

## Canadian Family Advisory Network (CFAN)

### Summary of October 14, 2007 Workshop in Montreal

Thirty two people attended all or part of this year's full-day CFAN workshop. Participants represented advisory bodies at IWK (Halifax), Montreal Children's, The Children's Hospital of Eastern Ontario (CHEO), Roger's Place (a children's hospice in Ottawa), Sick Kids (Toronto), McMaster Children's (Hamilton), The Children's Hospital of London Health Sciences Centre, and Glenrose Rehabilitation Hospital (Edmonton). There were also parents and a staff member from Stollery Children's Hospital in Edmonton which is forming an advisory body, a staff member from Rouge Valley Health System (Toronto) which is trying to form an advisory body, members of the Canadian Sickle Cell Society, a member of the Child and Youth Homecare Network, and a senior staff member of The Canadian Association of Paediatric Health Centres (CAPHC), the sponsoring organization that made the workshop possible.

**What's included in the summary?** Below you will find

- a high-level review of what happened at the workshop;
- copies of the presentation made by John Graf of The Family Forum at CHEO and Bonnie Pierotti of the FAC at London Children's about setting priorities and keeping track of progress;
- a summary by Sue Robins of the presentation she made about telling stories as a part of advocacy—unfortunately the powerpoint slides she used (including the flashing bear) can't be emailed;
- a summary prepared by Lisa Dutton of Montreal Children's of the points made by the small groups responding to the panel on communication from Montreal Children's;
- a report prepared by Frank Gavin on a child and youth mental health symposium he attended on behalf of CFAN and which he reported on at the workshop;
- a summary of the comments from all twenty of the evaluation forms submitted by the participants.

Please note that the CFAN Annual Report for 2006/07 and the brief History of CFAN to 2006 are already posted on the CAPHC website:

[http://www.caphc.org/partnerships\\_cfan.html](http://www.caphc.org/partnerships_cfan.html)

### What Happened at the Workshop

**Welcome and Introductions:** Frank Gavin as chair welcomed everyone. All present introduced themselves.

**Updates and Highlights:** Each group represented took five minutes to describe its major activities, challenges and accomplishments. Most also distributed various materials (reports, brochures, etc.). There was much interest in, among other things, the relations between family-based bodies and youth councils, ways of setting up an advisory body, and the processes many established bodies are going through to renew themselves.

**Setting Goals and Tracking Progress:** John Graf of the Family Forum at CHEO and Bonnie Pierotti of the Family Advisory Council at London Children's each described how their groups decide what to focus upon and how they keep track of the progress of their activities. The slides they used are below. Both John and Bonnie stressed that their groups' priorities had to be aligned, to a considerable degree, with the hospitals' priorities, that difficult choices need to be made, that it helps to make the plan visible on a work sheet that everyone sees and reviews, and that patience helps. There were many questions for each. The "voting system" at CHEO was of special interest.

**Helping to Define Quality:** Don Buchanan of McMaster Children's described how the hospital developed its own quality survey and how the FAC there helped to assess the results and make suggestions for improvement, especially with respect to parking and to the orientation of families of new inpatients.

**Using Stories to Advocate:** Sue Robins of the PAC at Glenrose Rehabilitation Hospital made a thoroughly and imaginatively illustrated presentation on how she advocates for her child for different purposes to different audiences. Her summary is below. There were many questions and much discussion.

**Lunch:** All the participants joined people attending other "satellite sessions" for lunch.

**Overcoming Communication Barriers:** A panel organized by The Family Advisory Forum at Montreal Children's and consisting of an adolescent patient (Tatiana Blasovic), a parent (Vanessa Dyett), a nurse (Dr. Frank Carnevale) and a physician (Dr. David Mitchell) talked from their own experiences about some of the more common or vexing communication barriers and some strategies they thought could or have overcome them. There were many questions, All participants then broke into small groups to identify strategies that they thought could help reduce or solve communication problems. Below is a summary of the those strategies.

**Logos and More:** The representatives from the FAC at London Children's briefly described an issue that had arisen when the hospital and the hospital foundation, which had recently undergone a name change and a rebranding, asked the FAC no longer to use the logo it had used and to use the hospital's logo instead. They asked if other groups had similar experiences or thoughts about the issue. Much animated discussion followed in the brief time available. Some suggested using both the hospital logo and the FAC logo. Others raised questions about the relationships that exist or should exist between advisory bodies and the institutions they advise.

