# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

## British Columbia Children's Hospital

## Partners in Care

**Overview:** By far the most distinctive advisory body in Canada, PiC is especially notable for 1) the parent liaison role, a staff position developed in 2004/05, 2) the range and size of its membership, 3) the range of its recruiting efforts, 4) the comprehensiveness of its bylaws, policies and procedures, 5) its active effort to solicit, gather and respond to "comment cards" from families, and 6) its high-profile family-centred care awards.

**Membership Matters:**

- 28 "regular" family members—there have been as many as 40.
- 18 staff members from professions and areas across the hospital
- 8 "regional family members" from places like the interior, the north, and Vancouver Island. They participate in meetings by audio conference. This has just begun, so it's not yet known how effective/satisfactory this will be.
- 5 "community and hospital partners" (the director of the Disabilities Association, someone representing Mental Health for Kids, another from the Children's Heart Network, and someone from The Red Cross which looks after coffee hours in the hospital.
- On average 15-20 people in total attend their monthly meetings, which, with two exceptions a year, are held in the day. (Susan said they would have far fewer staff if meetings were in the evening.)
- In addition, there are 56 "Virtual Focus Group Members)—the goal is to have 300 who, via email only, respond to surveys, review pamphlets, etc. Recently 27 responded with a week to a question about signage in the emergency department.

Recruitment

- "Bring a Friend"—members bring a friend to one meeting.
- Families who nominate someone for FCC Award are encouraged to apply
- Word of mouth
- Posters/brochures, hospital website
- Staff Referrals
- Staff Liaison in her bathrobe at display promoting FCC Awards.
- Coffee Recruitment Night

Interviewing, Orienting and Training

- Used to have "open membership"—no screening, interviewing, referrals, etc. Lots of problems resulted.
- Applicants now complete applications, are interviewed by two from PiC Exec and the Liaison, complete a police check, go through volunteer orientation, and a 3-hour PiC orientation. Members asked to commit for at least one year.

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

- Real need for further training for members serving on "higher level" i.e. hospital policy, committees.

Leadership

- Two volunteer parents co-chair PiC. They are not really elected but rather identified through a kind of "sifting" process by previous executive and the Parent Liaison. They and the Family Liaison form the Executive.

**Parent Liaison Role:**

- As far as I know, this role is unique in Canada, though there are many such roles in the U.S.
- Position was initially funded by Foundation, but is now funded out of hospital operating budget—a welcome change.
- Position developed with view that a non-health professional was needed to insure the perspective would be that of a parent
- Scouts out opportunities for parent representation, acts as model/mentor, serves a s navigational aide
- Works part-time (.6) and has admin assistance
- Reports directly to CEO and to VP. Meets with both about PiC budget.
- Requires high energy, commitment, advances organizational and communication skills, etc. (First person hired quit after one day.)

**Honoraria, Expenses, etc.**

- Members attending PiC and hospital committee meetings have parking paid for. No honoraria or stipends.

**Activities:**

- High-profile family-centred care awards. Not tied to other awards program. "Bravo Star Awards" given to staff singled out by families on "comment cards" for providing excellent care or service
- Course (one night/wk. for 8 weeks) for parents on "Coping with the Chronically Ill Child" now being redeveloped by educator on staff and delivered by PiC members.
- Educational activities—similar to FAC's—have fallen off. Intention to revive them.
- Comment cards are widely distributed, collected, and reviewed by Parent Liaison and trained PiC member and then acted upon, if appropriate, by Susan.
- Very informative newsletter for families.
- Regular review of hospital brochures, pamphlets, posters, etc.
- Representation on many hospital committees such as "Medication Reconciliation," "Child Health and Safety", "Patient Access and Flow", etc.

**Tracking and Accountability**

- Parent Liaison says accountability rests mainly in her position description: hers is two way.
- PiC does informal "look back" every year and publishes an annual report.

**The Future:**

- Much effort in the last couple of years has gone into developing new bylaws and PiC policies and procedures (about confidentiality, conflict of interest, recruitment practices, etc.) Intention now is to do much more training—along the "Lucille Packard" lines with different "tiers" of parents—to expand greatly the "virtual focus group" membership base, and to broaden activities and representation on hospital committees.

**Source:** Susan Greig, Parent Liaison to Partners in Care, and many documents she shared (new bylaws, new policies and procedures document, copies of their newsletters, glossy four-page update—similar to annual report—and presentation on development of Liaison role.)

