

## **Canadian Family Advisory Network (CFAN)**

### **Annual Report for 2007/08**

The past year has been one of continuity and consolidation for CFAN. We have also deepened key existing partnerships and formed a few new ones. Highlights include

- Joining The Canadian Child and Youth Health Coalition and undertaking a leadership role in a multi-year Coalition advocacy project, “The Child and Family in the Health Care System;”
- Helping to build a Knowledge Exchange Network and recruiting parents as Regional Development Champions for the national Continuity and Coordination of Care project; and
- Clarifying our own mission and goals and enhancing our capacity for growth by drafting new and comprehensive terms of reference and creating new and better-defined roles for Steering Committee members.

### **Activities and Partnerships**

**CFAN and The Coalition:** Last fall CFAN was invited to join The Canadian Child and Youth Health Coalition. (The Coalition includes seven other groups among which are The Canadian Association of Paediatric Health Centres (CAPHC), The Paediatric Chairs of Canada, and The Paediatric Surgical Chiefs of Canada. Information about the Coalition is available at [http://www.caphc.org/partnerships\\_ccyh.html](http://www.caphc.org/partnerships_ccyh.html)). We accepted the invitation with pleasure. Our two representatives on the Coalition Steering Committee, Tamara Krbavac and Frank Gavin, participate in monthly teleconferences and took part in the annual retreat in July. In addition, Tamara participates on the Coalition group working on identifying future human resource needs in child and youth health. The Coalition has encouraged CFAN to play a central role in an advocacy project, The Child and Family in the Health Care System, that will extend over at least three years. In the first year we will, with our Coalition partners, focus on the in-hospital and in-rehab centre experience, gather evidence to identify best or leading practices, and begin to make recommendations to institutions, health authorities, and governments.

**CFAN and The Canadian Association of Child Life Leaders (CACLL):** In the spring Diane Hart, CACLL’s incoming president, approached CFAN about the possibility—and desirability--of a collaborative relationship. Lisa Hawthornthwaite and Frank Gavin, on behalf of CFAN, teleconferenced with Diane and Cathy Humphreys, CACCL’s outgoing president, with all agreeing that an ongoing partnership appealed to both groups and that the Child and Family in the Health Care System advocacy project was a natural vehicle for beginning our work together.

**Continuity and Coordination of Care for Families of Children with Complex Care Needs:** CFAN has continued its involvement in this project being led by CAPHC. About a dozen CFAN members took part, with about 60 professionals, in an evening workshop at the 2007 CAPHC conference to help in the development of a Knowledge Exchange Network, an online resource that should, among other things, enable much greater

sharing of information among families and much more participation by families in the evaluation of existing programs and services. As well, CFAN helped to recruit three parents (Randy and Sue Bassett and Heather Caya) to become Regional Development Champions. (Information about the project is available at [http://www.caphc.org/programs\\_continuity.html](http://www.caphc.org/programs_continuity.html).)

**National Infant, Child, and Youth Mental Health Consortium:** CFAN is one of several family-based groups in the Consortium, which has over thirty member organizations and which is both supporting and informing the work of the still-new Mental Health Commission. Frank Gavin takes part in the Consortium's teleconferences and is seeking to establish both a mental health interest group within CFAN and more formal links between CFAN and other family or parent groups working to improve child and youth mental health services.

**Child Health in the 21<sup>st</sup> Century: The Role of the Paediatrician in an Inter-Professional Environment:** Many individuals and groups within CFAN contributed to the Symposium in November 2006. Its proceeding and the recommendations that largely grew out of the symposium are now posted at [http://www.caphc.org/partnerships\\_21century.html](http://www.caphc.org/partnerships_21century.html). Some of the recommendations focus particularly on engaging and partnering with patients and families and on the need for educational initiatives to make such engagement and partnership more common and more effective. The program directors of paediatric undergraduate education in Canada seem interested in working with CFAN and particularly with advisory groups in CFAN that have existing education programs to develop sessions and perhaps resources to meet this growing need. We expect this collaboration to take shape in the coming months.

**Support and Encouragement for New Groups and among Existing Groups:** Individuals and groups within CFAN continue to use the network, usually through email, to share and obtain information about terms of reference, family resource centers, policies related to parental presence during procedures, education programs, etc. In fact, the regularity of such contact suggests that if CFAN didn't exist, something very similar would have to be invented. This year's newsletter focused particularly on innovative practices developed by advisory groups and advisory group participation in facility design. As for new groups, there was just one this year: at Credit Valley Hospital in Mississauga Ontario. Frank Gavin met with them at one of their first meetings to tell them about CFAN, to address questions and to provide information and advice. Frank also met with staff from Mount Sinai Hospital in Toronto about the formation of program and hospital advisory bodies.

**CFAN and "Parenting Matters!":** We were asked by the principal investigators (Dr. Peter Rosenbaum of CanChild Centre for Childhood Disability and Dr. Lucy Lach of McGill University's Faculty of Social Work) of a proposed multi-year research project on parenting children with neuro-developmental conditions to participate in an advisory capacity. Frank Gavin met with the team of 12 investigators in the summer and has helped recruit three parents and a former patient—all with CFAN connections—to serve on the research advisory board. The project, if it is successful in the final round of the

Canadian Institute for Health Research application process, will investigate what affects parenting and what parenting affects. We hope it throws some light on some common and powerful assumptions about this topic of particular interest to families.

