



CANADIAN ASSOCIATION OF PAEDIATRIC HEALTH CENTRES (CAPHC)  
ASSOCIATION CANADIENNE DES CENTRES DE SANTÉ PÉDIATRIQUES (ACCSP)

## **Canadian Association of Paediatric Health Centres (CAPHC)**

**2008 National Symposium on Continuity and  
Coordination of Care  
October 22, 2008**

**CAPHC 2008 Annual Meeting – Transforming Services for  
Children and Youth: Turning our Thinking Inside Out**

**October 19 – 22, 2008  
Westin Edmonton  
Edmonton, Alberta**

2141 THURSTON DRIVE, SUITE 104, OTTAWA, ON K1G 6C9 PHONE 613 738-4164 FAX 613 738-3247

**[WWW.CAPHC.ORG](http://WWW.CAPHC.ORG)**

## **About the Canadian Association of Paediatric Health Centres (CAPHC)**

CAPHC was established in 2001 through a transformative process of organizational renewal of the Canadian Association of Paediatric Hospitals (CAPH - established in 1968). This watershed activity was undertaken to respond to member needs arising from emerging healthcare challenges and the shifting landscape of child and youth health service delivery in Canada.

Today CAPHC is a forty-two member organization representing multidisciplinary health professionals that provide health services for children, youth and their families within: quaternary and tertiary health centres; community health centres; rehabilitation centres; and home care provider agencies nationwide.

All children's hospitals and their respective Children's Hospital Foundations in Canada are members of CAPHC, thereby providing linkages to clinical care, education and research. A complete list of CAPHC member organizations is posted on CAPHC's web site – [www.caphc.org](http://www.caphc.org).

### **CAPHC's Mandate:**

CAPHC's mandate is to effect system-wide change in the delivery of health services to children and youth across Canada. CAPHC focuses on initiatives that have national and broad relevance, and at the same time are practical and actionable at the point of service delivery.

CAPHC is committed to enhancing the application of knowledge from research to practice, practice to health policy, to the development and promotion of evidence-based clinical practice guidelines for all children and youth.

CAPHC shares with all its members, a fundamental goal of advancing a national child and youth health service delivery agenda through knowledge creation and transfer in high priority areas. Central to this goal is the facilitation of linkages and partnerships to mobilize expertise and resources

The following proceedings are reflective of the discussion and outcomes of the 2008 National Symposium on Continuity and Coordination of Care, held on October 22, 2008, in Edmonton, Alberta, as part of the 2008 CAPHC Annual Meeting.

### **General inquiries regarding this document should be addressed to:**

Elaine Orrbine  
President & Chief Executive Officer  
Email: [eorrbine@caphc.org](mailto:eorrbine@caphc.org)

Or

Doug Maynard  
Associate Director  
Email: [dmaynard@caphc.org](mailto:dmaynard@caphc.org)

Canadian Association of Paediatric Health Centres (CAPHC)  
Association Canadienne des centres de santé pédiatriques (ACCSP)  
401 Smyth Road  
Ottawa, Ontario K1H 8L1

(613) 738-4164

web: <http://www.caphc.org>

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## ***2008 National Symposium on Continuity and Coordination of Care – Background***

In today's rapidly changing healthcare environment, timely access to and dissemination of information are of utmost importance. Expectations of professionals and of the public regarding not only access to information, but also access to services continue to rise, thus creating unprecedented pressures on the system and families alike. The need to streamline and modify services rapidly often leaves services disjointed and families bewildered at the array of services available, at times, with little support.

Better integration of services is essential in the delivery of quality, family-centered services. This is particularly evident for families of children and youth with complex care needs, who often transition between acute care and community settings. Given this reality, CAPHC accepted the challenge of improving the continuity and coordination of services across the continuum through the development and implementation of a multi-faceted national strategy, in partnership with key stakeholders.

In 2005, in partnership with Bell Canada, CAPHC began the Bridging the Gap Project. Bridging the Gap is a three phase project looking at identifying leading practices in continuity and coordination of care, knowledge sharing and dissemination of leading practice, and, in partnership with Accreditation Canada, the development of standards in continuity and coordination of care.

2006 saw the completion of Bridging the Gap - Phase 1, with the publication of the "Finding Our Way Back Home" resource document, which identified over 100 unique, innovative and/or promising practices in the area of continuity and coordination of care; began the development of a network of individuals and organizations across Canada; and initiated the engagement of stakeholders in a national discussion on continuity and coordination of care.

Throughout Phase 2 of the project, CAPHC has been focused on knowledge sharing, network development, and setting the stage to begin development of standards in this area of health service delivery.

This 2008 Symposium represents an opportunity to share the outcomes of our Phase 2 work, and to engage key stakeholders, and the larger CAPHC community in an initial discussion on the development of standards in this important area.

