



# Canadian Child & Youth Health Coalition (CCYHC)

## 2009-2010 Annual Report

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*The infrastructure of the CCYHC is generously supported by a grant from the SickKids Foundation – National Grants Program.*

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### Overview

There is strength in numbers. Eleven national organizations have come together under the umbrella of the Canadian Child & Youth Health Coalition (CCYHC) with a *common vision to advance the cause of child and youth health and health care in Canada.*

- Canadian Association of Paediatric Health Centres (CAPHC)
- Canadian Child Health Clinician Scientist Program (CCHCSP)
- Canadian Family Advisory Network (CFAN)
- Canadian Paediatric Society (CPS)
- Council of Canadian Child Health Research (CCCHR)
- Kids Health Foundation (KHF)
- Maternal, Infant, Child, & Youth Research Network (MICYRN)
- National Infant, Child, & Youth Mental Health Consortium (The Consortium)
- Paediatric Chairs of Canada (PCC)
- Pediatric Surgical Chiefs of Canada (PSCC)
- Safe Kids Canada (SKC)

Established in 2004, the collective mandate of CCYHC is to foster the development of new knowledge in the field of child and youth health and health care, promote the application of this knowledge, support education and strengthen national advocacy. The Coalition members represent a broad range of experts and stakeholders across the continuum of child and youth health including all children's hospitals, the majority of child and youth rehabilitation centres, all academic child health research institutes, all departments of paediatrics, all paediatric surgical departments, the national association of paediatricians, over 30 child and youth focused mental health organizations, a leading national child and youth injury prevention organization, and 15 family advisory groups. As such, CCYHC has an unparalleled capacity to develop, implement and assess national programs and efficiently effect changes in policy and practice that can lead to improvement in child and youth health outcomes.

The CCYHC is collaborative and consensus-driven. While each of the Coalition members holds distinct mandates, they share many common goals and objectives. The Coalition firmly believes that the synergistic strength gained through formal collaboration on jointly established strategic priorities provides a strong vehicle for achieving more in identified areas of concern than individual member organizations can accomplish independently. The Coalition is unique in Canada and has already demonstrated the importance of such collaboration.

In order to realize each of its primary objectives, the Coalition has implemented and /or supported several important initiatives and programs over the last five years such as the *National Child and Youth Health Indicators Program* including the *Canadian Pediatric Surgical Wait Times Strategy*; the *Maternal, Infant, Child and Youth Research Network (MICYRN)*; the first phase of a *Child & Youth Health Human Resources Strategy*; *The Child & Family in the Health Care System*; and *The Boulton Initiative - Child Rights Education for Health Professionals*.

Each of these initiatives is informed by the specific expertise and capacities of each of the Coalition members across the spectrum of new knowledge development from research, dissemination, translation, and application to policy and practice. Moreover, these initiatives

provide significant support and leadership to education and training strategies towards ensuring a workforce prepared to meet the health needs of children and youth at all levels of promotion, prevention and care.

The Coalition has also worked in an advocacy role to provide support and feedback to numerous child and youth health related initiatives on a national level and has actively sought to expand its membership to further strengthen its capacity to achieve its mandate.

To ensure that the work of the Coalition is supported and able to proceed in a well-organized and effective manner, the role of National Coordinator is recognized by the Coalition members as being an essential part of the CCYHC Management Team/Secretariat. The National Coordinator provides leadership to the Coalition, oversees the operations of the national network, and implements the strategic directions of the Coalition's Steering Committee.

## Goals

Capitalizing on the combined strengths of its many partnerships, the Coalition has specifically established the following six overall goals to guide its work and fulfill its mandate (*selected examples of Coalition initiatives designed to address each goal are identified in brackets*):

- Ensure rapid and efficient development of new knowledge through research in areas of national importance to the health and well-being of children and youth;  
(*e.g. Maternal, Infant, Child, & Youth Research Network (MICYRN)*)
- Facilitate and support the application of evidence-based practice and policy;  
(*e.g. Child and Youth Health Indicators Program; MICYRN; Child & Youth Health Human Resources Strategy*)
- Stimulate the development and evaluation of models of practice, quality care and safety, supporting efficient, effective, and accessible systems of child and youth health care;  
(*e.g. Canadian Pediatric Surgical Wait Times Pilot Project – Stage I and II; Child and Youth Health Indicators Program; Child & Youth Health Human Resources Strategy*)
- Develop and sustain excellence in transdisciplinary child and youth health education, research and training;  
(*e.g. MICYRN; Child & Youth Health Human Resources Strategy; The Boulton Initiative - Child Rights Education for Health Professionals*)
- Advocate on national child and youth health, health care and policy issues that will benefit from the collective expertise and influence of the Coalition;  
(*e.g. "Reaching for the Top: A Report by the Advisor on Healthy Children and Youth", "Racing for Kids' Health" – Establishing Priorities in Canadian Child & Youth Health Research (brochure), Canada's Child & Youth Health Charter; The Child & Family in the Healthcare System; The Boulton Initiative - Child Rights Education for Health Professionals; Letters of Support*)
- Actively seek out new members to strengthen the Coalition's capacity to achieve its goals  
(*Six new members welcomed to the Coalition since its inception – **one in the last year***).

The Coalition is committed to strategic growth and will continue to harness the broad multi-disciplinary expertise of its many members as it works to identify and implement priority national initiatives and programs to advance the cause of child and youth health and health care in Canada.

***CCYHC is proud of its achievements over the past twelve months and is very grateful to the SickKids Foundation – National Grants Program for their continued encouragement and financial support.***

## Operational Infrastructure

### □ **Communication Plan**

In 2007, a formal communication plan was developed by the Coalition National Coordinator to optimize the flow of information across the Coalition members as well as increase awareness of Coalition activities and accomplishments across the broader community of member constituents, stakeholders and external partner organizations. Among the specific communication tools identified in the plan were the development and implementation of a website and an e-Newsletter.

