

Canadian Association of Paediatric Health Centres
Children and Youth Home Care Network
Canadian Network for Child and Youth Rehabilitation
Canadian Family Advisory Network

**Bridging the Divide between
Health Centres and the Community –
Child and Youth Health Services
Across the Continuum**

**October 19, 2005
St John's Newfoundland**

Workshop Proceedings Paper

Overview of the Partner Organizations:

This workshop was organized collaboratively by members of the following four organizations:

Canadian Association of Paediatric Health Centres (CAPHC):

Established in 1968 as the Canadian Association of Paediatric Hospitals (CAPHC – www.caphc.org) is a national, not-for-profit, organization whose members are multidisciplinary health professionals that provide health services for children, youth, and families within community, regional and tertiary healthcare facilities; rehabilitation centres and home care provider agencies nationwide. CAPHC is affiliated with all the children's hospitals across Canada along with many community hospitals; rehabilitation centres and home care organizations that provide health services for children, youth and their families.

CAPHC is strongly committed to developing a firm understanding of emerging and evolving needs of child and youth health centres and their communities, recognizing child and youth health priorities, promoting collaborative opportunities and networks and facilitating national research strategies within priority areas. In addition, 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.

Children and Youth Home Care Network (CYHN):

The Children and Youth Home Care Network (www.cyhn.ca) is a Canada-wide network of individuals interested in home and community care for children, youth and their families. CYHN's vision is a country in which knowledge guides the health care of children in their homes, schools and in day care environments. The direction and activities of the network is set by a national steering committee. The network includes over 400 individuals, including researchers, practitioners, parents and policy makers, who receive a bi-monthly newsletter informing them of activities and issues in child and youth home care, can engage with one another on our web discussion board, and provide leadership and feedback on various projects. CYHN is funded by SickKids Foundation through its National Grants Program, which provides funding for research projects, scholarships and conferences related to home and community care issues for children, youth and families.

About the Canadian Network for Child and Youth Rehabilitation (CN-CYR):

The Canadian Network for Child and Youth Rehabilitation is a partnership of child and youth rehabilitation centres and services from across Canada. The network strives to promote excellence in the provision of rehabilitation services for children, youth and their families through a coordinated national voice.

The main activities of the CN-CYR focus on promoting best practices, knowledge transfer, bringing research into practice and creating a national forum for communication and networking with children's rehabilitation centres and associated partners. CN-CYR operates under the auspices of CAPHC and acts as an advisory body to the CAPHC Board of Directors as well as to the members of CAPHC on issues related to child and youth rehabilitation.

About the Canadian Family Advisory Network (CFAN):

Founded in 2002, the Canadian Family Advisory Network represents and connects nine paediatric health centre family advisory bodies from across Canada. The network members share a commitment and dedication to family-centred care for paediatric centres and attempt to promote and model this through engaging and collaborating with professionals and health care institutions.

CFAN strives to ensure that family-centred care can be found not only in institutional mission statements, but also within the everyday experiences of all children, youth and their families who move in and out of Canadian paediatric health centres.

General inquiries regarding this document should be addressed to:

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I. Introduction: Objectives

The 2005 Bridging the Divide between Health Centres and the Community – Child and Youth Health Services across the Continuum workshop was designed for the Canadian Association of Paediatric Health Centres, the Children and Youth Homecare Network and their partners to begin to look at child and youth health issues in terms of continuity of services received across the continuum and explore innovative ways to begin to address the gaps in transition.

The Workshop was made possible through the partnership of:

- Canadian Association of Paediatric Health Centres (CAPHC)
- The Children and Youth Homecare Network (CYHN)
- The Canadian Network of Child and Youth Rehabilitation (CN-CYR)
- Canadian Family Advisory Network (CFAN)

With increasing pressures in all aspects of the health care system, agencies are challenged to improve patient flow while at the same time balancing this with the needs of families. The workshop engaged multi-disciplinary child and youth health professionals from health/rehabilitation centres, home and community care and families from across Canada in the issue and challenged the participants to:

- Explore enablers within the system that enhance continuity of care between the sectors
- Identify interventions that would positively effect the system and improve the lives of children, youth and families at the local, provincial and national levels
- Begin to develop a national action plan for child and youth health services across the continuum

II. Presentations: Setting the Context

To set the context for the session, several expert speakers were called on to share information and personal experiences with conference delegates. Session speakers included:

- Brian Postl, Federal Advisor on Wait Times; President and CEO, Winnipeg Regional Health Authority; Board Member, Health Council of Canada and Board Member, the Canadian Patient Safety Institute (*Keynote speaker*)
The Importance of Integrated Care
- Ruth Hartanto, Canadian Family Advisory Network (CFAN), Parent Advisory Committee, Children's Hospital of Eastern Ontario, Ottawa, Ontario