## ***Introduction***

Jasmin Earle, Chair of the CAPHC Continuity and Coordination of Care Working Group, opened the event indicating there will be four parts to the National Symposium:

- A keynote speech setting the stage for the discussion by Sister Elizabeth Davis, Member of the Congregation of the Sisters of Mercy, Newfoundland and Labrador
- Presentations from key programs across Canada that may bring to light some of the concepts to be incorporated into standards.
- A response from a panel of experts
- A discussion involving the full audience
- The launch of the CAPHC Knowledge Exchange Network (KEN), an important knowledge sharing tool to used by the community.

## **Rotman Award Presentation**

Prior to introducing Sister Davis, Jasmin Earle opened the floor to Joanne Kviring, Director-National Grants Program, Sickkids Foundation, to make a presentation to the 2008 Rotman Award Winner. The *Rotman Award for Paediatric Home Care Innovation* has been created to recognize successful and innovative home and community health care programs serving children, youth and families in Canada. The 2008 Rotman Award was awarded to the Children's Treatment Network of Simcoe/York. On behalf of the Network, former CEO, Bob Morton accepted award.

## ***Keynote Address: Leadership – Spirals of Wisdom, Passion and Courage***

**Sister Elizabeth Davis**

*Member of the Congregation of the Sisters of Mercy, Newfoundland and Labrador*

Sister Elizabeth spoke on the importance of leadership in an ever-increasing changing and complex system and challenged the delegates to be innovative leaders and to see things with new eyes, dare with new thinking and act with passion.

The key elements of leadership are wisdom, passion and courage to act. Leaders must use wisdom to think and approach issues from multiple levels, while acting in a truly collaborative manner. Canada's communities and demographics are changing rapidly. These changes require new and different approaches to how we provide care to children, youth and families.

Good leaders must also act with passion. This passion must be intentional, persistent and relational. Leaders must be committed to implementation and be willing to work collaboratively

to bring about system change. Lastly, leaders must have courage – courage to be a catalyst, knowing vulnerabilities and willing to care.

Sister Elizabeth used the image of the inukshuk to illustrate that strong leadership requires directional communication which knows and acknowledges the limitations and vulnerabilities and is willing to use these imperfections to build change.

This presentation is available on the CAPHC website at:

[http://caphc.org/documents\\_annual/2008/conference\\_ppts/22\\_10\\_2008/e\\_davis.pdf](http://caphc.org/documents_annual/2008/conference_ppts/22_10_2008/e_davis.pdf)

## ***Presentation of Leading Continuity and Coordination of Care Programs***

### ***Capital Health Edmonton Area Home Care Children's Services, 2007 Rotman Award***

**Katie Mahon, Regional Manager; Deborah deVlaming, Professional Practice Leader; and Laurene Black, Director Child Health Networks**

Laurene Black, Katie Mahon and Deborah deVlaming provided an overview of the Capital health Edmonton Area Home Care Children's Services program. The program is situated within a larger adult system and has partnered across Ministries and Sectors in order to address the gaps in service delivery and sustain the program.

The program uses a case management model which focuses on family-centred care service delivery model and provides support services for children with complex needs for families.

The 2007 Rotman Award provided the program with the necessary support to conduct an external program evaluation and review the decision making framework that had been developed as part of the program. The evaluation worked with staff, managers and families to look at several components of the program.

Overall, parents and families expressed satisfaction with the program. However, there were concerns expressed around staff turnover within the case management as well as the lack of clarity for roles and responsibilities.

A unique feature of the program is to use unregulated caregivers in the home. Generally, families were satisfied with the balance between maintaining safety and the ability of choice. The characteristics most desired for a caregiver from both professional and family perspectives were honesty, love and care for the children and strong communication skills. It was found that these characteristics were seen as more important than specific skill sets.

This presentation is available on the CAPHC website at:

[http://caphc.org/documents\\_annual/2008/conference\\_ppts/22\\_10\\_2008/k\\_mahon.pdf](http://caphc.org/documents_annual/2008/conference_ppts/22_10_2008/k_mahon.pdf)

***Intensive Ambulatory Care Service (IACS), Montreal Children's Hospital, Montréal, Quebec, 2006 Rotman Award***

**Isabelle St. Sauveur, Clinical Nurse Specialist, and Dr. Hema Patel, IACS Program Director**

Isabelle St. Sauveur and Hema Patel presented on the Intensive Ambulatory Care Service program at the Montreal Children's Hospital. The 44-year old program provides comprehensive coordinated care for children, and their families, with complex needs.

Staff work as nurse case managers and focus their work on discharge planning, care coordination, assessment and ongoing monitoring of children and families once they are home. Within the care team there is a shared vision to improve the quality of life for children by maintaining family autonomy and coordinating needs with home, hospital and family services.

The 2006 Rotman Award provided the opportunity for the program to amplify its educational outreach and referral system. It was noted that complex care requires high availability of rapid care. This is accomplished through a number of methods including an after hours call line and work geared towards seamless care.

The program uses a variety of markers of effectiveness in its evaluation. Markers include care is successful and safely delivered, quality control measures, children sleeping at home as much as possible, children engaged and participating in school and parents supported as caregivers.