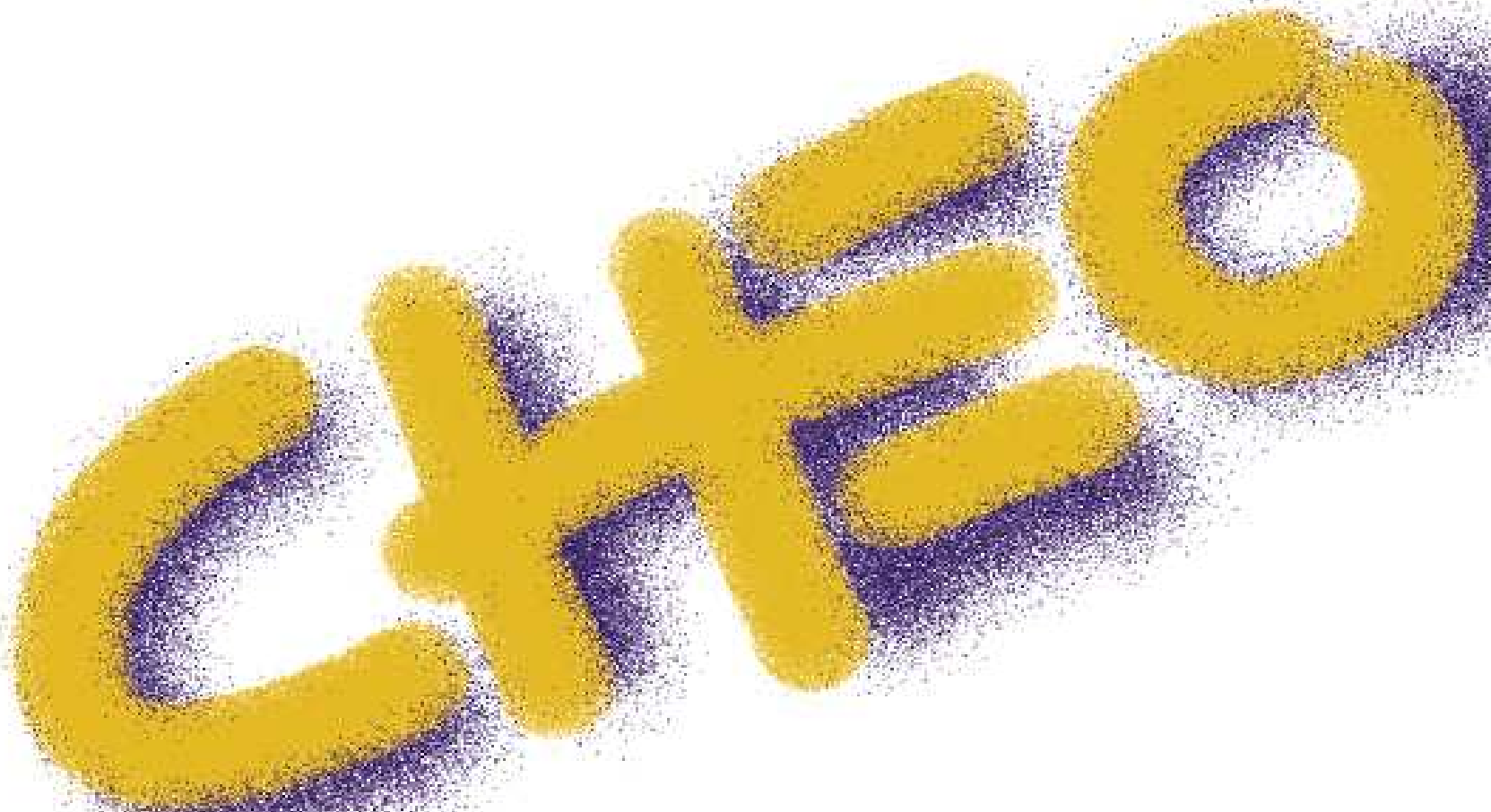
**Child and Youth Mental Health:** Frank Gavin reported on the Child and Youth Mental Health Symposium he attended on behalf of CFAN—the report is posted below—and on the Infant, Child, and Youth Mental Health Consortium on which he also represents CFAN. He suggested that interested CFAN members form a resource group on the issue. There were questions, but the group remains an idea rather than a reality.

**Improving Continuity and Co-ordination of Care:** Ruth Hartanto, a parent board member of Roger’s House, reviewed the progress to date of a major project led by CAPHC to improve the co-ordination and continuity of care for children with complex chronic conditions and their families. Ruth then led a discussion of what and how CFAN members might contribute to a Knowledge Exchange Network (KEN) that is now being developed and that will have it home on the CAPHC website. In particular, participants were asked to comment on the draft of an informal evaluation tool that programs will use to describe and assess what they do to help in the transition from acute care to community care settings and on what families would like to see in and how they might like to use the KEN themselves. There were many questions, some uncertainty about the overall context, and some specific suggestions. Several CFAN members present for the discussion took part the next night in a “regional development meeting” with about 70 other CAPHC delegates to talk about the tool and to share what they had heard and what they thought about what families might want from a KEN.

**CFAN and CAPHC:** Eva Szczerba, CAPHC’s Director, spoke briefly about CAPHC’s desire to partner even more closely with CFAN and to explore new ways to support CFAN—perhaps with CFAN’s infrastructure, CFAN’s use of the CAPHC website, etc. Frank Gavin noted that CFAN’s existence and certainly its workshop have from the start depended on the support and encouragement of CAPHC.

**CFAN Business Meeting:** 1) The annual report was approved as submitted with the addition, suggested by Christine Kouri, of a list of CFAN’s Steering Committee Members. 2) Frank Gavin outlined the need for a mission statement, some explicit goals, membership criteria, procedure for electing Steering Committee Members, etc. Participants noted there wasn’t sufficient time remaining to go into such matters with sufficient care and suggested Frank circulate draft bylaws for everyone to comment upon. [Draft circulated in late October.] 3) Diane Parr, Lisa Rosati-White, and Frank Gavin were acclaimed as continuing members of the Steering Committee. Vanessa Dyett agreed to join, as did Sue Robins—subject to an OK from the PAC at Glenrose [since obtained]. Frank said he would serve another year’s term as co-chair and noted that he’d welcome another co-chair to replace Susan Greig was unable to continue.

**Adjournment**



Family Forum Priorization  
Presentation to CFAN  
October 13, 2007

# Outline

- Operational Template
- Who we are
- How we function
- Priorization exercise
- 07/08 outcomes
- Tips from our past successes / challenges



# Family Forum Operational Template

- The co-operative and collaborative partnerships between patients, families and caregivers, and support for and enhancement of these partnerships, is the framework within which we will address our activities and efforts.



