

the three-day conference organized by the Institute for Family-Centered Care (Bethesda, MD) scheduled to take place in Toronto in the fall of 2003, and to work with members following this event.

- **Emphasizing the compatibility and commonality between embracing FCC standards and meeting the requirements of the Canadian Council on Health Services Accreditation (CCHSA).** Many of the FCC standards identified in the common framework are consistent with the accreditation standards set-out by the CCHSA.
- **Building on the past and current work and successes of CHN organizations who have embraced the concept of FCC.** Strategies here must look for ways to create opportunities for reflective practice, for staff and families to share personal and professional stories about family-centered care, and for them to discuss strategies for enhancing communication and collaboration skills. Highlighting and sharing experiences, best practices and lessons learned at the cluster level will be an important part of ensuring that members learn and “build on what works”.
- **Seeking opportunities to profile, demonstrate and evaluate the positive relationship between family-centered care practices and patient outcomes.** There is already strong evidence to support the link between FCC and higher levels of patient and family satisfaction. Increasing the capacity of the Network to profile the actual impact that FCC has on patient outcomes will, however, contribute significantly to the degree to which FCC is embraced across the Network and beyond.

Does family presence during medical procedures and treatment make a difference? Does it improve quality of care?

What impact does it have on patient and family satisfaction?

These questions require further exploration. To advance work in this area, the CHN is investigating the possibility of creating a Chair in FCC at an Ontario university as a vehicle for strengthening the focus on the academic and research opportunities related to the practice and outcomes of FCC.

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Shehnaz Alidina, Executive Director, CHN

Peter Azzopardi, Chief of Paediatrics, The Scarborough Hospital

Nesan Bandali, Client Services Manager, Scarborough CCAC

Frank Gavin, Member, Family Advisory Committee, Hospital for Sick Children

Jane Gildner, Trillium Health Centre

Matt Gysler, Chief of Obstetrics, Credit Valley Hospital & Chair of CHN's Maternal/Newborn Services Task Force

Janet Harris, Chief Executive Officer, Durham Access to Care & Member of CHN Board

Kathryn Hayward-Murray, Credit Valley Hospital & Member of CHN's Education Task Force

Sheila Jarvis, President & CEO, Bloorview MacMillan Children's Centre & Chair of CHN

Anne Jefferies, Director Neonatology, Mount Sinai Hospital

Moya Johnson, Clinical Advisor/Education Coordinator, CHN

Hume Martin, President & CEO, Rouge Valley Health System

Sue Palmiere, Member, Family Advisory Committee, Bloorview MacMillan Children's Centre

Nancy Shosenberg, Provincial Resource on Family-Centered Care

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Child Health Network for the Greater Toronto Area

180 Dundas Street West, Suite 1700, Toronto, Ontario, M5G 1Z8

Telephone: (416) 813-6137 Fax: (416) 813-8309

Web Site: www.childhealthnetwork.com

DISSEMINATING AND IMPLEMENTING THE FRAMEWORK

The dissemination of this common framework across the Network confirms the commitment of the CHN to embark on a continuing process of adopting and integrating family-centered care into the philosophy, practices and care of its member organizations as well as into the way the Network itself approaches issues. A key challenge in implementing the framework will be to find ways to implement FCC in ways that maximize interest and “buy-in” of administrators, health care providers and families.

Two points need to be recognized:

1. The concept of FCC is flexible by definition. It will not (and should not) be represented by any “one thing” or “one approach”. In fact, it is highly possible that the integration of FCC into practices and care will look quite different when implemented within various organizations.
2. Advancing understanding of FCC and integrating it into planning and care practices will be achieved through a multi-pronged approach that builds understanding and momentum of family-centered care across the Network. This multi-pronged approach will need to focus on promoting greater awareness and adoption of FCC through a variety of strategies.

Strategies to Advance FCC

- **Finding and nurturing the role of champions within organizations who promote awareness and interest in the benefits of FCC.** Champions are needed to fuel the process of change both from a top-down and bottom-up approach. Successful adoption of FCC into practice will be determined by the extent to which a number of small, incremental changes can be made. In turn, these changes will infiltrate the organization contributing to bigger changes within the organization.
- **Enhancing awareness of the fact that FCC is not about spending more money, time and energy to achieve something “new” but rather, is about integrating FCC principles into everyday practice in ways that will contribute to reducing workloads, saving money, time and energy.** Education is the vehicle for achieving greater awareness. Placing greater emphasis on program flexibility and choice where appropriate and promoting information sharing among patients, families and providers rather than information “gate-keeping” by professionals/providers reflects FCC principles. A pivotal event for the CHN will be to involve members in

