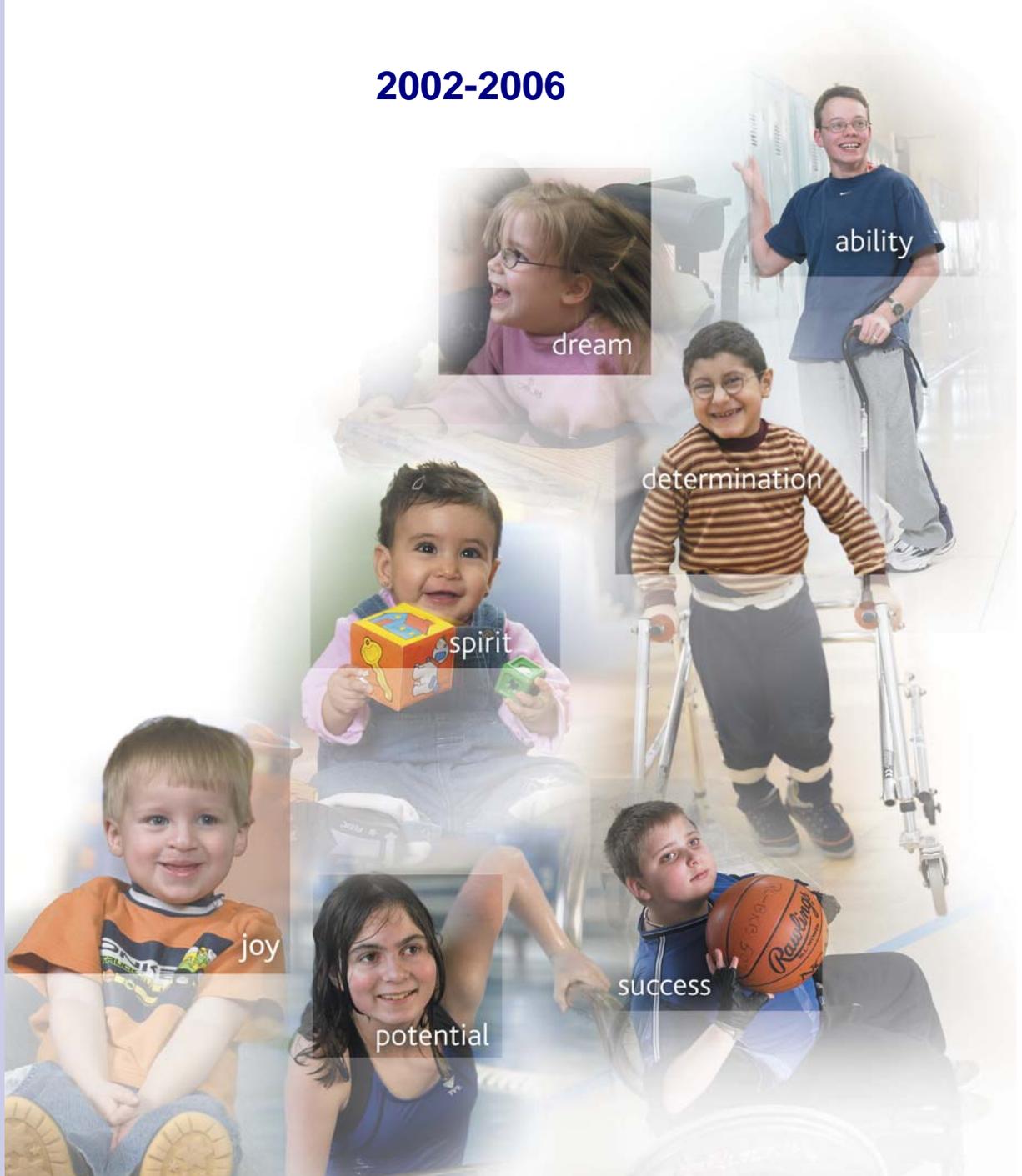


# Research

2002-2006





## **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 four 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 program areas. We use research evidence to inform our clinical and everyday practice and to help us in our decision-making processes.

In 2006, we restructured our Research Program: We shifted from a "clinician-researcher" model that aimed to support individual clinicians' skill development and knowledge generation, to more of a program evaluation/knowledge conduit approach that aims to support clinicians and leaders in evaluating services and to share research knowledge both within and beyond TVCC. As we move forward, we are building on our previous work, and we are producing this report to summarize the significant body of work developed over the past four years.

Enjoy reading about our accomplishments thus far, and do not hesitate to contact us for more information if anything sparks your interest. Linda Smith, Research Officer – who took on the challenge of summarizing all this information with grace and enthusiasm – can be contacted at 519-685-8680, or at [research@tvcc.on.ca](mailto:research@tvcc.on.ca).

*Karen Horgan*

Director, Community & Clinical Information Resources  
Thames Valley Children's Centre

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# 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 6,000 children ranging from newborns to young adults, every year.

## **Our Mission:**

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

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

## **Our Vision:**

Our Clients at Their Best.

*Beyond*  *disability*

## **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

Thames Valley  Children's Centre

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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 consultation, education, and resources to TVCC staff members. The Research Program also engages in research activities with other 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 program evaluation, 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, 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.).

The Research Program also provides feedback on research materials written by TVCC staff members such as questionnaires, completed application forms, presentation materials, and articles for publication.

Networking and collaboration are encouraged and facilitated with other researchers in London, in Ontario, across Canada, and internationally.

#### 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.

##### ◆ Musing and Munching

The "Musing and Munching" meetings are informal and informative discussions on research-related topics (e.g., mentoring, care management tools, the Life Needs Model, spirituality and belief systems, clients' pain experiences).



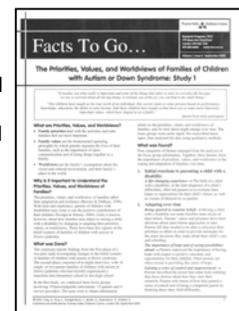
##### ◆ Discovery

The "Discovery" sessions provide researchers with a forum to present the results of their research projects to the TVCC staff – a stipulation of all research projects undertaken at the Centre.



##### ◆ 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 Program Director
- ◆ a Research Director
- ◆ a Research Officer
- ◆ Centre Research Associates

Recently, the Research Program joined the Clinical and Community Information Resources (CCIR) Program at the Centre and is under the direction of the CCIR Program Director.

The Research staff are funded through TVCC's Research Trust Fund and by research project grants. Project coordinators, data analysts, and research assistants are hired on an "as-needed" basis to work on specific projects and are funded by research project grants.

### Team Members

#### Program Director

- ◆ Karen Horgan (2006-present)

The **Program Director** provides overall direction to the Research Program and is responsible for the administrative aspects of the Program.

#### Research Director & Senior Researcher

- ◆ Gillian King, Ph.D. (1988-present)

The **Research Director** plays a knowledge brokering roles, as well as supporting and mentoring Research Associates in their endeavours.

The **Senior Researcher** works on research and writing activities supported by the Ontario Mental Health Foundation Fellowship.

#### Research Officer

- ◆ Linda Smith (1994-present)

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

#### Centre Research Associates

- ◆ Melissa Currie, M.Sc. (2000-2006)
- ◆ Janette McDougall, Ph.D. (1995-present)
- ◆ Michelle Servais, Ph.D. candidate (2000-present)

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

#### Research Project Coordinator

- ◆ Donna Baxter, M.Sc. (2002-2005)

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

#### Library Researcher

- ◆ Jon Batson (2001-present)

**Library Researchers** search databases and retrieve resource materials to support research activities.

## A LIFE NEEDS MODEL OF SERVICE

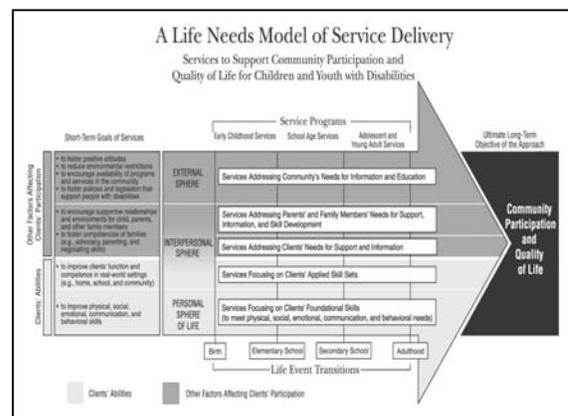
In conjunction with others at TVCC, the Research Program has played an instrumental role in the conceptualization of a model of services needed by children with disabilities, their families, and members of the community who play important roles in these children's lives.

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, dispel myths, 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.



### Publications:

**King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L. (2002).** A Life Needs Model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical & Occupational Therapy in Pediatrics*, 22(2), 53-77.

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

## TVCC RESEARCH SUPPORT

The Board of Directors and Leadership Team of Thames Valley Children's Centre provide a high level of support for staff pursuing research activities.

Prior to April 2006, there were 3 distinct sources of financial support for staff as summarized below.

As part of the restructuring of the Research Program in 2005-06, these formal financial supports for research activities were merged to support regular, core research staffing to support program evaluation activities throughout the Centre. A fund was also maintained to support individual projects and staff, to be used at the discretion of the Centre's Clinical Directors and the Director of CCIR.

### RESEARCH AWARDS

TVCC Research Awards encouraged staff members to do research at the Centre by providing money for their projects (up to \$5,000 per project). Awards were intended to cover contracted services (e.g., research assistants, consultants) and/or equipment. They were not intended to cover staff time spent on projects.

All full-time and part-time TVCC employees were eligible to apply for a Research Award. Although co-investigators need not be staff members, the principal investigator on the project had to be a TVCC employee.

Award winners were expected to present their research results at a conference and prepare a research article to be submitted for publication.

Competitions for these awards were held three times a year: February 28, May 31, and October 31.

Applications were reviewed and awards were made by the Centre's Research Advisory Committee.

#### Research Key Fact: TVCC Research Awards



- ◆ Between 1 April 2002 and 31 March 2006, **6 staff projects** received TVCC Research Awards totalling **\$26,092**.
- ◆ Since the creation of the Awards in 1989, **\$102,350** have been used to support **23 staff projects**.

#### Research Key Fact: Staff and Research



- Since the creation of the Research Program 17 years ago:
- ◆ **102 staff members** have been investigators on research projects.
  - ◆ TVCC staff members have been **lead investigators on 62 projects**.
  - ◆ Members from **all of TVCC's programs and therapy disciplines** have been involved in research.
  - ◆ **Forty-two** staff members have been involved in **more than one research project**.

#### Research Key Fact: Projects



- ◆ On average, there are **26 projects underway in a year**
- ◆ **21 projects were started** in the last 4 yrs (6 internal, 15 external)
- ◆ **20 projects received funding**
- ◆ Since 1989, **77 research projects** with TVCC staff members as investigators have been **completed**.

### STAFF RESEARCH SUPPORT FUND

The Staff Research Support Fund provided resources to encourage and support staff members to be investigators on research projects. The Fund applied only to investigator activities (such as writing grants and articles, and overseeing studies). It was not intended to cover other activities such as data collection (which should be covered by research grants).

The monies were used either as clinical relief (where a clinical replacement was arranged to allow staff members to take part in research within their regular work hours) or as honoraria (where money was given to staff members to acknowledge their contribution of personal time – on evenings and weekends – to do research). The amount received depended on the nature of the research activity (and therefore the amount of time required from staff members).

Staff members who received funds were expected to complete an agreed-upon research product (e.g., submit a grant proposal for funding or a paper for publication) and to present the study findings to other staff members.

#### Research Key Fact: Staff Research Support Fund



- ◆ Between 1 April 2002 and 31 March 2006, **12 staff members** received **\$10,550** to complete research activities including writing grants, collecting and analyzing data, or preparing presentations or publications.
- ◆ Since the start of the Fund in 1996, a total of **\$48,869** was used to support **36 staff members** to work on various aspects of their research projects.

### PROGRAM EVALUATION FUND

TVCC allocated \$20,000 per year to cover clinical, research, and other staff time needed to conduct mid-size program evaluation projects. This money was available through the support of the Centre's Board of Directors. The Program Evaluation Support Fund was available for program evaluations requiring between \$10,000-\$15,000 in salary support for involved staff members. Projects requiring a larger amount of financial support were encouraged to seek external funding.

Program evaluation is the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgements about the program, improve program effectiveness, and/or inform decisions about future programming (Paton, 1996).

Program evaluation may be necessary to evaluate a new service or a significant portion of a program service, and to provide external accountability to granting agencies. This fund was used for initial pilot program evaluations that might lead into a larger project requiring external funding.

Paton, M. Q. (1996). Utilization-focused evaluation (3rd ed.). Thousand Oaks, CA: Sage Publications.

#### Research Key Fact: Program Evaluation Fund



- ◆ Between 1 April 2002 and 31 March 2006, **2 staff members** received **\$13,560** to complete program evaluations.
- ◆ Since the creation of the Fund in 2001, a total of **\$39,910** was used to support **6 projects** evaluating TVCC programs.

## 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 improvement 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.

When projects are initiated by outside agencies or researchers, collaborative endeavours involving joint authorship are preferred over those that simply involve access to TVCC clients and resources. Our past experience has shown that collaborative studies are easier to implement, have a better chance of successful completion, and have more impact on clinical practice at the Centre.

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.

### PROJECT APPROVAL CRITERIA

- ◆ Ethics clearance from a University Ethics Review Committee
- ◆ Scientific merit
- ◆ Absence of an appreciable burden to clients/participants given other ongoing projects at the Centre
- ◆ Agreement/approval of the TVCC Program Director and cooperation of TVCC staff members (one to be a Research Contact for outside researchers)
- ◆ Relevance of the research to one of the Research Program's two key theme areas: (a) evaluation of programs, interventions, and aspects of service delivery; and (b) psychosocial aspects of disabilities and interventions

### 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 and to grant TVCC Research Awards. 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 Research Associate (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 2002-2006

- ◆ **Dr. Doreen Bartlett** (*Member: 1999-2002*)  
School of Physical Therapy  
University of Western Ontario
- ◆ **Dr. Timothy Carey** (*Member: 1995-2006*)  
Orthopaedic Surgeon  
London Health Sciences Centre
- ◆ **Dr. Mervyn Fox** (*Member: 1988-2003*)  
Medical Director  
Thames Valley Children's 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
- ◆ **Dr. Jan Miller Polgar** (*Member: 1993-present*)  
School of Occupational Therapy  
University of Western Ontario
- ◆ **Dr. Gillian King** (*Chair: 1988-2005*)  
Research Director  
Thames Valley Children's Centre
- ◆ **Dr. Janette McDougall** (*Chair: 2005-present*)  
Research Associate  
Thames Valley Children's Centre

#### Research Key Fact: Research Advisory Committee



- ◆ Between 1 April 2002 and 31 March 2006, the RAC reviewed and approved 21 projects – 6 of those also received TVCC Research Awards of \$26,092.
- ◆ Since 1989, the Research Advisory Committee has reviewed 97 proposals – an average of 6 proposals a year.

## PROJECTS AWARDED BY RAC

Between 1 April 2002 and 31 March 2006, the Research Advisory Committee reviewed, approved, and granted the following **6 TVCC staff member projects** Thames Valley Children's Centre Research Awards totalling \$26,092. The names of TVCC staff members are bolded and italicized.

### June 2002

Fractures in boys with muscular dystrophy (**Dorothy Harris**, Nirit Bernhard, Claire Mitchell, & Simon Levin), \$4,596.

### June 2003

Augmentative and alternative communication prescription review: Examining clinicians' perceptions (**Beata Batorowicz & Tracy Shepherd**), \$5,000.

### March 2004

Is a reduced dose of Deflazacort effective in maintaining strength in children with Duchenne Dystrophy? (Craig Campbell, **Linda Bolack**, Simon Levin, **Cheryl Scholtes**, Claire Mitchell, Brian Lyttle, & Timothy Carey), \$5,000.

### June 2004

Does a custom dynamic seating system maintain pelvis position and what do client's think of it (**Sue Kirkpatrick, Jim Wighton**, Sandra Spaulding, Thelma Sumsion, **Lucine Truscott, Joy Sommerfreund, & Beata Batorowicz**), \$5,000.  
Upper extremity strength in Duchenne Dystrophy (**Linda Bolack**, Craig Campbell, Simon Levin, **Cheryl Scholtes**, Claire Mitchell, Christen Shoesmith), \$4,850.

### June 2005

Effects of serial casting with and without Botulinum toxin injections as interventions for spastic ankle equinus (**Flora Stephenson, Cheryl Scholtes**, Timothy Carey, & Kellie Leitch), \$1,646.

## PROJECTS APPROVED BY RAC

The following **15 studies** were reviewed by the Research Advisory Committee between 1 April 2002 and 31 March 2006, and approved to proceed. The names of TVCC staff members are bolded and italicized.

### June 2002

Adolescents with CP: What happens to mobility and self-care? (Peter Rosenbaum, Robert Palisano, Doreen Bartlett, Steven Hanna, Maureen O'Donnell, Dianne Russell, Stephen Walter, & Ellen Wood).

Clinical decision making in pediatric rehabilitation (**Gillian King**, Doreen Bartlett, Colleen Willoughby, **Michelle Gilpin, Mary Ann Tucker, Melissa Currie**, & Deborah Strachan).

### September 2002

The relationship between aggressive behaviour and temperament in children with autism spectrum disorder (Beth Craven-Thuss, & Mary Konstantareas).

Evaluation of the school health support services consultation model of occupational therapy services for children with fine motor difficulties (**Mary Ann Tucker, Rebecca Sillett, Claudia Bayona, Barb Bocking**, Megan Scheid, & Maral Fielding).

### January 2003

Neurocognition, literacy, and numeracy in pre-schoolers with spina bifida (Marcia Barnes, & Susan Landry).

### June 2003

A needs survey of chronic and recurring pain in a specialized pediatric population (**Michelle Gilpin, Joy Sommerfreund, Liz Taylor, & Melissa Currie**).

An evaluation of the relevance, feasibility and validity of web-based data collection for children (David Nicholas, Nancy Young, Katherine Boydell, Ross Hetherington, **Gillian King**, Lucy Lach, Laurie Snider, & James Varni).

### November 2003

Correspondence of classification of motor function in children aged two to four years between families and professionals: A pilot study (Jamie Kneale Fanning, Kristen Abercrombie, Amy Dietrich, & Doreen Bartlett).

Development Resources for Infants: An evaluation (Jamie Kneale Fanning, **Mary Ann Tucker, Joanne Legros-Kelly, Alison McVittie**, Julia Pigache, & **Angela Conti-Becker**).

### November 2004

Youths' participation in physical activity (Doreen Bartlett, & **Karen Faragher**).

The incidence of secondary alveolar bone grafting post-gingivoperiosteoplasty (Stephanie Power, & Damir Matic).

### June 2005

A qualitative inquiry into reasons for continued or discontinued use of written communication systems (Larysa Sereda, & Nicole Thomson).

### November 2005

The transition of children with autism from intensive behavioural intervention programs into the school system (Alissa Levy).

The effectiveness of a Wilbarger based protocol on grooming occupations of preschoolers with autism spectrum disorder: A pilot single case design (**Teresa Mulligan**, & Kelly Roberts).

### January 2006

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

## 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 pose important research questions and 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.

## RESEARCH ALLIANCE FOR CHILDREN WITH SPECIAL NEEDS

From 2000-2005, Thames Valley Children's Centre was the lead agency of the Research Alliance for Children with Special Needs (RACSN), based in London, Ontario. RACSN was a multidisciplinary research partnership involving community and university partners.

The focus of the Research Alliance was to address the issue of enhancing the participation of children with special needs through an integrated research program bridging research and practice.

The Alliance was awarded three years of funding (2000-2003) from the Social Sciences and Humanities Research Council of Canada (SSHRC) as a part of their Community-University Research Alliance (CURA) program. The CURA program was created to promote joint research ventures between universities and community partners for the social, cultural, or economic development of communities. At the end of the first grant period, RACSN was awarded a CURA Completion Grant from SSHRC for a further two years (2003-2005) of funding to continue the efforts to enhance the participation of children with special needs. The Alliance disbanded in 2005 with the end of the grants.

RACSN's Investigators (and support team) were from the Alliance's partners: Thames Valley Children's Centre, Thames Valley District School Board (the local public school board), Child and Parent Resource Institute (a regional children's mental health centre) and The University of Western Ontario and Huron University College. In 2003, RACSN's partnership expanded to include the Centre for Addiction and Mental Health (a provincial mental health centre), and the London and District Catholic School Board (the local Catholic school board).

The RACSN partners worked together to identify and communicate practical ways to enhance the participation of children with special needs in important contexts of their lives—school, neighbourhood, and community through **Research Education and Training**, **Knowledge Generation**, and **Knowledge Sharing**.

### Research Education and Training

Research funding and training opportunities were provided to university students, teachers, school board staff, and service providers through RACSN research award competitions. These awards had a positive impact, encouraging a greater number of individuals to engage in research in the area of childhood disability. RACSN provided funded and unfunded research training opportunities to: 91 university students, 29 service providers, and 18 teachers and school board staff.

### Knowledge Generation

**Research Projects:** RACSN conducted and/or supported 61 research projects (including student, service provider, and teacher and school board staff projects).

**External Research Grants:** Seven of RACSN's Investigator projects received external research grants totalling over \$2,202,450.

**New Knowledge:** RACSN's research generated important new knowledge about children's participation that has had strong practical use and relevance. A few projects are: *Predictors of Canadian Children's Academic Performance and Social Competence*: RACSN Investigators used data from the National Longitudinal Survey of Children and Youth to determine the major predictors of Canadian children's academic performance and social competence.