# Who are we

- Advisory committee to the CHEO Board of Trustees
- Annual Reports to QM Council & Board of Trustees
- 14 Parents / Caregivers (+ 3 on orientation) and 8 CHEO Resource staff
- Monthly meetings September – June, 6:00-8:00 pm
- Recruit new members throughout the year
- Expertise as users of the system and being able to consider the needs of all families



Children's Hospital of Eastern Ontario  
Centre hospitalier pour enfants de l'est de l'Ontario

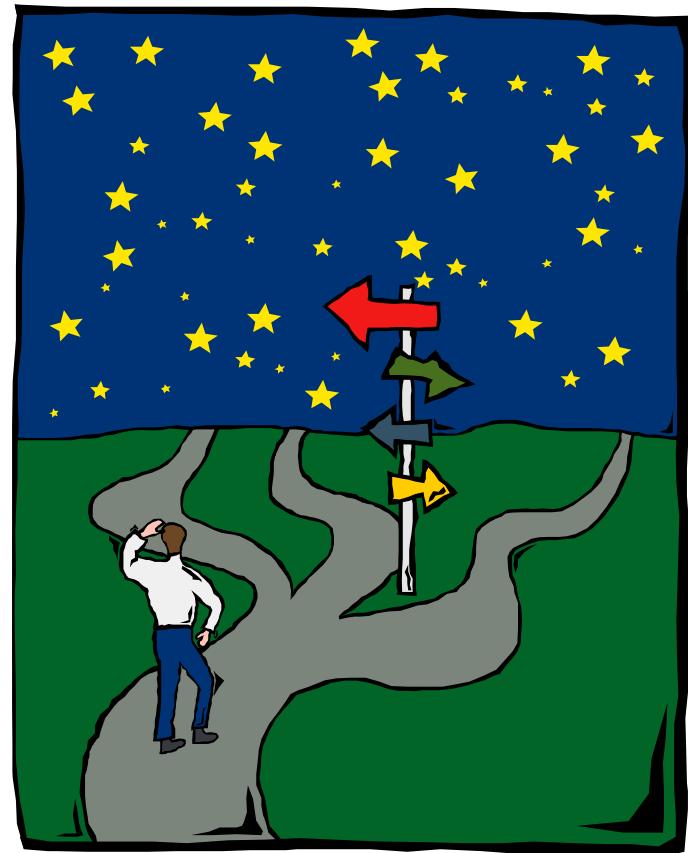
# How we function

- Focused monthly meetings: Hospital Exec updates, presentations by invitation, workshops on priorities, reports
- Work between meetings by staying informed via e-mails, monthly executive conference calls
- Representation on committees (quality management teams, task forces, on-going committees)
- Education of staff via Family Faculty
- Linkage to Youth Forum and annual joint priority
- Ownership of the Family Forum Lounge



# Prioritization Exercise

1. Environmental scan
2. Voting
3. Plan Development
4. Work



# Environmental Scan



- Hospital Strategic Plan
- Themes from family feedback (surveys, concerns)
- Forum member suggestions
- Staff suggestions
- Family suggestions
- Previous year's priorities



# Themes for Priorities 07/08

- 1. Family-Centred Care**
- 2. CHEO Partnership Councils**
- 3. Family Forum Visibility**
- 4. Parental Presence in the OR**
- 5. Family Faculty**
- 6. Continuity of Care**
- 7. Privacy and Confidentiality**
- 8. ER Waiting Times**
- 9. Pain Management**
- 10. Health Information**
- 11. Smoking Cessation Program for Patients / Families**
- 12. Family Forum Communication**
- 13. Critical Care (Garry Cardiff) Wing**
- 14. Family Forum Documents**
- 15. Ambulatory Care Report**
- 16. Outreach**



