



Health Services Research  
Impact Analysis  
2007 – 2008

A Report for  
The Ministry of Health and Long-Term Care, Ontario

Submitted on behalf of *CanChild*  
by  
Cheryl Missiuna, PhD, OT Reg (Ont)  
Director

May 28, 2008



Name of Research Institute/ Unit:	<b>CanChild Centre for Childhood Disability Research Health System-Linked Research Unit McMaster University</b>
Date:	May 28, 2008

*In an effort to better understand the impact of health services research, the Ministry of Health and Long-Term Care (MOHLTC) is developing a series of tools to measure the collective system impact of its health services research investments, and its own receptiveness to, and application and dissemination of, funded-research.*

*While there is no single definition of world-class health services research, or the most desirable system impact of this research, we wish to know who stands to benefit from the implementation and roll-out of this research. If a policy initiative growing out of the research has, in fact, been implemented, are there any outcome measures (e.g. efficiencies gained, improved health outcomes) that have been documented? How is the research positively influencing the public's experience and interaction with the health system today?*

*Research may have contributed to new processes, improved health outcomes, an intellectual framework or quality assurance techniques whose aim is to promote health services efficiency, or more equitable resource allocation. Or, through effective dissemination of a finding, the research may have helped decision-makers identify a structural problem (e.g. access block in the Emergency Department) that was previously unknown or provided the evidence needed to implement responsive and effective policy.*

Please note: Some of the questions that follow may not be relevant to the strategic objectives of your Research Institute, Unit or Centre; however, you are encouraged to answer all questions (entering "0", specific dollar figures, or "N/A", as appropriate) for tracking and development purposes. The analysis will take into account the unique mandate of each Institute/ Unit/ Centre and

1. Basic information:

What is your Institute/ Unit/ Centre's annual research budget? **\$3,129,658**  
 What is the *total* amount of funds received from MOHLTC? **\$426,500**

2. (a) How many researchers are affiliated with your Institute/ Unit/ Centre?

Researchers/ Scientists	<b>15</b>
Post-doctoral Fellows	<b>1</b>
Doctoral Students	<b>20</b>
Masters Students	<b>26</b>
Community-based researchers	<b>2</b>
Other (specify)	<b>0</b>

(b) Of these individuals, how many were recruited to your Institute/ Unit/ Centre from outside Ontario in the past year?

Researchers/ Scientists	<b>1</b>
Post-doctoral Fellows	<b>0</b>
Doctoral Students	<b>1</b>
Masters Students	<b>0</b>
Community-based researchers	<b>0</b>
Other (specify)	<b>0</b>

3. Please use the provided template to complete question 3.

(a) From January 1, 2006 to December 31, 2007, how many *peer-reviewed* research articles or reviews did researchers affiliated with your Institute/ Unit/ Centre publish in scholarly periodicals?<sup>1</sup>

Note: Do not include works that have been accepted for publication but have not yet been published or which are in submission.

Peer-reviewed articles/reviews published by researchers affiliated with <i>CanChild</i>	153
Peer-reviewed articles/reviews published by researchers affiliated with <i>CanChild</i> and related to childhood disability	106

(b) Do any 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? If so, how many? 0

(c) Do any of the research articles described in (a) document the extent of increased productivity, improved access or quality of care, better patient outcomes, changes in population health status, population health needs/ gaps, or any economic savings to the health system that may come as a result of recommended policy changes?<sup>1</sup>

**Yes.** Please refer to the document entitled "Impact of *CanChild* Research" dated June 21, 2007 that was submitted to MOHLTC, Research Unit .

(d) In the most recent fiscal year (April 1 2007 to March 31, 2008), 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)?<sup>2</sup> 3

4. Please use the provided template to complete question 4

(a) In the *most recent fiscal year*, how many published journal articles have cited Ministry-funded research or publications produced by your Institute/ Unit/ Centre? Please provide the source(s) for your response:

**Important note:** *CanChild* investigators have published hundreds of articles in peer-reviewed journals since 1989 so this question posed a nearly impossible task.

Further to a conversation with Sarah Caldwell, and in order to provide an idea of the frequency with which our work is cited, we selected only eight articles each for our two Co-Founders and Director, as well as 2 articles for each of the remaining *CanChild* investigators. We did not select any articles published by graduate students or researchers who are no longer affiliated with *CanChild*.

In the fiscal year, using only the articles indicated above, there were:

452*	citations of these articles (314 unduplicated).
0*	citations for articles resulting from Ministry-directed research

\*Note: Citations were located using ISI Web of Knowledge.

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<sup>1</sup> Please append a publication list which includes: a full citation for each journal publication, including all authors, and the title of the Ministry-funded project that gave rise to the published findings (if applicable). Please *also* make note in the above list which publications document any of outcomes mentioned in 3c.

<sup>2</sup> Please append a publication list which includes: a full citation for each report publication, including all authors, the title and date of the Ministry-commissioned project, and the program area which commissioned the work.

(b) Of those articles in the most recent fiscal year citing your Unit's/ Institute's/ Centre's Ministry-funded research, how many of these articles were systematic literature reviews or meta-analyses? **33\***

\*Again, please note the important limitation that we only included a few articles.

## 5. Knowledge Translation

- Do you have a Institution/ Centre/ Unit knowledge translation (KT) strategy? Yes  No
- Has this strategy been reviewed within the last fiscal year? Yes  No
- Does your Institution/ Centre/ Unit have a dedicated (including part-time) KT staff person? Yes  No
- Does each project have its own KT strategy? Yes  No
- Do you conduct knowledge translation or dissemination activities through a website? Yes  No
- Do you have a forum for exchange (listserv, message board, etc.) Yes  No

Describe any other KT activities in which you regularly engage, host, sponsor, etc. (limit 250 words)

*CanChild's* regular KT activities make findings from our own research, as well as those from other childhood disability researchers, available and accessible to a wide range of stakeholders. Our effective strategies include:

- Writing and distributing user-friendly educational materials and research summaries.
- Maintaining an up-to-date, award-winning website ([www.canchild.ca](http://www.canchild.ca)), which receives almost 4,000 visits per week by users in over 100 countries, viewing over 450 different topics?
- Overseeing an interactive Intranet site linking over 1,800 subscribers across Canada and several other countries in a "community of practice". The Intranet enables service providers and researchers with common interests to share ideas and resources and provides a forum for knowledge translation, discussions, presentations and other work not yet publicly available to the field. Over half of the members are from Ontario.
- Knowledge brokering activities that enhance sharing of evidence-based information within local contexts and build partnerships with members of our target audiences.
- Responding to individual questions and requests on a daily basis from parents, service providers, decision makers, policy makers and other researchers (received by email and also by telephone).