- **Website.** The Coalition website was developed and launched in 2007 and continues to be updated on a regular basis (<http://www.ccyhc.org>).
- **E-Newsletter.** The Coalition e-Newsletter was circulated in April and September of 2009 and in February 2010 ([http://www.ccyhc.org/news\\_newsletter.html](http://www.ccyhc.org/news_newsletter.html)). This newsletter is circulated to nearly 400 individuals including relevant constituents and stakeholders, project partners, and independent subscribers through the website. Distribution is then multiplied through institutional listserves of the Coalition members and other organizations.
- **Annual Report.** Once the 2008 - 2009 Coalition annual report to the SickKids Foundation – National Grants Program was completed and approved, an abbreviated version was developed and circulated to the Coalition members, stakeholders, and project partners; the report was also made available on the CCYHC website. This process will be followed again upon submission of the 2009-2010 report.

### □ **Membership Expansion**

From the outset, the Coalition has identified the engagement of new members as an important strategy to strengthen its capacity to address specific goals which have been identified. In the last year, CCYHC has been very pleased to welcome the Kids Health Foundation (KHF) to the Coalition:

- **Kids Health Foundation (KHF).** The Kids Health Foundation (The Sandbox Project) was founded in 2009 with a mission to make Canada the healthiest place on earth for kids to grow up. By working directly with parents, academia, the not-for-profit sector, government, and industry, KHF seeks to raise awareness, pursue research, and collaborate towards developing solutions and better public policy related to child and youth health in Canada. As such, KHF will provide valuable input to the Coalition as it continues to work towards achieving its mandate of improving the overall health and care of Canada's youngest citizens. The Kids Health Foundation joined the Coalition in March 2010.

□ **CCYHC Steering Committee**

Each member of the Coalition is represented on the Steering Committee by two individuals; one of the representatives is the Executive Director or equivalent of the member organization/program. Primary decision-making authority with respect to the determination of strategic directions and work plan development rests with the CCYHC Steering Committee.

- **Change in Co-Chair.** Bob Armstrong's (PCC) term as CCYHC Co-Chair came to an end in 2009. As per an e-mail nomination and voting process held in August 2009, Ian Manion (The Consortium) was confirmed as incoming CCYHC Steering Committee Co-Chair (joining continuing Co-Chair, Marilyn Booth (CAPHC)), effective October 18<sup>th</sup>, 2009.
- **Past Chair.** Bob Armstrong moved into the position of Past Chair on October 18th, 2009.

Until October 2009, the CCYHC Steering Committee met on a monthly basis (10 X/year). With the establishment of the new Executive Committee in October (see below), the Steering Committee meeting schedule was adjusted to accommodate meetings on a quarterly basis (i.e. 3 times a year via teleconference + 1 face-to-face retreat / business meeting). Attendance at meetings throughout 2009 and the beginning of 2010 was excellent with the majority of committee members participating at each teleconference.

□ **CCYHC Executive Committee**

As per the CCYHC Terms of Reference, when the Coalition reaches a minimum membership of 10 organizations, a smaller Executive Committee is to be established. The Executive Committee comprises the 2 Co-Chairs, the Past Chair, **2 member representatives** (see below); and the National Coordinator. The CCYHC Executive Committee was established in October 2009 and has been meeting on a monthly basis (via teleconference) since that time. Regular attendance at these meetings is excellent with at least 4 of the 5 members participating at each teleconference.

The CCYHC Executive Committee provides leadership and direction to the CCYHC Steering Committee in the implementation and advancement of the strategic plan which is established on a yearly basis by the CCYHC Steering Committee at its annual retreat.

The CCYHC Executive Committee is accountable to the CCYHC Steering Committee and each member of the CCYHC Executive Committee represents the interests of the full CCYHC Steering Committee and not their individual member organizations / programs.

- **Member Representatives.** In September 2009, a nomination and voting process was conducted to identify two Coalition member representatives to sit on the newly established CCYHC Executive Committee. Based on responses from 20 / 22 Steering Committee members, Elaine Orrbine (CAPHC) and Gwen Burrows (CCCHR) were elected to assume these positions.

The CCYHC Executive Committee meets via teleconference 10 times a year and at the discretion of the Co-Chairs to operationalize / implement the activities outlined in the strategic plan established by the CCYHC Steering Committee.

□ **Annual Retreat**

On July 9<sup>th</sup> and 10<sup>th</sup>, 2009, the Steering Committee of the Canadian Child and Youth Health Coalition (CCYHC) held a Retreat in Montreal to review and build upon the existing strategic plan and to discuss priority actions for moving the various Coalition initiatives forward. The first day of the Retreat was dedicated to discussion related to building research collaboration in Canada beginning with updates from the Maternal, Infant, Child & Youth Research Network (MICYRN), the CCYHC Child & Youth Health Indicators Program, and the Canadian Child Health Clinician-Scientist Program (CCHCSP) and culminating in the consideration of various strategies and partnerships to advance clinical and health services research.

Discussion on day two began with a recap of the previous day and then centered on key issues related to advocacy, health human resources, access and wait times, CCYHC steering and executive committee structures, and external evaluation. The Coalition Operating Budget and Membership Formula were also reviewed and potential new members to be invited to join the Coalition in the coming year were considered.

The Retreat was well-attended and productive with full representation from each of the Coalition's ten member organizations. Dr. Michael Kramer and Mr. Pierre Turcotte were also welcomed as special guests to participate in discussions related to building national research collaboration and the importance / feasibility of establishing a clinical and health services research agenda. Dr. Kramer is Scientific Director, CIHR-Institute of Human Development, Child, and Youth Health (IHDCYH); Pierre Turcotte, is Assistant Director, Partnerships and International Relations, CIHR-IHDCYH. CIHR-IHDCYH has been an important Coalition partner since its inception and has been integral to the development and advancement of the CCYHC Child and Youth Health Indicators Program.