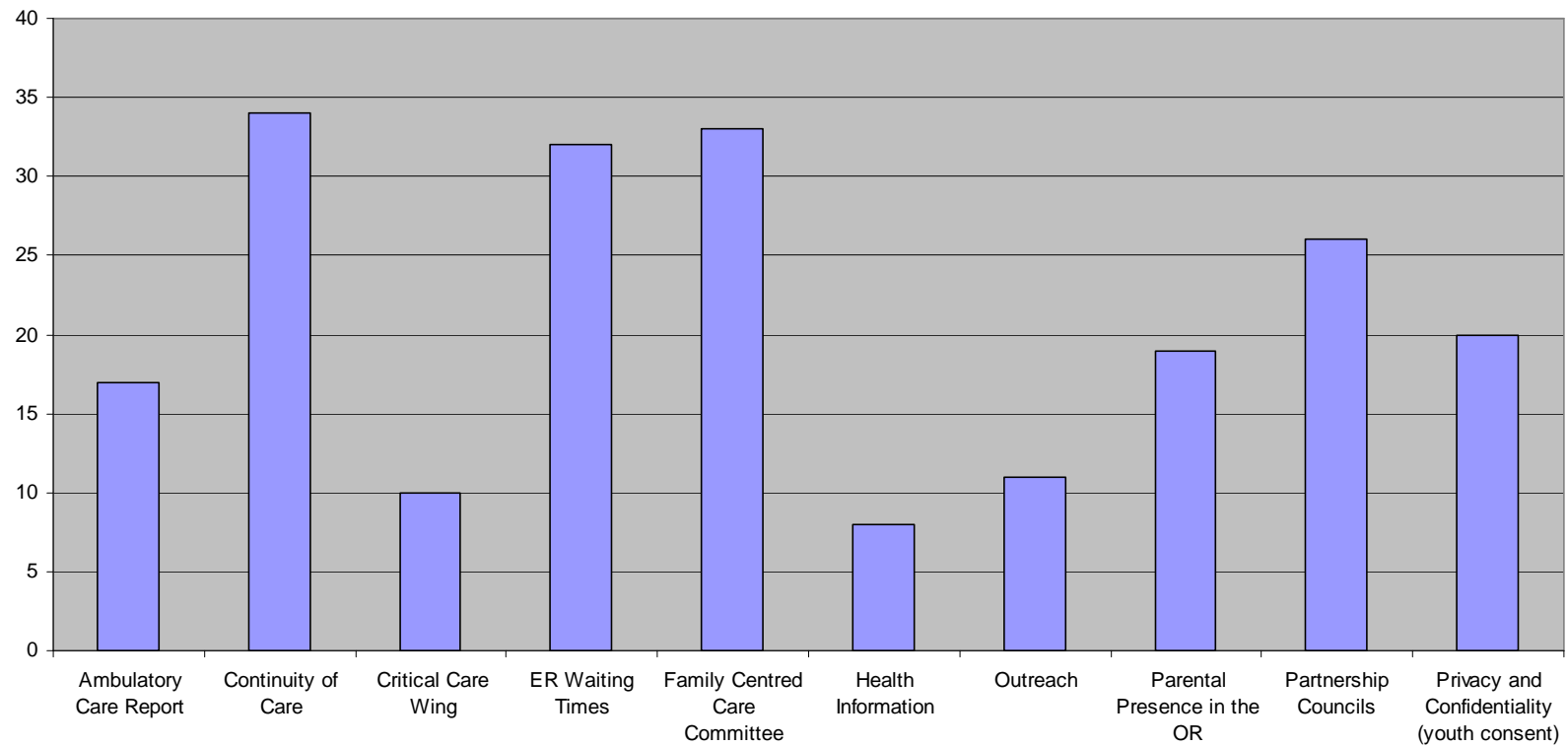
# Voting

- 2 lists: presentations and workshops
- Choose top 5 from EACH list
- Assigned 5 points for #1, 4 points for #2, etc
- Anonymous vote by e-mail to key liaison
- 1 week to vote



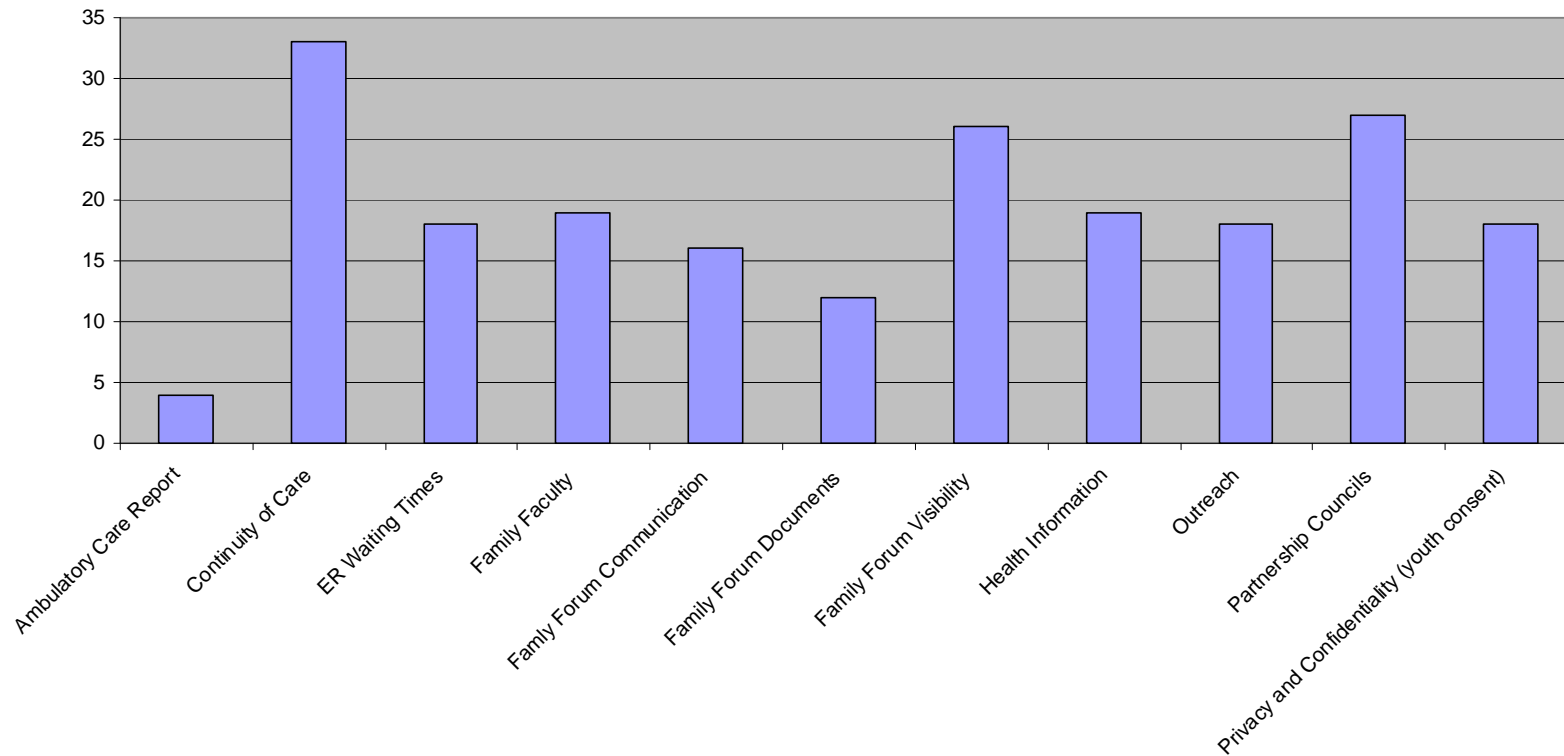
# Presentations

2007-2008 Presentations Priorization



# Workshops

2007-2008 Workshops Prioritization



# Plan Development

- Discussion by Executive of results
- Look at agenda for year
- Placement factors
  - Urgency
  - Staff availability
  - Other Forum commitments



