

Canadian Family Advisory Network (CFAN)

Summary of 2006 Workshop

Twenty-five people participated in CFAN's full-day workshop on October 14th in Vancouver. The participants represented ten family advisory bodies, two institutions (a hospital and a children's hospice) in the process of forming advisory bodies, and the Board of the Canadian Association of Paediatric Health Centres (CAPHC). The full list of participants, with their affiliations and their email addresses, is at the bottom of this summary.

Highlights from Each Group

After a brief welcome and introduction, a representative from each group presented highlights of his or her advisory body's priorities, challenges, and achievements while circulating more comprehensive information on a common template and, in most cases, in other printed materials as well. Shepherded by taskmaster Heather Fowlie, the group actually finished its series on time, two hours after starting. The information shared was very rich, ranging from how parents at IWK in Halifax are helping to design the first Ronald McDonald Family Room in Canada, to how McMaster Children's FAC succeeded in persuading the Hospital to redirect unexpected extra parking revenue produced by a tax cut to help financially strapped families of patients, to how Partners in Care at BC Children's gathers idea from families at the Hospital and makes use of "email members" who may never attend a meeting but who can provide feedback to the hospital and the committee on topical issues and review brochures, survey forms, etc.

Recruitment and Retention

Following suggestions made at last year's workshop, Susan Greig from BC Children's Partners in Care gave a very well-received presentation and led a discussion on enlisting younger parents and former patients to join advisory bodies and on ways to help members from three generations (each with its own distinct background, set of expectations, and reasons for joining) of working well together over time. The PowerPoint slides from the Presentation, "Unlocking Success—Recruitment and Retention of the Generational Family Advisory Committee Member," are attached. Conversations about Susan's presentation continued well after the workshop ended.

Making Our Advisory Bodies More Diverse and Inclusive

After lunch, Frank Gavin from The Family Advisory Committee at Sickkids made a presentation on the degree to which the memberships of advisory bodies reflect the populations of families who use the health centres they advise. All agreed that in terms of socio-economic class, language, cultural background, frequency of visits to the health centre, type of family structure, age, educational background, "able-bodiedness", etc. the advisory groups are not very reflective of those broader populations. There was helpful discussion of how much this matters if advisory bodies are mindful of this reality and try

to become more diverse or representative. There were suggestions that we should return to this topic in the future. Copies of the presentation are available from Frank Gavin.

Identifying and Clarifying the Roles of Staff and Volunteers on Advisory Bodies

There was a brief discussion led by Frank Gavin on the need for volunteers and staff on advisory bodies to model the kinds of collaboration that is at the heart of family-centred care. Some of the suggestions came from a presentation Frank gave in the spring at the Ontario Hospital Association conference on family-centred care—e.g. volunteers needing to be “up front” about the limits of their commitment and of not assuming either an adversarial or a cheerleading role or posture and staff needing sometimes to go the extra mile in adjusting meeting times and rearranging agenda items to accommodate family participation. Other suggestions came from a document that originated at IWK and that was later adapted at Sickkids on ways of fostering staff-volunteer collaboration, e.g. pairing two parents to serve on a hospital committee so they can share the responsibility and support one another. Both are available from Frank Gavin.

Checking In on CFAN’s Contribution to the Upcoming Symposium on Paediatricians in the 21st Century

There was an update on the background of the symposium and on the responses so far received from parents and from children to the survey circulated in the late spring. All present then broke into small groups to address three questions: 1) What do we most value in paediatricians and need them to do? 2) What do we wish paediatricians would do that they don’t do now or what did we hope or expect them to do that they didn’t? 3) What are some good models of paediatricians working in a team with other professionals? Each group reported on their very helpful answers.