6.(a) In the past fiscal year, has your Institute/ Unit/ Centre been successful in obtaining additional sources of funding – either on its own or in formal collaboration<sup>3</sup> with partnering research institutions – which supports ongoing research initiatives which currently receive or have received Ministry funds? [If "No," skip to Q. 7] Yes  No

<sup>3</sup> Formalized collaboration can be established via contract, joint Project Charter or joint funding submission.

(b) What are the sources/ amounts of external funding that were obtained during the past fiscal year that are being applied to the current fiscal year (i.e. monies from these funds that may be applied in the current fiscal year)?

Funding Source	\$ for fiscal year 2007/08*	In-kind contributions
Federal Government	\$1,830,393 + \$200,000 (Chair/career award) = <b>\$2,030,393</b>	
Provincial Government (external to the MOHLTC)	\$183,335 + \$60,000 (Career award) = <b>\$243,335</b>	
Community Partner	<b>\$50,000</b>	
Private Sector	<b>\$0</b>	
Canadian Charitable Foundation/Agency	<b>\$129,430</b>	
Hospital/ University	<b>\$0</b>	
U.S. Charitable Foundation/ Agency	<b>\$250,000</b>	
Other national or international donor	<b>\$0</b>	

\*Note:

We have interpreted this question to mean the 07/08 portion of monies that were brought in through grants initiated in years prior to the 07/08 year. Most of these grants would provide similar amounts for the 08/09 fiscal year, unless the grant ended in 07/08. We have included funds to two investigators for personnel (career scientist awards) but have not included any funds received for doctoral or post-doctoral students or chairs that provide interest that can be spent toward research.

Total Dollars Leveraged in 07/08 (that <i>CanChild</i> Holds):	\$2,703,158
Plus MOHLTC Dollars:	\$426,500
<b>Total Fiscal Year Dollars:</b>	<b>\$ 3,129,658</b>

7.(a) How many times in the most recently completed fiscal year did those affiliated with your Institute/ Unit/ Centre:

Receive an invitation to present at a national or international conference/ forum/ symposium (including poster presentations)	International	<b>58*</b>
	National	<b>25*</b>
	Provincial	<b>20*</b>

\*Note: These figures include peer-reviewed presentations as well, but do not include invited presentations at university events such as research rounds. There are no graduate student presentations and some investigators no longer record all invited talks or key note speeches, so these figures are an under-estimate.

Present to decision-maker organisations (e.g. LHIN(s)/ CCAC(s)/ etc.)<sup>4</sup> **14**

Decision-maker organisation	Topic
McGivney Children's Treatment Centre, presented by Peter Rosenbaum – April 13, 2007	Current concepts in childhood disability
Ministry of Children and Youth Services presented by Cheryl Missiuna and Peter Rosenbaum - April 24, 2007	Partnering for change: Promoting health and participation of school-aged children with developmental conditions in their



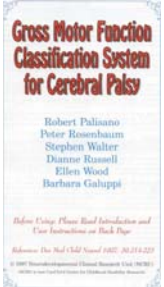
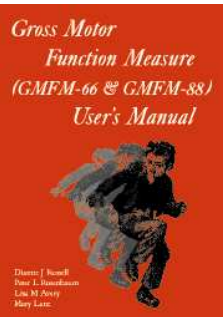
<sup>4</sup> Please provide a list of these presentations.





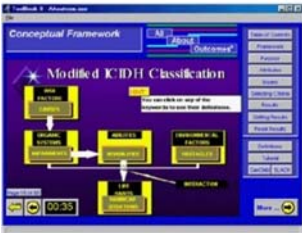
	communities
Thames Valley Children's Treatment Centre, presented by Peter Rosenbaum – May 30, 2007	Motor development in Cerebral Palsy
Ministry of Children and Youth Services, presented by Peter Rosenbaum, Mary Law, and Dianne Russell – September 24, 2007	Measuring Outcomes of Children and Youth with Special Needs in Ontario
Ontario Association of Children's Rehabilitation Services Annual Conference, presented by Rachel Teplicky – October 23, 2007	From Research to Clinical Practice: The <i>CanChild</i> Website and Intranet
Ontario Association of Children's Rehabilitation Services Annual Conference, presented by Virginia Wright - October 2007	From clinical observation to outcome measurement.
Ontario Association of Children's Rehabilitation Services Annual Conference, presented by Virginia Wright - October 2007	Results from the OACRS outcome indicators study.
Canadian Network for Child and Youth Rehabilitation (CN-CYR), Annual Conference, presented by Virginia Wright - October 2007	Results from the OACRS outcome indicators study
Aryeh Gitterman (Assistant Deputy Minister), Policy Development and Program Design, Ministry of Children and Youth Services, presented by Peter Rosenbaum – October 24, 2007	Measuring Outcomes for Children and Youth with Special Needs in Ontario
Ministry of Children and Youth Services presented by Terry Petrenchik and Dianne Russell – December, 2007	Mapping health indicators and outcomes for children with special needs in Ontario
Ministry of Health and Long-Term Care, presented by Peter Rosenbaum – January, 2008	McMaster Child Health Research Institute
Hamilton Family Health Team, presented by Cheryl Missiuna and John Cairney – January 29, 2008	Promoting inter-disciplinary identification and improved service delivery for children with developmental coordination disorder and their families.
Provincial Symposium on Assessment and Evaluation, Ministry of Education, presented by Cheryl Missiuna and Nancy Pollock – January 8, 2008	Are they ready to print?
Child and Family Research Institute of London, presented by Peter Rosenbaum – February 13, 2008	Why there has never been a better time to be in developmental pediatrics

(b) Please list any significant roundtables and networks, collaborations, etc. in which your Institute/ Unit/ Centre participated in the last year that were either Ministry-funded or directly related to Ministry-funded research.