**CFAN and The Canadian Association of Paediatric Health Centres (CAPHC):** Our partnership with CAPHC continues to deepen; it is, quite simply, what makes CFAN possible and what facilitates our development. CAPHC, for instance, covers the cost of our annual workshop and our teleconferences. And even more important, CAPHC continues to champion family participation in general and CFAN leadership in particular in project after project, venue after venue. One such venue was the 2007 CAPHC conference where Frank Gavin was a panelist in a half-day workshop on the use and abuse of stories in effecting change in healthcare practice and policy. Frank went on to join the planning committee for the 2008 conference where several parents and youth will be presenters and panelists.

### **Structure and Processes**

**Terms of Reference:** Since its founding in 2002 CFAN has operated quite informally and with the sketchiest of terms of reference. We intend to continue to be free of being fixated on bylaws, but we recognized the need to articulate our mission and goals, and to clarify our membership criteria and processes as well as the roles and responsibilities of each member of the Steering Committee. Lisa Hawthornthwaite, Sue Robins, and Frank Gavin developed new terms of reference, which were further refined by other Steering Committee members and then circulated throughout the network for discussion and possible amendment. They will be presented to the annual meeting on October 19<sup>th</sup> for final approval.

**Teleconferencing:** For the first time the Steering Committee has had quarterly meetings via teleconferencing, thanks to CAPHC. This has greatly improved the cohesion and efficacy of the group.

**Leadership Renewal:** Several individuals have assumed and exercised leadership in a variety of areas. The process will be facilitated by the better-defined Steering Committee positions: chair, vice-chair, past chair, secretary and membership director, treasurer, and three members at large. Frank Gavin, after chairing the network since its founding, will move to the past chair position with a mix of experienced and relatively new members assuming the other roles in October 2008. There are nominees for all positions before the annual meeting takes place—a first for CFAN.

### **Challenges and Opportunities**

**Communication:** We continue to see the need for and to talk about an electronic forum or discussion board that would be more efficient and inclusive than email as a means of raising questions, sharing information, making suggestions, etc. In addition, we need to make sure that groups that can't send a representative to the annual workshop are not

only kept in the loop but able to participate actively in the all that is initiated, advanced, and reported on at the workshop.

**Priorities:** Because of the realities of our lives—none of us is paid for our CFAN work; all of us are involved with local groups; and all of us have children who, to varying degrees, require an extra measure of parenting—we need to make difficult choices about which projects we can undertake and which we have to defer or pass up.

**Getting the Work Done:** In light of the realities just identified, the Steering Committee has begun to exchange ideas about creating a paid part-time position for someone who could provide some administrative support and perhaps some help with managing our various projects. We haven't got far, but we know we have to find a way to meet the need that stares back at us when we look at what we hope to do in the coming years.

**Funding:** CFAN has never had a budget. Support from CAPHC, from various health centres, and from the foundations linked to those centres, especially the SickKids Foundation in our early years, has kept us going. For what we think are obvious reasons, we need to have a stable source of funds for a number of years to undertake with full confidence the work that others are asking and encouraging us to do and that we very much want to do. So we'll be knocking on some doors.

### **Conclusion**

More accomplishments—and more challenges—could be added to this report, but perhaps the only remaining point that needs to be made is that CFAN in its six years as an entity has created a web of connections across vast spaces that is stronger, richer and more capable of growth than we first imagined it could be.

Frank Gavin, Chair  
October 2008

### **Steering Committee**

Frank Gavin (Family Advisory Committee to The Hospital for Sick Children, Toronto)  
Chair

Lisa Hawthornthwaite (Family Advisory Council, Children's Hospital at London Health Sciences Centre)

Dianne Parr (Family Advisory Council, McMaster Children's, Hamilton)

Sue Robins, (Parents Advisory Council, Glenrose Rehabilitation Hospital, Edmonton)

Lisa Rosati-White (Family Advisory Forum, Montreal Children's)

Sherri Wuetherick (Family Liaison Council, Alberta Children's Hospital, Calgary)

### **Member Groups**

Atlantic Canada

Youth Advisory Council, IWK Health Sciences Centre, Halifax, Nova Scotia

Quebec

Family Advisory Forum, Montreal Children's Hospital

Ontario

Family Forum, The Children's Hospital of Eastern Ontario, Ottawa

Family Advisory Council, Roger's House (Paediatric Hospice), Ottawa

Family Advisory Committee, The Hospital for Sick Children, Toronto

Family Advisory Committee, Bloorview Kids Rehab, Toronto

Family Advisory Council, Credit Valley Hospital, Mississauga

Family Advisory Council, McMaster Children's, Hamilton

Family Advisory Council, The Children's Hospital of London Health Sciences Centre,  
London

Manitoba

Family Advisory Committee, Winnipeg Children's Hospital

Alberta

Family Liaison Council, Alberta Children's Hospital, Calgary

Parents Advisory Council, Glenrose Rehabilitation Hospital, Edmonton

British Columbia

Partners in Care, BC Children's Hospital

Family Partners Advisory Committee, Vancouver Island Health Authority

Family Advisory Council, Prince George Regional Hospital