MONTH	PRESENT'N	PRESENTER	FORUM WORK	EXEC LEAD	EXECUTIVE TEAM
Sept. 13			Prioritization Work	Anne Brown	Michel Bilodeau, President and CEO, Jerry Bisson, CFO
Oct. 11	Partnership Council	Alistair Hunter / Louise Martin	Partnership Councils Prioritization outcomes / Proposed Agenda for the year /	A. Brown	Dr. Joe Reisman, Chief of Pediatrics
Nov. 8	Continuity of Care	Ruth Hartanto / Susan Richardson	Continuity of Care		Susan Richardson, VP Professional Services
Dec. 13	Family Centered Committee	Regis Vaillencourt	1st Report Back on Exec work on documents		Michel Bilodeau, President and CEO
Jan. 10	Privacy & Confidentiality (youth consent issue)	TBD	Privacy & Confidentiality (youth consent issue)		Pat Elliot-Miller, VP Pt Services & CNE
Feb. 17	ER Waiting Times	TBD	Family Forum Visibility ?ER Waiting Times		Jerry Bisson, CFO
March 13	Ambulatory Care Report	TBD	2 <sup>nd</sup> report back on Exec work		<b>Chief of Staff</b>
April 10					Dennise Albrecht, Ext. Dev. / Strategic Planning
May 8	Parental Presence in the OR update	TBD	Annual Report Preparation		Luce Lavoie, Director of Public Relations
June 12			Annual Report Feedback Membership Review		Michel Bilodeau, President and CEO



# Examples of Past Priorities

## Resolved

- Patient/Family Rep Role
- Family Resource Library
- Reopening of the Gift Shop
- Parking Pass Options
- Patient Directory
- Parental Presence in Recovery Room

## On-going

- Continuity of Care
- Parental Presence in Induction
- Use of the Family Faculty
- Improving the ER Wait
- Involvement in construction projects





# Tips

- ✓ Broad input into the list of possible priorities to choose from
- ✓ Remember you can't do it all in one year
- ✓ Don't lose track of past initiatives
- ✓ Keep some flexibility in the agenda for urgent or unpredicted requests
- ✓ Consider sub-committee work
- ✓ Accept that most items won't get resolved in one workshop or year sometimes
- ✓ May have to “park” some items for hospital to be ready to act on suggestions (e.g. sibling care)



# Questions?



Children's Hospital of Eastern Ontario  
Centre hospitalier pour enfants de l'est de l'Ontario



Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
<p><b>Monthly Inpatient Coffee Time:</b> Parent to parent support, family feedback and listening</p>	<p>FAC members meet with inpatient families offering conversation, a break from the bedside and an awareness of family centred care initiatives.</p>	<p>Lisa Pauline FAC members</p>	<p>Ongoing Volunteers needed for 2007/2008 schedule</p>
<p><b>Children and Youth Advisory Council:</b> Past or present patients between the ages of 10–17 years who work with hospital staff to improve the care experience at Children's</p>	<p>Regular communication and interaction between these two councils</p>	<p>Bonnie and Lisa</p>	<p>Ongoing</p>
<p><b>Child and Family Resource Centre:</b> Provides current and reliable information about health and medical care for staff and parents. Supports the FAC/CYAC office functioning.</p>	<p>Volunteer opportunities to support maintaining hours of service.</p>	<p>Melissa</p>	<p>One year commitment</p>
<p><b>Teddy Bear Picnic:</b> An annual outdoor picnic event for hospitalized children, youth and families.</p>	<p>Members to represent FAC at the event</p>	<p>Lisa–planning committee Fraser–volunteer</p>	<p>Yearly</p>
<b>Educate</b>			
<p style="text-align: center;"><u>Projects</u></p> <p><b>Family Faculty:</b> Families teaching health care professionals. A combination of formalized resources and personal experience that can help professionals learn how to provide the best care possible. Co–presenter model.</p>	<p><b>Recruit new presenters:</b></p> <ul style="list-style-type: none"> <li>➤ Update Family Centred Care presentation</li> <li>➤ Organize meeting with FF members, provide resources</li> <li>➤ Develop talks</li> </ul>	<p>Lisa  Bonnie, Angela, Melissa, Meg and Phil, Marc, Ann, Leslie</p>	<p>Complete  Complete Ready to Go</p>

Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
	<p><b>Speaking Opportunities:</b></p> <ul style="list-style-type: none"> <li>➤ New Hires–Donna McAnallen, Karen Laidlaw and Katie Wheeler</li> <li>➤ Medical Clerks–Carol Herbert</li> <li>➤ New Residents–Dr. Leaker</li> <li>➤ RN Undergrad program</li> <li>➤ Schulich Med and Dent faculty</li> </ul>	Members write letter of offer to groups identified	Ongoing
<p><b>Family Centred Care Committee:</b> Staff committee to advocate for the provision of family centred care.</p>	<p>Members to advise on projects and planning of this committee</p> <ul style="list-style-type: none"> <li>➤ The Family Guide: assist in the development of content</li> <li>➤ Family Feedback Program</li> <li>➤ Family Centred Care Conference</li> </ul>	<p>Ann Hovey</p> <p>Chantal Felthan Dina Quigg</p>	September 2007–June 2008
<p><b>Bridging the Gap Between Health Centres and the Community Project: Improving Services for Families of Children with Complex Care Needs:</b> CAPHC, Child and Youth Home Care Network (CYHCN, CFAN and the Canadian Network of Child and Youth Rehabilitation (CNCYR) project to develop a national strategy to improve transitions and continuity of care.</p>	<ul style="list-style-type: none"> <li>➤ Participate: email/teleconference to share a parental perspective and personal experiences (transitions between services in the community, hospital and home)</li> <li>➤ Collaborate with practitioners to improve systems and establish standards in continuity of care across the continuum</li> </ul>	<p>Ann Hovey Brenda Nesbitt</p>	<p>Phase 1–complete</p> <p>Phase 2–announced at CAPHC (October 2007)</p> <p>Completed by October 2008</p>