Event	Topic
Provincial Council on Child Health Symposium	Transforming the System
Ministry of Education Provincial Symposium 2008	Assessment and Evaluation
Ministry of Education OPA Advisory Board	OPA Student Assessment Project
Ontario Rehabilitation Research Advisory Network	Mary Law, Chair of ORRAN
Autism Spectrum Disorder Expert Panel	Evaluation of Available Research
Ministry of Health and Long-Term Care, Expert Panel	Pediatric Complex Care Coordination Peter Rosenbaum, Chair of Expert Panel



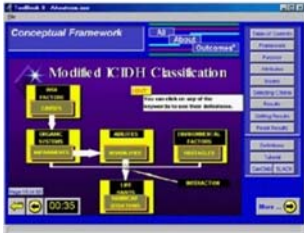
8.(a) In the past five (5) years, has your research resulted in the development of products or processes that increase the efficiency, quality, productivity, or decreased cost of providing healthcare? Has your research resulted in any new products or processes that increase the quality of life of people with illnesses or disabilities? If yes, please list the products or process and provide a brief description. (limit 250 words per product or process)

	<p>The <b>KIT: Keeping it Together™</b> is an organizational tool for parents caring for children with disabilities, developed by <i>CanChild</i> Centre for Childhood Disability Research, and the Hamilton Family Network. It is a way for parents to organize information for their child, and to assist them when interacting with different service systems, for example health, education, and recreation. Included is a User's Guide that will help parents through the initial process of how to use the KIT. It is useful for parents of children with a wide variety of special needs and all developmental ages from birth to 21 years. The KIT is produced at cost and sold through the bookstore at McMaster University.</p>
	<p>The <b>Measure of Processes of Care (MPOC)</b> is a well-validated and reliable self-report measure of parents' perceptions of the extent to which the health services they and their child(ren) receive are family-centred. The original version of MPOC was a 56-item questionnaire. There is now a shorter, 20-item version. The MPOC was published at <i>CanChild</i> and is available free of charge on the <i>CanChild</i> website. It is widely used in treatment centres, hospitals and programs across the province to measure parental satisfaction with care.</p>
	<p>The <b>Gross Motor Function Classification System</b> classifies the gross motor function of children and youth with cerebral palsy on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility.</p> <p>Both the original <b>GMFCS (1997)</b> and the new <b>GMFCS: Expanded and Revised or GMFCS – E &amp; R (2007)</b> can be downloaded free of charge from the <i>CanChild</i> website. <i>CanChild</i> grants permission for printing of this document.</p>
	<p>The <b>Gross Motor Function Measure</b> is a clinical measure designed to evaluate change in gross motor function in children with cerebral palsy. There are two versions of the GMFM: the original 88-item measure (GMFM-88) and the more recent 66-item GMFM (GMFM-66). Items on the GMFM-88 span the spectrum of activities from lying and rolling up to walking, running and jumping skills. The GMFM-66 is comprised of a subset of the 88 items that has been shown to be unidimensional.</p> <p>The GMFM User Manual is published by Blackwell Publishing and distributed by Cambridge University Press.</p>

 <p><b>COPM</b> Canadian Occupational Performance Measure</p>	<p>The <b>Canadian Occupational Performance Measure (COPM)</b> is an individualized, client-centred outcome measure designed for use by occupational therapists to detect change in a client's self-perception of performance of daily activities over time. Two <i>CanChild</i> members are authors of the COPM. It assists therapists in using a client-centred approach to service delivery by indicating client and family priorities. The COPM is published and distributed by the Canadian Association of Occupational Therapy.</p>
 <p><b>CAPE/PAC</b> Children's Assessment of Participation and Enjoyment &amp; Preferences for Activities of Children</p>	<p>The <b>Children's Assessment of Participation and Enjoyment (CAPE)</b> and the <b>Preferences for Activities of Children (PAC)</b> are companion measures of children's participation for children aged 5-18 years. Both are self-report measures of children's participation in recreation and leisure activities outside of mandated school activities. The CAPE is published by Psychological Corporation and distributed by Pearson Inc. (formerly Harcourt Brace Canada).</p>
 <p><b>PEGS</b></p>	<p>The <b>PEGS (Perceived Efficacy and Goal Setting)</b> is self-report measure that allows young children with a disability (6-9 years) to validly report their performance on everyday tasks and to establish and prioritize goals for therapy intervention. It also contains measures that are completed by caregivers and teachers to gain their perception of the child's strengths and challenges and to contribute to the goal setting process. The PEGS has been translated into several languages and is published by Psychological Corporation and distributed by Pearson Inc. (formerly Harcourt Brace Canada).</p>
 <p><b>DCD</b></p>	<p>The <b>DCD PACK</b> is an educational program designed to help primary care physicians effectively manage children with developmental coordination disorder. The DCD PACK (DCD Physician Allied Health Collaboration Kit) was developed as part of an interdisciplinary research project funded by the Primary Health Care Transition Funds that were administered by the Ontario Ministry of Health and Long-Term Care. The DCD PACK was published at <i>CanChild</i> and is available free of charge to physicians at <a href="http://www.dcdpack.ca">www.dcdpack.ca</a>.</p>
	<p><b>All About Outcomes</b> is an educational software program to help practitioners understand, evaluate, and choose pediatric outcome measures. It has been designed for students learning about outcome measures and for practitioners working in pediatric rehabilitation. This one-of-a-kind CD-ROM enables the user to select the most appropriate outcome measure for an individual, client, service, and/or program evaluation. This program guides practitioners through a protocol for making decisions about outcomes and is linked to an outcome measures database of critically appraised children's outcome measures. All About Outcomes was published by SLACK Incorporated and is currently not being produced.</p>

(b) Are you aware of whether the products and processes developed in (a) have been adopted, or had a policy/ clinical impact in Ontario? In other jurisdictions? Has your research had an impact on wait times, job creation, etc.) If yes, please list and provide a brief description. (limit 250 words per product or process)

