

Grant Information:

Grant Number:	02693/2008
Grant Title:	<i>CanChild</i> Centre for Childhood Disability Research
Reporting Period*:	April 1, 2008 – March 31 st , 2009
Submission Date:	April 30, 2009
Contact Information:	Cheryl Missiuna, PhD Director, <i>CanChild</i> Centre for Childhood Disability Research Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 408 Hamilton ON L8S 1C7

* Fiscal year: April 1st and March 31st

Instructions:

Please submit this report *electronically* to ResearchUnit@ontario.ca and to the ministry program area listed in the reporting requirements (usually Schedule D) of your funding agreement.

Discuss all research funded by the ministry, both ministry-directed research and non-ministry directed that is directly related to this grant.

A) Narrative Report (*Maximum of 25 pages*)

One Canadian family in five is raising a child with a significant emotional, behavioural or developmental disability – impairments that present special challenges for children and families in virtually every community in this country. *CanChild* Centre for Childhood Disability Research is a research and educational centre founded in 1989 with funding from the Ontario Ministry of Health and Long-Term Care. Located at McMaster University in Hamilton, ON, *CanChild* is recognized as an international leader in the field of childhood disability research. *CanChild* brings together a multi-disciplinary team of researchers from the fields of pediatrics, occupational therapy, physiotherapy, psychiatry, speech and language pathology, social psychology, epidemiology and biostatistics. Over the past year, we have been fortunate to have two new investigators join our team: Dr. Jan Willem Gorter (from the Netherlands) and Dr. Eyal Cohen (Hospital for Sick Children, Toronto, ON). Investigators affiliated with this research centre have received over \$27 million in external grant funding from provincial, federal, and international sources.

"I can think of no other collaborative group that has had more impact on changing assessment and clinical practice than CanChild."

-Stephen Haley, PhD
 Boston University, USA

CanChild's mandate is to "take a leadership role in identifying emerging issues for research, practice, policy and education; conduct high-quality research; effectively transfer knowledge into practice at clinical and health system levels; and provide education for consumers, service providers, policy makers and students." The team has developed strong linkages with other leading researchers in childhood disability, research units, parent networks, rehabilitation and health networks, professional societies, and child health organizations across Ontario, throughout Canada and around the world.

Section I: Staffing Information

- a) Please list the number of researchers in each of the categories that you would consider directly affiliated with your institute/ centre/ unit. This could include graduate students completing practicums or placements, but would not include those only using the centre for data purposes.

How many researchers are affiliated* with your Institute/ Unit/ Centre?

Researchers/ Scientists	___19___
Post-doctoral Fellows	___1___
Doctoral Students	___20 (PhD Supervisor) + 22 (PhD Committee Member)___
Masters Students	___2 (MSc Supervisor) + 20 (MSc Committee/Advisor)___
Community-based researchers	___1___
Other (specify)	___0___

- b) Please provide a listing of all ministry supported/funded staff and their roles (i.e. researcher, administration, etc.). Please indicate if they are full-time or part-time.

Donna Johnston, Financial Officer, PT

Dayle McCauley, Research Assistant/Coordinator, FT

Nancy Plews, Manager, PT

Susan Roberts, Research Staff, PT

Dianne Russell, Researcher, FT

Betty Yundt, Knowledge Transfer Staff, PT

Bluewire Computer Services Inc., Maintenance of *CanChild* server and computers, PT

Section II: Products (includes grey literature)

- a) How many research articles or reviews did researchers affiliated with your Institute/ Unit/ Centre publish, during this reporting period, in scholarly periodicals ___104___ and how many have been accepted for publication in scholarly periodicals but have not yet been published or which are in submission during this reporting period ___31 (in press)___
- b) How many systematic reviews have been completed ___4___ and how many are underway ___2___?
- c) How many of the above articles include findings or results based on, or related to, research activities at your Institute/ Unit/ Centre that was funded (in full or partially) by the Ministry? ___0___
- d) How many Ministry-commissioned reports/ evaluations/ etc did researchers affiliated with your Institute/ Unit/ Centre produce and complete for the Ministry or for LHIN(s)? ___4___

Publications by *CanChild* Investigators (since last reporting period)

2008

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2009

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****Note:** We have all 104 publications from 2008/2009 and 153 publications from 2006/2007 available in pdf format. However, due to copyright restrictions at McMaster University, we are unable to send copies of these publications via email.**

Section III: Research Exchange Activities

1. Knowledge Exchange activities at *CanChild*

Website Postings

CanChild continuously posts resources for parents, service providers, and policy-makers on our website (www.canchild.ca). Researchers are encouraged to prepare materials for the *CanChild* website based on their research results and expertise. The posting process involves preparing the evidence for a variety of audiences, having the materials reviewed by stakeholders and appropriately amending the documents prior to posting. The *CanChild* website receives over **4,000 views a week** by users in over 150 countries.

