

## Summary of 2005 CFAN Workshop

The Canadian Family Advisory Network (CFAN) held its largest and most successful workshop on Sunday, October 16<sup>th</sup> in St. John's Newfoundland. Representatives from nine hospital-linked advisory bodies, from a community hospital that doesn't yet have an advisory body, from two community-based support groups in Newfoundland, and a handful of staff members from different hospitals—twenty-four people in all—participated in the workshop, which ended up spilling over into Tuesday's lunch during the CAPHC conference for the conclusion of the CFAN business meeting. What follows is a summary of the proceedings with several attachments providing more details, contact information for the participants, and the participants' evaluations of the workshop.

Getting Started: The day-long workshop began with introductions and an icebreaker. All said what they most wanted to share and to take away from the workshop. They also said what they most wanted to see and do in St. John's with the local reps providing useful tips.

Accomplishments: A representative from each group then summarized his or her groups' main activities and accomplishments. While much of the information is available in the CFAN newsletters and in a condensed version on the CFAN poster, it was useful to hear more “inside versions” and to ask questions. We also heard some things for the first time, e.g how parental presence during induction became a reality at Humber River and how the Cerebral Palsy Association of Newfoundland has partnered with the RCMP, Walmart, etc. to help educate the public, especially schoolchildren, about children with disabilities.

Recruitment, Retention, and Sustaining Momentum: Participants identified several barriers to recruitment and retention: difficulties with transportation and babysitting, not having any time, young parents' lack of interest in “committees” (perhaps a word to avoid), the lack of a sense of accomplishment, the fear one isn't articulate enough, the sense of ownership of some long-time members who seem not to want to move on, etc.

Strategies to overcome these barriers included 1) focusing on parent-to-parent recruitment; 2) allowing people to participate via email and/or conference calls (BC Children's has some members who very rarely attend a meeting but who do “five to ten minute” tasks via email.); 3) appealing to and providing incentives, i.e. bribes to front-line staff to refer a potential member to the FAC; 4) asking employers to free up time for parents to attend meetings; 5) creating notices for posting and brochures in different languages; and 6) making meeting times regular and predictable.

More generally, many pointed to the need to keep track of initiatives and accomplishments through charts, minutes, annual reports, etc. to measure and document progress. Some spoke of how their groups devote part of each meeting to reviewing the commitments made and the initiatives begun at previous meetings. Several also pointed to the need for hospital staff to reschedule meetings—or, better yet, check with family reps before scheduling a meeting—they really want family reps to attend. Finally,

participants said groups should “look for passion”, which could be a “quiet passion”, when looking for new members.

Education: Frank Gavin from the FAC at Sick Kids made a presentation and led a discussion about the experience of parents in educating current and future health professionals. Among his points:

- However therapeutic the experience of telling their stories might be for parents, it's essential to remember the purpose of the sessions is to address the specific needs of the participants.
- It's better for parents to think of themselves as presenters than as teachers in these sessions. (It helps if an actual teacher or facilitator from the participants' professional group or area participates.)
- Parents are often keen to tell their families' stories and as much of those stories as time allows, but too many incidents (“and then ... and then ... and then ...”) can frustrate the participants and diminish the impact. A few well-chosen examples work better. Less is usually more.
- Practice sessions where other parents—and facilitators too, if available—are essential.
- Written evaluations from participants should be obtained and reviewed. (Samples were provided.) In response to comments on evaluations, a tipsheet for medical students was developed. (Copies were provided)
- Two presenters are better than one. The uniqueness of each family's experience—as well as some commonalities—becomes obvious, and there's less of a burden on each presenter to “represent families.”
- Photos of children and families are often helpful. They illustrate that at the heart of the experience is a child and family, not a diagnosis. They can also draw attention to the length, the continuity, and the changes that mark the family's experience.
- Honoraria, even quite small ones, would be beneficial because they would signal that the presenters' work and contribution are valued. They would also signal the presenters' willingness to be accountable.

Much discussion followed with participants sharing their own experiences and tips. All agreed that “live” presentations work better than taped ones, though the latter are useful in the training of presenters. All also agreed it would be preferable if the participants were drawn from different disciplines, though this has been a practical impossibility so far in many centres.

Breaking New Ground—A Parent on Staff: Susan Greig from BC Children's made a powerpoint presentation (slides attached) about her new role as the Family Liaison for Partners in Care, the hospital's family advisory body. Susan emphasized that the combination of her extensive experience as the parent of a child with a serious illness and of her not being a healthcare professional provided her and the hospital with a unique perspective working within the institution. Part of her role is to act as a model/mentor for other parents and to help resolve problems or disputes in their early stages. Susan reported that at first there was some resistance to the new role from some staff and from

some parents in Partners in Care but that the resistance has diminished over the several months she has been in the role.

There were many questions for Susan and much discussion and enthusiasm about her role. She mentioned that she reports directly to the hospital's president and that her position is part-time. She also detailed her work with Partners in Care, her role in helping to resolve disputes, and the pressure of working in a new role with uncertain long-term funding.