Business Meeting

Frank Gavin briefly reviewed CFAN’s main activities and accomplishments of the past year:

- Two substantial, visually appealing newsletters were compiled and circulated.
- A survey of each group’s operations (numbers and mix of members, staff roles, frequency of meeting, reporting relationships, etc.) was compiled and circulated.
- CFAN now has a higher profile on the CAPHC website with a “presence” on the homepage (www.caphc.org). Thank you to CAPHC.
- New groups have begun in Edmonton at The Glenrose Rehabilitation Hospital and in Prince George at the regional hospital there. Also, Stollery Children’s Hospital in Edmonton and Canuck Place Children’s Hospice in Vancouver are working, with assistance from CFAN, to establish its own family advisory body.
- A New York-based advisory body has contacted CFAN about how groups there can establish a similar network in the U. S. The Institute of Family-Centered Care is assisting.

- A number of parents were recruited through CFAN to participate via teleconferences in the “Bridging the Divide” project that is designed to improve transitions within the paediatric “system” and homecare for children with complex needs.
- CFAN has been asked to participate in an invitation symposium in November 2006 on “Child Health in the 21st Century: The Role of the Paediatrician in an Inter-Professional Environment.” Frank Gavin will make two presentations, based largely on responses he has received from parents across the country who were contacted through CFAN. A second parent from Bloorview Kids Rehab, Skye Gross, will participate in the two-day symposium.
- CFAN was again successful in obtaining a grant (\$4,000) from The Sickkids Foundation to help make the workshop possible. Various participants also received support from their “home” hospitals and foundations. CAPHC itself also offered support of all kinds in making the workshop happen.

Susan Greig and Frank Gavin then led a discussion of the “road ahead” for CFAN. The results are as follows:

- Membership: All agreed that member organizations can be any family-based advisory group attached to a paediatric health centre or to another organization (a regional or community hospital, a regional health authority, a homecare agency, etc.) that provides healthcare services to children and/or youth. Each advisory body will be asked to indicate its desire to be or remain a member once a year and to participate in at least one of CFAN’s activities (including the newsletter).
- Sponsorship and Support: Frank reported on his discussion with Claire Fortier of the Sickkids Foundation, which has provided support for each of the last three years. Claire suggested that CFAN articulate its vision, priorities, and plans—as well as its operating structure and processes—if it intends to attract ongoing sponsorship from a foundation. There was general agreement that we need to do this.
- Newsletter: Susan Greig asked that someone –perhaps but not necessarily someone on the new steering committee—should assume operational responsibility for the newsletter. There were no immediate takers, but the call will be repeated. Don Buchanan said he’d be willing to help archive various CFAN documents.
- New Steering Committee and New Leadership Structure: Frank Gavin and Susan Greig suggested that CFAN move from a single co-ordinator to two co-chairs. All agreed and agreed as well that that Susan and Frank fill those positions for the next year. Joining Frank and Susan on the Steering Committee are Lisa Rosati-while from The Family Advisory Forum at Montreal Children’s, Dianne Parr from The Family Advisory Council at McMaster Children’s, and Robin England from IWK. One more position remains vacant, to be filled, all hoped as they looked encouragingly to the Alberta delegation, by someone from the prairies.
- Thanks to CAPHC and the Sickkids Foundation: All expressed their heartfelt thanks to CAPHC and the Sickkids Foundation for helping to make the day possible.

Participants at 2006 CFAN Workshop (west to east)

Cheryl Thorpe, Family Partners Advisory Committee, Vancouver Island Health Authority: Cheryl.Thorpe@viha.ca

Laurie-Anne Keith, VIHA Family Advisory Committee: the rascalsmom@shaw.ca

Susan Greig, Partners in Care Family Liaison, BC Children's Hospital; Canuck Place Children's Hospice Family Advisory Council Co-Chair, Canuck Place Children's Hospice; CFAN Co-Chair: sgreig@cw.bc.ca

Heather Fowlie, Partners in Care Family Advisory Committee Co Chair, BC Children's Hospital: haf@deltastar.ca

Donna Tack, Partners in Care Family Advisory Committee Co-Chair, BC Children's Hospital: djstack@shaw.ca