The following major documents were posted on the *CanChild* website in 2008-2009:

Best Practice Guidelines:

The Best Journey to Adult Life for Youth with Disabilities: An Evidence-Based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities by D. Stewart, M. Freeman, M. Law, H. Healy, J. Burke-Gaffney, M. Forhan, N. Young, & S. Guenther

Discussion Paper:

Childhood Disability in the Context of Poverty by T. Petrenchik (Report commissioned by the Ministry of Children and Youth Services)

Educational Materials:

1. *Annotated Bibliography of Literature on Transition to Adulthood for Youth with Disabilities* by D. Stewart, M. Law, M. Freeman, M. Forhan, S. Guenther, J. Burke-Gaffney, H. Healy & N. Young
2. All *DCD Resources for Physicians* transferred to the new *CanChild* website
3. *About DCD* for parents and service providers

Keeping Current:

Knowledge Brokering in Health Care by L. Roxborough, L. Rivard, & D. Russell

Measures and Products:

1. *The McMaster Handwriting Assessment Protocol* by N. Pollock & J. Lockhart
2. *GMFCS Descriptors and Illustrations* modified by K. Graham, B. Reid, & A. Harvey
3. *GMFCS* has been posted in the following languages over the year: Danish, Portuguese, Spanish, and Arabic.

Study Summaries:

1. *Partnering for Change*
2. *Participation & Environment Project*
3. *Quality of Life Training Program*
4. *Youth KIT*

CanChild Intranet

The *CanChild* Intranet (now called Service Provider Communications) is a virtual 'community of practice' for service providers across Canada. Over the past year, membership has increased by over 750, and is currently **2000** service providers. Members share resources and discuss topics of interest on the forum. Postings for the Intranet are prepared and forum discussions are moderated by the *CanChild* Knowledge Transfer Coordinator. As well, a regular electronic newsletter informs members of new

postings. A group of paediatric physiotherapists and another group of occupational therapists have contacted *CanChild* to request forums to discuss issues of interest to their profession.

Change in Look and Feel for *CanChild* Website

The *CanChild* website (www.canchild.ca) was revitalized over the 2008-09 year and was launched in early April 2009. The goals of this project were to:

- improve navigation within the site for health care providers, families, policy makers and researchers
- make it easier to search for resources
- organize our resources in a user-friendly way

One of the significant changes is the addition of three microsites for topics which represent the most frequently accessed resources by users around the world. These microsites now link to our Motor Growth Measures, DCD, and Lifecourse and Transition resources. User groups such as families, service providers, and researchers were surveyed prior to the design phase and also prior to the launch to provide feedback. The new website continues to host a members-only resource area, the *Service Provider Communications*, formerly known as the Intranet, which networks and supports health care providers in accessing evidence.

2. Relationship with stakeholders

CanChild has strengthened its relationship with a number of organizations who have become active members of the *CanChild* Advisory Board over the last year including:

- Hamilton Niagara Haldimand Brant LHIN
- Ontario Association of Community Care Access Centres
- Special Education Policy and Programs Branch, Ministry of Education
- Mississauga Halton CCAC
- Ontario Association of Children's Rehabilitation Services (OACRS)
- ErinoakKids (a local children's treatment centre)

3. Research Uptake

One example of research uptake from our work in 2008-09 is the *CanChild* input into policy decisions regarding the Ministry of Health and Long-Term Care's Paediatric Wait Time Strategy. *CanChild* chaired the Expert Panel which submitted its report and recommendations to MOHLTC in May 2008. Once this report had been accepted by MOHLTC, *CanChild* conducted a pan-Ontario stakeholder consultation and was then asked to develop an Evaluation Framework. All 3 of these documents are directly informing the implementation of a paediatric complex care coordination model of service delivery in Ontario to meet the needs of children and youth with complex and chronic health care needs.