CATEGORY E: *Transitioning Along the Care Continuum*

	STANDARD	DESCRIPTION / NOTES
15	Children and families have an opportunity to collaborate in the development of hospital discharge planning and other transition planning for home care.	<ul style="list-style-type: none"> ▪ Families are provided with information about discharge planning well in advance of discharge and involved in the planning of care requirements post-discharge. ▪ Children and families are provided with information and educational resources on issues that will assist with transition planning from hospital to the home. ▪ Families are provided with ways to keep in touch with staff following discharge. ▪ Families and health care providers/agencies have access to a directory of community services to ensure information about services is available to all.
16	Families are provided with access to information and resources for designing and equipping home environments to address the needs of family members with special care needs.	<p>For example:</p> <ul style="list-style-type: none"> ▪ An occupational therapist can be sent into the home to help design the home environment so that it meets the needs of the client. ▪ Families can be provided with a list of resources where they can seek financial help to make home modifications.
17	Documentation systems provide information to all members of the health care team.	<ul style="list-style-type: none"> ▪ Charting and documentation procedures and forms are developed in consultation with families. ▪ Documentation procedures and forms support the incorporation of information about the child's and family's strengths, needs, concerns, preferences and goals.

BACKGROUND

On September 13, 2002, the Child Health Network for the Greater Toronto Area (CHN) convened a Working Group to discuss how the CHN might begin to integrate the philosophy and approach of family-centered care (FCC) into its work.¹ The Working Group focused on addressing two questions:

- 1. What can the CHN do to advance understanding of the concept of FCC across the Network?**
- 2. How can the Network build on past and current successes of CHN member organizations that have embraced the concept of FCC and integrated it into their practice?**

Members of the FCC Working Group confirmed the importance of the CHN's commitment to embarking on a *continuing process* of integrating family-centered care into its philosophy, practices and care. They also agreed that this commitment could best be met by focusing on the following strategies:

- 1. Working with providers and families across the Network to establish a common framework of understanding, including a common definition and core standards for FCC for adoption across the Network.**
- 2. Advancing understanding of the concept of FCC across the Network through the organization of education/training seminars and through the sharing of "best practices".**
- 3. Building on past and current work and profiling the successes of CHN organizations who have embraced the concept of FCC.**
- 4. Exploring options for promoting research into FCC, including the investigation of the establishment of an endowed Chair in FCC at an Ontario university, and documentation of "living lab" research based on innovative initiatives underway across the Network that demonstrate a commitment to and advancement of "best practices" across the Network.**

This document outlines the key elements of the common framework including the CHN definition and core standards of family-centered care. The components of the framework emerged from a one-day workshop held on November 20, 2002, involving CHN members as well as family representatives from across the Network.

¹ See Page 1 for a list of the members of the FCC Working Group.

A Note about FCC in the “New Normal” Health Care Environment

The recent challenges presented by the SARS crisis in the GTA has led some to question the relevance and importance of FCC in the “new normal” health care environment. The safety of patients and their families always needs to be the predominant concern. However, now is not the time to turn back the clock on gains that have been made in advancing the practice of family-centered care with respect to children and youth. In particular, the CHN is concerned that new visitor restrictions that have emerged in the post-SARS environment may overlook the fact that some visitors are essential providers of care who help to address physical care needs as well as emotional and social needs. New restrictions may result in seeing all visitors in a likewise fashion and detract both from families participating in hospital committees and from the application of FCC principles.

CATEGORY D: *Environment/Facility Design*

	STANDARD	DESCRIPTION / NOTES
11	Signage is worded positively and respectfully and is understandable by all users.	<ul style="list-style-type: none"> ▪ Language used conveys flexibility and a positive tone such as “offer”, “choose”, and “support” instead of negative and controlling words such as “allow”, “permit”, and “require”. ▪ Signage is clear and well positioned. ▪ Wherever possible, signage includes pictures so that it is understandable to those who do not read English.
12	Entrance points to all programs/services and individuals working on the “front line” convey a sense of warmth and welcome.	<ul style="list-style-type: none"> ▪ The lobby and entrances conveys a positive and welcoming first impression. ▪ Staff working at key entrance points to programs/services create positive first impressions for children and families. This includes parking attendants, hospital and clinic telephone operators, individuals working in main entrance areas, and receptionists/information desk personnel.
13	Design and furnishings are child and youth “friendly” and support and encourage 24-hour participation in care.	<ul style="list-style-type: none"> ▪ The design and allocation of space protects the privacy of children and families. ▪ Design is fully accessible and safe and age appropriate. ▪ There are comfortable places at each bedside for a family member to sleep.
14	Families have opportunities to actively advocate for adequate family space and to participate in facility design.	<ul style="list-style-type: none"> ▪ Mechanisms are established for families to liaise with the Family Advisory Council. ▪ Families are provided with opportunities to be involved in facility design/renovation.

