.

Development of a self-reflective tool to deepen relationship-centered practices of paediatric rehabilitation therapists with families of children with disabilities. *Servais, M., Tucker, M. A., & Baldwin, P.* (2009, May).
Facilitating the development of professional expertise in children's mental health, rehabilitation, and education services. Specht, J., *King, G.*, Bartlett, D., Stewart, S., Gilpin, M., Petersen, P., *Servais, M.*, Brown, H., Young, G., & Kessler, N. (2009, May).

Neurobehavioural Rehabilitation in Acquired Brain Injury 16th Annual Conference, Hamilton Health Sciences, Hamilton, ON.

School reintegration for children and youth with Acquired Brain Injury. Good, D., Rumney, P., *McDougall, J.*, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, May).

Ontario Association for Applied Behaviour Analysis Annual 2007 Conference, Markham, ON.

Peer-mediated social skills training: How do we generalize beyond the classroom? *Hall, C., & Chadwick, C.* (2007, November).

Ontario Association for Applied Behaviour Analysis (ONTABA) Annual 2008 Conference, Toronto, ON.

Effectiveness of peer-mediated social skills training: Prerequisites for generalization for students with autism. *Hall, C., Servais, M., & Chadwick, C.* (2008, November).

Ontario Association of Children's Rehabilitation Services 2006, Niagara Falls, ON.

A survey of chronic and recurrent pain in children and youth with disabilities. *Bolack, L., Crotagino, J., Gilpin, M., & Young, C.* (2006, October).
An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). *McDougall, J., & Somers, S.* (2006, October).
Augmentative and alternative communication devices: Reasons for continued or discontinued use. *Sereda, L., Sumsion, T., & Browning, N.* (2006, September).
From exploration to implementation: Integrating spirituality into a pediatric rehabilitation centre. *Baldwin, P., & LaPorta, J.* (2006, October).

Ontario Association of Children's Rehabilitation Services 2007, Waterloo, ON.

An evaluation of the School Support Program-Autism Spectrum Disorder. *McDougall, J., Meyer, K., Case, S., Dannenhold, K., Johnson, S., Riggan, C., & Servais, M.* (2007, October).
Beyond family-centred care: Deepening our clinical practice of relationship-centred care with families of children with disabilities. *Tucker, M. A., Servais, M., & Baldwin, P.* (2007, October).
Co-constructing solutions with clients & families using powerful questions. *Baldwin, P., & Evans, J.* (2007, October).
Developing a tool to track client and family outcomes of social work services. *McDougall, J., & Ryan, T.* (2007, October).
Open to possibilities: The role of "hope" in pediatric rehabilitation. *Baldwin, P., & Evans, J.* (2007, October).

Ontario Association for Children's Rehabilitation Services 2009, Conference, Toronto, ON.

- Changes in quality of life for youth with chronic conditions: The impact of personal, interpersonal and environmental factors. **McDougall, J.**, Wright, V., & Miller, L. (2009, November).
- Reflecting on effective communication and listening skills in therapeutic practice. **Bolack, L.**, **Shepherd, T.**, **Servais, M.**, **King, G.**, & **Willoughby, C.** (2009, November).
- School reintegration for children and youth with Acquired Brain Injury. **McDougall, J.**, Good, D., Rummey, P., DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, November).
- Supporting the development of relationship-centred practices through the use of a Self-Reflection Tool for pediatric therapists. **Baldwin, P.**, **Servais, M.**, & **Tucker, M. A.** (2009, November).

Ontario Association for Developmental Disabilities Research Special Interest Group 17th Annual Research Day, Barrie, ON.

- A preliminary evaluation of a school support program for children with autism spectrum disorders. **McDougall, J.**, **Servais, M.**, **Meyer, K.**, **Case, S.**, **Dannenhold, K.**, **Johnson, S.**, & **Riggin, C.** (2009, April).
- School reintegration for children and youth with Acquired Brain Injury. Good, D., Rummey, P., **McDougall, J.**, DeMatteo, C., McKeever, P., Guerriere, D., Loyst, S., Martinussen, R., Bennett, S., Kumpf, J., Wlodarczyk, K., & McCafferty, K. (2009, April).

Ontario Education Research Symposium, 5th Annual Conference, Toronto ON.

- Elementary school roles: Making sure all participate. Spencer, T., Specht, J., **Servais, M.**, Kertoy, M., **King, G.**, Pompeo, M., Young, G., & Puskarich, M. (2010, February)

Ontario Provincial 52nd Conference of the Council for Exceptional Children, London, ON.