4. Commercialized Inventions/products

Not applicable



Section IV: Research Capacity Building

Career Awards/Program

Investigator	Award
Anne Klassen	March 2008 <ul style="list-style-type: none"> •Canadian Cancer Society (Ontario Branch) Researcher of the Month July 2008 <ul style="list-style-type: none"> •Early Researcher Award (2-yr award), Ministry of Research and Innovation, Ontario \$190,000
Bob Palisano	Anniversary Award, 2008 <ul style="list-style-type: none"> •Section on Pediatrics, American Physical Therapy Association. Presented in acknowledgement of vision, service and support on behalf of the Section on Pediatrics.
Cheryl Missiuna	July 2006 – June 2011 <ul style="list-style-type: none"> •Ontario Ministry of Health Mid-career Rehabilitative Scientist Award (\$60,000/year for 5 years)
Dianne Russell	2008 – 2010 <ul style="list-style-type: none"> •Ontario Federation for Cerebral Palsy. Cerebral Palsy Research Scholar Award. 2009 - 2010 <ul style="list-style-type: none"> •McMaster Child Health Research Institute. Research Scientist Award (\$50,000).
Doreen Bartlett	2007 – 2009 <ul style="list-style-type: none"> •The University of Western Ontario, Faculty Scholar Award.
John Cairney	2008 <ul style="list-style-type: none"> •Inaugural recipient of the McMaster Family Medicine Professorship in Child Health Research
Mary Law	<ul style="list-style-type: none"> •John and Margaret Lillie Chair in Childhood Disability Research
Peter Rosenbaum	2009 <ul style="list-style-type: none"> •Emil Becker Award from the "Gesellschaft Neuropädiatrie" (German Neuropaediatric Society), Graz Austria 2008-2014 <ul style="list-style-type: none"> •Canada Research Chair in Childhood Disability – CIHR
Stephen Walter	2008 <ul style="list-style-type: none"> •Inaugural presentation: Statistical Society of Canada Award for Impact of Applied and Collaborative Work

Post-Doctoral	Award
Adrienne Harvey	2008 <ul style="list-style-type: none"> •McMaster Child Health Research Institute, Post-Doctoral Research Fellow

Mentoring Program/ Supervision Initiatives

Investigators at *CanChild* mentor/supervise more than 70 students each year including: undergraduate students, graduate students in both course-based and thesis based masters programs, students in professional masters programs, doctoral students, post-doctoral students, medical students, junior faculty, and faculty in developing countries. Each investigator spends anywhere between 4-15 hours/week in these activities.

PhD Students	Award
Beata Batorowicz	2008 <ul style="list-style-type: none"> ●CIHR Vanier Graduate Scholarship 2008-2009 <ul style="list-style-type: none"> ●Ontario Neurotrauma Foundation Award (\$8,000) ●CIHR Quality of Life Training Program Award (\$10,400) 2009-2010 <ul style="list-style-type: none"> ●McMaster Child Health Research Institute PhD Scholar (\$30,000)
Briano DiRezze	2008-2009 <ul style="list-style-type: none"> ●CIHR Quality of Life Training Program Award (\$17,850)
Nora Fayed	2008-2009 <ul style="list-style-type: none"> ●CIHR Quality of Life Training Program Award (\$11,750) ●Marie Curie Fellowship Award 2009-2010 <ul style="list-style-type: none"> ●Ontario Graduate Scholarship (\$15,000)
Susan Guenther	2008-2009 <ul style="list-style-type: none"> ●CIHR Quality of Life Training Program Award (\$10,400)
Danielle Levac	2008-2009 <ul style="list-style-type: none"> ●CIHR Quality of Life Training Program Award (\$10,000) 2009-2013 <ul style="list-style-type: none"> ●Canadian Child Health Clinician Scientist Award (\$50,000/year for 4 years)

Section V: Value and Impact

1. Paediatric Complex Care Coordination (PCCC)

While medical diagnostic and therapeutic advances have led to reductions in deaths related to birth complications and serious infant illnesses as well as fewer acute illnesses and hospitalizations, there has been a concomitant increase in the prevalence of children and youth who have chronic illnesses requiring complex continuing care.

Currently the health system is not meeting the needs of this paediatric population. Parents and providers alike struggle to navigate a complex cross-ministerial system in their attempts to secure services and resources for these children and youth. The health care system, as currently structured, suffers from inefficient use of scarce health resources and inadequate health system planning

In recognition of the need to address these issues, the Ministry of Health and Long Term Care (MOHLTC) convened a panel of experts chaired by Dr. Peter Rosenbaum, *CanChild* Centre for Childhood Disability Research, as part of the Ministry's Paediatric Wait Time Strategy. The panel's mandate was to develop consensus recommendations around innovative health care delivery models, implementation guidelines and an evaluation framework. The Model targeted three groups of children and youth: those who are medically fragile or technology dependent, those with severe complex obesity and those with significant mental illness and psychosocial risk.

The recommendations were presented to the MOHLTC in the Panel's May 2008 *Report of the Paediatric Complex Care Coordination Expert Panel*. The Ministry of Education has since used an adapted version of the PCCC Medically Fragile/Technology Dependent criteria to inform the 2009-10 Special Incidence Portion (SIP) Guidelines for children with special needs.



The MOHLTC subsequently asked *CanChild* to conduct a pan-Ontario Stakeholder Consultation on the proposed PCCC model. The purpose of the consultation was to solicit input from key stakeholders and engage them in refining the Model prior to the MOHLTC taking action on the recommendations put forward in the Expert Panel's Report.

Two groups of stakeholders were consulted. One group represented a broad range of patient/client/family and health care provider perspectives, including those of Francophone and Aboriginal populations. The other group comprised selected members of the Inter-Ministerial Reference Group representing the Ministries of Health and Long Term Care, Children and Youth Services, Community and Social Services, Education and Health Promotion. Individual telephone interviews were conducted with representatives of parent/patient support organizations,

service providers, managers and administrators; ministry representatives participated in a focus group held at the MOHLTC.