	<ul style="list-style-type: none"> ▪ Effectiveness of interpersonal communication. ▪ Cultural competence and overcoming linguistic barriers. ▪ Supporting children of all ages in developmentally appropriate ways. ▪ Sharing medical and other information effectively with children. ▪ Opportunities of benefits of family/ professional collaboration. <p>Staff appraisal and reward systems acknowledge and reward staff who demonstrate excellence in providing FCC care.</p>
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COMMON FRAMEWORK: CHN DEFINITION OF FAMILY-CENTERED CARE

The Child Health Network for the Greater Toronto Area (CHN) is a partnership of community and hospital providers working together to build an accessible, family-centered, high-quality regionalized health system for mothers, newborns, children and youth across the GTA. The Network developed the following definition as the basis for furthering the integration of family-centered care into the provision of care as well as programs and policies across the Network.

Family-centered care is a philosophy and an approach to health care that shapes the provision of care, programs, policies and facility design. It reflects values and attitudes more than protocol.

Family-centered practitioners recognize the vital role that families play as members of the health care team, and in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, cultural and developmental supports are integral components of health care. With this approach they:

- Empower children, youth and families and foster independence.
- Support children and families in decision-making and care-giving.
- Build on individual and family strengths and respect their choices.
- Involve children and families in all aspects of the planning, delivery and evaluation of health care services.

Members of the Network embrace the philosophy of family-centered care – both at the Network and organizational levels – in recognition of the central role played by families in ensuring the health and well-being of family members of all ages.

Supporting Definitions

Family: “Families” are understood to include anyone whom patients regard as significant in their lives, such as spouses, domestic partners, parents, siblings, grandparents or close friends. With respect to children, this may also include extended family members (e.g., aunts/uncles, peers, teachers).

Health care team: Health care team includes all members of a multi-disciplinary team, including physicians, nurses and other health providers, volunteers, support staff, clients and families.

COMMON FRAMEWORK: CHN STANDARDS OF EXCELLENCE FOR FCC

The following “standards of excellence” were developed based on broad input from family and provider representatives and are intended to serve as benchmarks for attainment by all CHN organizations. The standards are divided into the following categories:

<p>CATEGORY A: Philosophy and Approach to Care</p> <p>CATEGORY B: Family Participation and Support in Care</p> <ul style="list-style-type: none"> ▪ <i>Children and Families as Advisors</i> ▪ <i>Children and Families as Partners in Care</i> ▪ <i>Facilitating Family-to-Family Support</i> <p>CATEGORY C: Human Resource Practices</p> <p>CATEGORY D: Environment/Facility Design</p> <p>CATEGORY E: Transitioning Along the Care Continuum</p>

Although developed for maternal, newborn and paediatric services, all of the standards are applicable at a broad organizational (“corporate”) level. The hope is that the successful adoption of these standards by maternal, newborn and paediatric programs will – in time – infiltrate to other parts of the organization.

This framework includes a series of 17 standards. Each standard includes a brief description/note that provides general information on the standard including ideas on implementation. The standards are applicable to hospital and community service providers.

It is important to acknowledge that some organizations have already been successful in attaining some of these standards. Others are in the process of implementing reforms consistent with FCC practices. It is also recognized that some organizations within the CHN will require more time to achieve these standards that will necessitate development of a longer-term implementation strategy as well as support from other members.

The ultimate goal is for members to work together to encourage the consistent adoption of these standards across the entire Network.

CATEGORY C: *Human Resource Practices*

	STANDARD	DESCRIPTION / NOTES
10	<p>Human resource policies and practices ensure that FCC concepts are built into all activities in accordance with the philosophy of FCC. This includes:</p> <ul style="list-style-type: none"> - Posted staff position descriptions. - Selection/recruitment processes. - Education/orientation/skill development processes. - Staff appraisal and reward systems. 	<p>Youth/family representatives have an opportunity to participate in the development of staff position descriptions, recruitment processes, orientation/training sessions and performance appraisal processes.</p> <p>Staff physicians are briefed on the role, value and importance of FCC in care delivery.</p> <p>Staff job position descriptions and staff performance appraisals state expectations for behaviours that are consistent with FCC. (For example, all staff are briefed on the role, value and importance of FCC in care delivery and are expected to meet FCC practice standards and be provided with information about the consequences of not meeting this expectation.)</p> <p>Job descriptions include (but not limited to) the following concepts:</p> <ul style="list-style-type: none"> ▪ Staff collaborates with the child and family in developing, implementing and evaluating the plan of care. ▪ Staff recognizes the importance of peer support and family-to-family support and facilitates this support and other family and community support. <p>Selection/recruitment processes include questions that help to determine if an individual’s philosophy is rooted in the principles of FCC.</p> <p>Staff orientation/education/skill development processes include discussion about:</p> <ul style="list-style-type: none"> ▪ FCC principles.