The findings have strong implications for policy and community development in Canada and beyond.

**Physical Accessibility of Schools:** This research examined the extent of physical barriers in school buildings and schoolyards, and led to the development of a rating instrument to measure the physical accessibility of the school environment. This tool is currently being used to identify and remove physical barriers to accessibility in the London area, as mandated by new legislation.

**New Measures of Participation:** RACSN members and their colleagues at CanChild Centre for Childhood Disability Research created measures that examine how children and youth participate in everyday activities outside of mandated school activities, and their activity preferences. These measures, the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC), were published by PsychCorp /Harcourt (<http://harcourtassessment.com>).

**Innovation:** RACSN developed a number of innovative products including: a reliable and valid measure of the community impact of research partnerships (CIROP), and a reliable and valid system for measuring therapist expertise (MPR).

### Knowledge Sharing

Sharing research findings and information with community members was done to promote awareness of issues faced by children with disabilities, their families, and their teachers.

Information was shared using the following:

**Short, easy-to-read summaries called 'Focus On':** RACSN published and distributed 28 Focus Ons – summaries of research findings and topics of interest.

**Newsletters:** Six newsletters were published and distributed, which described RACSN's goals and activities, including highlights of research findings, new research projects, and upcoming events.

**Conference presentations and published articles:** Presentations and publications provided a forum for RACSN's research to contribute to thinking and practice in the disciplines of Education, Occupational Therapy, Physical Therapy, Psychology, Social Work, and Speech and Language Pathology. Ninety-six presentations were made and 41 articles were published in peer-reviewed journals and other publications.

**Community forums:** RACSN hosted three Community Forums involving over 140 people from 62 organizations that allowed dialogue with interested parties on new research directions and to promote awareness of issues related to children with special needs.

**Website ([www.racsn.ca](http://www.racsn.ca)):** The RACSN website was instrumental in establishing a link beyond our community that allowed us to share information with others interested in childhood disability research. Requests for information and usage continued to grow over the five years to include over 306,000 hits by individuals from 50 countries.

**Final Report:** The RACSN Final Report 2000-2006 includes the structure, goals, objectives, and accomplishments of the Research Alliance for Children with Special Needs.

**RACSN's Final Report is available to download from [www.racsn.ca](http://www.racsn.ca).**



## PROJECTS

There were 50 research projects that involved TVCC clients, their families, and TVCC staff members as participants underway between 1 April 2002 and 31 March 2006. 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. The names of TVCC staff members are bolded and italicized.

### INTERNAL PROJECTS

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## Evaluation Projects

### Program

#### 1. An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program

**Investigators:** *Joy Sommerfreund*, Ellen Rosen<sup>1</sup>, Jane Gillett<sup>1</sup>, *Sara Somers*, *Janice Gray*, & *Janette McDougall*

**Affiliation of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>

**Funding:** Ontario Ministry of Health, 2000-2006, \$55,000

**Status:** Completed

Acquired brain injury (ABI) is a leading cause of death and disability among children and adolescents in Canada. Children and youth often have medical, physical, cognitive, behavioural, and social problems that arise from their injuries. Families also experience difficulties related to their children's injuries.

The Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) provides a coordinated, family/community-focused continuum of care to children and youth with acquired brain injuries (ABI) and their families. PABICOP offers, among other services, help with transition from hospital to home, psychosocial support, information and education, school re-entry support, community-based clinics, and crisis intervention.

The results of a five-year quasi-experimental study to evaluate the program indicated that children and youth with ABI and their families receiving PABICOP services fared significantly better than a comparison group receiving standard clinic-based care on two of PABICOP's program objectives: (1) to enhance caregivers' knowledge about the characteristics of ABI and about effective strategies to deal with associated problems, and (2) to increase child and youth community reintegration/participation. Moreover, these group differences were maintained one year following initial involvement with PABICOP.

On average, caregivers perceived PABICOP services to be family-centred. That is, services were viewed as focusing on the family as a whole (rather than the child in isolation) and as seeing families as the experts on their children's abilities and needs. Moreover, on average, caregivers reported high overall satisfaction with the program.

Information from this study will be useful in helping to ensure PABICOP continues to meet the needs of children and youth with ABI and their families.

#### **Publications:**

*McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gillett, J., Gray, J., Somers, S., Frid, P., DeWit, D., Pearlman, L., & Hicoock, F.* (in press). An evaluation of the Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP). Brain Injury.

*McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gray, J., Somers, S., Gillett, J., & Frid, P.* (2006). An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) (Facts To Go, Volume 2 Issue1). London, ON: Thames Valley Children's Centre.

#### **Presentations:**

*McDougall, J., Sommerfreund, J., Rosen, E., Gillett, J., Somers, S., Gray, J., & Servais, M.* (2002, May). The Paediatric Acquired Brain Injury Community Outreach Program. Presented at the Danish Resource Centre of Brain Injury, Nyborg, Denmark.

*McDougall, J. & Somers, S.* (2006, September). An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). Presented at annual meeting of the Ontario Association of Children's Rehabilitation Services, Niagara Falls, ON.

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

#### 2. An evaluation of the School Support Program – Autism Spectrum Disorder

**Investigators:** *Kathy Meyer, Janette McDougall, Michelle Servais, Shirley Case, Karen Dannenhold, Susan Johnson, & Cathy Riggan*

**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 will be useful for enhancing services provided by the SSP-ASD program.

**Publication:**

**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.

### 3. An evaluation of the Youth En Route Program

**Investigators:** Jan Evans, Patricia Baldwin, Janette McDougall, Mary Ann Tucker, & Liz Ayearst<sup>1</sup>

**Affiliation of Collaborator:** Hutton House, London Association for Disabled Adults<sup>1</sup>

**Funding:** Thames Valley Children's Centre Research Award, 2000-2004, \$5,000

**Status:** Completed

Youth En Route (YER) is a program designed to involve youth in the transitional activities of career exploration, supported goal-setting and planning, skill development and community experiences. All of the program goals lead to the ultimate goal of improved quality of life for youth after exiting from secondary school programs. The goal of the program is to successfully launch these individuals into their communities so that they can experience quality lifestyles through their engagement in a combination of employment, post-secondary education, voluntarism, and leisure activities. The aim of this program evaluation study was to evaluate the effectiveness of the YER program in achieving its primary goals of increasing participants' self-determination skills, sense of control over their future directions, and community participation. A second aim of this study was to evaluate the satisfaction of participants and their caregivers with the services of the program.

The study found statistically significant and clinically meaningful improvements among youth with multiple disabilities for all three of the study outcomes following involvement with YER. On average, youth were highly satisfied with the services they had received from YER. Findings suggest the utility of ecologically-based transition programs with an underlying philosophy of self-determination that offer a flexible, multi-faceted approach to transition, including opportunities for self-discovery, skill development, and community experience.

**Publications:**

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

**McDougall, J., Evans, J., & Baldwin, P.** (2005). Youth En Route: An evaluation of a transition program (Facts To Go, Volume 1 Issue 3). London, ON: Thames Valley Children's Centre.

**Presentation:**

**Evans, J., McDougall, J., & Baldwin, P.**, (2004, October). Youth En Route: A program evaluation. Presented at the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

### 4. Development Resources for Infants: An evaluation

**Investigators:** Jamie Kneale Fanning<sup>1</sup>, Mary Ann Tucker, Joanne Legros-Kelly, Allison McVittie, Julia Pigache<sup>2</sup>, & Angela Conti-Becker

**Affiliations of Collaborators:** St. Joseph Health Centre<sup>1</sup>, Child and Parent Resource Institute<sup>2</sup>

**Funding:** Thames Valley Children's Centre Program Evaluation Support Fund, 2003-2004, \$10,000, and 2005-2006, \$6,060

**Status:** Completed

The provision of a coordinated system of services that emphasizes partnership among families, professionals, and agencies is critical in developing children and enhancing families' quality of life. In 1999, the Developmental Resources for Infants (DRI) program was initiated by 2 community agencies and 2 hospitals to provide a collaborative approach to healthcare services for children from birth to two years of age. Prior to the implementation of DRI, families of children at risk for developmental delays or with established physical, cognitive, and/or multiple disabilities were often referred to or received services from one or more of these agencies. This meant that services such as intake, assessment, and intervention were duplicated, resulting in system inefficiencies.

DRI was implemented with a common referral form, a central phone line, a coordinated intake, and a shared database. Through this collaboration, families with young, at-risk children could access the most appropriate and timely services to meet their needs through one point access. The collaboration provided an opportunity to increase communication among agencies and ensure services were not duplicated. In 2002, a research task force was formed to evaluate the DRI program. The study evaluated the DRI tools and processes, the staff and leaderships' perception of system collaboration, and the families' and community members' satisfaction with DRI services.

The study found that DRI had achieved an identity and operating procedure that were unique and separate from any of the four partner agencies.

**Publication:**

Kneale Fanning, J., Legros-Kelly, J., McVittie, A., Pigache, J., Tucker, M. A., & Servais, M. (2005). An evaluation of Developmental Resources for Infants: Collaborative health care services for infants and their families (Facts To Go, Volume 1 Issue 4, December 2005). London, ON: Thames Valley Children's Centre.

### 5. Evaluation of the Kids On-Track Program

**Investigators:** Theresa Malloy-Miller, Judy Arnett<sup>1</sup>, Barrie Evans<sup>2</sup>, Wayne Hobbs<sup>3</sup>, Carl Sinclair<sup>4</sup>, Anne Tims<sup>5</sup>, & Mary Ann Tucker

**Affiliations of Collaborators:** Middlesex-London Health Unit<sup>1</sup>, Madame Vanier Children's Services<sup>2</sup>, London District Catholic School Board<sup>3</sup>, Learning Disabilities Association of London-Middlesex<sup>4</sup>, Thames Valley District School Board<sup>5</sup>

**Funding:** Community Mobilization Program, National Crime Prevention Centre, 2000-2002, \$25,000; Thames Valley Children's Centre Research Award, 2001-2002, \$5,000

**Status:** Completed

Kids-On-Track (KOT) is a program for children with differences in learning, attention, and movement, who may be beginning to indicate social interaction problems. The intent of the KOT program is to have children (5 to 8 years) learn and use concepts related to thinking, motivation, and feeling.

These concepts are then used to guide the children to make their own personal learning strategies with the support of their families and teachers. The children assume a leadership role by teaching their classmates about the concepts. The concepts used in the KOT program are from the Cognitive Enrichment Advantage approach (Katherine Greenberg, 2000).

During two school years, the children met in small groups of up to 10 children where they had a chance to use thinking plans to deal with everyday difficulties. Parents and teachers were trained to be coaches and to help the children use the skills they had learned. The children in the program were more likely to use or talk about the concepts that they had learned if the use of the concepts were reinforced and supported at home and at school. Parents observed their children to become more playful. Teachers felt that the concepts gave them a way to talk to their students about their thinking (i.e., where they were getting stuck, and how they were successful). They saw their students becoming more independent and attributed this to the discussion and use of the KOT concepts and techniques. Changes in the social and school success of the 44 children who were in the program were measured. Parents, teachers, and school administrators were very satisfied with the service that they received from the Kids On-Track program. As of the fall of 2006, the Kids On-Track program has provided service to twenty-three schools in the London-Elgin-Oxford-Middlesex districts, reaching over 1,800 students annually.

**Reference:**

Greenberg, K. (2000). *Cognitive Enrichment Advantage*. Arlington Heights, IL: Skylight Professional Development.

**Presentations:**

**Malloy-Miller, T.** (2002, November). An evaluation of Kids On-Track. Presented at Pediatric Update at Thames Valley Children's Centre, London, ON.

**Malloy-Miller, T., & Currie, M.** (2003, October). An evaluation of Kids On-Track: A cognitive education program for 5-9 year olds with attention, learning, and motor difficulties. Presented at a Research Program Discovery Series at Thames Valley Children's Centre, London, ON.

and process by which these services are delivered. This study examined whether the written communication and fine motor skills of 23 children with fine motor difficulties improved after receiving school-based occupational therapy delivered according to a consultation model of service delivery. In addition, the study assessed the process of service delivery, including treatment fidelity (i.e., the extent to which consultation services were implemented as intended). Statistically significant and practically meaningful improvement was found in written communication on the Vineland Adaptive Behavior Scales-Classroom Edition (VABS-C) and School Functional Assessment-Version 3.0 (SFA), and in fine motor skills on the SFA, but not on the VABS-C. An examination of the service delivery process revealed that therapists deviated from a purely consultative model, with 86% providing some direct therapy to children. Parents were mostly satisfied with services received whereas teachers were indifferent or somewhat dissatisfied.

**Publications:**

**McDougall, J., Bayona, C., Tucker, M. A., Nichols, M., & King, G.** (2005). School-based occupational therapy: Evaluating service delivery models (Focus On, Volume 5 Issue 2). London, ON: Research Alliance for Children with Special Needs.

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

**Presentations:**

**Bayona, C., McDougall, J., Scheid, M., & Tucker, M. A.** (2004, September). Evaluation of a school health support services consultation model of occupational therapy for children with fine motor difficulties. Presented at the Thames Valley Children's Centre Discovery Series, London, ON.

**McDougall, J., Tucker, M. A., Bocking, B., & Nichols, M.** (2005, October). A study to evaluate a school-based consultation model of occupational therapy services for children with fine motor difficulties. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Centres, Niagara Falls, ON.



**6. Evaluation of a school health support services consultation model of occupational therapy for children with fine motor difficulties**

**Investigators:** *Mary Ann Tucker*<sup>1</sup>, Megan Scheid<sup>1</sup>, *Barb Bocking*, *Claudia Bayona*, Nupee Sadra<sup>2</sup>, Maureen Beamish<sup>3</sup>, & Nancy Patrick<sup>4</sup>

**Affiliations of Collaborators:** Community Care Access Centre London & Middlesex<sup>1</sup>, Paramed Health Services<sup>2</sup>, St. Elizabeth Service Delivery Centre<sup>3</sup>, Victorian Order of Nurses<sup>4</sup>

**Funding:** RACSN 2002 Service Provider Award, 2002-2003, \$10,000

**Status:** Completed

Consultative occupational therapy services are becoming widely used in the school environment. However, few studies have evaluated the utility of

## SERVICE DELIVERY

**7. A province-wide survey about services for children with disabilities and their families**

**Investigators:** Mary Law<sup>1</sup>, Peter Rosenbaum<sup>1</sup>, *Gillian King*, Susanne King<sup>1</sup>, & Marilyn Kertoy<sup>2</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>, The University of Western Ontario's School of Communication Sciences and Disorders<sup>2</sup>

**Funding:** Ontario Ministry of Health funding for CanChild, 1999-2001

**Status:** Completed

This cross-sectional survey involved participants at 16 sites from both the Ontario Association of Children's Rehabilitation Services and Community Care Access Centres. Data were collected from 494 parents of children with disabilities, 324 service providers, and 15 CEOs/managers. The data showed that a family-centred approach is endorsed and supported and, in general, is being provided well. The findings are summarized in three reports that outline how the findings will be useful for

parents, service providers, administrative decision makers, and legislative policy makers. All reports are available through the website [www.canchild.ca](http://www.canchild.ca).

**Reports:**

King, S., Law, M., **King, G.**, Kertoy, M., Hurley, P., & Rosenbaum, P. (2000) Children with disabilities in Ontario: A profile of children's services. **Part 1:** Children, families and services. Hamilton, ON: CanChild Centre for Childhood Disability Research. Copies are available from the CanChild website at [www.canchild.ca](http://www.canchild.ca).

King, S., Law, M., **King, G.**, Kertoy, M., Hurley, P., & Rosenbaum, P. (2000) Children with disabilities in Ontario: A profile of children's services. **Part 2:** Perceptions about family-centred service delivery for children with disabilities. Hamilton, ON: CanChild Centre for Childhood Disability Research. Copies are available from the CanChild website at [www.canchild.ca](http://www.canchild.ca).

King, S., Law, M., **King, G.**, Kertoy, M., Hurley, P., & Rosenbaum, P. (2000) Children with disabilities in Ontario: A profile of children's services. **Part 3:** Factors affecting family-centred service delivery for children with disabilities. Hamilton, ON: CanChild Centre for Childhood Disability Research. Copies are available from the CanChild website at [www.canchild.ca](http://www.canchild.ca).

**Publications:**

**King, G.**, Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care*, 30(2), 111-134.

Woodside, J. M., Rosenbaum, P. L., King, S., & **King, G. A.** (2001). Family-centred service in pediatric rehabilitation: Development and validation of a self-evaluation tool for service providers. *Children's Health Care*, 30(3), 237-252.

**King, G.**, King, S., Law, M., Kertoy, M., Rosenbaum, P., & Hurley, P. (2002). Family-centred service in Ontario: A "Best Practice" approach for children with disabilities and their families. Hamilton, ON: CanChild Centre for Childhood Disability Research. Copies are available from the CanChild website at [www.canchild.ca](http://www.canchild.ca).

**King, G.**, Kertoy, M., King, S., Law, M., Rosenbaum, P., & Hurley, P. (2003). A measure of parents' and service providers' beliefs about participation in family-centered services. *Children's Health Care*, 32(3), 191-124.

Law, M., Hanna, S., **King, G.**, Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family-centred service delivery for children with disabilities. *Child: Care, Health and Development*, 29(5), 357-366.

**8. Family-centred service: Moving ideas into practice**

**Investigators:** Mary Law<sup>1</sup>, Peter Rosenbaum<sup>1</sup>, **Gillian King**, Susanne King<sup>1</sup>, Jan Burke-Gaffney<sup>2</sup>, Theresa Szkut<sup>2</sup>, Stephen Walter<sup>1</sup>, Marilyn Kertoy<sup>3</sup>, Nancy Pollock<sup>1</sup>, & Linda Viscardis<sup>4</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>, Hamilton Family Network<sup>2</sup>, The University of Western Ontario<sup>3</sup>, PROSPECTS Parent Network<sup>4</sup>

**Funding:** Bloorview Children's Hospital Foundation, 2000-2004, \$77,122

**Status:** Completed

Family-centred service is a method and philosophy of service delivery for children and parents that emphasizes a partnership between parents and service providers. There is evidence to

indicate that family-centred service leads to improved outcomes for children and families. There are, however, few materials that have been shown to help service providers and families implementing family-centred service. The purpose of this research was to develop and evaluate educational materials about family-centred service that can be used by parents and service providers to facilitate the implementation of family-centred services for children with disabilities.

**Publications:**

Law, M., Teplicky, R., King, S., **King, G.**, Kertoy, M., Moning, T., Rosenbaum, P. & Burke-Gaffney, J. (2005). Family-centred service: Moving ideas into practice. *Child: Care, Health and Development*, 31(6), 633-642.

CanChild Centre for Childhood Disability Research at McMaster University has published an 18-part series of FCS (Facts, Concepts, Strategies) Sheets on family-centred service. All FCS sheets can be downloaded from CanChild's website at [www.canchild.ca](http://www.canchild.ca).

The titles of the FCS Sheets are:

1. What is family-centred service?
2. Myths about family-centred service
3. How does family-centred service make a difference?
4. Becoming more family-centred
5. 10 things you can do to be family-centred
6. Identifying and building on parent and family strengths and resources
7. Parent-to-parent support
8. Effective communication in family-centred service
9. Using respectful behaviours and language
10. Working together: From providing information to working in partnership
11. Negotiating: Dealing effectively with differences
12. Making decisions together: How to decide what is best
13. Setting goals together
14. Advocacy: How to get the best for your child
15. Getting the most from appointments and meetings
16. Fostering family-centred service in the school
17. Family-centred strategies for wait lists
18. Are we really family-centred? Checklists for families, services providers and organizations

**Presentation:**

Teplicky, R., Law, M., King, S., Kertoy, M., Rosenbaum, P., **King, G.**, Szkut, T., & Burke-Gaffney, J. (2004, October). Family-centred service: Moving ideas into practice. Presented at the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.



## TESTS AND MEASURES

### 9. Children's Assessment of Participation and Enjoyment

**Investigators:** *Gillian King*, Mary Law, Susanne King, Patricia Hurley, Steven Hanna, Marilyn Kertoy, Peter Rosenbaum, & Nancy Young.

**Affiliation of Collaborators:** CanChild Centre for Childhood Disability Research

**Status:** Completed, 2002-2004

The *Preferences for Activities of Children (PAC)* taps into children's preferences for involvement in each activity. A companion measure to the PAC is *The Children's Assessment of Participation and Enjoyment (CAPE)*. The CAPE is a 55-item

questionnaire designed to examine how children and youth participate in everyday activities outside of mandated school activities. The CAPE provides information about the diversity (number of activities done), intensity (frequency of participation measured as a function of the number of possible activities within a category), and enjoyment of activities. It also provides information about the context in which children and youth participate in these activities (i.e., with whom and where they participate).

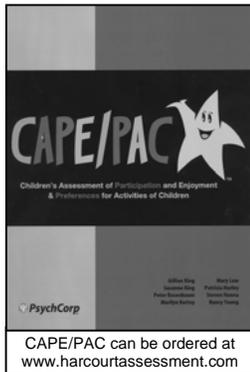
Both measures contain 55 activities related to children's day-to-day participation in activities outside of the school curriculum. There is a self-administered and interviewer-assisted version of the each measure. The CAPE takes approximately 30-45 minutes to complete, depending on the number of activities the child does. The PAC takes generally 15-20 minutes to complete.