□ **Annual Symposium**

To raise awareness of CCYHC and its activities as well as bring attention to critical areas of national importance in child and youth health the Coalition holds a Symposium once per year in conjunction with the annual meetings of many groups including the Canadian Association of Paediatric Health Centres (CAPHC), the Canadian Child Health Clinician Scientist Program (CCHCSP), the Canadian Family Advisory Network (CFAN), the Council of Canadian Child Health Research (CCCHR), the Paediatric Chairs of Canada (PCC), and the Pediatric Surgical Chiefs of Canada (PSCC).

On October 18th, 2009, CCYHC held a symposium in Halifax, Nova Scotia entitled ***“Developing Collaborative Partnerships with Government: How can we be more effective?”*** Focused on building collaborative relationships with government across sectors (municipal, provincial, territorial, and federal) towards advancing the cause of child and youth health and health care in Canada, the symposium attracted participants representing a broad range of constituents and stakeholders across the continuum of child and youth health including service providers, administrators, and researchers. Highly informative and inspiring presentations were provided by Ms. Keli Anderson (Executive Director, FORCE Society For Kids Mental Health Care), Ms. Pamela Fuselli (Executive Director, Safe Kids Canada / SecuriJeunes Canada), and Dr. Charlotte Moore (Provincial Lead, Maternal, Child and Youth Strategy, Health System Strategy Division, MOHLTC - Ontario).

Information from a variety of key perspectives was presented including but not limited to 1) the realities, structures, and constraints within government which impact the development of

collaborative partnerships; 2) effective strategies for engaging decision-makers across government sectors to implement changes in policy; 3) effective strategies for articulating the value of investing in children and youth; and, 4) leveraging alliances and opportunities beyond the child and youth health sector.

The Coalition looks forward to applying information gathered at this event to the development of an effective political advocacy plan informed by continued dialogue with the symposium speakers as well as the broad community of professionals dedicated to the health and well-being of Canada's children, youth, and their families.

The **2010 CCYHC Annual Symposium** will focus on interdisciplinary/inter-professional models of care and will explore and assess links between specific new and / or innovative interdisciplinary models and improved outcomes. This topic provides good synergy with the national symposium CCYHC is currently planning in partnership with SickKids centered on issues related to the non-MD health care practitioners clinician-scientist role as well as the theme of CAPHC's 2010 Conference entitled: ***"What's working? Strategies and practices that are improving the health outcomes of Canadian children and youth."***

## Programs and Initiatives

The Coalition has clearly articulated a process for defining national priorities, ensuring that the projects selected do not duplicate individual activities of the member organizations, and that the outcomes of the Coalition's national projects can be linked back to individual organizations for follow through. CCYHC identifies a lead organization and determines how each of the other member organizations will be engaged in the initiative; there is collective ownership of each Coalition project through regular feedback to the CCYHC steering committee. The Coalition has made significant progress towards achieving many of its goals and objectives within the context of several key initiatives and programs.

### □ **CCYHC Child and Youth Health Indicators Program**

It is widely accepted that the current lack of robust evidence-based indicators and standards severely impedes our ability to evaluate the status of the health of children and youth and the health care they receive. There is currently no consistent methodological basis for national comparative analyses to achieve an optimal level of health and health service delivery for Canadian children and youth. Building on work that began in May 2004, CCYHC has continued to develop a national child and youth health indicators strategy for indicator development, validation and uptake to support empirically based policy and decision-making. Under the auspices CCYHC, leadership of the national indicators program is undertaken by CAPHC.

As previously reported, following the implementation of several workshops between May 2004 and May 2006, CIHR-IHDCYH, the CCYHC, and 13 partners announced the launch of a **Request for Applications (RFA)** on *Partnerships for Child and Youth Health Indicators* in December 2006. The purpose of this RFA is to support teams of researchers and decision makers to develop and apply indicators of child and youth health and health care. Twenty-one applications were received and seven were awarded funding in January 2008. The successful applicant teams are currently conducting research projects of up to 3 years duration on pediatric indicators in thematic areas identified as high priority by CIHR, CCYHC and their partners.

Subsequent to the 2008 Retreat, the Coalition established the CCYHC Indicators Advisory Committee and, over the last years, the group has worked to further develop several strategic

partnerships and linkages designed to move the indicators program forward. Specific activities are summarized here:

- **Collaboration with the Canadian Institute of Child Health (CICH)**

CCYHC has been invited by the Canadian Institute of Child Health (CICH) to participate in the development of the fourth edition of *The Health of Canada's Children: A CICH Profile*. The last publication of the Profile was in 2000. The next edition of the Profile will be delivered as an electronic service that will allow for timely updating of information, inclusion of new research and addressing of emerging issues in a way that is not possible with a print version. An online version will greatly increase ease and accessibility for health professionals, academics, government departments, corporations, and the general public.

The Coalition Steering Committee has unanimously agreed that an online version of the Profile would be an efficient mechanism for reporting on national quality child and youth health care indicators which would capitalize on the ongoing work of CICH and align with the broader Coalition strategy of identifying and promoting the uptake of validated child and youth health indicators.

On February 9th, 2010 CCYHC and CICH finalized and signed a Memorandum of Understanding which will guide collaboration on a chapter of the Profile centered on indicators related to ***children and youth in the health care system***. As part of this agreement, the Coalition has committed to support CICH funding strategies related to health care indicators within the overall budget of the Profile.