Overall, impressions were positive and supportive. The Model was seen by most as comprehensive, well-conceptualized and overdue, and the objectives well-grounded. For most, the fundamental challenge was how the Model would be implemented and operationalized.

"Through this we would eventually have a better indicator of what is really happening with families with children and youth with complex needs"

- *Community Provider*

"It is a courageous step to invest now and see payments pay out in the longer term...[if you don't], you pay in the long term and compromise the well-being of the children."

- *Head of Parent Support Organization*

Stakeholders from the Ministry Focus Group:

Participants in the Ministry Focus Group	Affiliation
Trudy Blugerman (by e-mail)	Ministry of Education, Strategic Planning and Elementary/Secondary Programs Division-Special Education Strategic Planning Branch
Holly Big Canoe	Ministry of Children and Youth Services, Director - Strategic Planning Branch
Jane Cleve	Ministry of Children and Youth Services, Director (Acting) - Specialized Services and Supports Branch
Barry Finlay	Ministry of Education, Director (Acting) - Special Education Policy and Planning Branch
Karl Frost	Ministry of Community and Social Services, Senior Policy Analyst – Policy Operations and Program Design
Nancy Garvey	Ministry of Health and Long-Term Care, Asthma Program Coordinator – Acute Services and Chronic Disease Unit
Tamara Mohammed	Ministry of Health and Long-Term Care, Implementation Consultant – Access to Care and Wait Times
Charlotte Moore, MD	Ministry of Health and Long-Term Care, Provincial Lead, Maternal, Child and Youth Health Strategy, Office of the Assistant Deputy Minister, Health System Strategy Division
Sandy Palinski	Ministry of Education, Manager – Strategic Planning Unit
Lyndsey Saunders	Ministry of Health and Long-Term Care, Senior Policy Analyst – Population Health and Integration Strategy Unit
Pegeen Walsh	Ministry of Health Promotion, Director - Chronic Disease Prevention and Health Promotion Branch
Tanya Weber-Kinch	Ministry of Community and Social Services, Manager – Policy and Business Practices

Early in 2009, the Ministry also asked *CanChild* to develop a framework to provide guiding direction for evaluation of the PCCC service delivery model. The purpose of this framework was to:

- Provide a road map to guide those proposing to do an actual evaluation, in order to ensure a positive evaluation process.
- Develop a program logic model, specifying the conceptual basis to the CCC model, activities of the model, and indicators of outputs and outcomes.

- Establish key process and performance measures to be used to evaluate success of pilot care coordination programs and to allow policy makers to monitor the effectiveness of the care coordination approach.
- The Expert Panel identified four categories of outcomes, relevant to any patient population with complex health care needs, which should be measured: (1) improved health outcomes for children and youth with complex conditions, (2) improved quality of life for children and youth and their families, (3) appropriate utilization of the health system, and (4) stakeholder satisfaction.
- The Ministry requested that approximately 80% of the evaluation indicators be identical across the three populations of interest and was especially interested in indicators of financial impact, as well as medical indicators and indicators of satisfaction and utilization. A key desired component of the framework is the ability to address return on investment with respect to service utilization.

Advisory Group Members	Affiliation
Mary Beaudoin	Strategic Directions Coordinator, <i>CanChild</i> Centre for Childhood Disability Research
Barry Finlay	Ministry of Education, Director (Acting) - Special Education Policy and Planning Branch
Jan Burke-Gaffney	Co-Chair, Hamilton Family Network
Jill Hamilton, MD	Staff Endocrinologist, The Hospital For Sick Children
Danielle Levac	Project Staff, <i>CanChild</i> Centre for Childhood Disability Research
Pat Mandy	CEO, Hamilton Niagara Haldimand Brant Local Health Integration Network
Ian Manion, PhD	Executive Director, The Provincial Centre of Excellence for Child and Youth Mental Health, The Children's Hospital of Eastern Ontario
Dayle McCauley	Project Coordinator, <i>CanChild</i> Centre for Childhood Disability Research
Cheryl Missiuna, PhD	Director, <i>CanChild</i> Centre for Childhood Disability Research Associate Professor, McMaster University
Sandy Palinski	Ministry of Education, Manager – Strategic Planning Unit
Susan Pisterman, MBA, PhD	Consultant
Peter Rosenbaum, MD	Director, McMaster Child Health Research Institute Co-Founder, <i>CanChild</i> Centre for Childhood Disability Research Professor, Department of Pediatrics, McMaster University

Impact: The work completed by *CanChild* over the past year has enabled the MOHLTC to make evidence-based decisions regarding program funding. The Ministry has now requested *CanChild* to develop a research proposal to evaluate the PCCC service delivery model as it is implemented in the first Paediatric Academic Health Science Centre in Ontario.