There are eight components to the scores obtained from the CAPE: overall participation scores; scores for two domains (formal and informal activities); and scale scores for five types of activities (recreational, active physical, social, skill-based, self-improvement/educational). Scores are computed for each of these components for each of the five dimensions of participation of the CAPE (i.e., diversity, intensity, enjoyment, with whom and where). The PAC scores are average preference ratings for each of the eight components/activity types.

Reliability and validity of the CAPE and PAC was established using data from a longitudinal study involving 427 children with physical disabilities between the ages of 6 and 15 years from across Ontario. Analyses demonstrated sufficient internal consistency, test-retest reliability, content validity, construct validity, and convergent and discriminant validity of the CAPE.

**Publication:**

*King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P.* (in press). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health & Development*.



**Presentation:**

Law, M., *King, G.*, King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2002, September). The Children's Assessment of Participation and Enjoyment (CAPE). Presented at the American Academy of Cerebral Palsy and Developmental Medicine 56th Annual Meeting, New Orleans, LA.

The **CAPE and PAC** are available from PsychCorp, a brand of Harcourt Assessment, Inc.

*King, G.*, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2006). Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). San Antonio, TX: Harcourt Assessment, Inc.

### 10. Development of software for the Measure of Processes of Care

**Investigators:** Peter Rosenbaum<sup>1</sup>, Susanne King<sup>1</sup>, & *Gillian King*

**Affiliation of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>

**Funding:** The Jack & Ina Pollock Foundation, 2001-2003, \$7,500

**Status:** Completed

The Measure of Processes of Care (MPOC) Outcome Measure is a discriminative measure developed by members of CanChild to assess the implementation of quality and family-centred services within children's' rehabilitation centres.

It is thought that the development of a software system to accompany the MPOC may enhance the use of this tool in clinical practice in pediatric programs for children with disabilities. The purpose of this project is to create such a tool, and then evaluate its effectiveness. Specifically, this will involve developing both a software program and a user's guide and then evaluating the effectiveness of these in facilitating the use and analysis of MPOC data. The Grandview Centre in Oshawa will be involved with the evaluative portion of the study.

The MPOC is a discriminative measure developed by members of CanChild to assess the implementation of quality and family-centred services within children's' rehabilitation centres.

### 11. Keeping Information Together: Evaluation of a parent resource information kit: Use, utility, and impact

**Investigators:** Mary Law<sup>1</sup>, Debra Stewart<sup>1</sup>, Jan Burke-Gaffney<sup>2</sup>, Theresa Szkut<sup>2</sup>, Cheryl Missiuna<sup>1</sup>, Peter Rosenbaum<sup>1</sup>, *Gillian King*, & Susanne King<sup>1</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>, Hamilton Family Network<sup>2</sup>

**Funding:** Easter Seal Association, 2001-2003, \$70,600

**Status:** Completed

Research indicated that parents of children with special needs required a resource that would assist them to give, get, and organize information to meet the needs of their child. Keeping Information Together, or the KIT, is one such resource. The KIT is a collaborative work of researchers from CanChild, and parents from the Hamilton Family Network. The KIT was designed to be used by families to increase their skills and satisfaction in working together with service providers for their children. It includes a User's Guide, with tips and strategies for giving, getting, and organizing

information, and a Binder that parents use to organize their information. The study involved 439 parents and found that parents are using the KIT in a variety of situations, and with several different service systems (e.g., health care, education, social services). Most participants found the KIT easy to understand and well organized, but not everyone was able to use the KIT actively yet. Participants stated that lack of time was the primary barrier to use. Many excellent suggestions were made to improve on or add forms to meet all families' information needs. Due to the significant demand for the KIT, plans to revise the KIT using findings from this study are underway. CanChild is working together with Easter Seals to secure funding to produce and distribute more KIT's to families of children with special needs.

**Publication:**

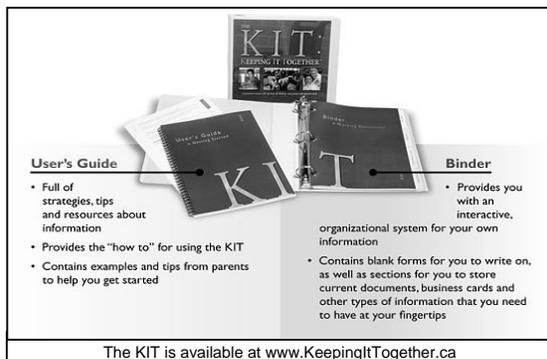
Stewart, D., Law, M., Burke-Gaffney, J., Missiuna, C., Rosenbaum, P., **King, G.**, Moning, T., & King, S. (2006). Keeping It Together™: An information KIT for parents of children and youth with special needs. *Child: Care, Health and Development*, 32(4), 493-500.

**Presentations:**

Stewart, D., Law, M., Missiuna, C., Rosenbaum, P., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2002, November). An information KIT for parents of children and youth with special needs. Presented at the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Stewart, D., Law, M., Missiuna, C., Rosenbaum, P., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2003, October). Evaluation of an information KIT for parents of children and youth with special needs. Presented at the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Stewart, D., Law, M., Rosenbaum, P., Missiuna, C., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2004, September). Evaluation of the use, utility and impact of an information KIT for parents of children and youth with special needs. Presented at the American Academy for Cerebral Palsy and Developmental Medicine, Los Angeles, CA.



**12. 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 of Collaborators:** CanChild Centre for Childhood Disability Research  
**Funding:** Ministry of Community and Social Services, 2002-2007, \$43,500  
**Status:** Ongoing

The goal of this project is to develop a Resource Kit that can be broadly circulated to families who receive individualized funding. It is expected to enhance the quality of life and community participation of young adults with disabilities. This five-year project will assist them in the management of the funding and their work as parents to find supports for their children and family. The Resource Kit will be developed with the 10 families who are involved in the Opening Doors project. Researchers will seek input from all families as to the content and format of such a kit. Another goal is to evaluate the Resource Kit as to its use, utility and impact. A prototype of the Research Kit will be given to all families to use during the Opening Doors project in years two to five.

**13. Measuring the external impact of university-community research alliances and partnerships addressing social/health issues**

**Investigators:** **Gillian King**, Mary Law<sup>1</sup>, Cheryl Forchuk<sup>2</sup>, Teena Willoughby<sup>3</sup>, Peter Rosenbaum<sup>1</sup>, Marilyn Kertoy<sup>4</sup>, Heather Chalmers<sup>5</sup>, Jacqueline Specht<sup>6</sup>, & **Melissa Currie**

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>; The University of Western Ontario Department of Nursing<sup>2</sup>; Brock University Department of Child and Youth Studies<sup>3</sup>; The University of Western Ontario School of Communication Sciences and Disorders<sup>4</sup>; Brock University Department of Psychology<sup>5</sup>; The University of Western Ontario Faculty of Education<sup>6</sup>

**Funding:** Social Sciences and Humanities Research Council of Canada, 2003-2006, \$150,000

**Status:** Completed

Research partnerships between universities and community organizations are proliferating in Canada. These community-university research partnerships provide an infrastructure from which research projects develop and findings are shared. They are assumed to produce knowledge that informs community members and leads to more efficient service delivery, more effective clinical programs, and enhanced community development. There is, however, little concrete evidence of these benefits, in part due to the lack of a reliable and valid tool to measure various types of community impacts on a generic level.

Five research partnerships joined together to develop a reliable and valid survey measure of the community impacts of research partnerships between universities and community agencies that address social or health services issues.

The five community-university research partnerships who joined together to develop the CIROP measure are:

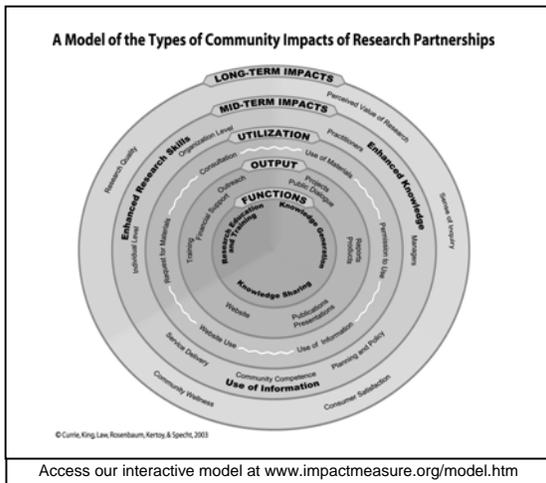
- The Research Alliance for Children with Special Needs (RACSN) based in London, Ontario. Website: [www.racsn.ca](http://www.racsn.ca)
- The Community-University Research Alliance (CURA) titled "Enhancement of Youth Resiliency and Reduction of Harmful Behaviours Leading to Healthy Lifestyle Choices (YLC-CURA)" based in St. Catharines, Ontario. Website: [www.ylc-cura.ca](http://www.ylc-cura.ca)
- The CURA titled "Partnerships in Capacity Building, Housing, Community Economic Development and Psychiatric Survivors" based in London, Ontario. Website: <http://publish.uwo.ca/~cforchuk/cura/index.htm>
- CanChild Centre for Childhood Disability Research based in Hamilton, Ontario. Website: <http://www.canchild.ca>

- A partnership project titled "Therapeutic Relationships from Hospital to Community - Implementation of Evidence Based Practice" based in London, St. Thomas, Hamilton, Penetanguishene, Whitby, and Toronto, Ontario. Website: <http://publish.uwo.ca/~cforchuk/tr/index.htm>.

**Development of a Model of Impact**

Alliances have long been an important strategy for health promotion and community development. They are now becoming an important approach to generating research that is thought to have real-world relevance and easy applicability because of the involvement of community members.

A comprehensive, dynamic model of community impacts of research partnerships in social or health services was developed. This process-oriented, systems model outlines three major domains of mid-term impact (Enhanced Knowledge, Enhanced Research Skills, and Use of Information) that correspond to the core functions of collaborative research partnerships discussed in the literature (i.e., knowledge generation, research education and training, and knowledge sharing).



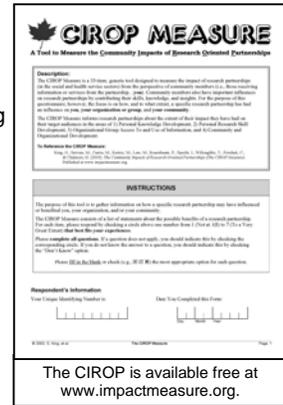
The model will assist research partners, intended recipients, and funders to understand and evaluate the real-world impacts of community-university research partnerships. The model provides research partnerships with a tool to demonstrate their accountability and to improve their operations and impacts, and evaluators with a tool to guide planning and evaluation efforts.

**Development of a Measure of Impact**

The Community Impacts of Research-Oriented Partnerships (CIROP) is a 33-item, generic measure of community members' perceptions of the impact of research partnerships addressing social and health issues. The CIROP was developed using information from the literatures on health promotion, community development, and research utilization, and from focus groups involving 29 key informants. Data from 174 community members were used to determine the factor structure, internal consistency, and test-retest reliability of the four CIROP scales, and to provide evidence of construct validity. The CIROP informs research partnerships about the extent of their impact in the areas of Personal Knowledge Development, Personal Research Skill Development, Organizational/Group Access To and Use of Information, and Community and Organizational Development.

The CIROP can be used to:

- assess the effectiveness of knowledge sharing approaches,
- determine the most influential activities of partnerships,
- determine structural characteristics of partnerships associated with various types of impact, and



- demonstrate accountability to funding bodies.

The CIROP provides a better understanding of community members' perspectives and expectations of research partnerships, which has important implications for knowledge transfer and uptake.

**Publication:**

**Currie, M., King, G., Rosenbaum, P., Law, M., Kertoy, M., & Specht, J.** (2005). A model of impacts of research partnerships in health and social services. *Evaluation and Program Planning*, 28, 400-412.

**Presentations:**

- Specht, J., **Servais, M., King, G., Law, M., Forchuk, C., Willoughby, T., Rosenbaum, P., Kertoy, M., Chalmers, H., & Currie, M.** (2003, May). Measuring the impact of community-university partnerships. Presented at the CUExpo 2003: Community-University Research: Partnerships, Policy & Progress Conference, Saskatoon, SK.
- King, G.** (2003, October). Measuring the impact of community-university research partnerships. Presented at the Dissemination Conference for the CURA on Partnerships and Capacity Building: Housing, Community Economic Development and Psychiatric Survivors, London, ON.
- King, G., & Currie, M.** (2003, December). A model of impacts of research partnerships in the fields of health or social services: Considering the community perspective. Presented at the UWO Rehabilitation Science Seminar Series, London, ON.
- Servais, M., King, G., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C., & Chalmers, H.** (2004, March). The development of a tool to measure the community impacts of research-oriented partnerships: The CIROP Measure. Presented for faculty and graduate students at the UWO Rehabilitation Sciences Seminar Series, London, ON.
- Servais, M., King, G., Currie, M., Kertoy, M., Law, M., Rosenbaum, P., Specht, J., Willoughby, T., Forchuk, C., & Chalmers, H.** (2004, July). A model of the research impacts of research partnerships and the development of a tool to measure the community impacts of research oriented partnerships. Presented at the 2004 First Annual Conference for the Joint PhD in Educational Studies Program: Innovative and Alternative Research Paradigms in Education, Brock University, St. Catharines, ON.
- King, G., Stewart, S., DeWit, D., Killip, S., Spencer, T., Bartlett, D., Kertoy, M., Miller, L., & Specht, J.** (2005, February). Enhancing the community participation of children with special needs. Presented at the Knowledge Project: Building Canadian Research Leadership, hosted by SSHRC, Ottawa, ON.

## THERAPY

### 14. A needs survey of chronic and recurring pain in a specialized pediatric population

**Investigators:** *Michelle Gilpin, Joy Sommerfreund, Liz Taylor, Melissa Currie, Jennifer Crotogino, & Linda Bolack*

**Status:** Completed, 2003-2004

Little is known about the prevalence of chronic pain in children generally and specifically in children with disabilities such as cerebral palsy, acquired brain injury, muscular dystrophy, and/or developmental delay. The first step to advancing clinician and family understanding of pediatric pain among children with disabilities is to establish better awareness of its prevalence. The information gathered from this survey of 100 children and families attending medical clinics at Thames Valley Children's Centre will determine if pain reports were at a level significant enough to merit further clinical attention and formal investigation, if certain diagnostic groups may be at greater risk for pain experiences than others, and if pain experiences vary with age and severity of diagnosis. Depending on the outcome, clinical protocols could be developed that would increase the awareness of pain experiences and serve to clearly identify what pain experiences require more responsive treatment approaches and pain management (e.g., if pain impacts participation in life, then treatment strategies may be introduced).

**Presentation:**

*Bolack, L., Crotogino, J., Taylor, L., Gilpin, M., & Young, C.* (2006, September). A survey of chronic and recurrent pain in children and youth with disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Centre, Niagara Falls, ON.

### 15. A proposal to evaluate the effectiveness of assistive technology and augmentative and alternative communication intervention strategies on enhancing the development of writing and reading skills of a child in senior kindergarten with severe physical and speech impairments

**Investigators:** Sharon Smith<sup>1</sup>, *Nadia Browning*, & Jan Miller Polgar<sup>1</sup>

**Affiliation of Collaborators:** The University of Western Ontario School of Occupational Therapy<sup>1</sup>

**Status:** Completed, 2001-2002

This single case study investigated the effectiveness of assistive technology (AT) on the development of literacy skills in a senior kindergarten child who had severe speech and physical impairments. Goal attainment scaling (GAS) was used as the outcome measurement tool. A total of 10 comprehensive goals were developed in a collaborative effort between the parents, school, and investigators. A total of 10 intervention sessions spanning 4 months were completed with the child. Both the home and school environments were incorporated in the study. The participant showed improvement on all goals, excluding numeral recognition. The participant benefited from regularly scheduled sessions with the primary investigator. Inconsistencies in scheduling tended to result in less productive sessions and fewer gains. Education provided to the educational assistant regarding the technology and possible applications resulted in gains in goal attainment for the child. This study supports the contention that AT can enhance the

development of literacy skills in children with severe physical and speech impairments when a collaborative effort between all parties is applied and adequate support and education regarding the AT are provided.

**Publication:**

Smith, S., *Browning, N.*, & Miller Polgar, J., (2002). Effectiveness of assistive technology on the development of literacy skills in a child with severe speech and physical impairments. Proceedings of The University of Western Ontario Occupational Therapy Conference on Evidence Based Practice, 2, (109-111).

**Presentation:**

Smith, S., *Browning, N.*, & Miller Polgar, J., (2002). Effectiveness of assistive technology on the development of literacy skills in a child with severe speech and physical impairments. Presented at The University of Western Ontario Occupational Therapy Conference on Evidence Based Practice, London, ON.

### 16. Augmentative and alternative communication prescription review: Examining clinicians' perceptions (Study I)

**Investigators:** *Tracy Shepherd & Beata Batorowicz*

**Funding:** RACSN 2003 Service Provider Award, \$5,000; TVCC Research Award, 2003-2004, \$5,000

**Status:** Completed

Prescription review (PR) is a discussion of the rationale for recommending specific Augmentative and Alternative Communication (AAC) equipment within a transdisciplinary team. It is mandatory in Assistive Devices Program (ADP) AAC designated centres in Ontario. PR allows professionals practicing in AAC to authorize government funding towards communication equipment for clients. PR has been practiced for over a decade and as never been evaluated. This study developed a measurement tool to examine the advantages and disadvantages of the PR process. The tool consists of 19 questions grouped into 4 subscales. The questions are scored on a 7-point rating scale. There are 7 questions in the Decision Making subscale, 5 in Team Support, 3 in Learning, and 4 in Developing Quality Services. Internal consistency reliabilities for the 4 subscales were excellent. Average test-retest reliability estimates (Intraclass Correlation Coefficients) were statistically significant.

**Publications:**

*Batorowicz, B., & Shepherd, T.* (2004). A model of team decision making in AAC. Proceedings of the 11th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC).

*Batorowicz, B., & Shepherd, T.* (2005).

Development of a questionnaire to measure perceptions of prescription review in AAC (Focus On, Volume 5 Issue 5). London, ON: Research Alliance for Children with Special Needs.

**Presentation:**

*Batorowicz, B., & Shepherd, T.* (2004, October). A model of team decision making in AAC. Presented at the 11th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC), Natal, Brazil.

**17. 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:** Underway

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 will examine 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 will be 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.

**18. Clinical decision making in pediatric rehabilitation**

**Investigators:** *Gillian King*, Doreen Bartlett<sup>1</sup>, Colleen Willoughby<sup>2</sup>, *Michelle Gilpin*, *Mary Ann Tucker*, *Melissa Currie*, & Deborah Strachan<sup>3</sup>

**Affiliations of Collaborators:** The University of Western Ontario, School of Physical Therapy<sup>1</sup>; DMARehability<sup>2</sup>, Child and Parent Resource Institute<sup>3</sup>

**Funding:** The Hospital for Sick Children Foundation, 2002-2004, \$112,671

**Status:** Completed

Therapists who provide clinical services to children with disabilities need to make appropriate decisions about goals and intervention strategies that are based on theory, evidence, and reflect the needs and priorities of the children and their families. Two qualitative studies (involving a total of 30 occupational, physical, speech-language, and behaviour therapists) were conducted to determine the most commonly used clinical practice schemas of expert, intermediate level, and novice therapists who deliver services to school-aged children. Clinical practice schemas are the knowledge structures that therapists use to guide their formulation of a clinical problem, their search for relevant information, and their selection of intervention strategies to propose to families. Study 1 was an interview study in which therapists were asked to reflect on critical incidents in their past practice that made them aware of their decision-making process. Study 2 involved interviews with therapists while they watched videotapes of themselves interacting with clients. Findings will assist therapists and managers in

providing informed, effective, and efficient rehabilitation services for children.

**Publications:**

*King, G.*, Bartlett, D., Willoughby, C., & *Currie, M.* (2002). Expertise in services for children with special needs (Focus On, Volume 2 Issue 1). London, ON: Research Alliance for Children with Special Needs.

*King, G., Currie, M.*, Bartlett, D., *Gilpin, M.*, Willoughby, C., Strachan, D., *Tucker, M. A.*, & *Baxter, D.* (2005). Clinical decision making expertise in pediatric rehabilitation therapists (Focus On, Volume 5 Issue 1). London, ON: Research Alliance for Children with Special Needs.

*Gilpin, M., King, G., Currie, M.*, Bartlett, D., Willoughby, C., Strachan, D., *Tucker, M. A.*, & *Baxter, D.* (2005). The Multidimensional Peer Rating of the Clinical Behaviours of Pediatric Therapists (MPR) (Focus On, Volume 5 Issue 4). London, ON: Research Alliance for Children with Special Needs.

**Presentations:**

Bartlett, D., Willoughby, C., *King, G.*, *Tucker, M. A.*, *Currie, M.*, *Gilpin, M.*, Strachan, D., & *Baxter, D.* (2004, June). Fostering the development of clinical expertise among pediatric therapists. Presented at Children's Developmental Rehabilitation Centre (CDRP), Chedoke Child and Family Centre, Hamilton Health Sciences, Hamilton, ON.

*King, G., Baxter, D., Currie, M.*, Willoughby, C., Bartlett, D., Strachan, D., *Gilpin, M.*, & *Tucker, M. A.* (2004, October). Clinical decision making in pediatric rehabilitation. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Bartlett, D., Willoughby, C., *King, G.*, *Tucker, M. A.*, *Currie, M.*, *Gilpin, M.*, & Strachan, D. (2005, October). Fostering the development of expertise among pediatric therapists. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Centres, Niagara Falls, ON.