On February 15th, CIHR launched a funding competition to support teams of researchers and knowledge users to produce knowledge syntheses and scoping reviews that will contribute to the use of synthesized evidence in decision-making and practice (<http://www.researchnet-recherchenet.ca/rnr16/vwOpprtntyDtIs.do?prog=944&view>). Applications to synthesize knowledge in any of CIHR's four themes - biomedical; clinical; health services and policy; population and public health - are eligible provided that they respond to a knowledge user identified need.

CICH has been identified as a Partner on this funding initiative and is working with the Coalition to determine the feasibility of developing a proposal. If a submitted proposal is successful, the funding obtained (\$100K) will be used to support the work of the Coalition (the Researcher Applicant) in the development of the CICH *Profile* chapter focused on children and youth in the healthcare system.

CICH will provide coordination of the process, liaison with the Profile National Advisory Group / Expert Advisors, publication of the resulting information as a module of the on-line Profile, and maintenance of currency of the material together with partners. The approach used to produce the synthesis will be collaborative and consultative and will be based on advice of the CICH Profile National Advisory Group combined with the input of the CCYHC Indicators Advisory Committee.

- **Continued collaboration with CIHR – IHDCYH**

***Joint Invitational CCYHC / CIHR-IHDCYH Health Services Research Workshop***

The health care system in Canada is an area in critical need of new and innovative research. Research in maternal, child, and youth health services is no exception – there

is a need to better define research priorities, identify gaps, plan for future research, and build capacity in this area.

In May 2009, members of the CCYHC Indicators Advisory Committee met with the CIHR – Institute for Human Development, Child & Youth Health (IHDCYH) and agreed to host a joint workshop in 2010 centered on indicator development / uptake and exploration of effective mechanisms for building health services research capacity in Canada. This workshop, entitled **“A Health Services Research Agenda: Building Capacity within the Maternal, Child, & Youth Sector”**, was held on February 18<sup>th</sup> and 19<sup>th</sup>, 2010, in Toronto at the Sheraton Gateway Hotel.

The workshop brought together 50 Canadian experts and key stakeholders in health services research in an effort to improve the quantity and quality in this important domain. This event provided an excellent opportunity to engage in dialogue towards identifying and prioritizing strategies for improving capacity in maternal, child, and youth health services research and to explore collaborative strategies for promoting indicator uptake, implementation, and knowledge-transfer across the funded projects in the *Partnerships for Child and Youth Health Indicators initiative*.

From the perspective of the Coalition, the workshop highlighted opportunities for CCYHC to play both a leadership and catalyst role in progressing health services research as well as indicator identification / development and application / uptake in maternal child and youth health. Michael Kramer’s participation was a critical element in the success of the workshop as it underlined the importance of our efforts. It was clear that there is potential to have a direct impact on IHDCYH’s activities and we will continue to explore opportunities going forward.

A workshop report is in development and will be disseminated through the Coalition networks over the coming weeks. Symposium organizers – CCYHC and CIHR-IHDCYH – will be responsible for facilitating implementation of recommendations contained in the report. Workshop presentations are available for viewing on the Coalition website at: [http://www.ccyhc.org/work\\_indicators\\_rfa.html#workshop](http://www.ccyhc.org/work_indicators_rfa.html#workshop)

▪ **Collaboration with the Ontario Ministry of Health - “Dashboard” Consultation**

In July 2009, Dr. Charlotte Moore, the Provincial Lead for Maternal, Child and Youth Health Strategy at the Ontario, Ministry of Health and Long-Term Care has asked the Coalition to take part in a formal stakeholder consultation to assist in the identification of key maternal, child, and youth health indicators to be used in the development and implementation of a “balanced scorecard” approach.

The Coalition Steering Committee has unanimously agreed that this is an important opportunity to link with provincial government for knowledge exchange and relationship building and looks forward to participating in the consultation later in 2010.

□ **Canadian Paediatric Surgical Wait Times Strategy**

In November 2005, Dr. Brian Postl, Federal Adviser on Wait Times to the Prime Minister, approached the Canadian Child and Youth Health Coalition to lead an initiative to develop recommendations for a national paediatric surgical wait times strategy. In February 2006, the Coalition, in collaboration with the Pediatric Surgical Chiefs of Canada (PSCC), brought together all sixteen paediatric academic health sciences centres in Canada in an

unprecedented collaborative initiative: the Canadian Paediatric Surgical Wait Times (CPSWT) Project.

On January 11th, 2007 Prime Minister Harper announced funding in support of a national paediatric surgical wait time project to identify children waiting longer than the acceptable time for surgery (CPSWT Project – Stage 1: March 2007 – June 2008). The CPSWT Project is the first collaborative in Canada to develop a standardized methodology to measure, monitor and manage paediatric wait times in all surgical subspecialties, at hospitals across jurisdictions. The database contains mature paediatric surgical wait time statistics for approximately 150,000 cases from September 2007. The data enables hospitals to benchmark their results thanks to the adoption of standardized access targets (the Paediatric Canadian Access Targets for Surgery, P-CATS). P-CATS were developed by over 100 paediatric surgeons in expert panels and furthermore accepted by the Paediatric Surgical Chiefs of Canada (PSCC).

The CPSWT Project received the *2009 Gold Leadership Award* by the Institute of Public Administration of Canada. The project won the award for its outstanding vision, innovation and collaboration, in pursuit of better outcomes for Canadian children and youth.

In June 2008, Health Canada announced further funding to implement CPSWT Project – Stage II (until March 2010) and, in a relatively short period of time, the CPSWT Project has had an unparalleled impact on wait times across Canada. Namely, the project has:

- Developed a common methodology to measure, monitor and manage paediatric surgical wait times and implemented it at 24 hospitals located in 8 jurisdictions;
- Generated an unprecedented central database containing data, benchmarks and trends from key paediatric facilities across Canada in all surgical subspecialties;
- Provided actionable management information and strategies for the reduction of wait times for its participating hospitals.