Internal Researcher	External Beneficiary/Reference
Dr. Peter Rosenbaum Professor, Department of Pediatrics Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 409 Hamilton, ON L8S 1C7 rosenbau@mcmaster.ca 905-525-9140 ext. 27834	Dr. Charlotte Moore Provincial Lead, Maternal, Child and Youth Health Strategy Office of the Assistant Deputy Minister Health System Strategy Division Ontario Ministry of Health and Long-Term Care 80 Grosvenor Street, 5th Floor Hepburn Block Toronto ON, M7A 1R3 (416) 314-7657 Charlotte.Moore@ontario.ca

2. Developing a Childhood Disability Knowledge Exchange Network

CanChild has been highly successful in traditional academic methods of dissemination, with thousands of peer-reviewed papers, books, manuals, and invited keynote talks around the world. In the early 1990s, *CanChild* researchers recognized that the traditional approaches to Knowledge Exchange were largely ineffective for making research accessible to busy service providers, parents, and policy makers. Well ahead of many research organizations, *CanChild* initiated a Knowledge Transfer Committee and began its tradition of developing KT documents written in plain language and tailored to the needs of various user groups.

"In the past decade it has been impossible to work in the field of childhood disability and be unaware of the outstanding work of the CanChild group of researchers."

-Chris Morris, DPhil
 University of Oxford, UK

CanChild has used modern technology to facilitate knowledge translation. This began in the mid-1990s with *CanChild's* award-winning website (www.canchild.ca). This month we have just launched a brand new website that moves our knowledge exchange efforts forward. The new site improves the user's ability to navigate within the site and find resources quickly. One of the most significant changes is the addition of three



significant changes is the addition of three microsites for some of our content that is frequently accessed. Our home page contains three 'hot buttons' which link directly to Developmental Coordination Disorder (DCD), Motor Growth Measures, and Lifecourse and Transitions resources. In addition, we now have a section specifically designed to facilitate knowledge translation to policy and decision makers. All information posted on the *CanChild* website is evidence-based and undergoes peer-review prior to posting. The *CanChild* website now boasts over 4000 'hits' a week from 150 countries around the world.

"No other single research unit we know of has produced research with such a broad perspective with direct clinical implication to pediatric rehabilitation as well as innovative concepts and products, all easily found through their informative web-site."

-Lena Krumline-Sundholm, PhD OT
 Stockholm, Sweden

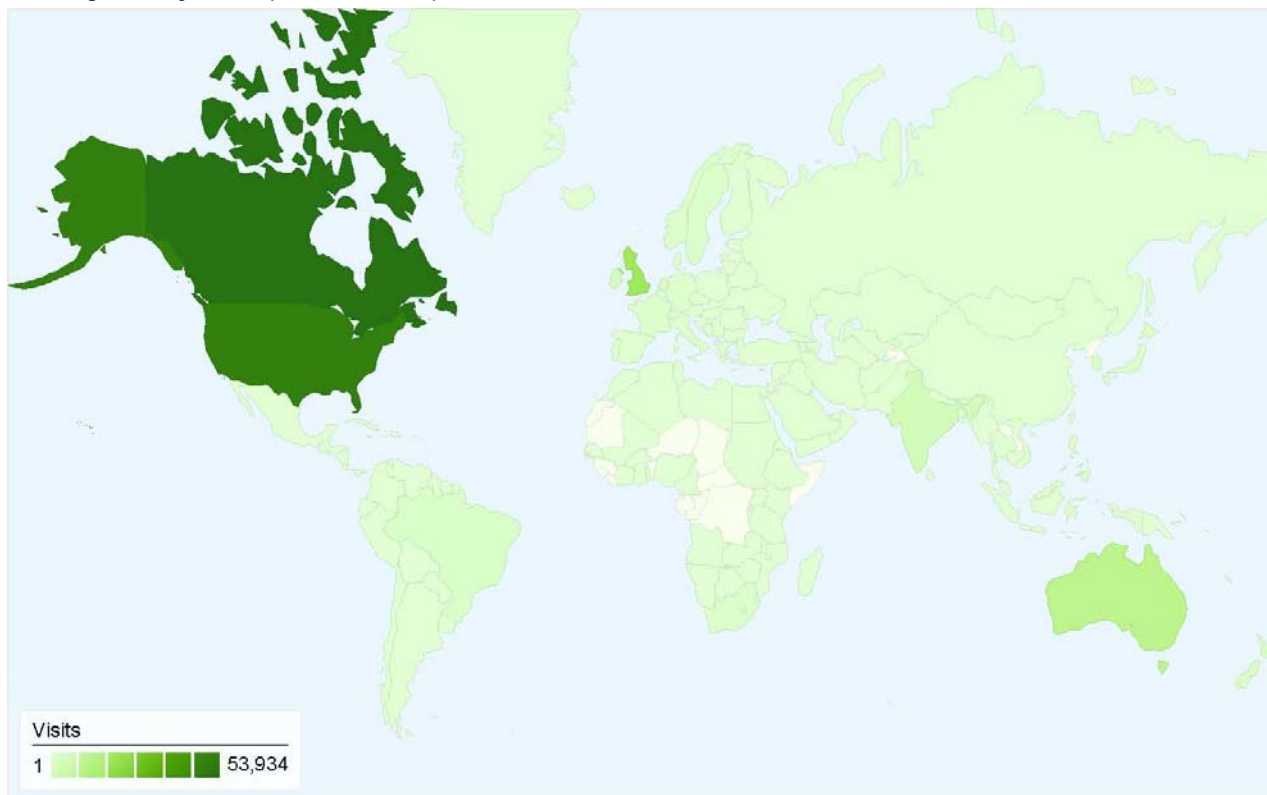
In 2005, *CanChild* created a network (now called Service Provider Communications) which was funded by the Canadian Foundation for Innovation.