	<p><b>The KIT: Keeping it Together™</b></p> <p><i>See "Success Stories" Section</i></p>
<p>The Measure of Processes of Care <b>MPOC</b> A Means to Assess Family-Centred Behaviours of Health Care Providers</p>	<p><b>The Measure of Processes of Care</b></p> <p><i>See "Success Stories" Section</i></p>
	<p><b>The Gross Motor Function Classification System and the Gross Motor Function Measure</b></p> <p><i>See "Success Stories" Section</i></p>
<p><b>COPM</b> Canadian Occupational Performance Measure</p>	<p>The Canadian Occupational Performance Measure (COPM) is used in Ontario and Canada to set goals for intervention with clients with a variety of disabilities and across all developmental ages. First published in 1990, the COPM is in its 4th edition, has been translated into 28 languages, and is used in over 40 countries around the world. Over 120 research studies have been published using the COPM. In 2008, the COPM will be included in the e-health record of a European country's health system.</p>
	<p>First published in 2006, the <b>Children's Assessment of Participation and Enjoyment (CAPE)</b> and the <b>Preferences for Activities of Children (PAC)</b> are assessments that are being used in Ontario and Canada to determine the participation of children with disabilities and guide therapy intervention. Studies with the CAPE have provided policy information to the Ontario Ministry of Children and Youth Services regarding environment, family and child factors that are most predictive of successful participation. The CAPE and PAC are widely used in Europe, the United States, and Australia and are being translated into Swedish, Dutch and Hebrew.</p>

	<p>The <b>PEGS</b> (Perceived Efficacy and Goal Setting) system is being used by occupational therapists throughout Ontario and Canada to help young children with disabilities have a voice and contribute to the goals that are established in therapy. Studies to date have indicated that parents appreciate having input into goal settings and that teachers have an increased perception of what therapy can offer to the child in an educational setting. The PEGS is widely used in the UK and Australia in both healthcare and educational settings for children with a variety of disabilities. It has been translated into Hebrew, Portuguese, and Swedish and translations are underway in Finland and Norway.</p>
	<p>The <b>DCD PACK</b> is accompanied by DCD knowledge translation materials that are used to educate and empower families of children with DCD. Materials are available for families, teachers, primary care practitioners and other members of the community. DCD educational materials are downloaded by hundreds of individuals every month and we receive numerous emails indicating their usefulness.</p> <p><i>"We have recently discovered your published information/resources on DCD and it has helped our family so much. We are very grateful to finally have some answers." (Parent, U.S.A.)</i></p> <p><i>See also "Success Stories" Section</i></p>
	<p><b>All About Outcomes</b> contains a searchable database of critically reviewed outcome measures. The database provides practitioners with the ability to select reliable and valid measures to evaluate specific outcomes. All about Outcomes has been used by practitioners and researchers in Ontario, Canada, the United States, Europe and Australia.</p>

(c) Over the past five (5) years, are you aware of any commercial inventions – i.e. inventions announced publicly by independent private companies (in press releases, public reports, etc) – that cite or reference Ministry-funded research undertaken at your Institute/ Unit/ Centre (e.g. a new IT consent management software invention that cites research describing health privacy breaches; a new telemedicine application to reduce ED visits that cites research relating to ED overcrowding)?

Yes  No  Not applicable

If yes, please provide details (limit 250 per product or process).

Not applicable

## Success Stories: Measuring Adoption and Impact

## The KIT: Keeping it Together™

Parents of children and youth with special needs told *CanChild* that they often have to repeat basic information about their child each time they encounter a new service provider and that there is a tremendous burden associated with completing different forms with each service organization and service provider. Families have a great deal of information that they need to give, to get and to organize in order to receive the best and most coordinated services for their child. This need for families to be able to organize and provide information in a way that enhances the efficiency of health care provision and reduces stress on families has been met with the KIT: Keeping It Together™, developed through the collaborative efforts of researchers at *CanChild* and parents from the Hamilton Family Network.



The KIT: Keeping It Together™ (KIT) was designed to help parents of children with special needs use information as a tool to communicate and interact with their child's service providers. Research has shown that it increases families' skills and satisfaction in working together with the wide variety of health care, education and social service providers who are often involved in the lives of children with special needs and their families.

It is useful for parents of children with **all types of chronic health conditions** from birth to 21 years, as well as for service providers who work within a family-centred model of care.

*"When your child is first diagnosed with a condition, you are in shock and a lot of information is usually being presented. Having a way to record and organize this information is very helpful and useful throughout your child's care. There are often many specialists involved and it makes it easier to share the info if you have good records."*

Parent

*"Best idea that anybody had. Just the amount of files, the tabs you have on it. The information on how to use it was wonderful because it is hard to try to organize something. . . . So putting all of that together, it was just amazing."*

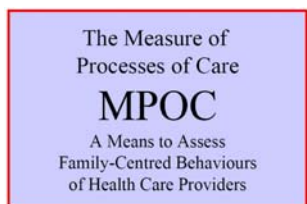
Parent

Evaluation indicated that parents' perceptions of their ability, confidence and satisfaction when using information improved significantly after using the KIT. Most parents who participated in the evaluation reported that the KIT was easy to use, easy to understand and well organized. Parents reported feeling empowered and indicated that they were more aware of their own informational needs. The KIT assisted them in finding new resources and also increased self-advocacy skills. Parents stressed that this tool would ideally be provided to families of a child who is first diagnosed with a problem requiring special healthcare and/or social services.

*CanChild* has sold at cost over 3,000 copies of the KIT, and are indebted to the many people who were involved in the design and evaluation process, the Easter Seal Society, and Hospital for SickKids Foundation for their support.

Internal Contact	External Beneficiary/Reference
Debra Stewart Associate Clinical Professor, School of Rehabilitation Science Co-Investigator, <i>CanChild</i> Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 409 Hamilton, ON L8S 1C7 905-525-9140 ext. 27803 <a href="mailto:stewartd@mcmaster.ca">stewartd@mcmaster.ca</a>	Jan Burke-Gaffney Family Alliance Ontario c/o Hamilton Family Network 22 Leeming Street Hamilton, Ontario, Canada L8L 5T3 905-526-7190 <a href="mailto:hamiltonfamilynetwork@bellnet.ca">hamiltonfamilynetwork@bellnet.ca</a>

## Family Centred Service: The Measure of Processes of Care (MPOC)



The links between service providers and the research and academic members of *CanChild* facilitate the identification of 'real-world' challenges that often form the basis of research programs. In response to a request from the Ontario Association of Children's Rehabilitation Services (OACRS), *CanChild* began to explore the importance of family-centred service (FCS) back in the early 1990s – then an emerging, vaguely defined concept unfamiliar to most service providers and programs. By creating a conceptual framework and developing several internationally-used

measures of FCS (e.g., Measure of Processes of Care), *CanChild* documented the relationship between FCS and parent satisfaction, stress, and mental health. Through these studies, *CanChild* has been able to provide feedback to each OACRS program about their progress in creating a family-centred environment. Subsequent to this, and in collaboration with parents from the Hamilton Family Network, *CanChild* developed and evaluated "fact sheets" that describe basic concepts related to FCS. These fact sheets are available for free from the *CanChild* internet. FCS is now recognized world-wide as a 'best-practice' approach to service delivery in children's rehabilitation.