		<ul style="list-style-type: none"> Family members are supported and encouraged to remain with the child (i.e., during anaesthesia induction; in the recovery room; in radiology; in the ER; during other treatments and procedures, including resuscitation).
8	A problem resolution process is in place.	<ul style="list-style-type: none"> The problem resolution process is developed with family input. The process is shared with all families, is accessible to them and is monitored and evaluated, as appropriate.

Facilitating Family-to-Family Support

	STANDARD	DESCRIPTION / NOTES
9	Access to information about family-to-family support and other family support programs is accessible and found in places where families are most likely to find it.	<ul style="list-style-type: none"> There is access to a family resource centre with useful program materials, including information about web sites and other resources that provide information to families and connect them with other families. For example, bulletin boards can be located in family waiting areas that include information about family-to-family support and other family support programs. Efforts are made to ensure information is accessible to all client groups including the provision of support and translation services, as appropriate.

CATEGORY A: *Philosophy and Approach to Care*

	STANDARD	DESCRIPTION / NOTES
1	Each organization has a philosophy of care that is consistent with the CHN's definition of family-centered care.	<p>A definition/statement of philosophy of care exists that:</p> <ul style="list-style-type: none"> Articulates and promotes a definition and/or concepts of FCC (as developed and agreed upon by the CHN). Is developed through a broadly collaborative process involving families and staff at all levels of the organization. Includes representation of non-English speaking families/culturally diverse families, children/ adolescents, extended family members. Embraces the central role of families in promoting their own health and well-being. Is shared widely with families and throughout the organization. <p>The philosophy of care is reflected in:</p> <ul style="list-style-type: none"> Care procedures. Operating procedures. Staff selection, evaluation and promotion. Strategic planning. Program planning and evaluation. Policies.
2	Families are encouraged to be full participants in care planning and decision-making with appropriate consents, as required.	<ul style="list-style-type: none"> All practices recognize the importance of conveying respect and preserving the dignity of each individual and family. All practices acknowledge the individuality, strengths, and culture of each family. All practices acknowledge the importance of families and other support persons. Families are involved in planning and in making decisions regarding the care of the child with youth involved directly in decision-making, as appropriate.

CATEGORY B: *Family Participation and Support in Care*

Children and Families as Advisors

	STANDARD	DESCRIPTION / NOTES
3	There is a functioning Family Advisory Council established and supported by the organization.	<ul style="list-style-type: none"> ▪ This is a permanent group whose membership is primarily comprised of youth/family members. The group provides a focal point for activities requiring input and involvement of consumers. ▪ The organization provides the infrastructure support to the Council. ▪ The organization supports continuing education of members on the Council.
4	There are a variety of mechanisms to involve families in the work of the organization.	<p>Involvement of families is encouraged in a range of activities, including:</p> <ul style="list-style-type: none"> ▪ Policy and planning development. ▪ Family and staff education activities. ▪ Research and ethics activities. ▪ Facility design planning, redevelopment, improvements. ▪ Quality improvement.
5	There are opportunities for youth and family advisors to participate in work of the Child Health Network.	<p>The Child Health Network encourages involvement of youth and families in a range of activities, including:</p> <ul style="list-style-type: none"> ▪ Policy and planning development. ▪ Education and evidence-based practice activities. ▪ Advocacy and communication. ▪ Performance evaluation initiatives.

Children and Families as Partners in Care

	STANDARD	DESCRIPTION / NOTES
6	<p>Families are provided with an orientation that includes:</p> <ul style="list-style-type: none"> - Information about members of the health care team. - An opportunity to share and clarify roles and expectations for themselves and for other members of the health care team. 	<ul style="list-style-type: none"> ▪ The orientation includes a tour of the unit and information about access to resources for children and families on the unit and in the facility. ▪ Team members identify themselves and explain their roles. ▪ Expectations with respect to team communication are clarified. ▪ There is a process for the team and family to share and agree on goals for care. ▪ Children and families are informed that they can have full access to the chart and other information (if desired) with support from other members of the health care team, as needed.
7	Families are welcome at all times and are supported in being with their family member during procedures and treatment.²	<ul style="list-style-type: none"> ▪ Visitation for family members, including siblings, is open throughout the day, with no age restrictions, where appropriate. ▪ There is flexibility in policies and practices to meet children and families' needs and preferences. ▪ Staff supports and encourages family members in their nurturing and care-giving roles. ▪ Staff encourages family participation by: inviting family members to team meetings; scheduling team meetings when families can attend; and, encouraging families to express their concerns, ideas and priorities.

² Involvement of families should be based on principles of safety, common sense, good judgement and appropriateness. Restrictions may limit parental presence/involvement in certain circumstances. For example, restrictions related to infectious disease/controls.