<b>Family Advisory Council Goals 2007–2008</b>	<b>Action Required</b>	<b>Responsibility</b>	<b>Status</b>
<b>Palliative Care and Bereavement Committee:</b>	Membership to provide family perspective to programs and policy	Karen	Not active Update in December
<b>Advise</b>			
<p style="text-align: center;"><u>Involvement</u></p> <p><b>UWO Medical School Admissions:</b> Community representative in the interview segment of the selection process @ Schulich Doctor of Medicine Program.</p>	Two members participate in interview training session and interview process for candidates over two weekends in the spring.	Lisa provided entire FAC list to Schulich.	Letter of invitation comes directly to members in the winter for end of May/April 2008
<b>The New Children's Hospital Design Teams:</b> Parent participation in design teams for the new hospital.	Participate in design meetings as requested. Ronald McDonald Room	Karen Davies Bonnie Pierotti Dina Quigg	2008–2010 Projected opening 10/10/10
<b>Children's Hospital Model of Care:</b> New service standards for the staff at Children's Hospital	Provide feedback and advice to Karen Davies	All	Complete until further notice
<b>Ontario Disabilities Act Committee:</b> Works to identify remove and prevent barriers (physical, informational, attitudinal, policy or practice) and improve access and opportunities for people with disabilities.	Participate in LHSC ODA Working Group <ul style="list-style-type: none"> <li>➤ Provide suggestions from the Children's Care Program for improvement to accessibility and disability needs through the Annual Accessibility Plan</li> </ul>	Lisa	Ongoing

Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
<b>Communication</b>			
<b>Educate staff and community partners about FAC</b>	Annual Report <ul style="list-style-type: none"> <li>➤ FAC meeting January 2008</li> <li>➤ Leadership Meeting</li> <li>➤ Children 's Health Foundation</li> <li>➤ Quality Council</li> <li>➤ COO</li> </ul> Hospital Bulletin Boards and Posters <ul style="list-style-type: none"> <li>➤ Level 7, PMDU and PCCU</li> <li>➤ Develop poster</li> </ul>	Lisa and Chairs	Ongoing
<b>Update Mission and Vision Statements</b>	<ul style="list-style-type: none"> <li>➤ Survey Members “What are the 3 most important results that need to be created from the actions of our FAC?”</li> <li>➤ Collect other FAC statements</li> <li>➤ Draft new statements and present to larger group</li> </ul>	Lisa, Ann, Heather, Pauline, Fraser	September 07: Development Phase: Collect Information, Brainstorm, Draft examples
<b>New Logo</b>	<ul style="list-style-type: none"> <li>➤ Partner with Children’s Hospital for branding and identity</li> <li>➤ All communication and documents as of October 1<sup>st</sup> will use the Children’s Hospital new logo</li> </ul>	Lisa	October 1 <sup>st</sup> Launch  All old branding and logo used up by March 31 <sup>st</sup> , 2008

Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
<b>Children's Hospital's Employee Interview Panels</b>	<ul style="list-style-type: none"> <li>➤ Participate as a team member on the interview panels for various roles</li> </ul>	Leadership Team at Children's	Ongoing
<b>Relationships</b>			
<b>Canadian Family Advisory Network:</b> Building bridges across the nation by linking paediatric patient and family advisory groups.	<ul style="list-style-type: none"> <li>➤ Communicate through CFAN newsletter</li> <li>➤ Attend annual meeting and present at CFAN meeting at CAPHC 2007</li> <li>➤ Support requests and activities of CFAN as needed</li> <li>➤ Listserv Membership</li> </ul>	Lisa, Bonnie and Angela	Ongoing

Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
<p><b>Children's Health Foundation:</b> Raises and grants funds to support specialized health care, programs such as family centred care initiatives, education and equipment at Children's Hospital and research into causes and cures of children's disease at the Children's Health Research Institute.</p>	<ul style="list-style-type: none"> <li>➤ Support the CHF events</li> <li>➤ Support events and activities of the CHF</li> </ul>	Karen and Lisa	Ongoing
<p><b>Canadian Association of Paediatric Health Centres:</b> A national organization whose members are multidisciplinary health professionals that provide care for children, youth, and families within community, regional, and tertiary/quaternary healthcare facilities, rehabilitation centres, community care access centres, and home care facilities nationwide. CAPHC is affiliated with the 16 Health Science Centres in Canada providing linkages to clinical care, education, and research.</p>	<ul style="list-style-type: none"> <li>➤ Attendance to conferences and meetings</li> <li>➤ Present at meetings and/or workshop as determined by members</li> </ul>	All-rotating Bonnie and Angela, Montreal 2007	Ongoing

Family Advisory Council Goals 2007–2008	Action Required	Responsibility	Status
<p><b>FAC Meeting Guests:</b> Ensure opportunities for collaborative working relationships are maintained and knowledge about programs is provided through appropriate meeting guest invitations.</p>	<p>January–Dr Filler (Chief/Chair) Graham Bland (End of Life) April–Dr. Leaker (Resident Training) September–Michelle Wilband (NAP) <b>2007/2008 suggestions:</b> October–Jennifer McCallum</p> <p>Ellen Rosen– Patient Safety Margaret Anderson–Ronald McDonald House Carol Herbert– Dean of Medicine and Dentistry Frank Gavin–CFAN Asst. Clerkship Training–Robbie Stein</p>	<p>All</p>	<p>Ongoing</p>