Marc Bacon, Canuck Place Board Member, Canuck Place Family Advisory Council Family Member, Canuck Place Children's Hospice: Mark_Bacon@pmc-sierra.com

Susan Beasley, Canuck Place Family Advisory Council Co-Chair, Canuck Place Children's Hospice: skb@shaw.ca

Tannis Sigfusson, Family-Centred Care Co-ordinator, Prince George Regional Hospital: tannis.sigfusson@northernhealth.ca

Diane Rogers, PGRH Family Advisory Council: postmus@telus.net

Sue Robins, Parents Advisory Council, Glenrose Rehabilitation Hospital, Edmonton: sue.robins@shaw.ca

Jennifer Callum, Stollery Children's Hospital, Edmonton: JenniferCallum@cha.ab.ca

Lisa Hawthornthwaite, Family Advisory Council, Children's Hospital of Western Ontario, London: Lisa.Hawthornthwaite@lhsc.on.ca

Kathleen Bruinsma, Family Advisory Council, Children's Hospital of Western Ontario

Don Buchanan, McMaster Children's Hospital, Hamilton: Buchanan@hhsc.ca

Dianne Parr, Family Advisory Council, McMaster Children's Hospital: dianne.parr@hwdsb.on.ca

Tamara Krbavac, Child Life Specialist, McMaster Children's Hospital

Sydney Cameron, Family Advisory Committee Co-Chair, Hospital for Sick Children, Toronto: justsyd@rogers.com

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Frank Gavin, FAC Member, The Hospital for Sick Children CFAN Co-Chair: frankgavin@rogers.com

Jill Adolphe, FAC Member, The Hospital for Sick Children: jill.adolphe@rogers.com

Vera Klein, Family Forum, Children's Hospital of Eastern Ontario, Ottawa: vklein@caep.ca

Vanessa Dyett, Family Advisory Forum, Montreal Children's Hospital: mamazulu2007@hotmail.com

Robin England, IWK, Halifax: Robin.England@iwk.nshealth.ca

Chuck Livingstone, IWK Parent Rep: Chucklivingstone@ns.sympatico.ca

Jasmin Earle, Saint Elizabeth Healthcare and CAPHC Board Member: jearle@saintelizabeth.com

Participants' Evaluations of the 2006 CFAN Workshop

Nineteen of the twenty-five participants completed evaluations at the end of the day.

Seventeen said the workshop was very worthwhile; two said it was somewhat worthwhile; none said it wasn't worthwhile.

Responses to "What did you like most about the workshop?"

1. Highlights. Recruiting and knowing/Retaining members
2. All the feedback from the various facilities. Opportunity to meet individuals who are not on contact list and where they are on their "journey."
3. The opportunity to hear the challenges other FACs face and the things that are going well.
4. Heard some great ideas that I want to follow up; made some great connections.
5. Networking with CFAN members—knowing what is happening in the rest of Canada. Info sharing.
6. The discussion and action that came out of the meeting. Loved the brainstorm sessions.

7. Frank's facilitation. He's such a fabulous speaker. Insight of other participants.
8. Ability to find out what's going on at other hospitals: best practices---to relay back to our organization. Troubleshooting tips from other advisories.
9. Hearing what's going on in all the different groups. I liked the handouts everyone prepared.
10. Updates on every group
11. Thought-provoking discussion
12. Sharing experiences, challenges, projects to glean ideas
13. Garnering of ideas, meeting and networking. Sharing of information.
14. Good exchange of ideas from other FACs.
15. Meeting "face-to-face" with members of other FACs across the country.
16. The addition of the new groups broadened our experiences, thinking, and understanding.

Responses to "What did you find most useful?"