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

## Children's Hospital of Philadelphia (CHOP)

### Family Advisory Council and "The Promise of Partnership"

**Overview:** CHOP is similar to Sick Kids in many ways: it's regarded as a world leader in patient care, the education of healthcare professionals, and research; it's in the middle of a large city and serves a very diverse population; and it's about the same size. Among the most noteworthy features of their FAC and their array of "Family Services" within which the FAC falls are 1) the four family consultant positions, 2) the focus of their FAC on "big picture" issues, 3) their emphasis on and methods of communicating to both staff and families, and 4) their efforts both to develop and apply standards of FCC that can be measured.

**Membership Matters:**

- There are 18 active "family" members (16 parents and 2 former patients).
- There are 13 staff members (the COO, a VP, several directors, the 4 family consultants, the chief resident, etc)
- Meeting attendance is usually 25-27.
- Meetings are held monthly between 5 and 7.
- Members' parking costs are covered and there is a dinner at each meeting, but no members receive stipends. (Family Faculty presenters used to receive a small honorarium, but that had to stop when they fell under "volunteer" designation. See information about Lucille Packard for a very different arrangement,)
- One of the family consultants co-chairs with a volunteer parent member

Screening, Orientation, and Training

- Applications are processed during one designated period of the year.
- Recruiting is done through word of mouth, staff referrals, information on hospital web site, CHOP Family News, and the Hospital's Director of Cultural Services who is their go-to guy" for getting members from under-represented communities.
- The Family consultants interview the candidates, usually with an FAC member. Those who "pass" the interview go through the Hospital's general orientation for volunteers and then a special 3-hour FAC orientation.
- Like many well-established groups, they have no formal bylaws about membership terms, etc. but they are planning to develop some.

**Family Consultants:**

- The role was originally developed in the early 90's.
- Initially the consultants reported to the Social Work Director but now they all report to The Executive Vice-President of Operations who is both their and the FAC's link to the Hospital Executive and Board.

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

- The consultants, whose numbers increased from 2 to 4 a couple of years ago, all have hospital-wide responsibility, except for one, who because of her experience, devotes one of her four days a week exclusively to the NICU.
- Consultants are all parents with extensive experience at the hospital. The three I have met are all extremely articulate, very familiar with how large organizations work and comfortable working in them. They all seem well versed in project management.
- Among their responsibilities are leading the FAC and the Family Faculty, representing CHOP regionally and nationally, leading FCC initiatives, addressing problems in clinical services, helping to resolve family-staff or family-Hospital disputes, and developing and acting on surveys obtained from families in a "blitz." They regularly work with program areas to make processes, materials, etc. more family-centred. A small portion of their time is spent working with the Development Dept—similar to the Foundation—raising funds for family-centred care initiatives.

**Council's Role and Activities:**

- They seem to focus mainly on "big picture issues" e.g. a hospital wide plan to improve "patient flow", rather than on, say, the wording of brochures. The time at each meeting is spent almost entirely on one or two main topics, usually with the person from the hospital most responsible.
- Under the leadership of the family consultants, the Council applied external standards—I think developed by the Institute of Family-Centred Care—to measure themselves against similar hospitals. They are also developing internal standards.
- A four-page summary of their work is included in the Hospital's Annual Report.

**Emphasis on Communication:**

- Major effort is being made to use both intranet and internet to make better known the work of the FAC and the nature and availability of all the Family Services
- "CHOP Family News" is published quarterly and is available both on the website and in hard copy. It contains lots of useful information about, for instance, involving siblings in care plans, using wireless devices in the hospital, new healthy food choices available. There's also one family story in each issue.
- All the family-centred care initiatives have been given a name/brand: "The Promise of Partnership."

**What are the "Family Services"?**

- Family Faculty, Family Consultant Program, FAC, Family Resource Centre (includes teaching facilities, sleeping accommodation, washers/dryers, etc—i8t's

beautiful), the Bereavement Service, Home Care Services and Child Life. (I don't know how all of these are, in practice, linked.)

**Family Faculty:**

- Includes a few people not in FAC, is directed by a Family Consultant, and provides presentations similar to the ones FAC provides. Only the Consultants, however, meet with residents. All "Family Faculty" members go through two-day training, three hours each day.