*King, G.*, Bartlett, D., *Currie, M.*, Willoughby, C., Gilpin, M., Strachan, D., *Tucker, M. A.*, & *Baxter, D.* (2006, February). Fostering the development of expertise among pediatric therapists. Presented at the Child and Parent Resource Institute, London, Ontario.

*King, G.*, Baxter, D., *Currie, M.*, Willoughby, C., Bartlett, D., Strachan, D., Gilpin, M., & *Tucker, M. A.* (2006, March). Expertise and clinical decision making in pediatric rehabilitation. Presented at Novita Children's Services, Adelaide, Australia.

*King, G.*, Baxter, D., *Currie, M.*, Willoughby, C., Bartlett, D., Strachan, D., Gilpin, M., & *Tucker, M. A.* (2006, March). Expertise and clinical decision making in pediatric rehabilitation. Presented at Scope, Melbourne, Australia.

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

**Investigators:** *Sue Kirkpatrick*, *Jim Wighton*, Sandi Spaulding<sup>1</sup>, Thelma Sumsion<sup>1</sup>, *Lucine Truscott*, *Joy Sommerfreund*, & *Beata Batorowicz*

**Affiliation of Collaborators:** The University of Western Ontario School of Occupational Therapy<sup>1</sup>

**Funding:** TVCC Research Award, 2004-2005, \$5,000

**Status:** Underway

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 is 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 will compare the participants' movements in the dynamic seating system and in a static system. Participants and their parents/caregivers will be 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.

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

**Investigators:** *Flora Stephenson, Cheryl Scholtes*, Timothy Carey<sup>1</sup>, & Kellie Leitch<sup>1</sup>

**Affiliation of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>

**Funding:** TVCC Research Award, 2005-2006, \$1,646

**Status:** Underway

The goal of this study is 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 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.

**21. Fractures in boys with muscular dystrophy**

**Investigators:** *Dorothy Harris*, Nirit Bernhard<sup>1</sup>, Clare Mitchell<sup>1</sup>, & Simon Levin<sup>1</sup>

**Affiliation of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>

**Funding:** Thames Valley Children's Centre Research Award, 2002-2006, \$4,596

**Status:** Underway

For over fifteen years, it has been suggested that children affected by Duchenne's muscular dystrophy have an increased prevalence of bone fractures. This study will examine the prevalence and distribution of fractures in boys with muscular dystrophy and try to determine whether there is a subset of boys with muscular dystrophy who are particularly susceptible to fractures. Researchers will also assess the effect of deflazacort treatment on fracture frequency and distribution.

**22. Is a reduced dose of Deflazacort effective in maintaining strength in children with Duchenne Dystrophy?**

**Investigators:** Craig Campbell<sup>1</sup>, *Linda Bolack*, Simon Levin<sup>1</sup>, *Cheryl Scholtes*, Claire Mitchell<sup>1</sup>, Brian Lyttle<sup>1</sup>, & Timothy Carey<sup>1</sup>

**Affiliation of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>

**Funding:** TVCC Research Award, 2004, \$5,000

**Status:** Completed

Deflazacort (DFZ) has been shown to be effective in preserving muscle strength and function, as well as pulmonary function, in Duchenne Muscular Dystrophy (DD), however few randomized trials have been completed making observational studies important. This study retrospectively reviewed all DD patients from a regional pediatric neuromuscular clinic. Twenty-eight patients met inclusion criteria with 14 patients treatment with DFZ and 14 untreated. Ambulatory status, pulmonary function and side effects were compared. Eight of the 14 patients treated with DFZ required a wheelchair fulltime. Five of the 6 treatment patients who were still walking were older than 10 years. Ten of the 14 untreated patients required a wheelchair fulltime. Pulmonary function at age 11 years was greater in the treated patients compared to those untreated. Scoliosis surgery was required in 3 of 16 untreated patients versus none of those treated. A non-significant increase in mean weight was noted at age 10 years in the DFZ group. There were an equal number of fractures between the two groups. DFZ did not delay the time to loss of independent ambulation in our sample, which is in contrast to other studies using similar protocols. DFZ significantly improves pulmonary function in DMD patients. Side effects were not substantially different between the groups.

**Publication:**

Hung, R., Campbell, C., Levin, S., *Bolack, L., Scholtes, C.*, Lyttle, B., & Mitchell, C. (2005). Analysis of deflazacort treatment of Duchenne muscular dystrophy. *The Canadian Journal of Neurological Sciences*, 32(2[Suppl1]), S43.

**Presentation:**

Hung, R., Campbell, C., Levin, S., *Bolack, L., Scholtes, C.*, Lyttle, B., & Mitchell, C. (2005, June). Analysis of deflazacort treatment of Duchenne muscular dystrophy. Presented at the Canadian Congress of Neurological Sciences, Ottawa, ON.

**23. 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<sup>1</sup>  
**Affiliation of Collaborator:** The University of Western Ontario School of Occupational Therapy<sup>1</sup>  
**Status:** Underway, 2005-2007

This study will evaluate the functional outcomes of four preschool-aged child with autism spectrum disorder (ASD) who are having problems completing self care activities. Using a single case design method with an A/B/A format, the children will 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 are to: use standardized measures (COPM, PEDI, PQRS) 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.

**24. Upper extremity strength in Duchenne Dystrophy**

**Investigators:** *Linda Bolack*, Craig Campbell<sup>1</sup>, Simon Levin<sup>1</sup>, *Cheryl Scholtes*, Clare Mitchell<sup>1</sup>, Christen Shoesmith<sup>1</sup>

**Affiliation of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>

**Funding:** TVCC Research Award, 2004-2005, \$4,850

**Status:** Completed

Upper extremity (UE) strength and function is known to deteriorate over time in children with Duchenne Muscular Dystrophy (DD), however, it is not clear which UE measures are best correlated with general disease progression. This cross-sectional study explores the relationship between disease characteristics and measures of UE strength and function in children with DD. Self-rating of performance and satisfaction regarding UE function has not been explored before in DD; the Canadian Occupational Performance Measure (COPM) was used to examine this issue. Fifteen patients with DD, attending a regional pediatric neuromuscular clinic participated in a study of UE strength. Participants rotated through 5 stations including: Brooke UE scale, grip strength and quantitative manual muscle testing (Lafayette system), arm MRC score, timed writing and typing tasks, and the COPM. Mean age of participants was 11.17 years. Pearson's correlation analysis of age with outcome measures revealed: a positive correlation with Brooke scale and a negative correlation with left arm MRC score; and was not significant with grip strength and Lafayette system measures. Writing and typing performance improved with age. The Brooke scale and right and left arm MRC scores were highly predictive of one another. The COPM showed that subjects were generally satisfied with each identified problem testing (mean equals 73.38%). Performance and satisfaction scores of the COPM were strongly correlated however did not correlate with the other measures. MRC scores and the Brooke scale are the best UE measures of stage of disease in this cross-sectional study. Grip strength,

writing/typing tasks, and the COPM were not found to be indicators of UE stage of disease in this study; this likely reflects the fact that the sample was relatively young.

**Publication:**

Upper extremity strength in Duchenne muscular dystrophy. Magalhaes, S., Campbell, C, *Bolack, L., Scholtes, C.*, Shoesmith, C., & Levin, S. (2005). The Canadian Journal of Neurological Sciences, 32(2[Suppl1]), S44.

**Presentations:**

Magalhaes, S., Campbell, C, *Bolack, L., Scholtes, C.*, Shoesmith, C., & Levin, S. (2005, June).

Upper extremity strength in Duchenne muscular dystrophy. Presented at the Canadian Congress of Neurological Sciences, Ottawa, ON.

*Scholtes, C.*, Campbell, C., & *Bolack, L.* (2005, October). Canadian Occupational Performance Measure: Results in a sample of children with Duchenne Dystrophy. Presented at the Ontario Association of Children's Rehabilitation Services, Niagara Falls, ON.

**25. Using computers for written communication**

**Investigators:** *Nadia Browning*, & *Beata Batorowicz*

**Funding:** Thames Valley Children's Centre Research Award, 1998-2002, \$4,200

**Status:** Completed

Twenty-four individuals aged 6 to 21 who were receiving Augmentative Communication (AC) services were evaluated for their level of independence in using their computers for written communication through observation and self-report. Complexity of access method was not found to be significantly associated with satisfaction with AC services in their written communication. Among other factors, the extent to which clients felt they knew how to use their computers was significantly associated with client/caregiver satisfaction with AC services in written communication.

**Publication:**

*Browning, N., & Batorowicz, B.* (2000). Using computers for written communication: What are the key elements of clients' and caregivers' satisfaction with this aspect of Augmentative Communication Services? (Facts To Go). London, ON: Thames Valley Children's Centre.

**26. Youths' participation in physical activity**

**Investigators:** Doreen Bartlett<sup>1</sup>, & *Karen Faragher*  
**Affiliation of Collaborator:** The University of Western Ontario's School of Physical Therapy<sup>1</sup>

**Status:** Discontinued due to lack of participants

Children and youth with disabilities have been identified to spend less time doing regular exercise and more time in sedentary leisure activities than those without disabilities. They are also at risk for the development of secondary conditions or impairment such as muscle hypoe extensibility, joint contractures, skeletal deformities, and reduced muscle strength and endurance associated, in part, with inactivity. Preventing these secondary impairments and promoting overall health through tertiary prevention programs is a focus of physical therapists working with children and youth with disabilities.

This study planned to investigate multiple personal determinants of physical activity. In terms of environmental factors, the investigators were particularly interested in the influence of families on their youth's participation in exercise. Investigation

of the determinants of physical activity would have assisted with identification of subgroups of youths with disabilities who should be specifically targeted for intensive health promotion interventions to prevent secondary impairments and optimise long-term health. A focus on this age group was important because lifelong patterns of self-management of chronic health conditions are established during adolescence. This study aimed to describe the physical activity patterns of youth aged 11 to 16 years receiving therapy services, to compare the physical activity patterns of youth at different stages of behavioural change with respect to exercise adherence, to determine the test-retest reliability of the exercise questionnaire over a period of three weeks, and to examine the personal and family factors associated with physical activity in this sample of youth.

## Psychosocial Projects

### 27. Child and family adaptation to childhood chronic health conditions: A comprehensive framework of psychosocial risk and resilience

**Investigators:** Judy Globerman<sup>1</sup>, Beverly Antle<sup>2</sup>, Ron Barr<sup>4</sup>, Jeff Jutai<sup>3</sup>, **Gillian King**, Lucy Lach<sup>4</sup>, Patricia McKeever<sup>1</sup>, Ted McNeill<sup>2</sup>, David Nicholas<sup>2</sup>, Barry Pless<sup>1</sup>, & Jan Wallander<sup>5</sup>

**Affiliations of Collaborators:** University of Toronto<sup>1</sup>, The Hospital for Sick Children<sup>2</sup>, The University of Western Ontario<sup>3</sup>, McGill University<sup>4</sup>, University of Alabama<sup>5</sup>

**Funding:** Social Sciences and Humanities Research Council of Canada, 2000-2003, \$278,000

**Status:** Underway

Today, young people with chronic and disabling conditions are living longer than ever. In spite of this positive advancement, young people with chronic health conditions continue to be at significantly greater risk for psychosocial adjustment problems when compared with their peers. A major stumbling block in efforts to more effectively advance the well-being of these young people is the vast array of factors and events that influence adjustment to a chronic health condition. Using appropriate meta-analytical techniques, these researchers will be synthesizing thirty years of quantitative and qualitative literature on adaptation and adjustment of chronic childhood health conditions, with the goal to develop a conceptual framework for understanding psychosocial risk and resilience.

### 28. Coordination difficulties and life experiences in adolescence

**Investigators:** Cheryl Missiuna<sup>1</sup>, **Gillian King**, K. McDonald<sup>2</sup>, & Debra Stewart<sup>3</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability<sup>1</sup>, The University of Western Ontario School of Physical Therapy<sup>2</sup>, Child and Parent Resource Institute<sup>3</sup>

**Funding:** Canadian Institutes of Health Research and Social Sciences and Humanities Research Council of Canada, 2003-2005, \$52,000

**Status:** Completed

Most current research on developmental coordination disorder (DCD) focuses on childhood, with little understanding of its impact during adolescence. This qualitative, phenomenological study of 10 young adults with DCD highlighted trajectories of resilience during adolescence, based

on changing social contexts and strategies employed to manage motor differences.

**Publication:**

Moll, S., Missiuna, C., Stewart, D., **King, G.**, & McDonald, K. (2006). Young adults with developmental coordination disorder: From disability to resilience. *Canadian Journal of Occupational Therapy Conference Supplement*, 73, F40.

**Presentation:**

Moll, S., Missiuna, C., Stewart, D., **King, G.**, & McDonald, K. (2006, June). Young adults with developmental coordination disorder: From disability to resilience. Presented at the Canadian Occupational Therapy Conference, Montreal, QC.

### 29. Early experiences and participation patterns of children with developmental coordination disorder

**Investigators:** Cheryl Missiuna<sup>1</sup>, Mary Law<sup>1</sup>, **Gillian King**, & Susanne King<sup>1</sup>

**Affiliation of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>

**Funding:** Canadian Institutes of Health Research, and Social Sciences and Humanities Research Council of Canada, 2000-2002, \$54,800

**Status:** Completed

Children who are so clumsy that they are unable to perform age-appropriate academic tasks and self-care activities have a syndrome known as Developmental Coordination Disorder (DCD). Children with Developmental Coordination Disorder (DCD) represent 5 to 6% of the school-aged population and are at risk for a number of secondary academic, social, and self-concept difficulties. Despite its prevalence, DCD is often unrecognized in the school system, and the needs of children are not addressed. In this qualitative research study, 13 parents of school-aged children who met the criteria for DCD, were asked about their observations and experiences during the preschool years and through the diagnostic process. Parents of school-aged children with DCD who are at various stages of the identification and intervention process were asked to share their observations about what they noticed and were concerned about in the preschool and early school years. Analysis of the study findings led to three primary themes that captured the experience of parents as they attempted to understand and get help for their child. The theme of unravelling the mystery highlights parents' impressions of their child's difficulties. The second theme of negotiating the maze refers to the many pathways followed by families as they sought to affirm their perceptions and obtain services for their child and the final theme of parenting dilemmas underscores some of the common challenges faced by parents in trying to deal with their child's limitations.

Study findings highlighted that these, often very bright, students struggled hard to produce in the classroom, with varied teacher responses. Outside the classroom, many children experienced social, self-concept, and emotional problems. Despite the support of some excellent teachers, families felt that the educational system displayed a lack of understanding and responsiveness to their child's needs. Implications of these findings include the importance of teachers in identifying children and modifying classroom environments, and the necessity of improving the responsiveness of the educational system to their needs. For occupational therapists, the study findings illustrate the

importance of focusing on occupational performance issues for children with DCD, facilitating the understanding of parents, and the need for early intervention.

**Publications:**

Moll, S., Missiuna, C., **King, G.**, King, S., & Law, M. (2002). Mysteries and mazes: Parents' perspectives on developmental coordination disorder. Proceedings of the Eighth International Qualitative Health Research Conference, 95.

Missiuna, C., Moll, S., Law, M., King, S., & **King, G.** (2006). Mysteries and mazes: Parents' experiences of developmental coordination disorder. *Canadian Journal of Occupational Therapy*, 73, 7-17.

Missiuna, C., Moll, S., King, S., Law, M., & **King, G.** (2006). "Missed and misunderstood": Children with coordination difficulties in the school system. *International Journal of Special Education*, 21, 53-67.

Missiuna, C., Moll, S., King, S., **King, G.**, & Law, M. (in press). A trajectory of troubles: Parents' impressions of the impact of developmental coordination disorder. *Physical & Occupational Therapy in Pediatrics*.

**Presentations:**

Moll, S., Missiuna, C., **King, G.**, King, S., & Law, M. (2002, April). Mysteries and mazes: Parents' perspectives on developmental coordination disorder. Presented at the Qualitative Health Research Conference, Banff, AB.

Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2002, June). New strategies to encourage earlier identification of children with developmental coordination disorder. Presented at the World Federation of Occupational Therapists' Conference, Stockholm, Sweden.

Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2002, November). Improving identification of children with developmental coordination disorder: Understanding the clues. Presented at the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2003, September). Early experiences and participation patterns of children with Developmental Coordination Disorder. Presented at the American Academy of Cerebral Palsy and Developmental Medicine 57th Annual Meeting, Montreal, QC.

Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2004, June). Early experiences and participation patterns of children with developmental coordination disorder. Presented at the Canadian Association of Occupational Therapists' Annual Conference, Charlottetown, PEI.

**30. Educators' attitudes toward inclusion**

**Investigators:** Jacqueline Specht<sup>1</sup>, **Melissa Currie**, Steve Killip<sup>2</sup>, **Gillian King**, Marla Burton<sup>1</sup>, Jasmine Eliav<sup>1</sup>, Susan Lambert<sup>1</sup>, Brooke Thornton<sup>1</sup>

**Affiliations of Collaborators:** Huron University College Department of Psychology<sup>1</sup>, Thames Valley District School Board<sup>2</sup>

**Status:** Completed

Much of the past research has examined attitudes towards inclusion of children with learning disabilities. The purpose of this study was to determine educators' opinions about the inclusion of children with special needs in regular classrooms. Focus groups were held with 47 educators who were divided into four categories according to their

experience with children with special needs: general educators with little experience with children with special needs, general educators with a great deal of experience, educational assistants, and special education educators. The transcripts of the interviews were analyzed for common themes. Consistent with past research, the educators we interviewed were positive about inclusion, but felt that many practical issues still remained unsettled. The most common issue identified was support. Both general educators and educational assistants felt the need for better training to work with children with special needs. Special educators expressed frustration with continuing discussions of inclusion without necessary improvements being implemented.

**Publications:**

Family Net. (2002, February 18). Study describes educators' attitudes toward inclusion: RACSN says educators believe in inclusion but need more support from government. Retrieved June 20, 2002, from Family Net Website: [http://www.familynet.on.ca/News/Apr\\_02/apr29.htm](http://www.familynet.on.ca/News/Apr_02/apr29.htm).

Ross, C., & Specht, J. (2002). Strategies to include children in the classroom (Focus On, Volume 2 Issue 6). London, ON: Research Alliance for Children with Special Needs.

Specht, J., **Currie, M.**, Killip, S., **King, G.**, Burton, M., Eliav, J., Lambert, S., & Thornton, B. (2001). Educators' attitudes toward inclusion (Focus On, Volume 1 Issue 3). London, ON: Research Alliance for Children with Special Needs.

**Presentation:**

Specht, J., **Currie, M.**, Killip, S., **King, G.**, Burton, M., Eliav, J., Lambert, S., & Thornton, B. (2002, August). Inclusion: Attitudes of Canadian educators. Presented at the American Educational Research Association, Chicago, IL.

**31. Evaluating the mental health of children and youth with Duchenne's Muscular Dystrophy (DMD): A neglected problem – Phase one**

**Investigators:** **Liz Taylor**, **Janice Gray**, Brian Lyttle<sup>1</sup>, Patricia McGrath<sup>2</sup>, Margaret Steele<sup>1</sup>, & **Cathy Young**

**Affiliations of Collaborators:** Children's Hospital of Western Ontario<sup>1</sup>, The University of Western Ontario<sup>2</sup>, and London Health Sciences Centre<sup>1</sup>

**Funding:** Thames Valley Children's Centre Research Award, 2000-2003, \$5,000

**Status:** Completed

Duchenne's Muscular Dystrophy (DMD) is the most common hereditary neuromuscular disease, affecting 1 out of every 3,500 males. DMD is an X-linked recessive disorder of the muscles that causes progressive muscle weakness as muscle cells are broken down and gradually lost. TVCC Investigators observed that four out of six individuals referred with DMD also had a psychiatric disorder. A focus group of interdisciplinary DMD team members at Thames Valley Children's Centre discussed the mental health of individuals with DMD and the potential contributing factors, which include medical symptoms such as respiratory function and pain, and social factors such as family communication, parental stress, marital functioning, support systems, and finances. This study is the initial phase of a comprehensive study of children with DMD. The ultimate objectives are to determine the status of mental health, pain experience, and quality of life among children with DMD and their families at different life stages. In this pilot project, the

objectives were: (1) to determine the levels of depression and anxiety in the parents of children with DMD, and (2) to assess the parental stress and family functioning in families with a child with DMD.

Ten children between the ages of 8 and 15 years were randomly chosen to participate using a block randomization design. Both children and parents were administered questionnaires.

Results indicated that more than half of the families had a parent with depression or anxiety. Seven of the families had high levels of overall parenting stress. Nine of the ten families had a child with comorbid psychiatric diagnosis, which included anxiety disorders, attention deficit hyperactivity disorder, or mental retardation. The majority of children did not identify high levels of anxiety, depression, or self-concept problems on self-report measures. Only one family of a child with a comorbid psychiatric diagnosis did not have any parental depression, anxiety or significant stress. Only one family had a child with no comorbid psychiatric diagnosis and no problems identified in the parent.

In conclusion, significant parenting stress is present in the majority of parents with children with DMD. More than half of the families had a parent with depression or anxiety. Children with DMD and their parents are at significant risk for mental health problems.