This project has demonstrated unprecedented achievements in the development and successful implementation of a common language to measure and address wait times in Canada. Surgeons and administrators at participating hospitals find this system easy to use, objective, and useful for making clinical and management decisions. The project is also leading initiatives that leverage and share the expertise of its participants to support the management of wait lists, as follows:

- The development of Clinical Practice Guidelines for the Management of Cryptorchidism in Children and Youth for both primary and tertiary care providers based on literature review and expert panel opinion, with key recommendations for referral, treatment and follow-up practices.
- An analysis of capacity at participating Paediatric Academic Health Sciences Centres to identify and estimate any gap between capacity and demand for paediatric surgery.
- A compilation of best practices in measuring operating room performance and efficiency based on literature review of best practices and a survey of current practices at participating hospitals.

At the national level, the P-CATS database represents the only source of paediatric wait time information from across Canada currently available in this country. The data, collected since September 2007 from key paediatric facilities, shows that on average, approximately one third of paediatric patients received surgery past their access targets.

At the local level, participating hospitals have used the P-CATS data to reduce the percentage of children not meeting access targets by active management of their wait lists and resources, with notable results. Monthly data analyses and reports have enabled participating hospitals to: 1- prioritize, schedule and manage wait list cases based on acuity; 2- distribute resources based on need; and 3- benchmark themselves with their paediatric peers in Canada.

The CPSWT Project is currently seeking funding to continue the collaboration, data collection and benchmarking, in order to support the effective management of wait lists and improve access to care for Canada's children and youth.

#### □ **Wait Times in Other Priority Areas**

Following on the successes of the Canadian Pediatric Surgical Wait Times Project, the Coalition has explored how this work could be leveraged to develop wait times strategies in other priority areas such as mental health and child development services. To this end, the *National, Infant, Child and Youth Mental Health Consortium* (The Consortium) was invited to join CCYHC in October 2007 in order to strengthen the focus on infant, child and youth mental health within the priorities of the Coalition. The Consortium was welcomed as an official CCYHC member in December 2007.

Over the last year, the Coalition has continued to actively support the agenda of this group - promoting and advocating nationally on behalf of child and youth mental health issues in a manner consistent with the identified priorities and activities of the Consortium. In particular, the Coalition is working to facilitate the development of a national strategy around access and wait times in child and youth mental health and, in November 2009, provided funding (\$10K) to support the ***2nd National Invitational Symposium on Child and Youth Mental Health: Getting in the Right Door at the Right Time.***

The purpose of the 2nd National Symposium was:

- To bring together key stakeholders, representing different areas of child and youth mental health from across Canada and share/develop provincial or territorial action plans that will help to inform the national mental health strategy.
- To analyze and discuss the Mental Health Commission's Mental Health Strategy and Evergreen Framework as it pertains to the diverse needs of each province and territory.
- To identify common issues and opportunities for child and youth mental health policies, program, research and activity development.
- To ensure the key issues and opportunities for different groups directly affected by child and youth mental health services are addressed.
- To draw up next steps for building more effective, integrated and inclusive models, research programs, plans and strategies that can further support the development of child and youth mental health in Canada.

The 2nd National Symposium built on the existing network of partnerships focused on child and youth mental health, and identified next steps and plans of action that will inform Canada's new mental health strategy. To the extent that the Coalition can bring important leadership and broad support of the health community to the child and youth mental health agenda, it is committed to ensuring that continued attention and resources are directed to this issue.

□ **Maternal, Infant, Child and Youth Research Network (MICYRN)**

In 2006, CCYHC identified a national clinical research network as a top priority and established the Maternal, Infant, Child, and Youth Research Network (MICYRN). MICYRN became a full Program Member of the Coalition in May 2007. The Director of MICYRN is appointed by CCYHC, sits on the CCYHC Steering Committee, and represents the interests of MICYRN to the Coalition; the Coalition brings to the Director the broader issues of the Coalition. The strategic and operational decision making of MICYRN is vested in the Director.

MICYRN's vision is that the synergistic strength gained from a formal collaborative network of leading researchers and integrated infrastructure will spur tremendous advances unattainable by individual groups. Research partners consist of established and emerging clinical teams, research networks and groups committed to integrating resources to maximize returns. MICYRN has established Core programs in research partnerships, training, knowledge translation (KT), research methods, research ethics and regulatory affairs and funding partnerships. All core programs support a diverse range of quality clinical research as part of a coordinated and aggressive research effort to optimize health behaviour, interventions and overall health care from pre-conception to maturity.

The last year has been a very productive time for MICYRN – the following comprises a brief overview of 2009 activities and highlights:

- In July 2008, Dr. Terry Klassen announced that he would be stepping down from his role as the Director of MICYRN in January 2009 in order to embark on a research sabbatical outside Canada. In April 2009, after a search process led by Dr. Victor Han (CCCHR) on behalf of the Coalition, Dr. Anne Junker and Dr. Aubrey Tingle were welcomed as Director and Associate Director of MICYRN, respectively.
- Since assuming leadership of MICYRN, Drs. Junker and Tingle have had numerous meetings with groups (CCCHR, Children' Hospitals Foundation Executives), the chairs of MICYRN's original Cores, and leaders and investigators associated with multicentre studies and national research networks. A prime agenda was to determine the "value add" that MICYRN brings to a very active national research community. Work done to-date by MICYRN demonstrates that there is a tremendous amount of collaborative research activity relevant to child-maternal health in Canada.