As a result of the research activities described above, and through the *CanChild*/OACRS health system linked partnership, children's rehabilitation services in Ontario now have more reliable and valid outcome measures to use to evaluate program effectiveness. *CanChild* is now partnering with the Ministry of Children and Youth Services in planning a framework and method of evaluating service provision that will lead to a substantial increase in knowledge about the effectiveness of children's rehabilitation services that are delivered within the province.

*"... a fairly dramatic change and orientation towards the whole idea of family-centred care is to be attributed to the behind the scenes work that CanChild has done, whether it's a specific piece of research or making that available to the centres, or talking up the benefits and value of that, or even coming and attending at the individual centres and giving inservices, all of which we've used. And so I attribute that type of significant shift as being something that CanChild has quietly but efficiently shepherded along."*

Children's Treatment Centre, CEO

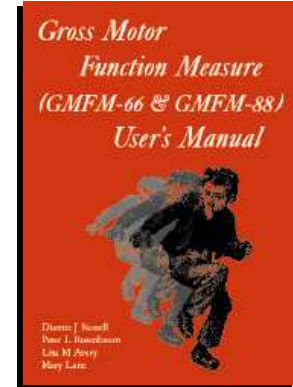
Internal Researcher	External Beneficiary/Reference
Dr. Peter Rosenbaum Institute of Applied Health Sciences, McMaster University 1400 Main Street West, Room 409 Hamilton, ON L8S 1C7 905-525-9140 ext. 27834 rosenbau@mcmaster.ca	Vicky Earle Executive Director Grandview Children's Treatment Centre – Main Site 600 Townline Road South Oshawa, Ontario L1H 7K6. 905-728-1673 Toll free: 1-800-304-6180 Fax: 905-728-2961

## Motor Measures

A project that began locally as a clinical-research partnership with children's rehabilitation service providers enabled *CanChild* to develop motor measurement materials that are now the **gold standard** among clinicians and researchers worldwide. The development, validation, and dissemination of the *Gross Motor Function Measure* (GMFM), the *Gross Motor Function Classification System* (GMFCS), and the *Ontario Motor Growth Curves* has provided rehabilitation professionals with the evidence-based information they need to talk knowledgeably with families about children's motor skills, appropriate goal setting, and prognosis for motor development. *CanChild's* clinical partners have been actively involved throughout the motor measures knowledge translation (KT) process by:

- Identifying important clinical questions (How do we know if what we do has an impact?)
- Providing input on the development and validation of the GMFM and the GMFCS
- Engaging children and families to enable the systematic collection of data over many projects and many years, which in turn led to the creation of *Ontario Motor Growth Curves*
- Working with *CanChild* to interpret the findings within the clinical and health service system (What do these results mean to each child and family and how can I change my practice?)

Clinical partners challenged *CanChild* to develop materials in addition to traditional peer-reviewed publications that are useful to them in everyday practice. In response, the *CanChild* team developed resources in a variety of user-friendly formats – including videotapes, self-instructional CD-ROMs, computerized tutorials and scoring programs, and a variety of web-based resources. To date, over 30,000 copies of the GMFCS flyer have been requested and distributed worldwide, and it has been translated into 12 languages. The motor measure work has been described as 'the single most important contribution to neurodevelopmental disability research in the past 25+ years' (Deborah O'Rourke, Department of Physical Therapy, Vermont, USA). A CIHR grant held by Dr. Russell has enabled the group to explore active KT strategies more fully.



Internal Researcher	External Beneficiary/Reference
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## Measuring Outcomes for Children with Special Needs in Ontario

Since April 2004, *CanChild* Centre for Childhood Disability Research at McMaster University has been funded by the MOHLTC to work in close collaboration with the Ontario Ministry of Children and Youth Services (MCYS) to:

- 1) Recommend an outcome measurement system that, for the purposes of resource and service planning, allows government to describe the functional status of children and youth with special needs who are currently receiving services funded through MCYS; and
- 2) Evaluate whether the services provided by government are making a difference to children and youth with disabilities and their families.

After developing, refining and seeking feedback on the framework and proposed measures from multiple stakeholders, a pilot project was undertaken in 2007-08 to test a targeted sub-set of measures within three Children's Treatment Centres (CTCs). Results of the pilot study indicate that the measures are well received by CTC administrators and program managers, and generally well accepted by parents.

*CanChild* and MCYS are now working collaboratively on a three-year program to implement the Outcome Measurement System across all 21 CTCs in Ontario.

### Possible Applications of this Information:

By MOHLTC, MCYS and CTCs

- To describe the number and complexity of cases of childhood disability within the CTCs
- To determine what services children are using/need, how much, and what gaps exist in services
- To use data to explore changes over time in families' perceptions of service, service use, and children's function and needs

By the Ministry of Education (MEDU)

- To prepare the MEDU for the number and complexity of cases of childhood disability that will be entering the school system in the coming years
- To provide MEDU and MOHLTC with information useful for planning services for children who are entering, or are already in the school system

By the Ministry of Community and Social Services (MCSS)

- To predict future need for Ontario Disability Support
- To enhance programs such as Special Services At Home for children with special needs

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## Transition to Adulthood

The transition from adolescence to the adult world is an important stage in life. The most common domains for this transition for all youth are education, employment, living arrangements, community life, financial independence, social situations, and leisure. Youth with disabilities go through the same transition processes as their peers without disabilities and face many of the same challenges. There are, however, unique issues and concerns related to having a disability. Personal challenges such as physical, cognitive and communicative limitations and also environmental barriers are significant challenges to youth as they move into the adult world. Environmental barriers include physical access, economic barriers to participation, misconceptions and stigma, and social attitudes. During times of transition, systems and services tend to be uncoordinated or fragmented and people lack the information needed to navigate the transition successfully.

