

The Canadian Family Advisory Network (CFAN)

Its Origin and Development to 2006

The first two family advisory bodies attached to Canadian paediatric hospitals (at Alberta Children's Hospital in Calgary and The Hospital for Sick Children—SickKids—in Toronto) were formed in the late 1980's. As other groups got started in the 90's, there were attempts, especially one led by Brent LaRose of the FAC at Winnipeg Children's in the middle of the decade, to establish a formal connection among all the groups, but nothing took hold—at least in part because many of the parent volunteers were not yet regular email users.

In 2000 Frank Gavin of the FAC at SickKids organized a session for parents active in various advisory bodies at what turned out to be the last conference of The Canadian Association of Paediatric Hospitals (CAPH). Parents from Montreal Children's, The Children's Hospital of Eastern Ontario (CHEO), Alberta Children's, B.C. Children's and SickKids attended, shared ideas, frustrations, and enthusiasms, took part in discussions at other conference sessions, and formed the kind of connections that nearly two years later gave rise to CFAN. As well, a senior administrator at The Children's Hospital of Western Ontario observed the parent group and returned to London to start a group there.

The member institutions that allowed CAPH to expire committed to a larger and more robust organization, The Canadian Association of Paediatric Health Centres (CAPHC), that began in 2001 and that held its first conference in Toronto in June, 2002. With the encouragement of Elaine Orrbine (CAPHC's CEO), Frank Gavin organized a two-hour workshop for family advisory body members—about 20 attended—at the conference. All present agreed to form and support an informal national network (CFAN) with Frank Gavin as co-ordinator. Again, the volunteer parents present took an active part in many of the conference sessions and took full advantage of the opportunity to share resources and experiences in lots of small- and large-group conversations.

Almost immediately after the Toronto meeting, parent members of advisory groups began contacting one another much more frequently to inquire about family access to charts within hospitals, advisory group bylaws, the sometimes difficult clarification and balancing of parent and staff roles on advisory bodies, etc.

CFAN had its first full-day workshop on the first day of CAPHC's Calgary conference in 2003. The Family Liaison Council (FLC) at Alberta Children's invited many community groups from southern Alberta to participate in discussions that focused on advocacy and on the relation between culturally competent and family-centred care. As well, Joanne Ganton, chair of the FLC and Frank Gavin represented parents at a full day symposium jointly sponsored by CAPHC and Health Canada about a specific paediatric patient safety issue and about patient safety more generally. It quickly became clear that patient safety and family-centred care went hand-in-glove. A full report on the workshop and the symposium were circulated to all known family advisory groups at paediatric health centres in Canada.

Turnovers in the leadership of several advisory bodies were perhaps one main reason the next CFAN meeting in Montreal in 2004 attracted members of just four advisory bodies. Nonetheless, the discussions were rich. Dr. Peter Rosenbaum gave a stimulating presentation to the group of about 15 on the identified clinical benefits of family-centred services. Those present also elected CFAN's first steering committee.

Since that meeting in Montreal CFAN has grown steadily, and not just in numbers. Formal newsletters began to be produced a few times a year with submissions from nearly every affiliated groups. As well, applications were made to The SickKids Foundation three consecutive years for funds to help make it possible for parents to attend the yearly workshops, and each year the grant application was successful. (Because the Foundation has a limit of three successive grants of this sort being awarded, CFAN has not applied for a grant this year, 2007.)

The workshop in St. John's in 2005 saw a breakthrough. Ten groups were represented, and much more detailed information about the recruitment and retention of advisory body members, about the development of a parent liaison position, about education sessions/family faculty programs, etc. was shared. CFAN also displayed a poster at the CAPHC conference about its growth and activities, and arranged for a parent, Ruth Hartanto from the Family Forum at CHEO, to be on the organizing committee of a major project, Bridging the Divide, about transitions between settings and to give a most memorable presentation launching the project. CFAN continued to support the project by helping to gather parents for two teleconferences about issues related to the co-ordination and continuity of care for children with complex chronic conditions.

The newsletters that followed the St. John's workshop were not only more visually attractive—thanks entirely to steering committee members Susan Greig in Vancouver and Erin Pearson in London—but also more focused on particular themes. For instance, a survey was undertaken to identify the “nuts and bolts” of how advisory bodies functioned and the useful results filled several pages of the December '05 newsletter. In early 2007 the newsletter focused on strategic planning by advisory bodies.

Between the 2005 and 2006 workshops, CFAN was active in assisting the start-up of a new advisory group at The Glenrose Rehabilitation Hospital in Edmonton and connected with parents in two locations in British Columbia: Prince George and Vancouver Island. And there continued to be a fair amount of informal email contact about issues such as the resources that are available or needed at Family Resource Centres.

The 2006 workshop in Vancouver had the most varied and comprehensive agenda, highlighted by Susan Greig's presentation on forming and sustaining inter-generational advisory bodies, and both the largest number of participants (26) and the largest number of groups represented (12), including Canuck Place (a paediatric hospice in Vancouver) and a regional health authority's family advisory council. Susan Greig joined Frank Gavin as a co-chair and the steering committee was expanded to six: Lisa Rosati-White from the Family Advisory Forum at Montreal Children's, Dianne Parr from the FAC at

McMaster Children, Sherri Wuetherick from the Family Liaison Council at Alberta Children's, and Robin England from IWK in Halifax—in addition to Frank And Susan.

Looking back, we can see great growth, the establishment and development of an essential and fruitful partnership with CAPHC, and many useful and fortifying connections among the various CFAN-linked groups. Looking ahead, we see the need to use technology, especially the CAPHC website, more regularly and strategically, to formalize our structure and processes, to make more connections across the country, including with French-speaking groups, and to choose which of the great many requests that come our way and which of the many projects we ourselves would like to initiate and pursue we can and should make our priorities.

Frank Gavin

Full summaries of the 2003, 2004, 2005, and 2006 workshops and several CFAN newsletters are available on the CAPHC website: www.caphc.org Just look under "Partnerships."