It is agreed that the value-add of MICYRN is its ability to deliver gains in efficiency, economies of scale, and reduced duplication of effort, that will allow more resources to be directed to research studies. Harmonization of standards and promotion of 'best practices' will increase the quality of clinical research conducted in Canada. Rapid and efficient linking of disciplines, new methods, and new technologies will give Canadians a maternal-child health research infrastructure that can quickly assess potential treatments and diagnostic tools. Through shared infrastructure and knowledge, MICYRN will hasten initiation of new studies, conserve and enhance intellectual and physical resources, encourage multi-disciplinary connections, and identify and support research in priority areas.

- In its first phase, after being founded in 2006, MICYRN was a 'virtual' network. While actively engaging enthusiastic participants, it was difficult for those not associated with the network to determine how to get connected. The new directors proposed a shift, which was unanimously endorsed by the Council for Canadian Child Health Research (CCCHR) and welcomed by the Canadian Children's Hospital Foundation executives when presented at meetings in October 2009, to firmly associate MICYRN with the

participating academic health centres across the country.

- The CCCHR also responded to a call for nominations of individuals willing to form a small ad hoc MICYRN Planning Committee, with a view to developing an action plan. A first meeting of this group was held in Ottawa, December 2009. There was affirmation of MICYRN's Vision and Mission, and subsequent development of a planning framework; goals, strategies and outcome measures.
- In terms of achievements to date, MICYRN has laid solid groundwork for continued growth and development. Work began by conducting reviews and environmental scans and further information was gathered through the sponsoring of workshops and meetings. MICYRN has many initiatives currently in progress, is assisting new networks in their start-up phase, and is offering support and guidance to researchers building new national collaborative research networks.

#### □ **Development of a Health Human Resource Strategy**

Health human resources (HHR) has been identified by CCYHC as an important area where the combined efforts and expertise of the individual member organizations could have significant influence. Over the last year, the Coalition has continued to explore health human resource issues in the child and youth sector and to identify specific opportunities and challenges which can be potentially addressed by Coalition initiatives in this area.

Specific areas of focus have included:

- 1) Exploring innovative models of care towards identifying novel paradigms to guide HHR planning within the child and youth sector;
- 2) Establishing collaboration with the Canadian Institute of Health Information (CIHI) to facilitate better data collection related to child and youth health human resources;
- 3) Examining the issue of job creation and support for non-MD clinician-scientists within academic health science centres.

#### ▪ **Innovative Models of Care**

In preparation for a focused workshop to facilitate discussion around models of care, the Coalition commissioned a scoping review / background document in March 2009 to examine innovative models of care across the child and youth health care system. The review yielded only limited information and did not provide significant models of best practice which could be arguably applied across the country and within other contexts. As a result, the Coalition opted not to proceed with the workshop and determined to identify a more productive and feasible course of action through continued dialogue.

At the Coalition retreat in July 2009, the Coalition Steering Committee agreed to a shift from an examination of innovative models of care (and corresponding HHR issues) generally to a more targeted / strategic approach focusing on models within specific populations (e.g. mental health, chronic illness, etc.). To this end, the Coalition is currently exploring opportunities to support HHR work being undertaken by the Consortium in relation to child and youth mental health as well as assessing the feasibility of considering HHR issues related to the way in which children with chronic illness receive care (i.e. consulting versus primary care paediatricians, the role of nursing / nurse practitioners, etc.).

- **Collaboration with the Canadian Institute of Health Information (CIHI)**

In June 2009, the Coalition established a collaborative partnership with the Canadian Institute of Health Information (CIHI) around the collection of child and youth health human resource data. A primary aim of this collaboration is to ensure that input from the child and youth health care community is used to inform the modification and improvement of national databases designed to capture accurate HHR information.

General objectives of this collaboration are to:

1. Establish precisely what kind of data CIHI is collecting and from where.
2. Establish a process whereby the Coalition and the HHR Working Group can have input into the enhancement and development of current and future databases intended to capture information about child and youth health professionals.
3. Ensure that the data CIHI collects is interpreted appropriately within the child and youth health care sector.

As one of its first projects, the Coalition and CIHI have agreed that collaboration towards enhancing the level of detailed information currently available to CIHI with respect to pediatricians and sub-specialists would be a useful enterprise; improved accuracy of the CIHI data related to pediatricians would facilitate research designed to analyze and address HHR related issues within the child and youth sector.

To this end, physician databases currently maintained by the CIHI, the Canadian Paediatric Society (CPS), and the Paediatric Chairs of Canada (PCC) are being reviewed in order to define the relative strengths and weaknesses of each and to determine possible synergies and opportunities for linking, comparison, and augmentation.

- **Clinician-Scientists / Training**

- **Partnerships to facilitate access to CCHCSP Training Modules**

Clinician-scientist training has long been considered a priority focus for Coalition action. To this end, MICYRN has established a relationship with the Canadian Child Health Clinician Scientist Program (CCHCSP), a CIHR funded Strategic Training Initiative in Health Research (STIHR) and has been working on developing relationships with other Canadian STIHRs. This relationship provides MICYRN members a vehicle to access the CCHCSP training modules that have been developed, as well as more STIHR resources in the future.

- **A National Non-MD Clinician-Scientist Symposium**

In addition to the partnership between MICYRN and CCHCSP, the Coalition is also participating in other collaborative clinician-scientist initiatives. Among the priority action items identified at the 2009 CCYHC Retreat was the examination of the issue of job creation and support for non-MD clinician-scientists within academic health science centres.

Over the past decade or more several academic centres have established, for the first time, doctoral training programs for the allied health professions; notably in nursing, rehabilitation sciences, clinical psychology, and pharmacology. In support of such trainees funding programs have emerged through personnel awards from CIHR central and its strategic training programs (e.g., Canadian Child Health Clinician Scientist Program, Autism Network) with the end result of building capacity for non-MD clinician-

scientists across the country. However, such investments in training and preparing these scientists for careers in clinical research, and any opportunities to benefit from their talent and skills, are negated when sustainable and stable career paths are not available to them and they forgo pursuing careers as clinician-scientists.