CFAN

2007 Annual General Meeting

Notes from panel discussion on how to Improve Communications

1. Parents should let caregivers know about their child
2. Parents should relay hopes and expectations
3. Have pictures of family on hand– gives perspective
4. Hospitals should teaching parents how to advocate for their child
5. Hospital should appoint patient advocate or ‘buddy’
6. Health care professionals should develop care plans for the entire family
7. Parents should have someone on hand when they are about to receive health information so they have another set of ears
8. Health professionals should share the treatment plan with parents an an appropriate time
9. Health professionals need to take the time! Go over things
10. Parents need an orientation to the ward: who is who
11. Education program for new health care professionals
12. Have in-depth discussions of case before asking parents to join the discussion
13. White boards – to help communications. Family communications board
14. Better us of advocates ombudsman
15. More family centered care
16. Communicate info in advance in less stressful situations
17. Don’t dub families ‘difficult’ – need broader perspective
18. Need an ombudsman for staff
19. Feedback to check to make sure info is understood (train staff)
20. Youth advisory committee
21. University need to evaluate potential medical students on more than just their grades...can they communicate, are they empathetic?
22. Accountability when bad decisions are made
23. Conflict resolution specialist for staff
24. Code of conduct when staff worried about colleague
25. Parents – write up care history
26. Know policies, parents must know policies, know treatment policies so you know what is traditionally done

## **Report on Child and Youth Mental Health Symposium**

A “National Invitational Symposium on Child and Youth Mental Health” took place in Toronto on September 17 and 18<sup>th</sup>. Just over 100 people, with representation from every province and two territories and from many different professional groups, agencies, health centres, and organizations, participated. I represented CFAN; there were a few other “family representatives” such as Susan Hess of “Parents for Children’s Mental Health.”

Several organizations, including the Child Welfare League of Canada and CAPHC, helped organize the Symposium. It was held, not coincidentally, a few weeks after the formation of the National Commission on Mental Health, which is led by Michael Kirby who spoke at the Symposium. (Senator Kirby’s report, Out of the Shadows at Last, has been a major driver in moving mental health onto the public agenda.) Dr. Simon Davidson of CHEO, who chairs the Commission’s Child and Youth Subcommittee, also spoke and was present throughout. One of the goals is to produce a national action plan to improve the mental health of children and youth.

Here are some highlights and things I learned. At the end is a brief outline of how CFAN might participate further in what the people at the Symposium hope becomes a powerful movement.

- About 15% of children and youth in Canada need mental health services, but only 20% of that 15% actually receive such services.
- The incidence of mental health problems, including suicide, is especially high in many aboriginal communities but, interestingly, not in all. (The degree of autonomy a community has apparently makes a large difference.)
- Dr. Stan Kutcher, the keynote speaker, emphasized the importance of seeing and presenting the mental health needs of children and youth within a human rights framework, especially the UN’s Declaration on the Rights of the Child.
- Dr. Kutcher also noted that young people, largely because of the state of their brain development, evaluate risk very differently. As a result, “just say ‘no’” messages have very little chance of working with them.
- The first of the several panels consisted entirely of adolescents and young adults. They all not only called for but demonstrated the value of including them (“No talking about me without me”) in all such discussions and planning. They, along with other speakers, said they very much favoured a “strengths-based” approach rather than a “deficits-based” approach to youth. They spoke eloquently and sometimes pleadingly that they be regarded as valuable for who they are now, not just for what they might contribute in the future.
- The second panel consisted mainly of parents. They emphasized the need to involve families in eliminating stigma and the all-too-automatic assignment of blame. (Families, especially parents, are often blamed for a child’s mental health illness. I found it very interesting that many of the professionals present informally—and in some instances, they said, for the first time formally—acknowledged that they had children with a mental health condition.)

- A couple of the parents also talked about how families, because of correct or incorrect invocations of confidentiality rules or laws, are often denied information about their child’s treatment or condition—and opportunities to share some of their own information or suggestions—even when they continue to bear and exercise a great deal of responsibility for their child’s day-to-day needs. It’s a complex area that needs more attention.
- The age when youth usually transition from paediatric to adult services (about 18) is precisely the time when many serious mental health problems (e.g. depression and psychosis) surface and when continuity of care is especially important. (Apparently the period between 13 and 25 usually marks one long phase of brain development, but I may be out of my depth here.)
- Dr. Kellie Leitch (orthopedic surgeon from CHWO and special advisor to the federal government on children’s health) said 1) how surprised and struck she was by the number of times people, especially parents, mentioned the mental health of children and youth as a priority during her consultations and 2) how important it is to identify “measurable outcomes” for recommended mental health interventions. (I’m especially keen to take up the “outcomes challenge” and to see that families and youth be involved from the start in identifying some of these outcomes, which will be different in kind from other health outcomes.)

A Suggestion: That CFAN establish a “Child and Youth Mental Health Interest Group” to collaborate with various other groups, especially The National Consortium on Infant, Child, and Youth Mental Health, in activities such as those which would 1) address the problem of stigma, 2) build the capacity of families to foster the mental health of their children, access the services their children and they may need, and advocate for accessible and appropriate services, 3) improve the continuity of services through childhood, adolescence and into adulthood, and 4) identify the most important outcomes of mental health treatments and interventions for children, youth, and families.

Frank Gavin

Co-Chair, Canadian Family Advisory Network (CFAN)

Member, Family Advisory Committee (FAC) to The Hospital for Sick Children

## **Participant Evaluations of the 2007 CFAN Workshop**

Of the 30 people who participated in all or part of the 2007 CFAN workshop in Montreal on October 14<sup>th</sup>, 20 handed in completed evaluation forms late in the afternoon. Here are the results.

Fifteen circled “very worthwhile”, two circled “somewhat worthwhile”, no one circled “not worthwhile, and three didn’t circle anything when asked how they found the workshop.