*CanChild* has been actively involved in research to facilitate positive transitions to adulthood for youth with disabilities. In 2005, *CanChild* conducted a literature review, gathered information about current Ontario initiatives and held a symposium to bring together relevant stakeholders who have expertise in this field. From this research, policy directions were proposed. Delving further into the issues affecting youth with disabilities as they transition into adulthood included conducting studies using qualitative methodology. Through this research, six recommendations for best practice in the area of transition to adulthood for youth with disabilities were proposed. Briefly:

1. Collaborative initiatives and policies for transition to adulthood are needed in Ontario.
2. Capacity Building is a critical element of transition services and supports at all levels (policy, services, communities, and families).
3. Information, supports, and resources need to be provided in accessible locations with a variety of easy to use formats for *all* members of the community to be able to use.
4. Community facilitators or 'navigators' are needed to support youth with disabilities and their families in planning for transition and navigating systems and resources 'out there'. The facilitator needs to be at arms length from existing systems.
5. A province-wide educational strategy needs to be developed for transition to adulthood.
6. Outcomes-based research and evaluation is needed to support the development and sustainability of transition to adulthood services, supports, resources and community initiatives.

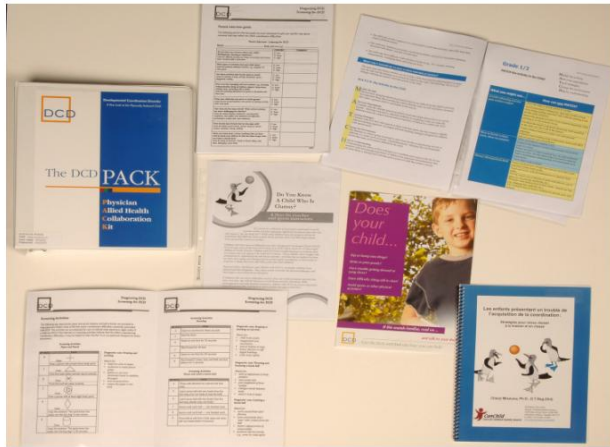
*"The on-going commitment to supporting youth with disabilities and their families through the transition years is incredibly relevant and helpful to "boomer" parents struggling to help their sons and daughters through these challenging years. There is no other organization in Ontario that has worked so hard and produced so much to aid this age group."*

Family Alliance Ontario

The success of this Ontario-based program of research has been recognized nationally and internationally. *CanChild* is now running a Canadian-wide research project to assist the Canadian government to determine future knowledge and research requirements for transition.

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Improving primary care service delivery for children with developmental coordination disorder.



**Developmental coordination disorder (DCD)** is a chronic health care condition that impacts on a child's ability to perform everyday tasks in self-care and academic areas. Consistent prevalence estimates of 5-6%, indicate that DCD is a very common condition that affects nearly 200,000 school-aged children in Ontario yet healthcare systems do not recognize or understand it. Evidence suggests that the majority of children with DCD who do not receive treatment have poor educational or physical health outcomes, mental health and substance abuse problems by adulthood.

Through research funded by the Primary Health Care Transitions Fund, administered by MOHLTC, *CanChild* researchers designed an educational program to support primary care physicians in acquiring the skills

and knowledge necessary for effective management of children with DCD and in gaining the confidence to apply these skills in practice. This research study demonstrated the effectiveness of using a model of interdisciplinary care in primary care offices. The practice and policy implications resulting from this study include\*:

- Physicians now know more about how to identify motor coordination problems, diagnose DCD and provide better long-term management for children with this condition.
- Involving rehabilitation professionals in primary care was effective in improving the quality of care for children with motor coordination problems.
- This shared-care model may be applicable to other developmental health conditions in which primary care physicians and families need to be educated and empowered.
- The model was shown to be cost effective and beneficial to patients, providers and the system in that it decreased wait times and improved the ability of parents to manage their child's needs.
- Shared-care and education of families decreased the need for referral to medical specialists.

*"There are things that they [rehabilitation] can do that we cannot do... the name of the game now-a-days is to pool our resources together and make the most of it. That means collaboration"*

Physician participant

*"It's been fantastic. I can't thank you enough because you've given me the tools I need to get my son through."*

Parent participant

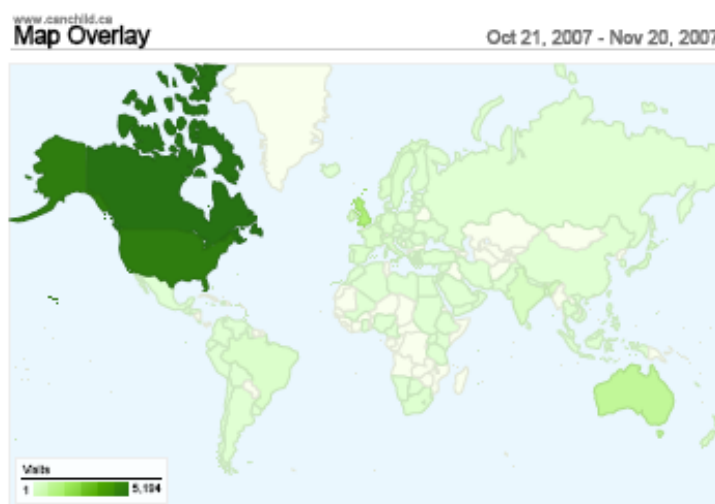
\*Report submitted to MOHLTC in August, 2006

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## CanChild Website and Intranet

CanChild's knowledge translation activities make findings from our own research, as well as those from other childhood disability researchers, available and accessible. Our effective strategies include:

- Writing and distributing user-friendly educational materials and research summaries
- Maintaining an up-to-date, award-winning website, which receives almost 4,000 visits a week by users in over 100 countries, viewing over 450 different topics (see right for map from Google Analytics)
- Overseeing an interactive Intranet site linking over 1,800 Canadian and international service providers in a community of practice (over half of the members are from Ontario)
- Knowledge brokering activities that enhance sharing of evidence-based information within local contexts and build partnerships with members of our target audiences
- Responding to individual questions and requests from parents, service providers and decision makers from around the world on a daily basis



*"CanChild has enabled therapists to have readily available access to current research in the field of paediatric rehabilitation and family-centred care. It has been our experience that the information is current, state of the art and clearly presented. It is a valuable resource in the continuing quest to employ evidenced based practice in our work with children and families."*

Linda Kenny, CEO  
Ontario Association of Children's Rehabilitation Services

*"We substantially depend on CanChild as a significant and reputable source of information, as well as being both a catalyst and enabler regarding best practice and current research in the area of pediatric rehabilitation."*

Children's Treatment Centre, CEO

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Betty Yundt, KT Coordinator CanChild, 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 CanChild's 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  (See quote above from CEO Linda Kenney)

### Question 3

(Please attach additional pages as needed)

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Zhu, B., Walter, S. D., Rosenbaum, P. L., Russell, D. J., & Raina, P. (2006).	Structural equation and log-linear modeling: A comparison of methods in the analysis of a study on caregivers' health.	<i>BMC Medical Research Methodology</i> , 6, 49.