**Presentations:**

Steele, M., **Taylor, E.**, Young, C., Davidson, B., & McGrath, P. (2003, January). Family functioning with a child who has Duchenne muscular dystrophy (DMD): A pilot study. Presented at the Ontario Psychiatric Association Conference, Toronto, ON.

Steele, M., **Taylor, E.**, Young, C., Davidson, B., & McGrath, P. (2003, May). Family functioning with a child who has Duchenne muscular dystrophy: A pilot study. Presented at the Child and Youth Health, Third World Congress, Vancouver, BC.

Steele, M., **Taylor, E.**, Davidson, B., McGrath, P., & Lyttle, B. (2003, November). Family functioning with a child who has Duchenne muscular dystrophy: A pilot study. Presented at the Canadian Academy of Child and Adolescent Psychiatry, Banff, AB.

Steele, M., **Taylor, E.**, Davidson, B., McGrath, P. & Lyttle, B. (2004, October). Cognitive functioning of children and youth with Duchenne's muscular dystrophy. Presented at the Canadian Academy of Child and Adolescent Psychiatry, Montreal, QC.

Young, C., Steele, M., Davidson, B., **Taylor, E.**, McGrath, P., & Lyttle, B. (2005, January). Cognitive functioning of children and youth with Duchenne Muscular Dystrophy (DMD). Presented at the Ontario Psychiatric Association Conference, Toronto, ON.

**32. Exploration of spirituality, spiritual beliefs, and paediatric rehabilitation**

**Investigator:** *Patricia Baldwin*

**Funding:** Thames Valley Children's Centre Program Evaluation Fund, 2004-2005, \$7,500

**Status:** Completed

The philosophy and practice of family-centred services provides the foundation of listening, respect, and an individualized response to child and family needs. Family-centred care is a strengths-focused, ecological approach that supports child and family values, strengths, hopes and preferences in a collaborative partnership with TVCC staff and the community. Historically, issues around spirituality

have been addressed within the realm of theology; however, we are now seeing increased interest in the spiritual dimension across many fields of study. There is a growing interest in the relationship between spirituality and health care with a body of literature pointing toward a positive correlation between spirituality, health and well-being. This project involved a broad literature review that identified key themes and needs regarding spirituality, spiritual beliefs and pediatric rehabilitation. Recommendations for clinical practice, staff development, resources, and future research were developed through discussion with these key themes in focus groups. A manuscript is being submitted for publication.

**Presentation:**

**Baldwin, P., & LaPorta, J.** (2006, October). From exploration to implementation: Integrating spirituality into a pediatric rehabilitation centre. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Niagara Falls, ON.

**33. Facilitating optimal life experiences and environments for children with disabilities and their families**

**Investigator:** *Gillian King*

**Funding:** Ontario Mental Health Foundation Senior Research Fellowship, 2005-2008, \$89,520

**Status:** Underway

The aim of this program of research is to contribute to knowledge about how pediatric rehabilitation therapists, families themselves, and managers and planners can more effectively bring about desired outcomes through ensuring that clients and families engage in optimal experiences both within the therapeutic context and in life more generally. The project involves several lines of research, all of which focus on the promotion of successful adaptation through principles of change involving client engagement in the therapeutic process, client control over the process through the provision of information and choices, and therapist use of approaches and strategies that make sense to the child and family (coherence). How therapists make clinical decisions and how clients and families view their situations are crucial determinants of outcomes ranging from the success of a single therapeutic session, to short-term goals, and to longer-range outcomes involving mental health and adaptation.

**34. High school-aged youths' attitudes towards their peers with disabilities: The role of school and student interpersonal factors**

**Investigators:** *Janette McDougall*, David DeWit<sup>1</sup>, *Gillian King*, Linda Miller<sup>2</sup>, & Steve Killip<sup>3</sup>

**Affiliations of Collaborators:** Centre for Addiction and Mental Health<sup>1</sup>, The University of Western Ontario School of Occupational Therapy<sup>2</sup>, Thames Valley District School Board<sup>3</sup>

**Status:** Completed

Negative peer attitudes are generally recognised as being a major barrier to full social inclusion at school for children and youth with disabilities. The present study examined the attitudes of 1,872 grade nine high school students in Ontario, Canada toward their peers with disabilities. A bioecological perspective and a structural equation modeling approach were adopted to investigate how various aspects of school culture and student interpersonal factors influenced attitudes. The majority of students

(61%) held attitudes toward peers with disabilities that ranged from slightly above neutral to very positive. However, a substantial number (21%) held slightly below neutral to very negative attitudes. Positive student relationships at the school level and a school goal task structure that promotes learning and understanding for all students, rather than social comparison and competition among students, were two aspects of school culture that had both direct associations with positive attitudes and indirect associations through student interpersonal factors. Teacher and student relationships at the school level were an aspect of school culture that had an indirect association with positive attitudes via interpersonal support from teachers. Results support the development of ecologically based programs aimed at promoting aspects of school culture that contribute to positive attitudes of students toward their peers with disabilities.

**Publications:**

- McDougall, J.,** DeWit, D., **King, G.,** Miller, L., & Killip, S. (2004). High school-aged youths' attitudes toward their peers with disabilities: The role of school and student interpersonal factors. *International Journal of Disability, Development, and Education*, 51(3), 287-313.
- McDougall, J.,** DeWit, D., **King, G.,** Miller, L., & Killip, S. (2005). Factors influencing students' attitudes toward their peers with disabilities. (*Focus On*, Volume 5 Issue 6). London, Ontario: Research Alliance for Children with Special Needs.

**35. Predictors of Canadian children's mental health and competence: A structural equation modeling approach using the National Longitudinal Survey of Children and Youth**

**Investigators:** Gillian King, Dan Offord<sup>1</sup>, David DeWit<sup>2</sup>, Kathy Meyer, John LaPorta, Janette McDougall, & Linda Miller<sup>3</sup>

**Affiliations of Collaborators:** Offord Centre for Child Studies<sup>1</sup>, Centre for Addiction and Mental Health<sup>2</sup>, The University of Western Ontario School of Occupational Therapy<sup>3</sup>

**Funding:** Canadian Institutes of Health Research, 2001-2002, \$48,500

**Status:** Completed

This study used structural equation modeling to analyze the data of approximately 10,000 children aged 6-11 from the 1994-95 National Longitudinal Survey of Children and Youth. The study: (1) examined the prevalence of chronic physical conditions, impairments, and activity limitations among Canadian school-aged children, described the presence of mental health conditions and learning disabilities among children by physical health status, and examined the relationship of children's physical health status to their education and service utilization; and (2) examined the most important factors associated with the academic performance and prosocial behaviour of Canadian school-aged children, including: child factors (physical health status, emotional, behavioural, and cognitive functioning, hyperactivity/inattention, recreational participation), family factors (family social support, family functioning), and environmental factors (neighbourhood cohesion). A theoretically- and empirically-based model of competence development was used that proposes that three types of relational processes, dealing with opportunity, support, and skill development through participation, lead to competence. The findings have been shared widely to inform policy makers, health

planners, health and social services managers, and those in education, about changing patterns of prevalence and utilization, and about the most important predictive factors affecting the academic performance and social competence of children.

**Publications:**

- McDougall, J., King, G.,** DeWit, D., Miller, L. T., Hong, S., Offord, D. R., **LaPorta, J., & Meyer, K.** (2004). Chronic physical health conditions and disability among Canadian school-aged children: A national profile. *Disability and Rehabilitation*, 26(1), 35-45.
- King G., McDougall, J.,** DeWit, D., Hong, S., Miller, L., **LaPorta, J., Meyer, K., & Offord, D.** (2004). Pathways to children's academic and social outcomes (*Focus On*, Volume 4 Issue 3). London, ON: Research Alliance for Children with Special Needs.
- McDougall, J., King, G.,** DeWit, D., Miller, L., Hong, S., Offord, D., **LaPorta, J., & Meyer, K.** (2004). A profile of Canadian school-aged children's health and disability (*Focus On*, Volume 4 Issue 4). London, ON: Research Alliance for Children with Special Needs.
- King, G., McDougall, J.,** DeWit, D., Hong, S., Miller, L. T., Offord, D., **Meyer, K., & LaPorta, J.** (2005). Pathways to children's academic performance and prosocial behaviour: Roles of physical health status, environment, family, and child factors. *International Journal of Disability, Development and Education*, 52(4), 313-344.

**Presentations:**

- McDougall, J.** (2003, April). Examining the health, functioning, and competence of Canadian school-aged children using the National Longitudinal Survey of Children and Youth. Presented at the Thames Valley Children's Centre Discovery Series, London, ON.
- McDougall, J., King, G., LaPorta, J., & Meyer, K.** (2003, October). Examining the health, functioning and competence of Canadian school-aged children using the National Longitudinal Survey of Children and Youth. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.
- King, G., LaPorta, J., & McDougall, J.** (2004, February). Examining the health, functioning, and competence of Canadian school-aged children using the National Longitudinal Survey of Children and Youth. Presented at the Thames Valley District Health Council, London ON. Invited presentation.
- McDougall, J., King, G.,** DeWit, D. J., Miller, L. T., Hong, S., Offord, D. R., **LaPorta, J., & Meyer, K.** (2004, June). Chronic physical health conditions and disability among Canadian school-aged children: A national profile using the National Longitudinal Survey of Children and Youth and the ICD-10 and ICF definitions of health condition and disability. Presented at the 10th North American Collaborating Center Conference on ICF, Halifax, NS.
- McDougall, J.** (2004, June). A profile of Canadian school-aged children's health and disability. Presented at the "Painting by Numbers: What is local data saying about our community?" Conference, London, ON.
- King, G., McDougall, J.,** DeWit, D., Hong, S., Miller, L. T., Offord, D., **Meyer, K., & LaPorta, J.** (2006, March). Developing competence: Pathways to children's academic performance and prosocial behaviour. Presented at the Early Childhood Intervention Australia 2006 National Conference, Adelaide, Australia.

### 36. Predictors of the physical and emotional health of parents of children with cerebral palsy

**Investigators:** Peter Rosenbaum<sup>1</sup>, Parminder Raina<sup>2</sup>, Maureen O'Donnell<sup>3</sup>, *Gillian King*, Susanne King<sup>1</sup>, Stephen Walter<sup>1</sup>, Jamie Brehaut<sup>4</sup>, Dianne Russell<sup>1</sup>, Ellen Wood<sup>5</sup>, & Micheline Wong<sup>6</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>, McMaster University<sup>2</sup>, Sunnyhill Health Centre for Children<sup>3</sup>, Ottawa Health Research Institute<sup>4</sup>, Dalhousie University<sup>5</sup>, British Columbia Children's Hospital<sup>6</sup>

**Funding:** Medical Research Council of Canada, 2000-2002, \$338,000

**Status:** Completed

Parents of children with disabilities experience extra demands on their time, energy, and resources. Most parents cope well, but are known to be under more stress than other parents, and to have increased rates of physical and emotional wear and tear. The purpose of this Ontario-wide study is to assess the well-being of up to 650 parents of children aged 3-13 with varying levels of 'severity' of cerebral palsy. By using advanced statistical analyses, researchers examined how a large number of factors in the child, the parents, the family, and the social environment influenced parents' well-being and physical health. Researchers also compared the health of these parents with a matched sample of Canadian parents drawn from current national health surveys.

**Publication:**

Raina, P., O'Donnell, M., Schweltnus, H., Rosenbaum, P., *King, G.*, Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *Biomedical Pediatrics*, 4, 1.

### 37. School role participation during times of transition: Perspectives of the child, the parents, and the teachers

**Investigators:** Jacqueline Specht<sup>1</sup>, *Gillian King*, *Michelle Servais*, Marilyn Kertoy<sup>2</sup>, & Terry Spencer<sup>3</sup>

**Affiliations of Collaborators:** The University of Western Ontario, Faculty of Education<sup>1</sup>, School of Communication Sciences and Disorders<sup>2</sup>, London District Catholic School Board<sup>3</sup>

**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:** Underway

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 will examine 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) will be interviewed about the roles in which children participate during the school day. We will use 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 will be carried out with students in Grades 7, 8, and 9 who will be followed for a period of 2 years. This sequential approach will allow us 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, we will be 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 will provide important information to help teachers, service providers, and parents understand the experiences of children in the school setting. Information about school roles will inform educators about the types of activities that should be encouraged and will provide useful, general guidance rather than limited, prescriptive advice. The application of this research will facilitate the inclusion of all children in a range of school activities. Ideally, participation of children with disabilities will include involvement in the same variety of roles that their non-disabled peers experience, and to the same intensity, thereby allowing them to enjoy the mental health benefits that result from their participation.

### 38. Successful transitions toward adulthood and self-management for young people with physical disabilities: Developing a comprehensive picture

**Investigators:** Beverley Antle<sup>1</sup>, Debra Stewart<sup>2</sup>, *Patricia Baldwin*, Jan Burke-Gaffney<sup>3</sup>, Teresa Carter<sup>4</sup>, Laura Forma<sup>5</sup>, Mary Law<sup>1</sup>, Yani Hamdani<sup>6</sup>, H. Healey<sup>6</sup>, *Gillian King*, Karen Margello<sup>4</sup>, Shubhra Mukherjee<sup>7</sup>, Reena Nikou<sup>8</sup>, & Susanne Palmiere<sup>9</sup>

**Affiliations of Collaborators:** The Hospital for Sick Children<sup>1</sup>, CanChild Centre for Childhood Disability Research<sup>2</sup>, Hamilton Family Network<sup>3</sup>, Hamilton Health Sciences Corporation<sup>4</sup>, West Park Health Care Centre<sup>5</sup>, Bloorview Kids Rehab<sup>6</sup>, Rehabilitation Institute of Chicago<sup>7</sup>, Consumer and Advocate<sup>8</sup>, Parent and OACRS Board Member<sup>9</sup>

**Funding:** The Hospital for Sick Children Foundation, 2004-2005, \$2,000; Ontario Rehabilitation Research Network, 2004-2005, \$5,000

**Status:** Completed

A critical appraisal of five review articles on the transition to adulthood for youth with disabilities was conducted to identify evidence about (1) the factors that help or hinder the transition process, and (2) "what's working" in transition services. The appraisal identified a number of important "success" factors and elements of service delivery that are worthy of consideration by service providers and researchers. These include the need for skill development of youth with disabilities, environmental supports, and

an individualized approach to service delivery. All of the reviews identified the need for more evidence to support the implementation and evaluation of best practice models/approaches that address the complex issue of the transition from paediatric to adult services for youth with disabilities.

**Publication:**

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

**39. The participation of children with disabilities**

**Investigators:** Mary Law<sup>1</sup>, **Gillian King**, Peter Rosenbaum<sup>1</sup>, Marilyn Kertoy<sup>2</sup>, Susanne King<sup>1</sup>, Nancy Young<sup>3</sup>, & Steven Hanna<sup>1</sup>

**Affiliations of Collaborators:** *CanChild* Centre for Childhood Disability Research<sup>1</sup>, The University of Western Ontario School of Communication Sciences and Disorders<sup>2</sup>, The Hospital for Sick Children<sup>3</sup>

**Funding:** National Institutes of Health, 2000-2005, \$1,860,000

**Status:** Completed

The World Health Organization, in the new International Classification of Functioning, Disability and Health, defines participation as involvement in a life

situation. For children and youth, involvement in life situations includes participation in recreational and leisure activities as well as school and work activities. Regular participation in day-to-day activities is an important aspect of children's health, well-being, and development. Participation in activities is the context in which children develop skills and competencies, form friendships and relationships, achieve mental and physical health, develop a self-identity, and determine meaning and purpose in life.

Studies indicate that children and adolescents with chronic disabilities are at risk for lower participation in ordinary daily activities. They tend to engage in less varied leisure activities than do children without disabilities and their participation is characterized by a greater frequency of quiet recreation activities and fewer social activities, especially social activities of a spontaneous nature. The factors that enable, promote, and reinforce the participation of children with disabilities have not been comprehensively studied.

The capacity of children with disabilities to participate in the life of their family and community is an essential goal for all health services. The primary objective of the study was to describe the patterns of participation of children and youth with physical disabilities, and to examine how these patterns change over time.

**Development and Testing of a Measure**

There was a need for psychometrically sound measures of children's participation in recreation and leisure activities, for both clinical and research purposes. As a result, the Children's Assessment of Participation and Enjoyment (CAPE) and its companion measure, Preferences for Activities of Children (PAC) were developed to assist with this study. Both measures are appropriate for children and youth with and without disabilities between 6 and 21 years of age, since the items reflect activities done by any child. The items were developed through a review of the literature, expert review, and

pilot testing of the CAPE and PAC with children both with and without disabilities.

The CAPE is a 55-item measure of 5 dimensions of participation (diversity, intensity, with whom, where, and enjoyment) providing 3 levels of scoring: (1) overall participation scores, (2) domain scores reflecting participation in formal and informal activities, and (3) scores reflecting participation in five types of activities (i.e., Recreational, Active Physical, Social, Skill-Based, and Self-Improvement Activities), which were determined through principal component analyses (King et al., 2004). The PAC is a parallel measure of preference for activities, which can be scored on the same three levels.

**Publications:**

**King, G.**, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2004). Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). San Antonio, TX: Harcourt Assessment, Inc.

**King, G.**, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (in press). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health & Development*.

**Presentations:**

Law, M., **King, G.**, King, S., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2002, September). The Children's Assessment of Participation and Enjoyment (CAPE). Presented at the annual meeting of the American Academy of Cerebral Palsy and Developmental Medicine, New Orleans, LA.

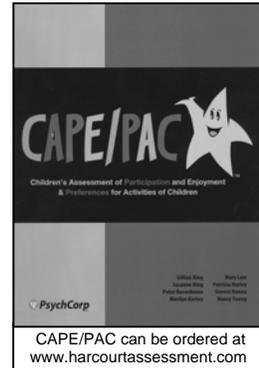
Law, M., **King, G.**, King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2002, November). The Children's Assessment of Participation and Enjoyment (CAPE). Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Law, M., **King, G.**, King, S., Kertoy, M., & Hurley, P. (2003, May). The Children's Assessment of Participation and Enjoyment (CAPE). Poster presented at the International Conference on Cerebral Palsy, Quebec City, QC.

**The Study**

A longitudinal study (using a cross-sequential design) was conducted to determine the environmental, family, and child factors that enhance participation in the formal and informal activities of childhood. Formal activities involve rules or goals and have formally-designated leaders whereas informal activities involve little or no prior planning.

Participants were 427 children with long-term, non-progressive physical conditions associated with physical functional limitations in day-to-day activities, and their families. They were recruited using random sampling from 12 children's community-based rehabilitation programs. The children were aged from 6-14 years (mean = 10.5 yrs), and included 229 boys and 198 girls with a range of neurological or musculoskeletal development problems.



Fifteen interviewers collected data during home interviews with children and their parents/caregivers at three points in time, with approximately 9 to 12 months elapsing between data collection periods. Other data were collected using self-administered, standardized questionnaires that parents returned by mail.

The Children's Assessment of Participation and Enjoyment (CAPE) was used to assess children's participation in formal and informal day-to-day activities outside of mandated school. The CAPE is a reliable and valid self-report measure of participation that includes both a formal and informal sub-domain.

Structural equation modeling was used to test a conceptual model of environmental, family, and child factors (determined from a comprehensive review of the literature) as predictors of the intensity of children's participation in informal and informal activities.

The major predictors of both formal and informal participation intensity were found to be: the child's cognitive, communicative, and physical functioning; family active-recreational orientation; and child preferences. As well, family intellectual-cultural orientation significantly predicted the intensity of children's participation in formal activities but not informal activities. Family income, environmental barriers, family cohesion, and social support to the child were found to influence the more proximal predictors of participation (i.e., child functioning, family orientations, and child preferences).

These findings confirm that explaining the participation of children with physical disabilities is complex; the study, however, points to several family and child factors that should be considered by community agencies when planning community development initiatives and services to promote children's participation. Understanding the factors that promote the participation of children, and the pathways by which these factors operate, is an obvious prerequisite to our ability to improve the personal and social well-being of children with disabilities and their families.

#### Publications:

**King, G.,** Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63-90.

Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., **King, G.,** & Hanna, S. (2004).

Participation of children with physical disabilities: Relationships with diagnosis, physical function, and demographic variables. *Scandinavian Journal of Occupational Therapy*, 11(4), 156-162.

Law, M., **King, G.,** King, S., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2004). Enhancing children's performance and participation: Client-centred rehabilitation. Proceedings of the 8th Congress of the European Federation for Research in Rehabilitation - EFRR. Bologna, IT: Medimond.

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

Law, M., Petrenchik, T., Ziviani, J., & **King, G.** (2006). Participation of children in school and community. In S. Rodger and J. Ziviani (Eds.), *Occupational therapy with children:*

*Understanding children's occupations and enabling participation* (pp.67-90). Oxford: Blackwell.

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

#### Presentations:

Law, M., **King, G.,** King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2001, April). The participation of children with disabilities in everyday life. Presented at the American Occupational Therapy Association's 81st Annual Conference and Exposition, Philadelphia, PA.

Law, M., Coster, W., Cohn, E., **King, G.,** & Bedell, G. (2002, June). Social participation in children with disability. Presented at the World Federation of Occupational Therapists' Conference, Stockholm, Sweden.

**King, G.,** Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2002, September). A model of factors affecting the participation of children with disabilities. Presented at the annual meeting of the American Academy of Cerebral Palsy and Developmental Medicine, New Orleans, LA.

**King, G.,** Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2002, November). A model of the factors affecting the participation of children with disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Law, M., **King, G.,** King, S., Rosenbaum, P., Hurley, P., Kertoy, M., & Young, N. (2002, November). Participation of children with physical disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.