Families Supporting Families: Erin Pearson, the Liaison for The Family Advisory Council at The Children's Hospital of Western Ontario, reported on her group's "Family Buddies" project. The idea was to pair families who, in many cases, have children with similar diagnoses so they can share tips and experiences. The process of developing the program has been a long one. They've worked mainly with Risk Management and have addressed concerns about privacy and confidentiality. They've developed a brochure and applications forms, all of which contain a disclaimer. The program itself will be managed by the hospital's inpatient co-ordinator and facilitated by hospital social workers. Some of the buddies will be FAC members, but other parents are being recruited as well. The program will begin early in 2006.

There was a great deal of interest in the project and many questions for Erin. Several people said they thought it would be helpful to develop a tipsheet for parents by parents. Copies of the brochure and the application forms can be obtained by emailing Erin: [Erin.Pearson@lhsc.on.ca](mailto:Erin.Pearson@lhsc.on.ca)

The Role of Families and FACs in Patient Safety: Dr. Anne Matlow, an infectious diseases specialist and the leader of the patient safety initiative at Sick Kids, made a powerpoint presentation (slides attached) in which she covered a great deal of ground in outlining the recent history of the patient safety movement, in describing the "systems approach" as opposed to the "blame approach" re: patient safety, in giving some sense and several examples of the complexity of the systems in hospitals that make errors so possible, and in identifying the several prongs of the patient safety work at Sick Kids. Dr. Matlow then reviewed how in other hospitals and countries families had been engaged as partners in patient safety and she suggested some ways patients and families could help improve safety: by reporting "near misses" and perceived safety hazards, by joining "safety rounds" and committees, etc.

Discussion ensued. One topic was how families can contribute to a hospital's reporting system when that system is housed within the hospital's internal computing system and when the forms are complex. Families may need another means of access. There was also mention of the value of encouraging families to raise questions or report concerns about safety when they're initially oriented to a unit or a service.

CFAN Business Meeting

At the end of a long and exhausting (though satisfying) day, CFAN reps reviewed the last year. All agreed the newsletters were effective in keeping people and groups connected and in sharing useful information. There were suggestions that in the future each newsletter should have a particular focus with fewer summaries of each group's recent activities and accomplishments. (The Steering Committee has since begun planning for just such newsletters.)

Membership: In order to get a clear picture of just what CFAN's membership is, all agreed that the Steering Committee should contact each group linked to a health centre and ask if it wishes to be a CFAN member and, if they do, to identify two people (a staff member and a parent volunteer) as contact people for the group.

Steering Committee: Erin Pearson from The Children's Hospital of Western Ontario, Susan Greig from BC Children's Hospital, Lisa Rosati-White from Montreal Children's Hospital, and Frank Gavin from Sick Kids agreed to remain of the Steering Committee for another year. (Frank agreed to serve a final year as co-ordinator.) Christine Hughton from the Family Liaison Council at Alberta Children's Hospital was acclaimed as a new Steering Committee member. There was a hope expressed that someone from the Atlantic provinces will also join the group. The reps from IWK agreed to consider the suggestion.

Priorities for the Next Year: In a brief discussion of what areas or issues CFAN might focus on in the next year the following were identified: patient safety, transitions from paediatric to adult care, family involvement in the plan of care, ways to sustain FACs, and gathering and sharing information about what hospital does what.

As CFAN reps continued to talk with one another during the CAPHC Conference, it became clear than an extension of the business meeting would be valuable for identifying specific tasks for the next year and for strengthening our communication links. So at lunch on Tuesday most were able to meet and decided

- to circulate two surveys and the results of those surveys to all CFAN groups. The first will gather information about the internal operations of each group (budgets, frequency of meetings, recruiting mechanisms, etc.). The second will gather information about the choices and services each health centre offers to families (family presence during induction or resuscitation, family lounges, reduced parking rates, access to computers and exercise facilities, etc.) The first will go out this fall. Christine Hughton agreed to help prepare the surveys.
- to ask CAPHC for space on its website to archive CFAN documents (workshop summaries, newsletters, etc) and to post current CFAN news and for help establishing a CFAN listserv so CFAN members can stay in closer touch, pose quick questions to one another, etc. (Frank and Susan met with Elaine Orrbine, CEO of CAPHC, the next day. Elaine said she'd be happy to help make these happen.)

- to seek greater involvement in planning the next CAPHC Conference in Vancouver in October 2006. Several people thought a session on the connection between diversity or cultural competence and family-centred care would be very useful and appealing, and they hoped parents would be among the presenters at such a session. (Frank and Susan mentioned this to Elaine Orrbine on Wednesday and will follow up.)

A special thanks to the Sickkids Foundation for a generous grant of \$5,000 that made a great difference in helping many parents who might not otherwise have been able to travel to St. John's participate in the workshop and in the whole conference.

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