

Canadian Family Advisory Network (CFAN)

Annual Report for 2006/07

The past year has been one of rapid growth and wide involvement for CFAN. What follows is a list of many of the projects CFAN has joined or initiated with some comments about each. The report concludes with a brief discussion of some of the main challenges and opportunities CFAN faces.

Projects

Child Health in the 21st Century: the Role of the Paediatrician in an Interprofessional Environment: Frank Gavin, co-chair of CFAN and a member of the FAC at SickKids, and Skye Gross, a parent from Bloorview, represented CFAN at this symposium with the world's longest name in November 2006. The event and the project of which it was a part were sponsored by The Canadian Association of Paediatric Health Centres (CAPHC), The Canadian Paediatric Society, Health Canada, and the Paediatric Chairs of Canada—among others. Frank served on the event's steering committee and made two presentations at it: one on "Vulnerable Populations: The Family's Perspective" and the other on "Children, Youth and Families with Complex Needs." Both presentations were well received largely because of the contributions to them by scores of parents, children, and youth from across the country, contributions that the network provided by CFAN made possible.

A summary of the proceedings, including Frank's presentations, will soon be available on the CAPHC website: www.caphc.org

Co-ordination and Continuity of Care for Children with Complex Chronic Conditions: CFAN, which was a partner in this project (led by CAPHC) when it started in 2005, has become much more widely and deeply involved in it. Ruth Hartanto, a parent board member of Roger's Place—a paediatric hospice in Ottawa, is leading CFAN's participation, and several parents from across the country have already begun contributing ideas for a web-based Knowledge Exchange Network that will go live in a matter of months. The parents who are involved are keen to see that the leading practices that are identified and the standards that are developed to improve transitions and care in the community, especially homecare, are truly grounded in the day-to-day experiences of paediatric patients and their families.

Rotman Award: Frank Gavin represented CFAN on the panel that assessed applicants and decided on the winner—this year Capital Health of Edmonton--of this award given to an organization that has demonstrated exemplary innovation in paediatric homecare.

Presentation at the Institute for Family-Centered Care International Conference: Susan Greig, Co-Chair of CFAN and Parent Liaison for Partners in Care at B. C. Children's Hospital, made a presentation on intergenerational family advisory councils

and on the development and work of CFAN—she changed hats mid-presentation—at this conference in Seattle in July of 2007. Susan reports that it was very well received.

Links with a Growing U.S.-based Network: Several CFAN members joined a listserv operated by the Patient and Family Advisory Council Network in which groups share information about the recruitment and training of family advisors, education and “family faculty” programs, family involvement in patient safety, etc. Frank Gavin is an “international member” of this network’s steering committee that is preparing a “Family Day Exploratorium” at the annual conference of the National Initiative for Children’s Healthcare Quality (NICH-Q).

Measuring Quality in Hospital–Provided Paediatric Care: CFAN has been invited to participate in this national project to identify the most important elements that should be measured in assessing the quality of care provided by hospitals to children. Dianne Parr of the FAC at McMaster Children and a CFAN steering committee member, has agreed to serve on the project’s advisory committee.

Patient Safety: CFAN made a submission to a survey by The Canadian Patient Safety Institute about a draft policy on the disclosure of adverse events. The submission advocated more directness in communicating with patients and families, more attention to the complexities of patient and family roles and responsibilities, especially with respect to adolescent patients and their families, and the inclusion of patients and families in the process of defining or identifying exactly what adverse events are. At least two individual members of CFAN also made submissions.

Mental Health: CFAN joined the Infant, Child, and Youth Mental Health Consortium—a very comprehensive group composed of mental health professionals, community groups, agencies, and institutions—in the spring. Frank Gavin represented CFAN at a two-day symposium, held in Toronto, on child and youth mental health and circulated a report identifying highlights of the event and proposing that CFAN create a “Mental Health Interest Group” to provide information and advice about such questions as “what outcomes in mental health treatment matter most to patients and families?” The symposium followed closely on the heels of the announcement of the new Canadian Mental Health Commission.

Child Health Summit: Several CFAN members suggested changes and additions to the draft of “Canada’s Child Health Charter,” most of which—including one that noted that “healthy families” (broadly defined) are crucial to the good health of children and youth—were incorporated into the draft of the document discussed at the April event in Ottawa organized by the Canadian Medical Association, The Canadian Paediatric Society, and The Canadian College of Family Physicians. Although originally an initiative of physicians’ groups, many organizations have joined the project that is intended to raise the profile of issues related to child and youth health and to establish some national targets and priorities. The appointment of a National Commissioner for Children and Youth was strongly recommended at the Summit.

Support and Encouragement for One Another and for New Groups: Throughout the year members of the network contact one another with various questions and ideas about everything from what families want in hospital-issued pajamas for inpatients to how advisory committees can best contribute to and align themselves with the strategic directions of the organizations they advise. As well, members continue to encourage the development of new groups by offering advice grounded in their own experience. This past year Rouge Valley Health System in Toronto and Durham Region and the Stollery Children’s Hospital in Edmonton moved toward the establishment of family advisory bodies.

Challenges and Opportunities

Challenges and opportunities come together, of course. Here are some of CFAN’s:

Communication: The number of formal newsletters we once produced has dwindled from four per year to just one this last year. We need to decide how useful it is to have a newsletter, how often one should appear, and who will assume responsibility to produce it. As well, we’ve known for years we need to make more and better use of the CAPHC website both to store and update documents of interest to many if not all—bylaws and annual reports of member groups, information about recruiting and training advisors, etc.—and to facilitate the conversations we need to have with one another about events and topical issues. CAPHC is more than willing to help; we need to decide what we want and what we need to do on our end.

Membership: Right now membership is fuzzy. While leaving the door wide open to any group that wishes to be part of CFAN, we need to define what constitutes membership and what it entails. As well, to be truly national CFAN needs to be informed and nourished by groups in every part of Canada. Right now we have no francophone affiliates and none from Newfoundland, Saskatchewan, or the territories.

Mission, Goals, Structures and Processes: Few if any enjoy hashing out mission statements and bylaws that prescribe structures and process, but we all know that at least in simple form they are needed, not least when seeking financial support from other organizations, foundations, etc. In fact, the work required to produce mission statements, bylaws, etc. can provide focus and impetus.

Leadership: CFAN has many leaders in different parts of the country and in different kinds of advisory bodies. Most are volunteer parents; some are health centre staff. Still, the roles and responsibilities of the CFAN Steering Committee remain somewhat vague. One other challenge is the need for the founder, long-time co-ordinator and now co-chair, Frank Gavin—that’s me, to help others assume more responsibility and do a much better job of “succession planning.” This is not an area of strength for him (i.e. “me), so everyone’s help is especially welcome.

Frank Gavin
Co-Chair

Steering Committee Members for 2006/07

- Frank Gavin (Co-Chair), Family Advisory Committee to The Hospital for Sick Children, Toronto
- Susan Greig (Co-Chair), Parent Liaison for Partners in Care, BC Children's Hospital (Vancouver)
- Robin England, IWK Health Centre (Halifax)
- Dianne Parr, Family Advisory Council, McMaster Children's Hospital (Hamilton)
- Lisa Rosasti-White, Family Advisory Forum, Montreal Children's Hospital (Montreal)
- Sherri Wuetherick, Family Liaison Council, Alberta Children's Hospital (Calgary)