Kertoy, M. K., Partyka, L., **King, G.,** Law, M., Hurley, P., King, S., Rosenbaum, P., & Young, N. (2003, April). Participation in formal and informal activities by children and adolescents with disabilities. Presented at the annual meeting of the Society for Research in Child Development, Orlando, FL.

**King, G.,** Law, M., King, S., Rosenbaum, P., & Kertoy, M. (2003, May). A model of the factors affecting the participation of children with disabilities. Presented at the International Conference on Cerebral Palsy, Quebec City, QC.

Law, M., **King, G.,** King, S., Kertoy, M., Young, N., Hanna, S., Rosenbaum, P., & Hurley, P. (2003, September). Participation patterns of children with physical disabilities. Presented at the American Academy of Cerebral Palsy and Developmental Medicine's 57th Annual Meeting, Montreal, QC.

Law, M., **King, G.,** King, S., Kertoy, M., Young, N., Hanna, S., Rosenbaum, P., & Hurley, P. (2003, October). Participation patterns of children with physical disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill.

Law, M., **King, G.,** King, S., Hurley, P., Kertoy, M., Rosenbaum, P., Young, N., & Hanna, S. (2004, June). Enhancing children's performance and participation: Client-centred rehabilitation. Workshop presented at the 8th Congress of the European Federation for Research in Rehabilitation, Ljubljana, Slovenia.



- Law, M., King, S., Rosenbaum, P., Hurley, P., Hanna, S., **King, G.**, Kertoy, M., & Young, N. (2004, October). Patterns of participation of children and youth with physical disabilities. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Services, Richmond Hill, ON.
- Kertoy, M. (2005, January). Participation of youth with special needs: Patterns and influences. Presented at the Rehabilitation Sciences Seminar Series at The University of Western Ontario, London, ON.
- King, G.**, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2005, April). A longitudinal study of the predictors of the participation of children with physical disabilities. Presented at the biennial meeting of the Society for Research in Child Development, Atlanta, GA.
- King, G.**, Law, M., Hanna, S., King, S., Hurley, P., Kertoy, M., Rosenbaum, P., & Young, N. (2005, September). A longitudinal study of the predictors of the participation of children with physical disabilities. Presented at the annual meeting of the American Academy for Cerebral Palsy and Developmental Medicine, Orlando, FL.
- King, G.**, Law, M., Hanna, S., King, S., Hurley, P., Kertoy, M., Rosenbaum, P., & Young, N. (2006, March). The participation of children and youth with physical disabilities. Presented at Scope, Melbourne, Australia.
- King, G.**, Law, M., Hanna, S., King, S., Hurley, P., Kertoy, M., Rosenbaum, P., & Young, N. (2006, March). The participation of children and youth with physical disabilities. Presented at Novita Children's Services, Adelaide, Australia.
- King, G.**, Law, M., Hanna, S., King, S., Hurley, P., Kertoy, M., Rosenbaum, P., & Young, N. (2006, May). The participation of children and youth with physical disabilities. Presented at the International Meeting in Paediatric Neuromuscular Rehabilitation, Vingstedcentret, Denmark.
- Law, M., **King, G.**, Kertoy, M., Hurley, P., Hanna, S., Petrenchik, T., Rosenbaum, P., & Young, N. (2006, June). Participation of children with physical disabilities in out of school occupations. Presented at the Canadian Occupational Therapy Conference, Montreal, QC.



communication and of doing things together as a family.

- ◆ **Worldviews** are the family's assumptions about the social and cultural environment, and their family's place in the world.

The priorities, values, and worldviews of families affect their adaptation and resilience. Little is known, however, about how families may adjust to raising a child with a disability by changing or adapting their priorities, values, or worldviews. Findings from the first phase of a two-part study investigating changes in the belief systems of families of children with autism or Down syndrome are reported in a TVCC Facts To Go. Three focus groups involving 19 knowledgeable individuals (15 parents and 4 service providers) were conducted to obtain information about the priorities, values, and worldviews of families, and how these might change over time. Four categories of themes emerged from the analysis of the focus group information:

- (1) initial reaction to parenting a child with a disability (a life-changing experience),
- (2) adapting over time (being spurred to examine beliefs, importance of hope, gaining a sense of control and empowerment),
- (3) changes in priorities (giving up "trying to fix the child," refocusing on the needs of other family members), and
- (4) changes in worldviews and values (stronger values and broader worldviews, areas of personal growth, learning what is important in life).

Implications for families of children with disabilities and service providers are included. This information could help ease the challenges commonly faced by families of children with disabilities.

**Publications:**

**King, G.**, King, S., Zwaigenbaum, L., **Baxter, D.**, Rosenbaum, P., & Bates, A. (2005). The priorities, values, and worldviews of families of children with autism or down syndrome: Study 1 (Facts To Go, Volume 1 Issue 2). London, ON: Thames Valley Children's Centre.

**King, G.**, Zwaigenbaum, L., King, S., **Baxter, D.**, Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development*, 32(3), 353-369.

**Presentation:**

**King, G.**, Zwaigenbaum, L., Rosenbaum, P., King, S., Bates, A., & **Baxter, D.** (2006, June). Belief systems of families of children with autism spectrum disorders. Presented at the International Meeting for Autism Research, Montreal, QC.

**40. Understanding the values, priorities, and world views of families raising children with chronic developmental conditions**

**Investigators:** Gillian King<sup>1</sup>, Peter Rosenbaum<sup>1</sup>, Susanne King<sup>1</sup>, & Anita Bates<sup>2</sup>

**Affiliations of Collaborators:** CanChild Centre for Childhood Disability Research<sup>1</sup>, Parent Representative<sup>2</sup>

**Funding:** Canadian Institutes of Health Research, 2002-2005, \$85,644

**Status:** Completed

This three-year study looked at how parenting a child with a disability affects family values, priorities, and views of their place in the world. Families were queried at two transition points—entry into school and transition into high school.

- ◆ **Family priorities** deal with the activities and roles families feel are most important.
- ◆ **Family values** are fundamental operating principles by which parents organize the lives of their families, such as the importance of open

## 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 10 external research projects underway between 1 April 2002 and 31 March 2006. Abstracts of the projects are located on the listed pages. The names of the TVCC Research Contacts are bolded and italicized.

41. A qualitative inquiry into reasons for continued or discontinued use of written communication systems. ....28
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### 41. A qualitative inquiry into reasons for continued or discontinued use of written communication systems

**Investigators:** Larysa Sereda, & Nicole Thomson  
**Affiliation:** The University of Western Ontario  
School of Occupational Therapy  
**TVCC Research Contact:** *Nadia Browning*  
**Status:** Underway, 2005-2006

This qualitative study was developed to address the success of recommendations for written communication systems from acquisition to long-term usage. Semi-structured interviews were conducted with AAC users and their caregivers to identify reasons for continuing or discontinuing use of recommended devices. Themes clearly indicate there are factors that significantly impact device usage that can be addressed by professionals when recommending written communication systems. These themes include expectations, needs, training and support, equipment, and client and caregiver factors. The results of this study provide clinicians with information that will be useful in the assessment

process, and will assist teams in the recommendation of written communication systems that are likely to be adopted and maintained for long-term use.

### **Presentation:**

Thomson, N., Sereda, L., Sumsion, T., & **Browning, N.** (2006, September). Augmentative and alternative communication devices: Reasons for continued or discontinued use. Presented at the annual meeting of the Ontario Association of Children's Rehabilitation Centres, Niagara Falls, ON.

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

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

**Affiliation:** CanChild Centre for Childhood Disability Research

**TVCC Research Contact:** *Ann MacPhail*

**Status:** Underway, 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. The Ontario Motor Growth Study (1996-2001) followed a cohort of over 650 children with CP to create motor development curves; the ASQME Study (2002-2007) will continue to follow some of these same young people as adolescents to assess patterns of activity, forms of mobility and factors associated with changes of function specific to adolescence. Over 300 adolescents and their parents will be invited to participate in annual assessments for four years, providing unique information on maturation in one of the more prevalent developmental disabilities of childhood. While we are using mainly standardized questionnaires and assessment protocols to collect data about factors that the researchers feel are relevant, we are also excited about a qualitative component to the study that will allow us to ask (or ASQ!) a subgroup of adolescents for some self-generated feedback about themselves and their goals. This study will pave the way for a new generation of studies directed at secondary prevention and health promotion.

### 43. Correspondence of classification of motor function in children aged two to four years between families and professionals: A pilot study

**Investigators:** Jamie Kneale Fanning<sup>1</sup>, Kristen Abercrombie<sup>2</sup>, Amy Dietrich<sup>2</sup>, & Doreen Bartlett<sup>2</sup>  
**Affiliations:** St. Joseph's Health Centre<sup>1</sup>, The University of Western Ontario School of Physical Therapy<sup>2</sup>

**TVCC Research Contact:** *Joanne Legros-Kelly*  
**Status:** Completed, 2003-2004

The past two decades have witnessed an increased survival of very premature and low birth weight infants who are at increased risk for cerebral palsy. Neonatal programs typically follow the development of their graduates for a number of years reporting on developmental outcomes. The participation of families in follow up has increased as data collection of functional outcome and increasing emphasis on Family Centered Care have emerged.

Typically, children with a diagnosis of cerebral palsy have been described according to distribution of involvement and determined as mild, moderate or severe using individual follow up clinical guidelines. Recently follow up has become increasingly focused

on functional outcomes and health status with the move to standardized assessment tools, which measure functional ability. The Gross Motor Function Classification System (GMFCS) is one such tool recently used to report functional outcome in neonatal follow up.

Recently, attention has been directed to studying the correspondence between health care providers and parents' judgements of classifying children. Parents are acknowledged as experts with regard to their infants' and children's developmental status, thus contributing to greater efficiency of service delivery by participating in the assessment process. Parents of children with cerebral palsy aged 6 to 12 years obtained a high level of agreement with health professionals when classifying their children using a modified questionnaire; work is currently underway in the UK to determine the correspondence between parents and health professionals with a sample of children aged 6 to 16 years. We intend to add to this body of research by determining the degree of correspondence between parents and health professionals on a sample of children in the 2 to 4 year age band of the GMFCS.

**Publication:**

Dietrich, A., Abercrombie, K., Fanning, J. K., & Bartlett, D. J. (2005). Correspondence of classification of motor function of children with cerebral palsy aged two to four years between families and professionals: A pilot study. *Pediatric Physical Therapy*, 17, 69-70.

**44. Development of motor function in children with cerebral palsy: Creation of "Motor Growth Curves"**

**Investigators:** Peter Rosenbaum, Stephen Walter, Dianne Russell, & Ellen Wood

**Affiliation:** CanChild Centre for Childhood Disability Research

**TVCC Research Contact:** *Kathy Meyer*

**Status:** Completed, 1996-2002

Little is known about the patterns of development of children with cerebral palsy that lead to their ultimate functional motor outcome. A lack of a valid classification of severity of cerebral palsy and the absence of longitudinal data on which to base an opinion have made it difficult to consider prognostic issues accurately and making rehabilitation goals and gains are often difficult to evaluate. The objective of this project was to describe the natural history of movement development in this population of children. This will help us to understand how the "severity" of cerebral palsy might influence how independent a child is eventually able to become.

Over five years, the Ontario Motor Growth Study charted the gross motor progress of a randomly-selected sample of 657 children aged 1 to 13 years at study onset, representing the full spectrum of clinical severity of motor impairment in Ontario children with cerebral palsy.

Based on a total of 2,632 GMFCS assessments that used the five levels of the Gross Motor Function Classification System (GMFCS), five distinct "motor growth curves" were created that describe the patterns of motor development of children with varying "severities" of cerebral palsy. These "motor growth curves" are similar to the growth charts that are used to follow the height and weight of children as they grow.

These motor growth curves describe important and significant differences in the rates and limits of gross motor development among children with

cerebral palsy by severity. There is substantial within-stratum variation in gross motor development. Evidence-based prognostication about gross motor progress in children with cerebral palsy is now possible, providing parents and clinicians with a means to plan interventions and to judge progress over time. Further work is needed to describe motor function of adolescents with cerebral palsy

**Publications:**

Palisano, R. J., Walter, S. D., Russell, D. J., Rosenbaum, P. L., Gemus, M., Galuppi, B. E., Cunningham, L. (2001). Gross motor function of children with down syndrome: Creation of motor growth curves. *Archives of Physical Medicine and Rehabilitation*, 82 (4), 494-500.

Rosenbaum, P. L., Walter, S. D., Hanna, S., Palisano, R. J., Russell, D. J., Raina, P. F., Wood, E., Bartlett, D., & Galuppi, B. E. (2002). Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *JAMA*, 288, 1357-1363.

Hanna, S. E., Law, M. C., Rosenbaum, P. L., King, G. A., Walter, S. D., Pollock, N., Russell, D. J. (2003). Development of hand function among children with cerebral palsy: Growth curve analysis for ages 16 to 70 months. *Developmental Medicine & Child Neurology*, 45, 448-455.

**45. Parent involvement in intensive behavioural intervention**

**Investigators:** Abbie Solish & Adrienne Perry

**Affiliation:** York University Department of Psychology

**TVCC Research Contact:** *Louise LaRose*

**Status:** Completed, 2006

This project is 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. These factors included (1) parent self-efficacy about participating in their children's programs (e.g., how confident parents feel participating, how effective parents believe they are at being involved, and how much parents feel their involvement makes a difference to their children's progress); (2) parents' knowledge of autism and IBI; (3) parents' belief in IBI (e.g., how strongly parents believe that IBI is the best choice of intervention for their children and for children in general); (4) parents' perceptions of their children's progress in various areas since beginning the IBI

program; and (5) parents' level of parenting distress at the time of the study.

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. We hope that such involvement may, in turn, result in the child making greater progress in therapy. Therefore, our results add support to the notion of providing supportive services to parents with children in IBI programs.

**Presentation:**

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

**46. Spina bifida assessment of neurobehavioral development international (SANDI) Project**

**Investigators:** Maureen Dennis, Marcia Barnes, Ross Hetherington, Susan Blaser, Raymond Buncic, James Drake, Daune MacGregor, & Stephen Scherer

**Affiliations:** The Hospital for Sick Children, Departments of Psychology, Neuroradiology, Ophthalmology, Neurology, and Genetics

**TVCC Research Contacts:** *Michelle Gilpin* and *Dorothy Harris*

**Status:** Underway, 2002-2006

Spina bifida meningomyelocele is the major severely disabling birth defect in North America, but our knowledge of the factors responsible for neurobehavioural outcome is fragmentary. This program project aims to make these fragments coherent. The overall objective is to identify sources of variability – genetic, environmental, and central nervous system – that explain variations in the neurobehavioural outcomes of children with spina bifida meningomyelocele and hydrocephalus.

To accomplish this objective, researchers will evaluate 583 children with spina bifida and 159 controls in five projects and three cores at two primary data collection sites: the University of Texas-Houston Medical School, and The Hospital for Sick Children, including clinics serving children with spina bifida at Texas Children's Hospital and Shriners Hospital for Children in Houston, Texas, the Bloorview MacMillan Rehabilitation Centre in Toronto, and Thames Valley Children's Centre in London. This five year multimillion dollar study plans "to uncover the secrets of spina bifida" and attempt to understand how spina bifida changes brain development and how the brain adapts to these changes. The SANDI project is now in its 7<sup>th</sup> year.

**Publication:**

Dennis, M. (2002). The SANDI project: Unlocking the mysteries of spina bifida and hydrocephalus. Current Magazine, Fall-Winter.

**47. The incidence of secondary alveolar bone grafting postgingivoperiosteoplasty**

**Investigators:** Stephanie Power, & Damir Matic  
**Affiliation:** The University of Western Ontario  
**TVCC Research Contact:** *Anne Dworschak-Stoken*

**Status:** Underway, 2004-2006

Alveolar clefts may either be repaired by gingivoperiosteoplasty at age 3 months or more traditionally by primary bone grafting at 8 or 9 years of age. Alveolar bone is important for normal facial growth and also contributes aesthetically to one's facial appearance by providing support to the upper lip. It is a prerequisite for normal tooth eruption and the prevention of subsequent decay and tooth loss. Possible advantages of gingivoperiosteoplasty are alignment and consolidation of the maxillary dental arch and the avoidance of later bone grafting procedures. Some surgeons, however, believe that gingivoperiosteoplasty may disrupt facial growth and result in a poorer quality of bone at the cleft site than that achieved post-primary grafting.

The objective of this chart review study is to identify the necessity of secondary bone graft procedures for closure of alveolar clefts after previous gingivoperiosteoplasty. The investigators will also quantify the amount of bone production achieved at the cleft site post-gingivoperiosteoplasty vs. bone consolidation post-primary grafting.

**48. The psychosocial impact of assistive devices: Children who use a mobility device**

**Investigators:** Sonya Silver, & Jeff Jutai  
**Affiliations:** The University of Western Ontario Rehabilitation Medicine  
**TVCC Research Contact:** *Lucine Truscott*  
**Status:** Completed, 2002-2002

This study investigated the psychosocial impact of a mobility device on a child's quality of life (QOL). The Psychosocial Impact of Assistive Devices Scale (PIADS) measures assistive devices' impact on adults' QOL. Currently, no such measure exists for children. This study builds on previous student research to (a) determine the constructs for QOL of a child as reported by children who use a mobility device and a parent or guardian, (b) compare these constructs to those from both the adult version of the PIADS and previous students with children, and (c) compare the relevance that children place on QOL domains to that of adults. Three themes emerged from the interviews, with direct reference made to six of the 26 items on the PIADS, and indirect reference made to 10 items. The themes identified were directly related to those found in previous studies.

**Publication:**

Silver, S. (2002). The psychosocial impact of assistive devices: Children who use a mobility device. Proceedings of The University of Western Ontario Occupational Therapy Conference on Evidence Based Practice, 2, 107-108.

**49. The relationship between aggressive behaviour and temperament in children with autism spectrum disorder**

**Investigators:** Beth Craven-Thuss, & Mary Konstantareas  
**Affiliations:** University of Guelph Department of Psychology  
**TVCC Research Contact:** *Kathy Meyer*  
**Status:** Completed, 2002-2003

Aggression in children with autism spectrum disorder (ASD) is one of the most problematic

behaviours to successful integration and is therefore of great concern, however a detailed examination of it has lacked in the ASD literature. In research with typically developing children, an important distinction between proactive and reactive aggression has been supported. Proactive aggression is defined as unprovoked, aversive behaviour intended to do harm, dominate, or coerce another person. By contrast, reactive aggression is considered to be a defensive response to a perceived threat, fear, or provocation. In the case of reactive aggression, behaviour is supposed to always be preceded by frustration. We expected that since many symptoms associated with autism lead to frustration (e.g., poor communication skills, reliance on a routine), children with ASD would be more likely to display reactive aggression. This was supported as children with ASD were reported to display significantly more reactive than proactive aggression.

One of the directions research into aggressive behaviour in typical children has taken has been to identify contributing factors at the individual level. An obvious dimension that possibly underlies aggressive behaviour on which individuals differ is that of temperament. Furthermore, individual differences must be considered in research on children with ASD because ASD is one of the most heterogeneous of the developmental disorders.

Temperament can be defined as individual differences in reactivity and self-regulation assumed to have a constitutional basis. Reactivity refers to motor, emotional and attentional responses to internal and external stimuli. Self-regulation refers to processes that serve to modulate reactivity, including approach/withdrawal, inhibitory control and allocation of attention. Research on the temperament of children with ASD and indeed other a typical child population had just begun. The relationship between amount of aggressive behaviour and specific aspects of temperament were examined. We found that children with ASD that display higher levels of aggressive behaviour also showed higher levels of anger/frustration, impulsivity, and lower levels of inhibitory control. Similar relationships have been reported in past research on typically developing children.

The findings from this study suggested that individual differences in temperament are much more predictive of the amount of aggressive behaviour than level of functioning (academic or communication) and/or autistic symptom severity. Information regarding the child's temperament also appears to be relevant to the type of aggression displayed. The findings suggested that negative affectivity was the best predictor of reactive aggression. Thus, future research addressing the children's aggression should be informed by data on the children's temperamental characteristics.

**Presentations:**

Craven-Thuss, B., & Konstantareas, M. M. (2003, April). Reactive and proactive aggression in children with autism spectrum disorder: Relevance of temperament and other characteristics. Presented at the Eleventh Annual OADD Research Special Interest Group Research Day, Richmond Hill, ON.

Craven-Thuss, B., & Konstantareas, M. M. (2006, June). Aggressive behaviour and temperament in children with autism spectrum disorder. Presented at the International Meeting for Autism Research, Montreal, QC.

**50. 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, 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. This investigation is necessary in order to begin to delineate what, if any, changes should be made within IBI programs and/or the school system to best support the transition of children with autism and their parents. 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 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 Behaviour Analysis, Markham, ON.

## GRANTS RECEIVED FOR TVCC PROJECTS

Between 1 April 2002 and 31 March 2006, a total of **\$1,031,978** in funding from granting agencies was awarded to **19 research projects** with TVCC staff members as investigators. The names of TVCC staff members who were investigators on the grants are bolded and italicized.

### Canadian Institutes of Health Research .....\$212,628

An evaluation of the relevance, feasibility and validity of web-based data collection for children, 2004-2006 (D. Nicholas, N. Young, K. Boydell, R. Hetherington, **G. King**, L. Lach, L. Snider, & J. W. Varni), \$126,984.