In order to begin to address this issue, CCYHC, in partnership with The Hospital for Sick Children, will host a day-long forum that will bring together national, provincial and local stakeholders to share information and strategize ways to fund and support the career viability of non-MD clinician-scientist roles in academic health science centres (AHSC) across the country. The event will include 2 keynote speakers to highlight the value of the non-MD clinician-scientist role to health care within society, barriers currently impacting the role's viability in AHSCs, and examples of existing models which have successfully secured the role in hospitals. Significant time will be dedicated to developing short-, medium-, and long-term strategies to ensure the ongoing sustainability of the non-MD clinician-scientist role.

Following the symposium, the organizers – The Hospital for Sick Children and the Canadian Child and Youth Health Coalition – will develop and disseminate an action strategy report recommending next steps and potential short-, medium-, and long-term solutions. Symposium organizers will be accountable for driving the implementation of recommendations contained in the action strategy report.

## Advocacy Activities

In addition to the identification and development of specific national priorities and strategies, the Coalition has also worked in an advocacy role to initiate and / or support several national child and youth related initiatives we believe stand to benefit from the Coalition's expertise and influence. A summary of specific advocacy work conducted over the last year follows:

### □ **The Child & Family in the Healthcare System**

While tremendous progress has been made in the supportive environments for children and families and their inclusion as part of the health care team, there continue to be concerns about significant variability across institutions and examples of poor practices that have had significant impacts on health outcomes. The Coalition believes that developing a common vision of how this interaction should occur and identifying / sharing best practices is an important undertaking, especially given the opportunity to have the Canadian Family Advisory Network (CFAN) centrally engaged in this initiative.

The *Child & Family in the Health Care System Working Group* was established in January 2009 and is comprised of representatives from CFAN, CAPHC, The Canadian Association of Child Life Leaders (CACLL), and several youth councils across Canada. Through a process of identifying priority issues, reviewing the literature, collecting data, anecdotal information and stories, this group is working to determine best practices and develop recommendations to be delivered to hospitals, rehabilitation centres, and government. The working group consults with the Coalition Steering Committee in a collaborative process to define feasible priorities and appropriate recommendations.

#### ▪ **Parent / Caregiver Presence at Surgical Induction and Recovery**

As its first priority, the *Child & Family in the Health Care System Working Group* has focused on the issue of parent / caregiver presence at surgical induction and recovery. Over the last year a literature search was conducted and surveys were developed,

piloted, and administered to hospitals, family, and youth councils to collect information about institutional policies and practices as well as patient and family experiences.

Data collection was completed in March 2010 and the working group is now engaged in the process of preparing a summary report and list of recommendations which to be reviewed by the Coalition Steering Committee at its 2010 Annual Retreat. Once the specific recommendations are finalized, an appropriate internal advocacy strategy will be implemented to ensure that messages are positioned and rolled out appropriately across the networks and institutions represented by the CCYHC members.

▪ **Transition from Hospital to “Real Life”**

Integration of the youth perspective is considered critical to the identification and development of priority action items. As such, the next priority under the umbrella of the *Child & Family in the Healthcare System* initiative focuses on a key issue of concern identified by participating youth members – the transition from hospital to “real-life”. A smaller independent youth group was established in November 2009 (facilitated by a child life specialist) to further refine target activities within this area and, in consultation with the larger working group, the specific transition back to school was selected for consideration.

A preliminary checklist of issues and needs for use by programs and staff helping youth move successfully from being in-patients back to school has now been developed and will soon be circulated to youth councils across Canada for review and input. In addition, the current president of the Canadian Association of Child Life Leaders (CACLL) is facilitating the collection of information about existing services and resources to help with this transition through the two Ambassadors of the Telus-Upopolis project.

The Coalition will report on these projects and the recommendations which emerge in greater detail as part of the 2010-2011 Annual Report.

□ **Child Rights Education for Health Professionals (The Boulton Initiative)**

The *Boulton Initiative* (BI) is a project which seeks to provide a strategy for educating health professionals around the use of the *UN Convention on the Rights of the Child* in practice. It is dedicated to promoting the well-being, health and development of children through establishing, infusing, and sustaining a child rights approach in child and youth focused health professional education and services. Involvement in this initiative is in keeping with CCYHC’s mandate and the Coalition has become a national partner supporting its planning and implementation.

The Boulton Initiative is in a partnership with the international Child Rights Education for Professionals (CRED-PRO) program of the International Institute for Child Rights and Development (University of Victoria, British Columbia). CRED-PRO has produced and tested a methodology for the development of culturally-applicable child rights education for health professionals. The BI intends to refine, strengthen, and augment this model as it is applied in different cultures and countries globally to be implemented in a manner specifically appropriate for Canada.

Through the voluntary contributions of time and expertise of health and child rights specialists; funding support from Public Health Agency Canada and the B.C. Children’s Hospital Department of Paediatrics; and the supportive interest of the Canadian Paediatric Society and the Canadian Child & Youth Health Coalition; a series of early planning

sessions, information programs, and exploratory research were conducted as definitive first steps in this endeavor.

An initial organizational and planning meeting for the Initiative was held March 28-29, 2008 that was sponsored by the Department of Paediatrics (UBC & BC Children's Hospital) and IICRD. It had financial support from the Public Health Agency of Canada. Other stakeholders included the Canadian Paediatric Society, UBC family practice medicine, the Canadian Child & Youth Health Coalition, and the Society for Children and Youth of BC. At this meeting an advisory council was established and plans were made for carrying the Boulton Initiative forward through close cooperation between paediatrics, family practice medicine, and nursing. As well, the planning team began to construct and engage with steering, education & curriculum, partners, First Nations, and child/youth consultation committees.