#### Question 4 - ONLY A FEW PUBLICATIONS HAVE BEEN SELECTED FROM THE WORK OF EACH INVESTIGATOR

(Please attach additional pages as needed)

Author(s)	Total Cited	Cited 07/08 Fiscal Year	Title	Publication	Index	Type
Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B	518	135	Development and reliability of a system to classify gross motor function in children with cerebral palsy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 39 Issue: 4 Pages: 214-223 Published: APR 1997	ISI Web of Knowledge	
Russell DJ, Rosenbaum PL, Cadman DT, Gowland C, Hardy S, Jarvis S	259	26	The Gross Motor Function Measure – A means to evaluate the effects of physical therapy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 31 Issue: 3 Pages: 341-352 Published: JUN 1989	ISI Web of Knowledge	
Saigal S, Feeny D, Rosenbaum P, Furlong W, Burrows E, Stoskopf B	136	9	Self-perceived health status and health-related quality of life of extremely low-birth-weight infants at adolescence	JAMA-JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION Volume: 276 Issue: 6 Pages: 453-459 Published: AUG 14 1996	ISI Web of Knowledge	
Saigal S, Hoult LA, Streiner DL, Stoskopf BL, Rosenbaum PL	123	11	School difficulties at adolescence in a regional cohort of children who were extremely low birth weight	PEDIATRICS Volume: 105 Issue: 2 Pages: 325-331 Published: FEB 2000	ISI Web of Knowledge	
Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N	91	36	Proposed definition and classification of cerebral palsy, April 2005 - Introduction	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 47 Issue: 8 Pages: 571-576 Published: AUG 2005	ISI Web of Knowledge	Literature Review
Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, Raina PS, Galuppi BE	88	21	Validation of a model of gross motor function for children with cerebral palsy	PHYSICAL THERAPY Volume: 80 Issue: 10 Pages: 974-985 Published: OCT 2000	ISI Web of Knowledge	
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Cadman D, Rosenbaum P, Boyle M, Offord DR	69	2	Children with chronic illness – family and demographic characteristics and psychosocial adjustment	PEDIATRICS Volume: 87 Issue: 6 Pages: 884-889 Published: JUN 1991	ISI Web of Knowledge	
Russell DJ, Avery LM, Rosenbaum PL, Raina PS, Walter SD, Palisano RJ	63	16	Improved scaling of the gross motor function measure for children with cerebral palsy: Evidence of reliability and validity	PHYSICAL THERAPY Volume: 80 Issue: 9 Pages: 873-885 Published: SEP 2000	ISI Web of Knowledge	

Liptak GS, O'Donnell M, Conaway M, Chumlea WC, Worley G, Henderson RC, Fung E, Stallings VA, Samson-Fang L, Calvert R, Rosenbaum P, Stevenson RD	53	16	Health status of children with moderate to severe cerebral palsy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 43 Issue: 6 Pages: 364-370 Published: JUN 2001	ISI Web of Knowledge	
Law M, Cadman D, Rosenbaum P, Walter S, Russell D, DeMatteo C	45	5	Neurodevelopmental therapy and upper-extremity inhibitive casting for children with cerebral-palsy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 33 Issue: 5 Pages: 379-387 Published: MAY 1991	ISI Web of Knowledge	
Law M, Russell D, Pollock N, Rosenbaum P, Walter S, King G	36	4	A comparison of intensive neurodevelopmental therapy plus casting and a regular occupational therapy program for children with cerebral palsy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 39 Issue: 10 Pages: 664-670 Published: OCT 1997	ISI Web of Knowledge	
Ronen GM, Streiner DL, Rosenbaum P	31	6	Health-related quality of life in children with epilepsy: Development and validation of self-report and parent proxy measures	EPILEPSIA Volume: 44 Issue: 4 Pages: 598-612 Published: APR 2003	ISI Web of Knowledge	
Kennes J, Rosenbaum P, Hanna SE, Walter S, Russell D, Raina P, Bartlett D, Galuppi B	30	8	Health status of school-aged children with cerebral palsy: information from a population-based sample	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 44 Issue: 4 Pages: 240-247 Published: APR 2002	ISI Web of Knowledge	
Eliasson AC (Eliasson, Ann-Christin), Krumlind-Sundholm L (Krumlind-Sundholm, Lena), Rosblad B (Rosblad, Birgit), Beckung E (Beckung, Eva), Arner M (Arner, Marianne), Ohrvall AM (Ohrvall, Ann-Marie), Rosenbaum P (Rosenbaum, Peter)	29	13	The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 48 Issue: 7 Pages: 549-554 Published: JUL 2006	ISI Web of Knowledge	
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Cairney J, Boyle M, Offord DR, Racine Y	26	8	Stress, social support and depression in single and married mothers	SOCIAL PSYCHIATRY AND PSYCHIATRIC EPIDEMIOLOGY Volume: 38 Issue: 8 Pages: 442-449 Published: AUG 2003	ISI Web of Knowledge	
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Morris C, Bartlett D	23	6	Gross motor function classification system: impact and utility	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 46 Issue: 1 Pages: 60-65 Published: JAN 2004	ISI Web of Knowledge	