**Sources:** Amy Martiner, Laura Bedrossian, and Juliette Schlucter (Family Consultants) and the hospital website (www.chop.edu)

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

## Children's Hospital of Eastern Ontario (CHEO)

## Family Forum

**Overview:** Its history, membership, activities, reporting relationship and culture suggest the Family Forum is quite similar to FAC. Among its notable features are 1) a very deliberate, inclusive process for choosing priorities and tracking progress and 2) a clear reporting relationship to the Hospital Board through the Board's Quality Management Council. Also, two former chairs have served on the hospital board.

**Membership Matters:**

- There are currently 14 members plus 3 being oriented
- Particular effort is made to identify underrepresented services and look for parent from those clinical areas.
- Recruitment in done mainly through posters, staff referrals, newsletter for families, and word of mouth.
- Applicants have initial telephone interview with main staff advisor, receive information package, are interviewed by member(s) of executive, and attend at least three "trial meetings." Executive then decides on final approval.
- The committee executive consists of two co-chairs elected by the committee, an at-large family member and a former chair (currently on the hospital board)

**Staff Representation and Roles:**

- Patient Rep is the main staff advisor. Other staff who attend regularly are from child life, social work, nursing, discharge planning, quality management, and the operations manger. Also members of the hospital executive—one a month—usually take turns attending and participating depending on the main issue of the meeting.

**Priorities and Activities:**

- Each year all the members take part in a unique method of selecting priorities. Mindful of the hospital's strategic priorities, they prepare a list of possible priorities, circulate it, and then each member ranks all of the items. The results determine the Forum's priorities, the hospital staff they invite to meetings, etc.
- Main priorities: collaborating with CHEO's family-centred care initiative, e.g two members on FCC committee, developing Family Forum Lounge (Christine Kouri said "The Family Forum Lounge opened in May of 2007. It is a place for families to relax and have some amenities; free use of a computer with internet, shower, washer and dryer. It's been a huge success, particularly the washer and dryer which we thought would get minimal use. We put up relevant info and have some pamphlets as well. It's "supervised" by myself and I have volunteer Greeters who round once a day to tidy up

and report problems. Housekeeping goes by daily to clean.") for use by families at the hospital, and helping hospital communicate better with families by reviewing materials, suggesting ways to improve website, etc.
- Members serve on 11 hospital committees, including Chronic Complex Pain, Research Ethics, and The Multicultural Community Advisory Committee (Christine Kouri said "The Multiculturalism Committee is co-chaired by our multiculturalism officer and a member of the community. There are representatives from different cultural groups, usually via settlement offices, we have community centre reps, CAS, a public school board and many CHEO representatives. The goal is an exchange of info so we hear how we are perceived by the community and what we can better do to assist their work. It recently became an official member of the Child and Youth Network of our area."
- Progress—or lack of progress—is carefully tracked. Family Forum reports once a year to Board Committee and publishes an annual report.

**Connecting with Other Family Advisors at CHEO:**

- Christine Kouri (patient rep) said: "Some clinical areas have chosen parents on their own to sit on committees. The problem is a lack of information flowing about what is going on in that area. The parent is not supported in their role in case of problems. Also the ability of that parent to represent other and function within a committee is less certain. This winter we set a standard that additional new representatives on the quality teams by clinical area (called partnership councils) should at least perform the orientation with the Forum and be linked to a member of the Forum exec, i.e. they do not have to attend all the monthly meetings but should have a connection and information exchange with the Forum.

Sources: Christine Kouri, Patient Representativ and main staff advisor/support as well as materials shared at CFAN Workshop (annual report, presentation on choosing priorities and tracking progress, etc.)

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

## Lucille Packard Children's Hospital

### Family Centered Care Program

**Overview:** Lucille Packard, located just south of San Francisco, has a very distinctive, probably unique in many ways, approach to family-centred care. Among its most notable features are 1) an endowed position for a director of the family-centered care program, 2) a requirement that all parents who act in any advisory capacity at the hospital have to come "through the same door" and receive the same training, 3) a strong emphasis on careful screening and ongoing training, 3) a three-tier system for categorizing advisors according to the kinds of work they do at the hospital, 4) a compensation system that sees all advisors paid either a flat rate (e.g. for attending a meeting) or an hourly rate (e.g. for working on policy development) 5) a designation of all advisors not as volunteers but as "sub-contractors"—though they all go through volunteer orientation and training, 6) steams of advisory roles—parents as educators, as mentors, as policy partners, 7) a strong and growing research component, and 8) a commitment to evaluation and measurement.