1. Consciousness raising on diversity of members
2. Susan's presentation on diversity and generational awareness
3. The updates from other FACs
4. The am—hearing what each of the different communities is doing—so, in part, we don't have to reinvent the wheel.
5. Sharing ideas on recruitment, retention. Recognizing other advisory groups face similar issues and challenges.
6. Networking and discussion. Learning from what others have done.
7. Ideas for paediatricians, making us more representative.
8. Networking, new alliances.
9. Hearing what other groups are doing so that we can learn from them.
10. Discussions on representation.
11. Hearing ideas from other centres (FAC, structure). Meeting people
12. Info on other groups' projects
13. Info on youth advisory council. Resource parent contact
14. Hearing what other FACs are doing.
15. Learning/hearing how the various FACs function, address different issues, and their best practices.
16. The initial session with groups doing 10 min overviews of hospital/group. Obtained the most valuable and broad spectrum of great ideas.
17. Hearing about specific activities of each group and the problems they encounter.

Responses to "Is there a topic you wish the workshop had addressed but didn't?"

1. "Ideas" of implementing family-centred care philosophy amongst professionals (in collaboration with councils.)
2. Staff liaison roles for FACs.
3. More solutions for retention and recruitment. Could have done an ice-breaker at the beginning.
4. Would be great to have a forum re: challenges / troubleshoot for shared knowledge, examples, and advice.
5. Child and youth councils

6. Resource to start a council
7. Family faculty programs
8. Expand on these great ideas that were revealed during the open session.

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

1. Less use of acronyms
2. More small-group work to meet others. More around the room.
3. Another day to met with everyone
4. Two days! Like the theme idea. Guest speakers. Maybe business meeting the evening before. Would have been good to have 2 reps from each council—parent and staff.
5. Less rushed—but understandable given the time frame.
6. Topic. i.e. Cultural diversity—go around and have each group explain what they’re doing in that particular area. Learn from each other, and then open the discussion.
7. It was very effective
8. More small-group work, more opportunity to network and share.
9. Particulars in dealing with palliative care. Patients and guidelines for that specific interest group.
10. Perhaps having representation from more hospitals, health authorities, etc. across the country so that all provinces are represented.
11. With the addition of more groups, more great ideas—we need more time!

Responses to “Do you have suggestions for future workshops?”

1. Session with presentation on “best examples of family-centred care and on “best structures of family advisory” volunteers/ committees in hospitals or health authorities.
2. Perhaps more information or awareness of workshop to administration or hospital leaders.
3. How do we train family advisory members to maximize their effectiveness
4. Hand out a list of attendees with contact information and site they are from.
5. Talk specifically about issues that PAC deal with. Orientation—how to set up a committee—step-by-step building blocks
6. Could we go longer? Even two days? Such a wealth of knowledge/experience and many new advisories/initiatives are underway. Lots to talk about and learn: support.
7. Check back on cultural diversity; child and youth councils
8. Handouts for presentation ahead of time.
9. Solutions to some of the challenges raised at the meetings, i.e. future meetings have one theme and solutions.
10. End with evening dinner/reception so there’s more time for informal discussion.
11. Youth councils
12. Divide groups—usually two people from each centre, to cover more material—one goes one way, the other learns about something else.

Responses to “Do you have any other comments?”

1. Set 2007 workshop date and time early so we can borrow airline points to get there.
2. Grateful for the opportunity! Thank you Frank and Susan.
3. Good opportunity to meet other FAC members.
4. Also want more information on how CFAN groups educate local healthcare professionals about family-centred care. Thank you! For all your hard work in organizing this event.
5. Excellent session—very informative—I love the energy of the group and of you Frank! [I wish I had all the energy required. FG]
6. Great space and lunch—thanks!
7. Great job!
8. Thanks for hosting / chairing and providing this group.
9. I had no expectations coming to this workshop. I was educated and overwhelmed by all the enthusiasm from other FACs across the country. I felt a bond that was nation-wide.
10. It was a well-organized workshop.
11. Wonderful job with presentations. Great moderating. Great to see growth and enthusiasm.

Prepared by Frank Gavin and Susan Greig, CFAN Co-Chairs