Klassen A, Miller A, Raina P, Lee SK, Olsen L	22	2	Attention-deficit hyperactivity disorder in children and youth: A quantitative systematic review of the efficacy of different management strategies	CANADIAN JOURNAL OF PSYCHIATRY-REVUE CANADIENNE DE PSYCHIATRIE Volume: 44 Issue: 10 Pages: 1007-1016 Published: DEC 1999	ISI Web of Knowledge	Quantitative systematic review
Law M, Hanna S, King G, Hurley P, King S, Kertoy M, Rosenbaum P.	22	7	Factors affecting family-centred service delivery for children with disabilities	CHILD CARE HEALTH AND DEVELOPMENT Volume: 29 Issue: 5 Pages: 357-366 Published: SEP 2003	ISI Web of Knowledge	
Palisano RJ, Tieman BL, Walter SD, Bartlett DJ, Rosenbaum PL, Russell D, Hanna SE	19	5	Effect of environmental setting on mobility methods of children with cerebral palsy	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 45 Issue: 2 Pages: 113-120 Published: FEB 2003	ISI Web of Knowledge	
Samson-Fang L, Fung E, Stallings VA, Conaway M, Worley G, Rosenbaum P, Calvert R, O'Donnell M, Henderson RC, Chumlea WC, Liptak GS, Stevenson RD	19	8	Relationship of nutritional status to health and societal participation in children with cerebral palsy	JOURNAL OF PEDIATRICS Volume: 141 Issue: 5 Pages: 637-643 Published: NOV 2002	ISI Web of Knowledge	
Palisano RJ, Cameron D, Rosenbaum PL, Russell D	16	10	Stability of the Gross Motor Function Classification System	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 48 Issue: 6 Pages: 424-428 Published: JUN 2006	ISI Web of Knowledge	
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Miller LT, Polatajko HJ, Missiuna C, Mandich AD, Macnab JJ	15	4	A pilot trial of a cognitive treatment for children with developmental coordination disorder	HUMAN MOVEMENT SCIENCE Volume: 20 Issue: 1-2 Pages: 183-210 Published: MAR 2001	ISI Web of Knowledge	
Shriberg LD, Flipsen P, Thielke H, Kwiatkowski J, Kertoy MK, Katcher ML, Nellis RA, Block MG	15	1	Risk for speech disorder associated with early recurrent otitis media with effusion: Two retrospective studies	JOURNAL OF SPEECH LANGUAGE AND HEARING RESEARCH Volume: 43 Issue: 1 Pages: 79-99 Published: FEB 2000	ISI Web of Knowledge	
Wilson K, Elliott S, Law M, Eyles J, Jerrett M, Keller-Olaman S	14	3	Linking perceptions of neighbourhood to health in Hamilton, Canada	JOURNAL OF EPIDEMIOLOGY AND COMMUNITY HEALTH Volume: 58 Issue: 3 Pages: 192-198 Published: MAR 1 2004	ISI Web of Knowledge	
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Bartlett, DJ; Palisano, RJ	9	3	A multivariate model of determinants of motor change for children with cerebral palsy	PHYSICAL THERAPY Volume: 80 Issue: 6 Pages: 598-614 Published: JUN 2000	ISI Web of Knowledge	Literature Review
Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S.	9	7	Patterns of participation in recreational and leisure activities among children with complex physical disabilities	DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY Volume: 48 Issue: 5 Pages: 337-342 Published: MAY 2006	ISI Web of Knowledge	

Klassen, AF; Miller, A; Fine, S	7	2	Agreement between parent and child report of quality of life in children with attention-deficit/hyperactivity disorder	<b>CHILD CARE HEALTH AND DEVELOPMENT</b> Volume: 32 Issue: 4 Pages: 397-406 Published: JUL 2006 Times Cited: 7	ISI Web of Knowledge	
Hanna SE, Law MC, Rosenbaum PL, King GA, Walter SD, Pollock N, Russell DJ	7	4	Development of hand function among children with cerebral palsy: growth curve analysis for ages 16 to 70 months	<b>DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY</b> Volume: 45 Issue: 7 Pages: 448-455 Published: JUL 2003	ISI Web of Knowledge	
DeMatteo, C; Matovich, D; Hjartarson, A	6	2	Comparison of clinical and videofluoroscopic evaluation of children with feeding and swallowing difficulties	<b>DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY</b> Volume: 47 Issue: 3 Pages: 149-157 Published: MAR 2005	ISI Web of Knowledge	
King GA (King, G. A.), Law M (Law, M.), King S (King, S.), Hurley P (Hurley, P.), Hanna S (Hanna, S.), Kertoy A (Kertoy, A.), Rosenbaum P (Rosenbaum, P.)	5	4	Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC	<b>CHILD CARE HEALTH AND DEVELOPMENT</b> Volume: 33 Issue: 1 Pages: 28-39 Published: JAN 2007	ISI Web of Knowledge	
Stewart D, Law M, Russell D, Hanna S	4	1	Evaluating children's rehabilitation services: an application of a programme logic model	<b>CHILD CARE HEALTH AND DEVELOPMENT</b> Volume: 30 Issue: 5 Pages: 453-462 Published: SEP 2004	ISI Web of Knowledge	
Gaines, R	3	1	Therapist self-disclosure with children, adolescents, and their parents	<b>JOURNAL OF CLINICAL PSYCHOLOGY</b> Volume: 59 Issue: 5 Pages: 569-580 Published: MAY 2003	ISI Web of Knowledge	
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Missiuna C (Missiuna, Cheryl), Gaines R (Gaines, Robin), Soucie H (Soucie, Helen)	2	1	Why every office needs a tennis ball: a new approach to assessing the clumsy child	<b>CANADIAN MEDICAL ASSOCIATION JOURNAL</b> Volume: 175 Issue: 5 Pages: 471-473 Published: AUG 29 2006	ISI Web of Knowledge	
Magalhaes LC (Magalhaes, Livia C.), Missiuna C (Missiuna, Cheryl), Wong S (Wong, Shirley)	2	2	Terminology used in research reports of developmental coordination disorder	<b>DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY</b> Volume: 48 Issue: 11 Pages: 937-941 Published: NOV 2006	ISI Web of Knowledge	Literature Review
Missiuna C, Pollock N, Law M, Walter S, Cavey N	2	1	Examination of the perceived efficacy and goal setting system (PEGS) with children with disabilities, their parents, and teachers	<b>AMERICAN JOURNAL OF OCCUPATIONAL THERAPY</b> Volume: 60 Issue: 2 Pages: 204-214 Published: MAR-APR 2006	ISI Web of Knowledge	
King G (King, Gillian), Law M (Law, Mary), Hanna S (Hanna, Steven), King S (King, Susanne), Hurley P (Hurley, Patricia), Rosenbaum P (Rosenbaum, Peter), Kertoy M (Kertoy, Marilyn), Petrenchik T (Petrenchik, Terry)	1	1	Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis	<b>CHILDRENS HEALTH CARE</b> Volume: 35 Issue: 3 Pages: 209-234 Published: SUM 2006	ISI Web of Knowledge	