The *CanChild* Intranet is a members-only, interactive web-based resource for service providers, researchers, and students interested in childhood disability. Supported by an enthusiastic partnership with the Canadian Network for Child and Youth Rehabilitation (CN-CYR), the Intranet provides a forum for communication and networking among child and youth rehabilitation centres and services from across Canada and internationally – what we think of as a virtual "Community of Practice" or knowledge exchange network. The Intranet currently has nearly 2000 subscribers, and provides a forum for knowledge exchange, discussions, presentations and sharing of other work not yet publicly available to the field.

CanChild documents the impact and comments received from individuals and organizations, and systematically evaluates its approach to KT through Impact Surveys, and Buxton and Hanney's Payback Model. *CanChild's* KT lessons were published in the

2006 CIHR casebook of health services and policy research knowledge translation stories. Moreover, in 2005 and again in 2006, *CanChild* was externally nominated and was considered by CIHR as one of the premier knowledge translation websites in health care in the country.

Google Analytics: April 9, 2008 – April 8, 2009 - 178,076 visitors to *CanChild* website from 193 countries/territories



Internal Researcher	External Beneficiary/Reference
Betty Yundt, KT Coordinator <i>CanChild</i> , McMaster University I.A.H.S. Room #408 1400 Main Street West Hamilton, ON L8S 1C7 Ph: 905 525 9140 ext. 27849 Fax: 905 522 6095 (Note – ALL investigators contribute to <i>CanChild's</i> knowledge translation activities)	Linda Kenny, CEO Ontario Association of Children's Rehabilitation Services 150 Kilgour Road Toronto, Ontario M4G 1R8 Telephone: 416-424-3864 Fax: (416) 467-7083

3. Moving Research into Clinical Practice using Knowledge Brokers

It is well documented that there are significant gaps between the generation of new knowledge and its application in clinical practice. Knowledge transfer is an iterative process which evolves over time based on collaboration between the knowledge producers and the knowledge users. Helping busy service providers keep up to date with the most current research evidence is an ongoing challenge in health care. A three year, CIHR funded study, explored the value of engaging and training ‘Knowledge Brokers’ (KBs), or local champions within Children’s Treatment Centres (CTCs) in Ontario, British Columbia and Alberta, in an effort to bridge the gap between new, validated ideas and their clinical application. We used a group of “motor measures” for children with cerebral palsy (CP) as our evidence-based knowledge example. Findings from our study have shown that supporting a multi-faceted intervention and support of a KB for 2hrs/week for 6 months increased therapist’s knowledge and use of evidence-based measures in clinical practice. These changes were maintained 12 months following withdrawal of financial support for the KB role. The lessons learned should have wide generalizability across settings, content areas and KB roles.

Here’s what administrators from participating sites were saying:

“We’re all very, very busy in our work, our therapists are up to their ears in children that they are trying to serve. I think the opportunity to participate in something that keeps them up to date, provides them with knowledge based on the latest research is really beneficial because that’s difficult for us to access unless we’re you know attending conferences or those kinds of things. But to have someone directly to turn to who is trained and something that’s being used internationally from what I understand I think was a real benefit to us and developing a consistent approach across agencies and across the country.”

“I really feel strongly that it’s the way to go in terms of that Knowledge Broker...having somebody designated as having the time to be able to mentor and assist others...really facilitated their learning in terms of the usefulness of the measures. It’s not that they haven’t known about the measures but in terms of feeling that confident with the measures to be able to truly integrate them into their practice.”