- Donna McLean, Canadian Family Advisory Network (CFAN), Parent Advisory Committee, Eastern Regional Integrated Health Authority, Child and Women's Health Program, St. John's Newfoundland
- Stacey Daub, *Toronto Community Care Access Centre, Toronto, Ontario*
[Tele-homecare: A Family Centred Option for Bridging the Divide?](#)
- Katherine McRae, Winnipeg Children's Hospital, Winnipeg Regional Health Authority
[Care Coordination: a Tool for System Integration](#)
- Jane Mealey, Vice President, Children's Health, IWK Health Centre, Halifax, Nova Scotia (*Moderator*)

An overview of the presentations is provided below. All workshop PowerPoint presentations can be found on the CAPHC website www.caphc.org.

Welcome

Jane Mealey welcomed the delegates to the Bridging the Divide Workshop of the CAPHC 2006 annual conference. The objective of this workshop is to engage multi-disciplinary child and youth health professionals and families to explore ways continuity of services for children and youth received from hospital to health centres to the community can be nationally supported and strengthened across the country.

Brian Postl, Keynote Speaker

The Importance of Integrated Care

Dr. Postl provided an overview of the importance of integrated care for child and youth health and described some of the issues and challenges families and service providers are facing when health and home care systems are fragmented.

Some of the issues identified for children and youth include: multiple funding sources (health, education, social services and federal/ provincial jurisdictions); multiple agencies involvement with different funding sources; inconsistent policies and the competition between organizations for funding and service provision contracts.

These issues have lead to a system of care which is fragmented, creates barriers for families to access services and is difficult for families to navigate. Often within the fragmented system, the points of transitions are lost, where sectors, departments and agencies alike are not held accountable for the gaps in service and coordination.

Integrated services are essential to the delivery of quality, family-centred services that effectively manage risk and provide greater coordinated care for children, youth and families. Examples of integrated care and services include: centralized and coordinated intake and wait list management, care that focuses on the family and engages the family throughout the process, and open communication with families and between agencies and sectors.

It was recommended that in order for the systems to evolve and move forward to reduce fragmentation and increase integration, all levels of service must work together in a holistic manner and develop relationships that are respectful, open and based on trust and a willingness to make positive changes to improve the health and well being of children, youth and their families.

Ruth Hartanto

Walking with a Family – Sydney’s Experience

Ms. Hartanto provided a first-hand look at her family’s experience navigating through the homecare system for Sydney, Ruth’s 9-year old daughter who was born with Coffin-Siris Syndrome.

Ms Hartanto’s story highlighted the need for parents and health professionals to work together in order for children to lead the fullest life possible and the importance of family centred care and culture within hospitals and community care settings.

Donna McLean

Walking with a Family – Kevin’s Experience

Ms. McLean gave an overview of her and her family’s experience when her son Kevin had a sudden brain injury. She highlighted the difficulty of Kevin’s recovery and the challenges and successes they faced as Kevin returned to his life at home and school.

Stacey Daub

Tele-homecare: A Family Centred Option for Bridging the Divide?

Ms. Daub introduced the Tele-home care initiative. This project is a partnership between The Hospital for Sick Children and the Toronto Community Care Access Centre as a tool for delivering homecare. The Tele-homecare project is an effort to care for children with intermediate intensity health care needs at home using integrated services and supportive technology. The goals of the project include: to improve the quality of life for children and the family’s satisfaction with the care

experience as they move through the continuum of care; to enhance and foster collaborative partnerships between families, community providers and hospital providers; to advance the availability of appropriate quality and cost effective health care for children who require care for intermediate acuity and severity illnesses.

The project evaluation found that organizations can overcome traditional boundaries and limitations through the adoption of a shared model of care and the project was successful in providing support in a safe manner to children and families with intermediate intensity needs. Families who used the tele-homecare system did not become dependent on the technology, but instead used it to support the transition period between hospital and home.

The project evaluation found that children enrolled in this program had improved physical, mental and social health and well-being, as well as improved eating and sleeping. Relationships within the house between siblings and parents were enhanced. Parents also saw benefits to the system in enhancing their relationships at home. The Tele-HomeCare project created opportunities for families and health care professionals to better support children in transition from hospital to home in a safe and effective manner with improved access to expert care.

Katherine McRae

Care Coordination: a Tool for System Integration

Ms. McRae provided an overview of the integrated children and youth service system within the Winnipeg Regional Health Authority. Components of the system and the projects the Regional Health Authority have engaged in were reviewed. Key features of the system include centralized intake, and having interagency lead coordinator and one key contact person for the family.