Understanding the values, priorities, and world views of families raising children with chronic developmental conditions, 2002-2005 (**G. King**, P. Rosenbaum, S. King, & A. Bates), \$85,644.

### Canadian Institutes of Health Research, and Social Sciences and Humanities Research Council of Canada .....\$52,600

Coordination difficulties and life experiences in adolescence, 2003-2005 (C. Missiuna, **G. King**, D. Stewart, & K. McDonald), \$52,600.

### Ministry of Community and Social Services \$43,500

Development and testing of a resource kit for parents of young adults who receive individualized funding for support, 2002-2007 (D. Stewart, M. Law, C. Missiuna, **G. King**, & P. Rosenbaum), \$43,500.

### Ontario Mental Health Foundation, Senior Research Fellowship .....\$89,520

Facilitating optimal life experiences and environments for children with disabilities and their families, 2005-2008, (**G. King**), \$89,520.

### Ontario Rehabilitation Research Network, and the Hospital for Sick Children Foundation .....\$7,000

Successful transitions towards adulthood and self-management for young people with physical disabilities: Developing a comprehensive picture, 2004-2005 (B. Antle, D. Stewart, **P. Baldwin**, J. Burke-Gaffney, T. Carter, L. Forma, M. Law, Y. Hamdani, H. Healey, **G. King**, K. Margello, S. Mukherjee, R. Nikou, & S. Palmiere). Funded by the Ontario Rehabilitation Research Network, \$5,000, and The Hospital for Sick Children Foundation, \$2,000.

### Provincial Centre of Excellence for Child and Youth Mental Health .....\$7,065

School role participation: Perspectives of the child, the home, and the school, Grant in Aid, 2005-2006 (J. Specht, **G. King**, **M. Servais**, M. Kertoy, & T. Spencer), \$7,065.

### REPAR (Réseau Provincial de Recherche en Adaptation-Réadaptation) .....\$13,600

Children's Assessment of Participation and Enjoyment: A content validation study, 2002-2003 (A. Majnemer, A. Cotelleso, M. Law, **G. King**, & M. Dilenge), \$13,600.

### Research Alliance for Children with Special Needs, Service Provider Award .....\$3,000

Augmentative and alternative communication prescription review: Examining clinicians' perceptions, Study II, 2004-2005 (**B. Batorowicz**, & **T. Shepherd**), \$3,000.

### Social Sciences & Humanities Research Council of Canada ..... \$576,973

Enhancing the participation of children with special needs, 2003-2005 (**G. King**, D. Bartlett, M. Kertoy, S. Killip, L. Miller, J. Specht, D. DeWit, T. Spencer, & S. Stewart), \$397,800.

Fathers of children with special needs, funded by the Fatherhood Involvement Research Alliance of SSHRC, 2004-2007 (T. McNeill, J. Beaton, **G. King**, G. Montgomery, & D. Nicholas), \$40,000.

School role participation: Perspectives of the child, the parents, and the teachers, 2006-2009 (J. Specht, **G. King**, **M. Servais**, M. Kertoy, & T. Spencer), \$109,563.

Youth with disabilities and the new economy: Enhancing transition into adulthood (Letter of intent), 2003, (M. Law, V. Bartee, C. Gibson, M. Beck, J. Burke-Gaffney, D. Stewart, R. Wilton, **G. King**, J. Darrah, & J. Magill-Evans), \$29,610.

### Thames Valley Children's Centre, Staff Research Awards ..... \$26,092

Augmentative and alternative communication prescription review: Examining clinicians' perceptions, 2003-2004, (**B. Batorowicz**, & **T. Shepherd**), \$5,000.

Does a custom dynamic seating system maintain pelvis position and what do client's think of it, 2004-2005 (**S. Kirkpatrick**, **J. Wighton**, S. Spaulding, T. Sumsion, **L. Truscott**, **J. Sommerfreund**, & **B. Batorowicz**), \$5,000.

Effects of serial casting with and without Botulinum toxin injections as interventions for spastic ankle equinus, 2005-2006 (**F. Stephenson**, **C. Scholtes**, T. Carey, & K. Leitch), \$1,646.

Fractures in boys with muscular dystrophy, 2002-2003 (**D. Harris**, N. Bernhard, C. Mitchell, & S. Levin), \$4,596.

Is a reduced dose of Deflazacort effective in maintaining strength in children with Duchenne Dystrophy? 2004, (C. Campbell, **L. Bolack**, S. Levin, **C. Scholtes**, C. Mitchell, B. Lyttle, & T. Carey), \$5,000.

Upper extremity strength in Duchenne Dystrophy, 2004-2005 (**L. Bolack**, C. Campbell, S. Levin, **C. Scholtes**, C. Mitchell, & C. Shoemsmith), \$4,850.

#### Research Key Fact: Project Grants/Funding



- ◆ Between 1 April 2002 and 31 March 2006, TVCC staff members were named investigators on **19** projects receiving **\$1,031,978** in grants.
- ◆ Since 1990, staff members have been named investigators on projects receiving **115** grants totalling **\$6,625,055**.
- ◆ Over the last 17 years,
  - **5** projects received over \$250,000 in funding
  - **20** projects received funding between \$50,001 and \$250,000
  - **26** projects received between \$10,000 and \$50,000 in funding
  - **8** projects received between \$5,001 and \$9,999
  - **18** projects were funded for \$5,000
  - **38** projects were funded for under \$5,000
  - **17** projects received multiple grants (2 or more)

## PUBLICATIONS

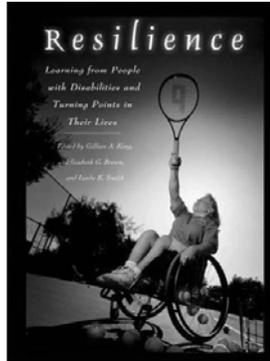
TVCC produces and transfers knowledge about children with special needs and our research findings through professional publications, books and book chapters, and other publications. Findings have clear implications for enhancing services and therapeutic interventions.

The following is a list of abstracts, articles, book chapters, and book that were published or were accepted for publication between 1 April 2002 and 31 March 2006. Names of TVCC staff members are bolded and italicized.

### BOOK

Resilience: Learning from people with disabilities and the turning points in their lives. **King, G., Brown, E., & Smith, L. K.** (Eds.) (with **Cathers, T., MacKinnon, E.**, Miller Polgar, J., Specht, J., & Willoughby, C.) (2003). Westport, CT: Praeger. ISBN: 0275979431.

Resilience is available at Greenwood Publishers, Chapters, and Amazon.



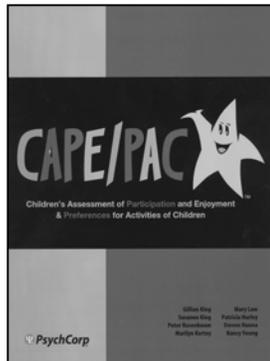
### BOOK CHAPTER

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.

### MEASUREMENT TOOL

Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). **King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N.** (2005). San Antonio, TX: Harcourt Assessment, Inc.

The CAPE/PAC is available to order from [www.harcourtassessment.com](http://www.harcourtassessment.com)



### JOURNALS

#### American Journal of Occupational Therapy

The importance of leisure in the lives of individuals with congenital physical disabilities. Specht, J. A., **King, G., Brown, E., & Foris, C.** (2002). *American Journal of Occupational Therapy*, 56, 436-445.

#### American Journal of Orthopsychiatry

The meaning of life experiences: Application of a meta-model to rehabilitation sciences and services. **King, G.** (2004). *American Journal of Orthopsychiatry*, 74(1), 72-88.

#### Archives of Physical Medicine and Rehabilitation

Selecting outcome measures in children's rehabilitation: A comparison of methods. Law, M., Hurley, P., Russell, D., **King, G.**, & Hanna, S. (2003). *Archives of Physical Medicine and Rehabilitation*, 84(4), 496-499.

#### 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.

#### Biomedical Pediatrics

Caregiving process and caregiver burden: Conceptual models to guide research and practice. Raina, P., O'Donnell, M., Schweltnus, H., Rosenbaum, P., **King, G.**, Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). *Biomedical Pediatrics*, 4, 1.

#### 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.

#### Canadian Journal of Occupational Therapy

Mysteries and mazes: Parents' experiences of developmental coordination disorder. Missiuna, C., Moll, S., Law, M., King, S., & **King, G.** (2006). *Canadian Journal of Occupational Therapy*, 73, 7-17.

Young adults with developmental coordination disorder: From disability to resilience. Moll, S., Missiuna, C., Stewart, D., **King, G.**, & McDonald, K. (2006). *Canadian Journal of Occupational Therapy Conference Supplement*, 73, F40.

#### Child: Care, Health and Development

A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. **King, G.**, Zwaigenbaum, L., King, S., **Baxter, D.**, Rosenbaum, P., & Bates, A. (2006). *Child: Care, Health and Development*, 32(3), 353-369.

Factors affecting family-centred service delivery for children with disabilities. Law, M., Hanna, S., **King, G.**, Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). *Child: Care, Health and Development*, 29(5), 357-366.

Family-centred service: Moving ideas into practice. Law, M., Teplicky, R., King, S., **King, G.**, Kertoy, M., Moning, T., Rosenbaum, P. & Burke-Gaffney, J. (2005). *Child: Care, Health and Development*, 31(6), 633-642.

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.**, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (in press). *Child: Care, Health & Development*.

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.

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### Children's Health Care

A measure of parents' and service providers' beliefs about participation in family-centered services. **King, G.**, Kertoy, M., King, S., Law, M., Rosenbaum, P., & Hurley, P. (2003). *Children's Health Care*, 32(3), 191-124.

Evaluating health service delivery to children with chronic conditions and their families: Development of a refined Measure of Processes of Care (MPOC-20). **King, S.**, **King, G.**, & Rosenbaum, P. (2004). *Children's Health Care*, 33(1), 35-57.

Planning successful transitions from school to adult roles for youth with disabilities. **King, G.**, **Baldwin, P.**, **Currie, M.**, & **Evans, J.** (2005). *Children's Health Care*, 34(3), 193-216.

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.

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### Counseling and Values

Spirituality: A coping mechanism in the lives of adults with congenital disabilities. Specht, J., **King, G.**, Willoughby, C., **Brown, E.**, & **Smith, L.** (2005). *Counseling and Values*, 50(1), 51-62.

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### Developmental Medicine and Child Neurology

Development of hand function among children with cerebral palsy: Growth curve analysis for ages 16 to 70 months. Hanna, S., Law, M., Rosenbaum, P., **King, G.**, Walter, S., Pollock, N., & Russell, D. (2003). *Developmental Medicine and Child Neurology*, 45, 448-455.

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). *Developmental Medicine and Child Neurology*, 48(5), 337-342.

Success in life for older adolescents with cerebral palsy: A qualitative study. **King, G.**, **Cathers, T.**, Miller Polgar, J., **MacKinnon, E.**, & **Havens, L.** (2003). *Developmental Medicine and Child Neurology Abstracts*, 45 (Suppl. 94), 39-40.

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### Disability and Rehabilitation

Chronic physical health conditions and disability among Canadian school-aged children: A national profile. **McDougall, J.**, **King, G.**, DeWit, D., Miller, L., Hong, S., Offord, D. R., **LaPorta, J.**, & **Meyer, K.** (2004). *Disability and Rehabilitation*, 26(1), 35-45.

Measuring chronic health condition and disability as distinct concepts in national surveys of school-aged children in Canada: A comprehensive review with recommendations based on the ICD-10 and ICF. **McDougall, J.**, & Miller, L. (2003). *Disability and Rehabilitation*, 25(16), 922-939.

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### European Federation for Research in Rehabilitation Proceedings

Enhancing children's performance and participation: Client-centred rehabilitation. Law, M., **King, G.**, King, S., Hurley, P., Kertoy, M., Rosenbaum, P., Young, N., & Hanna, S. (2004). Proceedings of the 8th Congress of the European Federation for Research in Rehabilitation. Bologna, IT: Medimond.

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### Evaluation and Program Planning

A model of impacts of research partnerships in health and social services. **Currie, M.**, **King, G.**, Rosenbaum, P., Law, M., Kertoy, M., & Specht, J. (2005). *Evaluation and Program Planning*, 28, 400-412.

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### Healthcare Management Forum

A test of a centre's vision. **LaPorta, J.**, **King, G.**, **Cathers, T.**, **Havens, L.**, **Young, C.**, & **Aylward, S.** (2003). *Healthcare Management Forum*, 16(1), 34-36.

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### Internet Journal of Allied Health Sciences and Practice

Helpful organizational factors of a community-linked research unit: A qualitative study. **King, G.**, Law, M., Rosenbaum, P., **Currie, M.**, Plews, N., Russell, D., King, S., Missiuna, C., & Walter, S. (2005). *Internet Journal of Allied Health Sciences and Practice*, 3(3).

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### International Journal of Disability, Development, and Education

High school-aged youths' attitudes toward their peers with disabilities: The roles of school and student interpersonal factors. **McDougall, J.**, DeWit, D., **King, G.**, Miller, L., & Killip, S. (2004). *International Journal of Disability, Development, and Education*, 51(3), 287-313.

Pathways to children's academic performance and prosocial behavior: Roles of physical health status, environment, family, and child factors. **King, G.**, **McDougall, J.**, DeWit, D., Hong, S., Miller, L., Offord, D., **Meyer, K.**, & **LaPorta, J.** (2005). *International Journal of Disability, Development and Education*, 52(4), 313-344.

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### International Journal of Special Education

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#### Research Key Fact: Publications



- ◆ Between 1 April 2002 and 31 March 2006, TVCC staff members were named authors on **91 published articles**:
  - 48 in peer reviewed publications, including:
    - 1 book
    - 1 book chapter
    - 1 measurement tool
    - 45 articles in professional journals
  - 43 easy-to-read publications
- ◆ Since 1990, TVCC investigators were named authors on **210 publications**:
  - 1 book
  - 9 book chapters
  - 1 measurement tool
  - 60 easy-to-read summaries
  - 20 research reports
  - 119 articles in professional journals

"Missed and misunderstood": Children with coordination difficulties in the school system. Missiuna, C., Moll, S., King, S., Law, M., & **King, G.** (2006). *International Journal of Special Education*, 21, 53-67.

#### International Society of Augmentative and Alternative Communication (ISAAC)

A model of team decision making in AAC. **Batorowicz, B., & Shepherd, T.** (2004). Proceedings of the 11th Biennial International Conference of the International Society of Augmentative and Alternative Communication (ISAAC).

#### Journal of Anxiety Disorders

Gender differences in the effects of family adversity on the risk of onset of DSM-III-R social phobia. DeWit, D., Chandler-Coutts, M., Offord, D., **King, G., McDougall, J.**, Specht, J., & Stewart, S. (2005). *Journal of Anxiety Disorders*, 19(5), 479-502.

#### Physical & Occupational Therapy in Pediatrics

A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. **King, G.**, Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2003). *Physical & Occupational Therapy in Pediatrics*, 23(1), 63-90.

A Life Needs Model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. **King, G., Tucker, M. A., Baldwin, P., Lowry, K., LaPorta, J., & Martens, L.** (2002). *Physical & Occupational Therapy in Pediatrics*, 22(2), 53-77.

A trajectory of troubles: Parents' impressions of the impact of developmental coordination disorder. Missiuna, C., Moll, S., King, S., **King, G.**, & Law, M. (in press). *Physical & Occupational Therapy in Pediatrics*.

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., **McDougall, J., Tucker, M. A.**, Nichols, M., & Mandich, A. (2006). *Physical & Occupational Therapy in Pediatrics*, 26(3), 89-110.

#### Qualitative Health Research

Mysteries and mazes: Parents' perspectives on developmental coordination disorder. Moll, S., Missiuna, C., **King, G.**, King, S., & Law, M. (2002). Proceedings of the Eighth International Qualitative Health Research Conference, 95.

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.

Turning points and protective processes in the lives of people with chronic disabilities. **King, G., Cathers, T., Brown, E.**, Specht, J., Willoughby, C., Miller Polgar, J., **MacKinnon, E., Smith, L., & Havens, L.** (2003). *Qualitative Health Research*, 13(2), 184-206.

#### Scandinavian Journal of Occupational Therapy

The participation of children with physical disabilities: Relationships with diagnosis, physical function, and demographic variables. Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., **King, G.**, & Hanna, S. (2004). *Scandinavian Journal of Occupational Therapy*, 11(4), 156-162.

#### Seminars in Pediatric Neurology

Family-centered service for children with cerebral palsy and their families: A review of the literature. King, S., Teplicky, R., **King, G.**, & Rosenbaum, P. (2005). *Seminars in Pediatric Neurology*, 11(1), 78-86.

#### The Canadian Journal of Neurological Sciences

Analysis of deflazacort treatment of Duchenne muscular dystrophy. Hung, R., Campbell, C., Levin, S., **Bolack, L., Scholtes, C.**, Lyttle, B., & Mitchell, C. (2005). *The Canadian Journal of Neurological Sciences*, 32(2[Suppl1]), S43.

Upper extremity strength in Duchenne muscular dystrophy. Magalhaes, S., Campbell, C., **Bolack, L., Scholtes, C.**, Shoesmith, C., & Levin, S. (2005). *The Canadian Journal of Neurological Sciences*, 32(2[Suppl1]), S44.

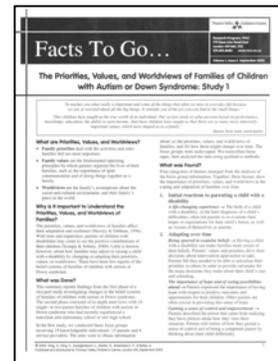
## EASY-TO-READ SUMMARIES

#### "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/](http://www.tvcc.on.ca/)

- An evaluation of Developmental Resources for Infants: Collaborative health care services for infants and their families (Volume 1 Issue 4, November 2005), Kneale Fanning, J., **Legros-Kelly, J., McVittie, A., Pigache, J., Tucker, M. A., & Servais, M.**
- The priorities, values, and worldviews of families of children with autism and down syndrome: Study 1 (Volume 1 Issue 2, October 2005), **King, G.**, King, S., Zwaigenbaum, L., **Baxter, D.**, Rosenbaum, P., & Bates, A.
- The quality of services delivered by Ontario Children's Rehabilitation Centres (Volume 1 Issue 1, May 2005), **King, G.**
- What are the motivations of volunteers with and without disabilities? (May 2002), **Baldwin, M.**
- What is the relationship between parental involvement in early intervention services and feelings of parenting stress and self-competence? (March 2003), **Gilpin, M.**
- What leads to successful rehabilitation research? (June 2003), **King, G.**
- Youth En Route: An evaluation of a transition program. (Volume 1 Issue 3, November 2005), **McDougall, J., Evans, J., & Baldwin, P.**



**"Focus On..."**

Focus On was the name of easy-to-read summaries published and distributed by the Research Alliance for Children with Special Needs. Focus Ons contained findings from a partnership research project or information relevant to a partnership investigator's expertise.



Focus Ons can be requested from the website: [www.racsn.ca](http://www.racsn.ca)

- "Best Approaches" in pediatric rehabilitation: Intervention principles for service providers (Volume 3 Issue 3, September 2003), **King, G.**
- A profile of Canadian school-aged children's health and disability (Volume 4 Issue 4, May 2004), **McDougall, J., King, G., DeWit, D., Miller, L., Hong, S., Offord, D., LaPorta, J., & Meyer, K.**
- Action plans to increase the participation of children with special needs in our community. (Volume 6 Issue 3, March 2006), **Servais, M.**
- Clinical decision making expertise in pediatric rehabilitation therapists (Volume 5 Issue 1, February 2005), **King, G., Currie, M., Bartlett, D., Gilpin, M., Willoughby, C., Strachan, D., Tucker, M. A., & Baxter, D.**
- Community awareness & attitudes toward the participation of children with special needs (Volume 3 Issue 1, June 2003), **Servais, M., & Currie, M.**
- Development of a questionnaire to measure perceptions of prescription review in AAC (Volume 5 Issue 5, September 2005), **Batorowicz, B., & Shepherd, T.**
- Factors influencing students' attitudes toward their peers with disabilities (Volume 5 Issue 6, November 2005), **McDougall, J., DeWit, D., King, G., Miller, L., & Killip, S.**
- Findings from a community forum on the participation of children with special needs (Volume 2, Issue 4, October 2002), **Currie, M., Servais, M., & Bartlett, D.**
- Pathways to children's academic and social outcomes (Volume 4 Issue 3, May 2004), **King, G., McDougall, J., DeWit, D., Hong, S., Miller, L., LaPorta, J., Meyer, K., & Offord, D.**
- Planning successful transitions from school to adult roles for youth with disabilities (Volume 4 Issue 5, September 2004), **King, G., Baldwin, P., & Currie, M.**
- Promoting success in school for children with special needs (Volume 4 Issue 2, April 2004), **King, G., Specht, J., & Willoughby, C.**
- Researching child disability: Impact through community involvement (Volume 2 Issue 2, June 2002), **Currie, M., Servais, M., & Bartlett, D.**
- Resilience: Learning from people with disabilities and turning points in their lives (Volume 3 Issue 4, September 2003), **King, G., Specht, J., Cathers, T., Brown, E., Willoughby, C., Miller Polgar, J., MacKinnon, E., Smith, L., & Havens, L.**
- School-based occupational therapy: Evaluating service delivery models (Volume 5 Issue 2, May, 2005), **McDougall, J., Bayona, C., Tucker, M. A., Nichols, M., & King, G.** London, ON: Research Alliance for Children with Special Needs.