Internal Researcher	External Beneficiary/Reference
Dianne Russell, PhD Associate Professor, School of Rehabilitation Science Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 409 Hamilton, ON L8S 1C7 rosenbau@mcmaster.ca Tel: 905-525-9140 ext. 27834 Fax: 905-522-6095	Stephen Swatridge, CEO KidsAbility 500 Hallmark Drive Waterloo, ON N2K 3P5 519-886-8886 Fax: 519-886-7292

4. Parenting Matters: Understanding the Impact of Raising a Child with a Disability

Parenting is among the most challenging of human endeavours. When parents are raising children with lives that are ‘complicated’ by long-term problems of physical or mental health, developmental or illness, parenting challenges are multiplied significantly. In clinical practice, there is an implicit assumption that the type and quality of parenting provided by mothers, along and/or in conjunction with fathers, or by fathers alone, plays a significant role in the emotional, behavioural, social and quality of life outcomes of this vulnerable population. Studies increasingly demonstrate the difference that parenting behaviours (what parents do when they parent), parenting cognitions (attributions, beliefs, representations of self as a parent) and parenting styles (patterns that best describe the nature of their child) make to children with and without neurodevelopmental disorders (NDD). However, less is known about how the social and family context of parenting makes a difference to how parents parent their child. Similarly, the extent to which parenting is informed by child characteristics is not well understood in this population. How mothers alone and/or in conjunction with fathers experience and negotiate parenting children with various types of NDD may be completely different from parent of children who do not have NDD.

CanChild has conducted many studies that have led to this grant which was recently funded by the Canadian Institutes for Health Research for \$800,000. A number of projects will be conducted over a three year period to answer these questions: a synthesis of existing literature, quantitative analysis of Canadian population-based data, qualitative analysis of interviews conducted with mothers and fathers of children with NDD, and a review of federal/provincial/territorial policies. Better understanding of the economic, health and social costs of raising a child with a disability will lay the foundation for developing policy and practice guidelines as well as future studies that will evaluate uptake of this knowledge.

Internal Researcher	External Beneficiary/Reference
Dr. Peter Rosenbaum Professor, Department of Pediatrics Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 409 Hamilton, ON L8S 1C7 rosenbau@mcmaster.ca Tel: 905-525-9140 ext. 27834 Fax: 905-522-6095	Jan Burke-Gaffney Family Alliance Ontario c/o Hamilton Family Network 22 Leeming Street Hamilton, Ontario, Canada L8L 5T3 hamiltonfamilynetwork@bellnet.ca Tel: 905-526-7190

5. Partnering for Change: An Innovative Model for School Health Support Services in Ontario

Nearly 400,000 children across Canada struggle to perform everyday activities due to an underlying motor-based disorder called developmental coordination disorder (DCD). The difficulties of these children often worsen when they enter school and they are referred to School Health Support Services. In each region of Ontario, hundreds of children are now on school health waitlists, many for over 24 months. The problem is complex: 1) by the time children are finally seen, they have usually developed secondary problems; 2) therapists are still using traditional intervention models that are individualized and lengthy; 3) interventions are not meeting the needs of children and families. This innovative initiative will close the demand gap in health care services by shifting service provision away from individual interventions that are designed to change children's impairments to an approach that changes the environment.

In this project, researchers from *CanChild* are partnering with representatives from 3 Ministries (Ministry of Health, Ministry of Education, Ministry of Children and Youth Services), decision-makers from the Mississauga-Halton Local Health Integration Network, and representatives from Ontario Association of CCACs, Ontario Home Care Association, multiple school boards, educators, services providers, community agencies and families (examples of stakeholders below). *CanChild* has a strong history of translating knowledge into practice through the development and evaluation of educational materials and is the first centre in the world to develop evidence-based materials about children with DCD. Together, we are working with all stakeholders to plan and evaluate an intervention in which OTs translate knowledge to help families and teachers better support children with DCD. This study will provide the evidence needed to recommend potential change to existing services and funding structures and will support policy decisions regarding school health support services.

STAKEHOLDERS	
Ontario Government Representatives	
Debra Bell	Ministry of Health and Long Term Care
Jane Cleve	Ministry of Child and Youth Services, Specialized Services and Supports Branch
Maureen Cox	Ministry of Education, Special Education Policy and Programs Branch
Julie Erbland	Ministry of Child and Youth Services, Specialized Services and Supports Branch
Barry Finlay	Ministry of Education, Special Education Policy and Programs Branch
Mary Iannuzziello	Ministry of Health and Long Term Care, Health Program Policy and Standards
Sandra Montgomery (Dell)	Ministry of Education, Special Education Policy and Programs Branch
Charlotte Moore	Ministry of Health and Long Term Care
Lisa Schultz	Ministry of Child and Youth Services, Specialized Services and Supports Branch
Provincial Representatives	
Gillian Hogan	Ontario Association of Children's Rehabilitation Services
Georgina White	Ontario Association of Community Care Access Centres
Sue Vanderbent	Ontario Home Care Association
LHIN Partner (Mississauga-Halton) (Co-principal decision-maker is now at Central West LHIN)	
Agency Partners New Ventures (formerly Community Rehab)	
Representatives from Boards of Education, including: Halton District School Board, Hamilton Catholic District School Board, Hamilton Wentworth District School Board York District School Board	