In 2001, the Transitional Care Unit was created within the Children's Hospital. The objectives of the unit include: providing care coordination, developing staff expertise in the discharge process, reduce resources through staffing lower levels of acuity and reducing lengths of stay in hospital. A central feature of the unit is care coordination.

Care coordination is a system of collaborative services with interrelated processes that support children and families in navigating through the health and home care system. Through the integrated care coordination system, the bridge between the health setting and home and community care is slowly being built.

III. Priority Setting – Recommendations for Bridging the Divide

The workshop had rich table discussions around bridging the divide between health centres and community care organizations and how CAPHC/CYHN and partners can contribute to help address these issues.

A. Key Components of Continuity of Care

Through geographically-based table discussions, delegates were asked to identify key components and enablers of continuity of care for children and youth. A number of components which bridge the gap between health centres and the community were identified.

- A system that is child focused and family-centred
- The political and organizational will to move forward
- Funding that focuses on service requirements of the child/youth and family and is from a single source which follows the child/youth through their transitions and lifespan to help to create seamless transitions as well as reduce age-limit service issues
- Communication across all sectors that helps build relationships, break down silos and share information across disciplines and between organizations
- Centralized intake and coordination of care between organizations and sectors including information sharing between organizations, shared accountability
- Accessible information for families
- Infrastructure that supports integration and knowledge transfer across the systems
- Seamless transitions and interdigitated paediatric and adult teams to facilitate transitions to adult services
- Equity and access to services in all regions (rural, urban and between client populations) with the recognition of specific community issues (isolation, diversity etc)
- Increased use of technology to minimize lengths of stays and maximize care opportunities (e.g. computer rounds at home, video conferencing, school telehealth)

- Creation of a system that is driven by measurable outcomes of function, effectiveness of services and performance indicators

B. Interventions and changes that can effect children, youth and families

Small group discussions explored local, regional and national interventions and changes to the systems which would make a significant difference within the system and in the lives of children, youth and their families.

- Creation of administrative norms with organizational recognition and practice of child/family centred care
- Consistent policies that support a cultural shift of sharing information and integration at all levels
- Single point of access/central intake for families with consolidated funding and case management models with one contact person for each family
- Care coordination model with parental involvement including in service planning
- Shared accountability between systems and a shift from a framework which counts patients to one that looks at outcomes of care
- Flexibility for individuals
- Building community capacity through the use of technology
- Direct access to a provider rather than going through the general Emergency Department

C. Implementation Strategies

Several recommendations emerged from the discussions for CAPHC/CYHN national Home Care Working Group to consider in building a national strategy to bridge the divide between health centres and home and community care for child and youth health. Based on the small group discussions, delegates identified implementation strategies to improve transition and continuity of care.

- The Working Group was encouraged to develop a national strategy for improved transition and continuity of care for children and youth and make this a central theme for 2006.

- Develop and distribute a national questionnaire that will identify resources and potential partners from across the country. The result of which will lead to the creation of a steering group represented from various partner organizations and the identification of a champion.
- Develop performance indicators and link these to a report card.
- The four partner organizations should work with universities to provide interdisciplinary training opportunities with a shared vision around continuity of care and the needs of families.
- Encourage all partner organizations to adopt a child and family centred care culture.
- Develop public education campaigns to raise the profile of children and youth with special needs. Conferences, media targeted messages and family/service provider forums were suggested.
- Health Centres across the country should use CAPHC and CYHN networks and linkages to advocate to government funders for a system of funding that focuses on the service needs of children and youth and for legislative changes for children and youth with special needs.
- Create a forum in which formal cross-ministerial collaboration and communication between health, social service and education can work together for children with special and complex needs.
- Create pilot projects across the country where CAPHC and CYHN would assign a budget to a family and track them through the system on how their needs were met, their challenges and successes and compare their story to a control group family.

D. Moving Forward

Through the CAPHC/CYHN national Home Care Working Group, this workshop is a preliminary step forward in bridging the divide between health centres and community care for child and youth health services.

In closing, Dr. Brian Postl recommended to the Home Care Working Group and delegates that in order to move forward and make significant positive changes, the focus needs to be on the patient and the family. In doing so, a system will be created which serves each child and youth's individual needs for care and services, where there is ownership of the transition points and where children, youth and their families are able to navigate through the health and service system seamlessly.

V. Summary

The 2005 Bridging the Divide between Health Centres and the Community – Child and Youth Health Services across the Continuum workshop was designed for CAPHC, CYHN and its partners to begin to look at children and youth health issues in terms of continuity of services received across the continuum and to identify innovative ways to begin to address the gaps in transition.

Over the next 12 months, in collaboration with national partners, the CAPHC/CYHN national Home Care Working Group will begin to address the issues raised and explore ways to implement some of the recommendations from the workshop. The proceedings report and on-going work directed towards this issue will be provided on the CAPHC website.

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