This presentation is available on the CAPHC website at:

[http://caphc.org/documents\\_annual/2008/conference\\_ppts/22\\_10\\_2008/patel\\_stsauveur.pdf](http://caphc.org/documents_annual/2008/conference_ppts/22_10_2008/patel_stsauveur.pdf)

***Provincial Eating Disorders Program: Service Planning & Community Capacity***

**Dr. Anna Dominic, Adolescent Medicine Paediatrician, Assistant Professor of Padiatrics, Memorial University**

Anna Dominic presented the Newfoundland model of building localized community capacity for eating disorders. Since 2004, the Eating Disorder Working Group has been working collaboratively to develop a multi-media interactive educational module for community professionals in preventing and dealing with eating disorders. The group aims to provide seamless continuity of care through building capacity in communities for children, youth and families to receive services closer to home.

Because of the large geographic make-up of Newfoundland and Labrador, the group felt it was critical for patients to receive services and programs within their own community and reduced the number of youth being sent out of province to receive care. The inter-professional educational multi-media package aims to provide professionals and families with tools and resources. The six sections of the package include: primary prevention, early identification, an inter-professional care model, early and uncomplicated intervention, referral and follow up. Each

section contains learning objectives, PowerPoint presentations and videos, exercises and references. The project will be piloted in the community starting November 2008 with a subsequent evaluation plan.

Following the pilot, rural community representatives will be invited to attend a learning session to launch the program as a train the trainer model. The project will be evaluated by looking at the number of communities involved and the overall impact of the materials. Pre and post measures will be completed for both families and professionals.

This presentation is available on the CAPHC website at:

[http://caphc.org/documents/annual/2008/conference\\_ppts/22\\_10\\_2008/a\\_dominic.pdf](http://caphc.org/documents/annual/2008/conference_ppts/22_10_2008/a_dominic.pdf)

### ***Response from the Expert Panel and Audience Discussion***

The following individuals were invited to participate on an Expert Panel. The panel's role was to comment on the program presentations, provoke debate and elicit new ideas amongst the delegates, towards systems change. The panel reflects the perspectives of accreditation, federal policy makers, provincial policy makers, senior healthcare administrators, and families.

The panel included the following individuals:

- **Danielle Dorschner**  
Director of National Services, Accreditation Canada, Ottawa, Ontario
- **Catherine McCourt**  
Director, Health Surveillance & Epidemiology Division, Public Health Agency of Canada
- **Deb Gordon**  
Vice President & Chief Operating Officer, Stollery Children's Hospital; Edmonton, Alberta
- **Charlotte Moore**  
Provincial Lead, Access to Paediatric Services, Ontario Ministry of Health and Long-Term Care
- **Heather Caya**  
Family representative, Alberta
- **Cathy Laycock**  
Family representative, Alberta

Each panelist highlighted the cross cutting themes of each of the presentations and how these themes are reflected in daily practice, policy and decision making roles. The major themes from the discussion included:

- The importance of engaging and empowering the child and family in the overall care.
- Wisdom, passion and courage are not only the key elements of leadership, but are also what helps a family through the experience of caring for a child with complex needs. Effective continuity of care is critical in providing families with these elements.
- Strong effective leadership is critical for system change. Leadership is not only the responsibility of decision-makers and administrators, but needs to come from providers, parents and families. Families can play a lead role in advocating and ensuring education and information is brought out into the community.
- Leaders need to push boundaries, support risk taking and challenge people to look outside their sector, profession or network and reach for new partners.
- Communication and case management are critical to coordinate care.
- Evaluation must underlie programs and services.
- All levels of government must communicate with each other with the focus of servicing the health needs of children and families and look at ways to make contributions in order to “support individuals to do their best”.
- Be prepared to seize for rare events and opportunities where they may exist.
- Accreditation and quality improvement can be part of regular daily practice when it is considered as a means to look at how to improve services and programs.
- Although children and youth are only a small proportion of the overall healthcare system; they are what tomorrow will be. What our country looks like tomorrow will be dependent on how we treat children and youth today.

### ***Launch of the CAPHC Knowledge Exchange Network (KEN)***

Doug Maynard, CAPHC Associate Director, provided a brief overview of the CAPHC Continuity and Coordination of Care Knowledge Exchange Network (KEN).

As part of this Symposium, and in partnership with Bell Web Solutions, CAPHC launched the Knowledge Exchange Network (KEN). The KEN is a wiki-based, interactive, online knowledge sharing community, which allows members to author and share content, comment on various entries, and engage in online discussions on a variety of issues. Originally developed as part of the Bridging the Gap project, the KEN has generated interest across all of CAPHC’s programs, and will be used as a knowledge sharing tool across the child and youth health service delivery community.

Membership is inclusive and open to all those who identify with child and youth health issues. This includes researchers, policy makers, families, consumers, as well as health care professionals and services providers.

The KEN will be opened for public use following this Symposium, and will hopefully become a dynamic repository of information, ideas, and discussion for the child and youth health community.