- The Multidimensional Peer Rating of the Clinical Behaviours of Pediatric Therapists (MPR) (Volume 5 Issue 4, May 2005), **Gilpin, M., King, G., Currie, M., Bartlett, D., Willoughby, C., Strachan, D., Tucker, M. A., & Baxter, D.**
- Volunteers: What motivates them? (Volume 4 Issue 1, April 2004), **Baldwin, M., & Specht, J.**
- What adolescents with disabilities want in life: Implications for service delivery (Volume 3 Issue 5, October 2003), **King, G., & Cathers, T.**

**"In Brief"**

In Brief provides a short summary of a research study or other CanChild activity, with a focus on the bottom-line message and implications for potential users.

This In Brief is available from CanChild's website at [www.canchild.ca](http://www.canchild.ca).

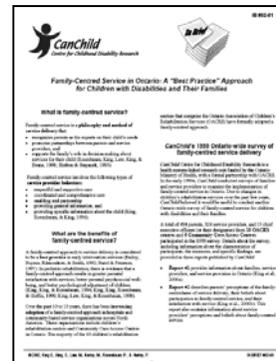


- Family-centred service in Ontario: A "best practice" approach for children with disabilities and their families, In Brief #02-01 (**King, G., King, S., Law, M., Kertoy, M., Rosenbaum, P., & Hurley, P.**)

**"Facts, Concepts, Strategies Sheets"**

The FCS Sheets were written as an 18-part series on family-centred service in 2003 by Mary Law, Peter Rosenbaum, **Gillian King**, Susanne King, Jan Burke-Gaffney, Theresa Moning-Szkut, Marilyn Kertoy, Nancy Pollock, Linda Viscardis, & Rachel Teplicky.

FCS Sheets are available from CanChild's website at [www.canchild.ca](http://www.canchild.ca).



**RACSN Final Report**

The RACSN Final Report 2000-2006 includes the structure, goals, objectives, and accomplishments of the Research Alliance for Children with Special Needs.

The RACSN Final Report is available to download at [www.racsn.ca](http://www.racsn.ca)



## PRESENTATIONS

Our research findings have been communicated through presentations at international, national, provincial and regional conferences, and meetings.

TVCC staff members made the following **83 external presentations** between 1 April 2002 and 31 March 2006. Names of TVCC staff members are bolded and italicized.

### INTERNATIONAL

#### American Educational Research Association, Chicago, IL.

Inclusion: Attitudes of Canadian educators. Specht, J., **Currie, M.**, Killip, S., **King, G.**, Burton, M., Eliav, J., Lambert, S., & Thornton, B. (2002, August).

#### American Academy of Cerebral Palsy and Developmental Medicine 2002, New Orleans, LA.

A model of the factors affecting the participation of children with disabilities. **King, G.**, Law, M., King, S., Rosenbaum, P., Kertoy, M., Young, N., & Hurley, P. (2002, September).

The Children's Assessment of Participation and Enjoyment (CAPE). Law, M., **King, G.**, King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2002, September).

#### American Academy of Cerebral Palsy and Developmental Medicine 2003, Montreal, QC.

Early experiences and participation patterns of children with Developmental Coordination Disorder. Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2003, September).

Participation patterns of children with physical disabilities. Law, M., **King, G.**, King, S., Kertoy, M., Young, N., Hanna, S., Rosenbaum, P., & Hurley, P. (2003, September).

#### American Academy of Cerebral Palsy and Developmental Medicine 2004, Los Angeles, CA.

Evaluation of the use, utility and impact of an information KIT for parents of children and youth with special needs. Stewart, D., Law, M., Rosenbaum, P., Missiuna, C., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2004, September).

#### American Academy of Cerebral Palsy and Developmental Medicine 2005, Orlando, FL.

A longitudinal study of the predictors of the participation of children with physical disabilities. **King, G.**, Law, M., Hanna, S., King, S., Hurley, P., Kertoy, M., Rosenbaum, P., & Young, N. (2005, September).

#### American Occupational Therapy Association, Philadelphia, PA.

The participation of children with disabilities in everyday life. Law, M., **King, G.**, King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2001, April).

#### Child and Youth Health, Third World Congress, Vancouver, BC

Family functioning with a child who has Duchenne muscular dystrophy: A pilot study. Steele, M., **Taylor, E.**, **Young, C.**, Davidson, B., & McGrath, P. (2003, May).

#### European Federation for Research in Rehabilitation, Ljubljana, Slovenia.

Enhancing children's performance and participation: Client-centred rehabilitation. Law, M., **King, G.**, King, S., Hurley, P., Kertoy, M., Rosenbaum, P., Young, N., & Hanna, S. (2004, June).

#### 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).

#### Interdisciplinary Advances in Qualitative Methods Conference, Edmonton, AB.

Enhancing research dissemination: Using community forums as a tool to promote research utilization. **Servais, M.**, (2005, February).

#### International Conference on Cerebral Palsy, Quebec City, QC.

A model of the factors affecting the participation of children with disabilities. **King, G.**, Law, M., King, S., Rosenbaum, P., & Kertoy, M. (2003, May).

The Children's Assessment of Participation and Enjoyment (CAPE). Law, M., **King, G.**, King, S., Kertoy, M., & Hurley, P. (2003, May).

#### International Conference on Family-Centered Care, Boston, MA.

Family-centered service: A look at concepts, measures, evidence, and implications. **King, G.**, King, S., Rosenbaum, P., Law, M., Kertoy, M., & Hurley, P. (2003, September).

#### North American Collaborating Center Conference on ICF, Toronto, ON.

Measuring chronic condition and disability as distinct concepts in National Surveys of School-Aged children in Canada: With recommendations based on the ICD-10 and the ICF. Presented at the 8<sup>th</sup> annual North American Collaborating Conference on ICF, Toronto, ON. **McDougall, J.** (2002, June).

#### North American Collaborating Center 10<sup>th</sup> Conference on ICF, Halifax, NS.

Chronic physical health conditions and disability among Canadian school-aged children: A national profile using the National Longitudinal Survey of Children and Youth and the ICD-10 and ICF definitions of health condition and disability. **McDougall, J.**, **King, G.**, DeWit, D. J., Miller, L. T., Hong, S., Offord, D. R., **LaPorta, J.**, & **Meyer, K.** (2004, June).

#### Society for Research in Child Development, Orlando, FL.

Participation in formal and informal activities by children and adolescents with disabilities. Kertoy, M., Partyka, L., **King, G.**, Law, M., Hurley, P., King, S., Rosenbaum, P., & Young, N. (2003, April).

#### Society for Research in Child Development, Atlanta, GA.

A longitudinal study of the predictors of the participation of children with physical disabilities. **King, G.**, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. (2005, April).

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**World Federation of Occupational Therapists' Conference, Stockholm, Sweden.**

- New strategies to encourage earlier identification of children with developmental coordination disorder. Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2002, June).
- Social participation in children with disability. Law, M., Coster, W., Cohn, E., **King, G.**, & Bedell, G. (2002, June).

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**NATIONAL**

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**Canadian Academy of Child and Adolescent Psychiatry, Banff, AB**

- Family functioning with a child who has Duchenne muscular dystrophy: A pilot study. Steele, M., **Taylor, E.**, Davidson, B., McGrath, P. & Lyttle, B. (2003, November).

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**Canadian Academy of Child and Adolescent Psychiatry, Montreal, QC.**

- Cognitive functioning of children and youth with Duchenne's muscular dystrophy. Steele, M., **Taylor, E.**, Davidson, B., McGrath, P. & Lyttle, B. (2004, October).

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**Canadian Association of Occupational Therapists' Annual Conference, Charlottetown, PEI.**

- Early experiences and participation patterns of children with developmental coordination disorder. Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2004, June).
- Facilitating family-centred service: Impact of problem-based learning. Teplicky, R., Law, M., **King, G.**, & Dobbins, M. (2004, June).

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**Canadian Congress of Neurological Sciences, Ottawa, ON**

- Analysis of deflazacort treatment of Duchenne muscular dystrophy. Hung, R., Campbell, C., Levin, S., **Bolack, L.**, **Scholtes, C.**, Lyttle, B., & Mitchell, C. (2005, June).
- Upper extremity strength in Duchenne muscular dystrophy. Magalhaes, S., Campbell, C., **Bolack, L.**, **Scholtes, C.**, Shoemsmith, C., & Levin, S. (2005, June).

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**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.**, & McDonald, K. (2006, June).

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**CUExpo 2003: Community-University Research: Partnerships, Policy & Progress conference, Saskatoon, SK.**

- Examination of a multidisciplinary research unit: Helpful factors and lessons learned. **Currie, M.**, **King, G.**, Law, M., Rosenbaum, P., Plews, N., Russell, D., King, S., Missiuna, C., & Walter, S. (2003, May).
- Measuring the impact of community-university partnerships. Specht, J., **Servais, M.**, **King, G.**, Law, M., Forchuk, C., Willoughby, T., Rosenbaum, P., Kertoy, M., Chalmers, H., & **Currie, M.** (2003, May).
- Strategies for improving research dissemination and uptake: Supporting community collaboration as a tool for success. **Servais, M.**, **King, G.**, Bartlett, D., DeWit, D., Kertoy, M., Killip, S., Miller, L., Specht, J., Spencer, T., & Stewart, S. (2003, May).

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**Qualitative Health Research Conference, Banff, AB.**

- Mysteries and mazes: Parents' perspectives on developmental coordination disorder. Moll, S., Missiuna, C., **King, G.**, King, S., & Law, M. (2002, April).

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**St. Amant 13<sup>th</sup> Annual Conference on Developmental Disabilities, Winnipeg, MB.**

- Family-centred service: A look at concepts, measures, evidence, and implications. King, S., **King, G.**, Rosenbaum, P., Law, M., Kertoy, M., Hurley, P., & Teplicky, R. (2004, October.).

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**PROVINCIAL**

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**Ontario Association of Community Care Access Centres, Toronto, ON.**

- Family-centred service: An evidence-based best practice. Teplicky, R., Law, M., Rosenbaum, P., **King, G.**, King, S., Burke-Gaffney, J., Szkut, T., & Kertoy, M. (2004, June).

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**Ontario Association of Children's Rehabilitation Services 2002, Richmond Hill, ON.**

- A model of the factors affecting the participation of children with disabilities. **King, G.**, Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2002, November).
- A multi-dimensional model of caregiver health. Brehaut, J., **King, G.**, King, S., O'Donnell, M., Raina, P., Rosenbaum, P., Russell, D., Schwellnus, H., Swinton, M., Walter, S., & Wood, E. (2002, November).
- An information KIT for parents of children and youth with special needs. Stewart, D., Law, M., Missiuna, C., Rosenbaum, P., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2002, November).
- Family-centred service in Ontario: A "best practice" approach. King, S., Kertoy, M., **King, G.**, Law, M., Rosenbaum, P., Hurley, P., & Hanna, S. (2002, November).
- Improving identification of children with developmental coordination disorder: Understanding the clues. Missiuna, C., Moll, S., Law, M., **King, G.**, & King, S. (2002, November).
- Participation of children with physical disabilities. Law, M., **King, G.**, King, S., Rosenbaum, P., Hurley, P., Kertoy, M., & Young, N. (2002, November).

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**Research Key Fact: Presentations**



- ◆ Between 1 April 2002 and 31 March 2006, TVCC staff members were named on **83 presentations**:
  - 21 at international conferences
  - 13 at national conferences
  - 27 at provincial conferences
  - 4 non-peer reviewed presentations
  - 18 invited presentations
    - 12 at international conferences
    - 2 at national conferences
    - 4 at provincial conferences
- ◆ Since 1989, TVCC staff members have been named on **253 presentations**:
  - 84 at international conferences
  - 37 at national conferences
  - 97 at provincial conferences
  - 17 non-peer reviewed presentations
  - 18 invited presentations
    - 12 at international conferences
    - 2 at national conferences
    - 4 at provincial conferences

The Children's Assessment of Participation and Enjoyment (CAPE). Law, M., **King, G.**, King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2002, November).

The road to accountability: Using research as a tool for success. **Servais, M.**, & **Currie, M.** (2002, November).

Well-being of caregivers of children with disabilities. Rosenbaum, P., Brehaut, J., **King, G.**, King, S., O'Donnell, M., Raina, P., Russell, D., Swinton, M., Walter, S., & Wood, E. (2002, November).

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#### Ontario Association of Children's Rehabilitation Services 2003, Richmond Hill.

Evaluation of an information KIT for parents of children and youth with special needs. Stewart, D., Law, M., Missiuna, C., Rosenbaum, P., **King, G.**, Burke-Gaffney, J., & Szkut, T. (2003, October).

Examining the health, functioning, and competence of Canadian school-aged children using the National Longitudinal Survey of Children and Youth. **McDougall, J.**, **King, G.**, **LaPorta, J.**, & **Meyer, K.** (2003, October).

Participation patterns of children with physical disabilities. Law, M., **King, G.**, King, S., Kertoy, M., Young, N., Hanna, S., Rosenbaum, P., & Hurley, P. (2003, October).

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#### Ontario Association of Children's Rehabilitation Services 2004, Richmond Hill, ON.

Clinical decision making in pediatric rehabilitation. **King, G.**, **Baxter, D.**, **Currie, M.**, Willoughby, C., Bartlett, D., Strachan, D., **Gilpin, M.**, & **Tucker, M. A.** (2004, October).

Facilitating family-centred service: Impact of problem-based learning. Teplicky, R., Law, M., **King, G.**, & Dobbins, M. (2004, October).

Family-centred service: Moving ideas into practice. Teplicky, R., Law, M., King, S., Kertoy, M., Rosenbaum, P., **King, G.**, Szkut, T., & Burke-Gaffney, J. (2004, October).

Patterns of participation of children and youth with physical disabilities. Law, M., King, S., Rosenbaum, P., Hurley, P., Hanna, S., **King, G.**, Kertoy, M., & Young, N. (2004, October).

Youth En Route: A program evaluation. **Evans, J.**, **McDougall, J.**, & **Baldwin, P.**, (2004, October).

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#### Ontario Association of Children's Rehabilitation Services 2005, Niagara Falls, ON.

A study to evaluate a school-based consultation model of occupational therapy services for children with fine motor difficulties. **McDougall, J.**, **Tucker, M. A.**, **Bocking, B.**, & Nichols, M. (2005, October).

Canadian Occupational Performance Measure: Results in a sample of children with Duchenne Dystrophy. **Scholtes, C.**, Campbell, C., & **Bolack, L.** (2005, October).

Fostering the development of expertise among pediatric therapists. Bartlett, D., Willoughby, C., **King, G.**, **Tucker, M. A.**, **Currie, M.**, **Gilpin, M.**, & Strachan, D. (2005, October).

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

An evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP). **McDougall, J.** & **Somers, S.** (2006, September).

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#### Ontario Psychiatric Association Conference, Toronto, ON.

Family functioning with a child who has Duchenne muscular dystrophy (DMD): A pilot study. Steele, M., **Taylor, E.**, **Young, C.**, Davidson, B., & McGrath, P. (2003, January).

Cognitive functioning of children and youth with Duchenne Muscular Dystrophy (DMD). **Young, C.**, Steele, M. M., Davidson, B., **Taylor, E.**, McGrath, P., & Lyttle, B. (2005, January).

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#### Ontario Society of Occupational Therapists, London, ON.

Towards best practices in transition services for youth with disabilities. **Baldwin, P.**, **Evans, J.**, **King, G.**, & **McDougall, J.** (2005, October).

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#### Rehabilitation Network of Ottawa Carleton, Ottawa, ON.

Turning points and protective processes in the lives of people with chronic disabilities. **King, G.**, **Cathers, T.**, **Brown, E.**, Specht, J., Willoughby, C., Miller Polgar, J., **MacKinnon, E.**, **Smith, L. K.**, & **Havens, L.** (2003, March).

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#### 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).

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### NON-PEER REVIEWED

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#### "Painting by numbers: What is local data saying about our community?" Research Day, London, ON.

The road to accountability: Using research as a tool for success. **Currie, M.** (2004, June).

A profile of Canadian school-aged children's health and disability. **McDougall, J.** (2004, June).

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#### Occupational Therapy Annual Conference on Evidence Based Practice, London, ON.

The Research Alliance for Children with Special Needs (RACSN): A model of successful collaboration. **Servais, M.**, **Currie, M.**, Bartlett, D., Kertoy, M., Killip, S., **King, G.**, Miller, L., Specht, J., & Willoughby, C. (2001, July).

Theory into practice: The importance of research for service providers. **Servais, M.**, & **Currie, M.** (2002, July).

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### INVITED PRESENTATIONS

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#### International

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#### Australasian Academy of Cerebral Palsy and Developmental Medicine, Sydney, Australia.

Family-centred service: Concepts, measurement, and implications. **King, G.** (2002, September).

Family-centred service: What is it and why is it important? **King, G.** (2002, September).

Selecting and using outcome measures in practice. Law, M., & **King G.** (2002, September).

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#### Danish Resource Centre of Brain Injury, Nyborg, Denmark.

The Paediatric Acquired Brain Injury Community Outreach Program. **McDougall, J.**, **Sommerfreund, J.**, Rosen,

E., Gillett, J., **Somers, S., Gray, J., & Servais, M.** (2002, May).

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**Early Childhood Intervention Australia 2006 National Conference, Adelaide, Australia.**

A Life Needs Model of pediatric service delivery. **King, G., Tucker, M. A., Baldwin, P., & LaPorta, J.** (2006, March).

Developing competence: Pathways to children's academic performance and prosocial behaviour. **King, G., McDougall, J., DeWit, D., Hong, S., Miller, L., Offord, D., Meyer, K., & LaPorta, J.** (2006, March).

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**International Conference on Cerebral Palsy, Quebec City, QC.**

Success in life for older adolescents with cerebral palsy: A qualitative study. **King, G., Cathers, T., Miller Polgar, J., MacKinnon, E., & Havens, L.** (2003, May).

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**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).

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**Novita Children's Services, Adelaide, Australia.**

Expertise and clinical decision making in pediatric rehabilitation. **King, G., Bartlett, D., Currie, M., Gilpin, M., Willoughby, C., Baxter, D., Tucker, M. A., & Strachan, D.** (2006, March).

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, March).

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**Scope, Melbourne, Australia.**

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, March).

Expertise and clinical decision making in pediatric rehabilitation. **King, G., Bartlett, D., Currie, M., Gilpin, M., Willoughby, C., Baxter, D., Tucker, M. A., & Strachan, D.** (2006, March).

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**National**

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**CURA on Partnerships and Capacity Building: Housing, Community Economic Development and Psychiatric Survivors, London ON.**

Measuring the impact of community-university research partnerships. **King, G.** (2003, October).

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**Ready, Set, Go: Improving the Odds Through Integrated Research, Policy and Practice Conference, Ottawa, ON.**

Research to practice: A model of successful collaboration. Kertoy, M., **Servais, M., Bartlett, D., Currie, M., Killip, S., King, G., Miller, L., Specht, J., & Willoughby, C.** (2002, January).

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**Provincial**

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**Rehabilitation Science Seminar Series, University of Western Ontario, London, ON.**

A model of impacts of research partnerships in the fields of health or social services: Considering the community perspective. **Currie, M. & King, G.** (2003, December).  
The development of a tool to measure the community impacts of research-oriented partnerships – The CIROP Measure. **Servais, M.** (2004, March).

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**Knowledge Project: Building Canadian Research Leadership. Hosted by Social Sciences and Humanities Council of Canada, Ottawa, ON.**

Enhancing the community participation of children with special needs. **King, G., Stewart, S., DeWit, D., Killip, S., Spencer, T., Bartlett, D., Kertoy, M., Miller, L., & Specht, J.** (2005, February).

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**Thames Valley District Health Council, London ON.**

Examining the health, functioning, and competence of Canadian school-aged children using the National Longitudinal Survey of Children and Youth. **King, G., LaPorta, J., & McDougall, J.** (2004, February).

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**Research Key Facts: International Conferences**



Since 1990, TVCC staff members have made **84 presentations** at the following International Conferences:

- o American Academy for Cerebral Palsy and Developmental Medicine
- o American Cleft Palate/Craniofacial Association
- o American Educational Research Association
- o American Occupational Therapy Association
- o American Psychological Association
- o American Society for Surgery of the Hand
- o American Speech-Language and Hearing Association
- o Association for the Care of Children's Health
- o Australian Academy of Cerebral Palsy and Developmental Medicine
- o Australian Cerebral Palsy Association
- o Child and Youth Health, Third World Congress
- o Child Health Psychology
- o Danish Resource Centre of Brain Injury
- o Early Childhood Intervention Australia National
- o European Congress on Psychology
- o European Federation for Research in Rehabilitation
- o European Speech Communication Association
- o Interdisciplinary Advances in Qualitative Methods
- o International Conference on Cerebral Palsy
- o International Conference on the Scientific Basis of Health Sciences
- o International First Conference on Family-Centered Care
- o International Institute for Qualitative Methodology
- o International Meeting for Autism Research
- o International Paediatric Neuromuscular Rehabilitation
- o International Seating Symposium
- o International Society of Augmentative and Alternative Communication
- o Joint Congress of the Canadian Physiotherapy Association and American Physical Therapy Association
- o North American Collaborating Centre Conference on ICF
- o North American ICIDH-2 Conference
- o North Coast Regional Conference of the Society of Pediatric Psychology
- o Society for Research in Child Development
- o World Congress on Brain Injury
- o World Federation of Occupational Therapists Congress

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