- Reaching beyond the student with Autism: A school-wide, peer-mediated approach to social skill teaching. **Hall, C.**, **Chadwick, C.**, & **Servais, M.** (2008, November).
- School participation: How educators can help. Specht, J. A., Spencer, T., **Servais, M.**, Kertoy, M., Young, G., Pompeo, M., Cressman, C., & Puskarich, M. (2008, November).
- The I Can Newsletter: Sharing information to increase participation. **Steckle, G.**, & **Vessoyan, K.** (2008, November).

Toronto ABI Network Conference, Toronto, ON.

- An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). **McDougall, J.**, **Gray, J.**, **Somers, S.**, **Servais, M.**, **Sommerfreund, J.**, **Rosen, E.**, **Gillett, J.**, & **Frid, P.** (2006, November).

Transitions Conference 4, Toronto, ON.

- Open to possibilities: The role of "hope" in pediatric rehabilitation-adolescent perspectives. **Baldwin, P.**, & **Evans, J.** (2008, May).

When Faith Meets Pedagogy Conference, Toronto, ON.

- The effects of a peer-mediated social skills training approach. **Hall, C.**, **Chadwick, C.**, & **Bruneel, M.** (2007, October).

INVITED PRESENTATIONS

International

International Meeting in Paediatric Neuromuscular Rehabilitation, Vingstedcentret, Denmark.

- The participation of children and youth with physical disabilities. **King, G.**, **Law, M.**, **King, S.**, **Hurley, P.**, **Hanna, S.**, **Rosenbaum, P.**, **Kertoy, M.**, & **Petrenchik, T.** (2006, May).

National

Isaac Walter Killam Health Centre, Halifax, NS.

- Facilitating change through solution-focused coaching for rehabilitation professionals. **Baldwin, P.**, & **Evans, J.**, (2008, October).

Provincial

Augmentative Communication Rounds, Toronto, ON.

- Team decision making. **Shepherd, T.**, & **Batorowicz, B.** (2007, November).
- And the survey says. **Shepherd, T.** (2009, May).

Bloorview Kids Rehabilitation Centre, Toronto, ON.

- An exploration of spirituality, spiritual beliefs and pediatric rehabilitation. **Baldwin, P.** (2007, January).

Canadian Institute of Health Information, Toronto, ON.

- Applying the ICF/ICF-CY to enhance the health of children and youth. **McDougall, J.** (2010, March).

Children's Treatment Centre of Chatham-Kent, Sarnia, ON.

- Positive connections with people: Solution-focused coaching in pediatric rehabilitation. **Baldwin, P.** (2009, September).

Early Years Regional Systems Day, Hamilton, ON.

- Focusing on relationship-centred clinical practice with families of children with disabilities. **Tucker, M. A.**, **Servais, M.**, & **Baldwin, P.** (2009, May).

Hamilton Preschool Speech and Language Service, Hamilton, ON.

- Providing family-centered service through relationship-centered practice. **Tucker, M. A.**, **Servais, M.**, & **Baldwin, P.** (2009, May).

Home Visiting Program for Infants, Child & Parent Resource Institute, London, ON.

- Using a solutions-focus in working with children and families. **Baldwin, P.** (2010, March).

Huron Perth Catholic District School Board, Dublin, ON.

Generalizing social skills outside the classroom: A peer-mediated approach for students with autism. *Chadwick, C., Hall, C., & Servais, M.* (2009, November).

Ministry of Children & Youth Services, Preschool Speech and Language Program, Toronto, ON.

Using a solutions-focus in working with children and families. *Baldwin, P.* (2010, February).

Pathways Children's Health Centre, Sarnia, ON.

Positive connections with people: Solution-focused coaching in pediatric rehabilitation. *Baldwin, P.* (2009, September).

Staff forum on relationship-centred practice. *Baldwin, P.* (2009, April).

Thames Valley District School Board, London, ON.

Generalizing social skills outside the classroom: A peer-mediated approach for students with autism. *Hall, C., Chadwick, C., & Servais, M.* (2009, November).



Research Key Facts: International Conferences

Since 1989, TVCC staff members have made 281 presentations. On average, staff members make 13 presentations at conferences in a year. International presentations have been made at the following:

- American Academy for Cerebral Palsy and Developmental Medicine
- American Cleft Palate/Craniofacial Association
- American Educational Research Association
- American Occupational Therapy Association
- American Psychological Association
- 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
- 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 Seating Symposium
- International Society for Applied Behaviour Analysis
- International Society of Augmentative and Alternative Communication
- 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

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