**Structure:**

- The FAC is but one part of a large, somewhat complex program that focuses on and builds on partnerships.
- Responsible for the whole program is Karen Wayman, who has a doctorate in education and is the "Endowed Director of Family-Centred Care."
- Karen reports to both the Director of Patient Care Services and to a Dean in Stanford's medical school.
- The main elements of the program are classed either as "Caregiving Partnerships" (which focus on helping families navigate, interact, participate, etc. in their children's care) and "Program and Policy Partnerships" (which promote family participation in practice/policy/program development through parents acting as educators, mentors, and council members).
- There are five advisory councils: the FAC, The Hispanic FAC, and three "service line councils", e.g. NICU

**Membership Matters:**

- There are three "tiers" of parent participants: 1) Advisory Council Members, 2) Service Line Leaders, and 3) FCC Parent Leader. Tier one members receive stipends for each meeting attended; tier two and three members get an hourly wage.
- All advisors enter through the same door and, though not "volunteers" because they receive compensation, do go through the volunteer orientation.

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

- Potential advisors first have a phone interview and an in-person interview with two people, usually the director and perhaps a social worker. The interviewers are very alert to "red flags" indicating a potential problem, e.g. focus on a single issue, inability to see "the big picture," etc. Both the parent and the hospital are "protected " by the early identification of these "red flags."

- Those who "pass" the interview then have five hors of training, broken in to three sessions—"parent participant training". Training focuses on the roles of parent advisors, the structures and processes they will become a part of.
- There's a new initiative for "advanced training" for tier two and three parents.
- There are no term limits (though of course advisers leave or take breaks for a number of reasons.) Strong sense that advisors take time to "grow into" roles and need training, support and experience to do so.
- There are now 40 advisors in total, 15 on the FAC, 3 or 4 on the HFAC, 5-6 on each service line council, and the rest working as mentors only or as educators only.

**Hispanic Advisory Council:**

- Began three years ago when Hispanic families invited to join FAC decided they'd rather have an "independent" council. (Hispanic families represent 40% of patient population. Two members of the HFAC sit on larger FAC
- Current projects include review of hospital's Spanish materials, panel presentation to bilingual staff on better ways of serving families waiting for clinic appts, and creating a survey for Spanish-speaking families related to FCC issues in their inpatient and outpatient experiences.
- Program leaders and HPAC members are now discussing, partly because of the current low numbers on the HFAC, whether a council is the right structure/vehicle for participation by Hispanic family advisors.

**Projects:**

- The FAC's work falls into four areas: 1) Hospital Space Architecture, e.g. renovation of parent lounges, better signage; 2) Hospital Operations, e.g. admitting processes, visitation policies; 3) Family Information, e.g. PICU family information guide, 4) Patient Safety, e.g. "Pack 'em and Track 'em" project to develop strategies to help parents track meds for clinic visits.
- Parents as Education Partners: Video prepared for staff and also presentations given to staff—similar to ours; web-based toolkit for parents now in development; also participate (with staff) in "parent hours" for new parents in hospital.

Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

- Parents as Mentors: Parents, working with social workers, act as mentors in four program areas: liver and intestinal transplant, cystic fibrosis, etc.

**Research;**

- Families are participating in the design and evaluation of research into aspects of family-centred care. One current project is looking at shared decision-making. A completed project looked at "maternal efficacy in caring for a child with a chronic illness."

**Keys to Success:**

Karen Wayman, the Program Director, wrote in October: "How do we prevent duplication—with lots and lots and lots of management—along with clear-cut protocol regarding lines of authority, reportage and parent roles—a friend of mine says we've become the IBM of Family Centered Care—but I'd prefer to think of us as more in the Apple mode—innovation paired with a solid infrastructure rather than the stodginess of IBM. Can you tell we "live" in the Silicon Valley? (my apologies to any employees of IBM)

But I should also point out that all of our Tier 2 and Tier 3 parents are members of 1 to 2 advisory councils—so we always have a mix of parents in our FACs—with new perspectives coming in for the 'advisory' part of our program and more veteran parents working in close & on-going partnership with health care providers in different venues—committees; rapid improvement cycles; visioning meetings & trainings."