"This is a wonderful project. It is contributing so much – and our teachers are learning so much."
 -Vice Principal



Internal Researcher	External Beneficiary/Reference
Dr. Cheryl Missiuna, PhD, OTReg(Ont) Associate Professor, School of Rehabilitation Science Director, <i>CanChild</i> McMaster University 1400 Main Street West, IAHS 414 Hamilton, ON L8S 1C7 missiuna@mcmaster.ca Tel: 905-525-9140 ext 27842 Fax:905-524-0069	Georgina White Director, Policy and Research OACCAC (Ontario Association of Community Care Access Centres) 800 Bay Street, 7 th Floor Toronto ON M5S 3A9 georgina.white@ccac-ont.ca Tel: 416-640-7735

B) Summary Chart

In the chart below, please track progress made in the past year in achieving the program or centre's objectives as stated in the Project Description section of your funding agreement (usually Schedule A). Please list the activities that contributed to the goals achieved. Add as many entries as needed.

Workplan Milestone(s) and Objective(s)	Outcome(s) / Deliverable(s)
<ul style="list-style-type: none"> Develop and finalize agreement with MCYS on the 3 year proposal to implement an Outcome Measurement System in Children's Treatment Centres across Ontario Commence implementation of Outcome Measurement System in 5 centres and pilot specific sub-components of the system 	<ul style="list-style-type: none"> Presentation to MCYS Deputy Minister and ADMs regarding the proposed Outcome Measurement project – April, 2008 Report outlining strengths, weaknesses and costs of 6 possible options for the three year Outcome Measurement System – submitted April 25, 2008 MCYS multi-year proposal with budget – submitted May 23, 2008 Written response to reviewers comments on the Outcome Measurement System – August 2008 Project launch was contingent on approval from MCYS – <i>CanChild</i> was notified on October 15, 2008 that the Ministry was very pleased with the work but was currently unable to finance the project
<ul style="list-style-type: none"> Determine Stakeholder response to Pediatric Complex Care Coordination Expert Panel report (requested by the Maternal, Child and Youth Health Strategy) Develop an evaluative framework for the Pediatric Complex Care Coordination model 	<ul style="list-style-type: none"> Chaired Expert Panel comprised of 35 experts across the province Expert Panel report – submitted May 2008, approved for release to the public October 6, 2008 Provincial PCCC Stakeholder Consultation Advisory Group formed – October, 2008 Stakeholder consultation findings and recommendations to MOHLTC report prepared – submitted March, 2009 Evaluative framework – submitted March, 2009
<ul style="list-style-type: none"> Produce and disseminate research evidence to families, service providers and policy makers via the <i>CanChild</i> website Provide opportunities for service providers to ask questions, to be active members of a 'community of practice', and expand knowledge via the <i>CanChild</i> Intranet Work to establish a sustainable knowledge translation strategy Develop proposals and seek funding for research projects that inform health service delivery for children in Ontario 	<ul style="list-style-type: none"> Maintenance of <i>CanChild</i> knowledge translation services including website, intranet and email response Health Services Research Impact Analysis – submitted May 28, 2008 Redesigned the <i>CanChild</i> website to make it easier to navigate and maintain – new website launched April 9, 2009 Have engaged in several efforts to obtain funding to sustain <i>CanChild's</i> knowledge translation activities including: engagement of McMaster University's Advancement Office, submission of a funding proposal to a private foundation, approached the Ontario Association of Children's Rehabilitation Services (OACRS), The Change Foundation and the Ontario Home Care Research Network's Knowledge Exchange Network for Children with Chronic Illness and Complex Needs. Developed grant applications for funding for various research projects (submitted to Canadian Institutes of Health Research, Physicians' Services Incorporated Foundation, etc.)

C) Funds Leveraged Chart (Please provide the following amounts only for the fiscal year being reported on)

Institute/ Unit/ Centre's research budget: ___\$2,955,011___

Total amount of funds received from MOHLTC: ___\$556,500___

(a) In the past fiscal year, has your Institute/ Unit/ Centre been successful in obtaining additional sources of in-kind support – either on its own or in formal collaboration¹ with partnering research institutions – which supports ongoing research initiatives which currently receive or have received Ministry funds?

Yes No

Funding Source	Funding (April 1 – March 31)	Type of In-kind contribution
Federal Government	\$1,417,295 + \$200,000 (Career Award) =\$1,617,295	
Provincial Government (external to the MOHLTC)	\$94,835 + \$135,000 (Career Awards) =\$229,835	
Community Partner	\$50,000	
Private Sector	\$75,000 (Career Award)	
Canadian Charitable Foundation/ Agency	\$131,018	
Hospital/ University	\$0	
U.S. Charitable Foundation/ Agency	\$295,363	
Other national or international donor	\$0	

Note: These totals do not include funding/scholarships brought in by graduate students