### **Responses to “What did you like most about the workshop?”**

1. Being able to compare practices among FACs and put faces to names.
2. The interaction with parents/staff of other paediatric health centres.
3. Sue Robins’ presentation, the brief discussion of logos / identity of advisory bodies, and the overall spirit of the day.
4. Opportunity to learn, to share, to see the scope of possibilities to contribute to the systems of health across the country.
5. The opinions expressed by members across Canada.
6. Format open and sharing in general
7. The sharing of info
8. Panel discussion that was inclusive: doctor, nurse, parent, patient—talking about aspects of communication
9. The panel discussion—very helpful to watch and listen to how all members (in their respective roles) answered questions.
10. Discussion Q&A Periods. Round table discussion—sharing of info.
11. Room setup: circle tables provide us with opportunity to get to know one another.
12. Presentation about sharing stories—Sue Robins—gave me insight into how to present my story.
13. Listening to speakers, then networking / brainstorming with other centres.  
Gathering new ideas—what works and doesn’t from experienced members.
14. Panel, table discussion. Having teen on panel.
15. Topics—relevant and stimulating
16. Interactive approach. Representation from various areas/regions.
17. The panel of 4 people—story sharing of ideas and feedback.
18. Hearing about other FACs across Canada. Keeping on time.
19. Frank’s facilitation.
20. Panel discussions: good to get different perspectives.

### **Responses to “What did you find most useful?”**

1. Hearing about which centres have youth advisory councils
2. Finding out what other FACs are doing to enhance their paediatric health centres’ services
3. Having documents and hearing experiences, getting opportunity to hear from patient, parent, and health professionals.
4. The adolescent who was on the panel presented a very serious problem that must be addressed.

5. Group discussion and sharing. Youth Advisory Council.
6. Programs from other institutions. Buddy family system.
7. Talk and discussion on communication and ideas (brainstorming in groups).
8. The information from each group on what works for them and they are currently doing.
9. Sharing of info.
10. Patient panel!—different perspectives on same theme/question—excellent!
11. Listening to introductions. Gauging your level of success, what you have accomplished compared to other settings.
12. Using stories to advocate.
13. Overcoming communication barriers and helping family members become part of the multidisciplinary team.
14. All of the insight that we can take back to form a council.
15. Hearing what FACs do, how they operate, etc.
16. The presentations on priority-setting, Sue's presentation on story-telling.
17. Networking, panel on communications. Thanks for keeping things on time.

**Responses to “Is there a topic you wished the workshop had addressed but didn't?”**

1. Family centred care practices in other institutions.
2. French content of CFAN's documents and membership of French populations.
3. How to advocate for your child—tips, contacts, etc.
4. No, I learnt a great deal.
5. Working / Role of hospital reps in the FAC (i.e. role of the Manager vs. the role of the parent and transference of roles.)
6. Further discussion on recruitment screening.
7. Would have enjoyed more opportunity to hear successes / failures of advisory groups. Some of us haven't started one so this would have been more helpful.
8. No.
9. Encouraging advisory members to greater participation levels. 20% of members doing 80% of work. Any rules identified during interview process.
10. You could go much more in depth with many of the topics.
11. Session on how to set up an FAC.
12. Hearing the perspective from a young adult on what their thoughts are on their experiences.
13. Roles of staff members on advisory groups. Training of advisory members.

**Responses to “What would have made the workshop more effective or useful to you?”**

1. More time to compare practices.
2. Ensure that we don't sit together, e.g. those from CHEO don't sit together, must intermingle.
3. To have the workshop also in French.
4. Interactive questions during presentations and panel.
5. More patients/kids. Youths should have a forum with them on the panel. Youth committee.
6. Longer Q&A period.

7. Healthy snacks to keep me more alert.
8. Longer time to network.
9. More family based stories—info.
10. More members joining us, more ideas, more voices.
11. a) More time to discuss communication b) The transition project—more background may have been needed to understand the process.
12. I like hearing about different PAC's programs—any way to keep an inventory of them on the website?
13. Speakers go to front of room or have tables set up for eye contact.

**Responses to “Do you have any suggestions for future workshops (topics, format, speakers, etc.)?”**

1. Have quarterly teleconferences so we can hear more about one topic in depth from every side. Topics: Faculty uses and messages, youth advisory councils, recruitment strategies, funding, committee membership.
2. Multicultural training—to develop training tools for patients, parents and health and social service professionals.
3. Patient safety exploration—security issues. Impact of family member illness on siblings
4. Communication is an ongoing topic year after year.
5. a) communication—media and role of media b) health and safety—roles and responsibilities c) role of media in illness and role of hospital (Media at times give half information or misleading information about discoveries—child illness, etc. Too often sensational or hot illnesses get press coverage and others are not covered ....)
6. What is useful from the Executive level for FACs to be doing or helping with.
7. Talk more about family buddies. Speaker from successful long-running FAC in the USA.
8. I know it's hard, but a lot of different sessions were jam-packed into one day. Felt like we were always trying to catch up to be on time.
9. How to better deal with doctor-family relations.
10. Promotion within your own facility.
11. Family Buddies—research? Workshop to work on CFAN business.
12. The sharing of personal stories makes this real and why we have to drive forward and continue to be intuitive.
13. There seems to be a lot of interest in parent to parent support—research, value, anecdotal real life examples. Buddy programs and visiting parents programs in both hospitals and communities. Good idea to break group into new groups, older groups.

**Responses to “Do you have any other comments?”**

1. Very interesting to see degrees of involvement for different FAC groups.
2. Can we look at teleconferencing in centres that can't attend in person?
3. Develop workshops to teach groups about funding sources.
4. I'm pleased that CAPHC shows real interest in CFAN.
5. Tape workshop segments for those unable to attend.

6. Great speakers, coordination and issues. Keep outline with timeline.
7. Great job!
8. Thanks for organizing this great day. I know how much work is involved.
9. Thanks for all your hard work, Frank! A great atmosphere to learn in!
10. Too business in afternoon. Morning fast-paced—afternoon dragged with too much official business based info.
11. Wonderful effort, good topics, great speakers.
12. Thanks for all you do, Frank!
13. Very insightful and interesting.
14. I think the host city participants should pitch in and help with chairing and logistics. It is too much for one person to handle chairing, introducing, moderating, and logistics (although Frank did a superb job). Can the other steering committee members kick in?