**Sources:** Lisa Wise, Lead Parent, Families as Policy Partners, and Karen Wayman, Director, Family-Centered Care Program, and Hospital website (www.lpch.org )

# Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

## Cincinnati Children's Hospital

## Family Advisory Council

**Overview:** The FAC at Cincinnati Children's has several distinctive features: 1) a website (http://www.cincinnatichildrens.org/about/fcc/family/ ) that offers an abundance of clear, well-organized, detailed, and visually appealing information, 2) a leadership structure that is carefully thought-out and inclusive, 3) a great range of activities that involve ongoing collaboration with hospital staff and departments, and 4) paid co-chairs who are family reps and *ex officio* members of the hospital board.

**Membership Matters:**

- 37 members: 20 adult family advisors, 2 paid parent co-coordinators (co-chairs), 10 staff from different areas of hospital, one FAC Alumnus, one staff liaison, one VP representing hosp. exec., two board members appt. by board chair, and a webmaster.
- The roles of each "type" of member are carefully defined and listed on website. The adult "family advisors", for instance must serve on one FAC sub-committee
- Membership terms till now have been two years—non-renewable—but co-chair reports they realize they need to lengthen the terms or make them renewable
- Meetings are monthly and alternate between day and evening.
- Meetings are "open to anyone" though prior notice is requested. The meeting schedule and agenda are posted on the website.
- Transportation costs and child care expenses (up to $15/hr) are paid for meeting/committee attendance. Meals are served at council meetings.

Recruitment, Screening, Orienting

Website an excellent tool in addition to word of mouth, staff referrals, etc.

- Applications processed once a year
- Potential family advisors complete an application form and are interviewed by two FAC members. They must also complete a background check.
- New members have a formal orientation session which covers, among other things, suggestions about participating effectively in meetings, e.g. "If you do not understand something, ask for an explanation."
- The 10 staff must also apply—using the form available on line.
- Particular stress on insuring diversity (ethnicity, linguistic, socioeconomic, "diagnostic") of family advisors.

**Hispanic Advisory Committee**

- A committee of the FAC, one of its members sits on the FAC and reports monthly at the FAC meeting and all FAC members are welcome at HAC meetings.

Comparative Notes on Five Hospital Family Advisory Structures: British Columbia Children's Hospital, Children's Hospital of Philadelphia, Children's Hospital of Eastern Ontario, Lucille Packard Children's Hospital and Cincinnati Children's Hospital

Prepared by Frank Gavin, FAC to SickKids, 2007 (all errors or omissions are mine alone)

- The HAC has a long list of accomplishments, most of which related to acquiring or expanding Spanish language services to families, e.g. Outpatient pharmacy now has phone allowing three way conversation with pharmacist, family, and interpreter.

**Leadership:**

- Given the size and diversity of the FAC, there's a need for "a core of ad hoc positions" which looks like a steering committee: the two co-chairs (responsible for "running the council and facilitating family feedback to the hospital"), the staff liaison, the exec. liaison, and the two board members. Recently they added the webmaster and reps from the Hispanic AC and the Patient Advisory Council (a teenager). "All these positions have no set terms." "We are documenting and creating leadership guides so that the next time a transition of leadership occurs, the new leaders will have something to help get them up to speed."

**Family Faculty**

- Trained FAC members participate in 1) "Developmental Disabilities Small Group Discussions" with residents—facilitated by a physician and a nurse practitioner 2) Noon Sessions with 100 residents. Under development now are three videos—on the initial interview, delivering bad news, and stressed parents—in which FAC members participate in vignettes of good and bad experiences. The videos are professionally produced and the parents get training and advice from experienced Family Faculty members.

**Family-Centered Care Awards:**

- Included on the website of profiles of the winners and accounts of what makes the care they provide family-centred.

**Other Initiatives and Projects:**

- The Council has been involved in reviewing the "clinical content" of hospital's website for "usability", in working with Child Life in establishing video-viewing guidelines for patients and families, in making a video that is used in the orientation of all new employees about the experiences and needs of families at the hospital.

**Website as a Resource for Families:**

- The Website offers families, whether they're interested in the Council or not, some very useful, detailed information about family-centred rounds, including

tips on how to "level the playing field" to make sure rounds are truly family-centred. It also offers families access to a Grand Rounds presentation by Thomas Kimball, MD (a Council member) on "Redefining Bedside Manner."

**Source:** Joy Bennett, Co-Chair of the Family Advisory Council, and the hospital's website: www.cincinnatichildrens.org