Over the course of 2009 through funding support from the Public Health Agency of Canada supplemented by support from the UBC Department of Pediatrics, a national plan has been developed to advance child rights education in the health care sector. The plan emphasizes assessment, planning and building on current programs to integrate a child rights approach in child health education, policies, and practices. It sets the expectation for making a child rights orientation a pervading component of, and influence in, pre-service and in-service training and train-the-trainer for health professionals. It envisions a national network of professionals working with a regionally and culturally adapted curriculum and articulated program. Over and above the focus on infusing the child rights approach through the training highlighted above, of particular importance is the development of plans for integration of child rights into health policy and a model of accountability for monitoring and evaluation of a child rights approach for the Canadian child/youth health sector. The plan can be viewed on the [CCYHC website](#).

A subsequent grant application is in preparation to the Public Health Agency of Canada to begin the implementation of this plan. This will include support for establishing a national advisory committee of child health professionals (pediatrics, family medicine, nursing, child psychiatry and Psychology) to guide an across-Canada survey to evaluate existing child rights education for health professionals and assess the gaps in the education for health professionals, development of a national generic child rights curriculum for health professionals and adapted to the different health specialties noted above, and the hosting of a meeting in Vancouver that would bring together the national representatives of this initiative.

#### □ **CCYHC Letters of Support**

##### ▪ **National Strategy on Childhood Injury Prevention - Throne Speech**

On March 10<sup>th</sup>, 2010 the Coalition wrote a letter to Prime Minister Harper conveying strong support for the Conservative government's commitment to a National Strategy on Childhood Injury Prevention as stated in the speech from the throne by Governor General Michaëlle Jean on March 3<sup>rd</sup>.

In the letter, the Coalition also took the opportunity to once again applaud the initiative of the Conservative government in appointing Dr. K. Kellie Leitch as special Advisor on Healthy Children and Youth and for taking an important leadership role in defining the pressing health issues facing Canada's children and youth within the context of *Reaching for the Top: A Report by the Advisor on Healthy Children & Youth*. The Coalition fully supports the identification of child and youth injury, childhood obesity and child and youth mental health as foci of health issues



impacting Canadian children and youth and commended the government on addressing the first of these priority issues.

▪ **NeuroDevNet - Networks of Centers of Excellence Application**

NeuroDevNet is the first trans-Canada initiative dedicated to studying children's brain development from both basic and clinical perspectives. In view of the essential role that clinical research and basic developmental neurobiology can and should play in child health research, and given the potential economic and social impact of improved child health outcomes, the Canadian Child & Youth Health Coalition was very pleased to write a letter strongly endorsing the **NeuroDevNet** application to the Networks of Centers of Excellence.

The network, led by Dr. Daniel Goldowitz, Senior Scientist at the Centre for Molecular Medicine and Therapeutics (CMMT) and the Child & Family Research Institute (CFRI), will be hosted by the University of British Columbia (UBC). It will receive \$19,572,000 in funding over five years from the Networks of Centres of Excellence of Canada (NCE). For more information about NeuroDevNet, please visit <http://www.neurodevnet.ca/>

▪ **Consultation – CIHR Draft Strategic Plan 2009/10 - 2013/14**

On May 28<sup>th</sup>, 2009, in response to a consultation request, the Coalition wrote a letter conveying general support for CIHR's draft Strategic Plan 2009/10 - 2013/14 - *Health Research Roadmap: creating innovative research for better health and healthcare*. The Coalition applauded the CIHR on the development of a comprehensive plan to continue its mission of facilitating new knowledge development and ensuring the transformation of knowledge into policies, practices, and services towards improving the health of Canadians and strengthening the Canadian health care-system.

While strongly endorsing the four key directions outlined in the plan as essential measures towards achieving the ultimate goal of better health for Canadians (i.e. investing in world-class excellence, addressing health and health system research priorities, accelerating the capture of benefits of health research, and achieving organizational excellence), the Coalition also expressed disappointment in the near absence of any significant acknowledgement of the specific challenges facing Canada's children and youth.

The health of our children and youth is a reflection of the health of our nation as a whole. As such, the Coalition recommended that the strategic plan incorporate language that reflects the life cycle and places importance on understanding the early influences on health and well-being and the impact discovery in this area will have on adult onset chronic diseases and disorders.

## 5. CCYHC External Evaluation

The Coalition is currently developing an evaluation framework for its activities. The draft logic model attached gives an overview of the Coalition's activities as a whole, with anticipated outcomes (our long term goals) from Coalition activities identified. Each of the projects/initiatives in which the Coalition is currently engaged is identified and some broad outputs and outcomes are identified. With this broader framework in place, the Coalition will now implement a more specific logic model for each of the programs and initiatives

described above to identify key inputs, outputs and outcomes. These more specific evaluative frameworks will be in place in the next six months, in order to ensure that the Coalition is collecting evaluation data prospectively.

The collection of prospective evaluation data will greatly enhance the Coalition's ability both to track the successes of its activities and to adjust course as necessary, as well as facilitate an evaluation of the Coalition's effectiveness overall after its first six years. External evaluators will be invited to undertake this evaluation at that time.

## **In Summary**

Year II of funding under the SickKids Foundation *Children's Health Agenda Grant* has been an active and productive time for the Canadian Child and Youth Health Coalition as we have continued to strive to achieve our many goals and objectives. The encouragement and continued infrastructure support of the SickKids Foundation – National Grants Program has been integral to the success of the Coalition since 2005 and our ability to leverage funds in support of specific Coalition initiatives (i.e. MICYRN and Paediatric Surgical Wait Times). On behalf of all members of the CCYHC, we wish to express our sincerest appreciation to the Foundation for your commitment and national leadership.

Respectfully submitted on behalf of the Canadian Child & Youth Health Coalition by:



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