



Family Advisory Councils in Pediatric Health Centres in Canada: Key Issues and Leading Practices

1.0 Background

The Canadian Family Advisory Network (CFAN) holds an annual workshop every October, in conjunction with the Canadian Association of Paediatric Health Centres conference. On October 18, 2009, the workshop was held in Halifax and was attended by thirty eight participants, including family representatives and staff liaisons.

The afternoon session was entitled: **Best Practices Discussion**. It was an open forum, and was facilitated by Frank Gavin, CFAN Past Chair. It was documented by David Nicholas from the University of Calgary (Edmonton division), Faculty of Social Work.

The intent of the Best Practices Discussion was to gather information about Family Advisory Councils' challenges and successes across Canada. Representation from the participants ranged across the country from Halifax to Alberta, and included children's hospitals, rehabilitation facilities, and community health centres with paediatric units.

2.0 Participants

The forum comprised a range of participants consisting of health centre staff members and parent volunteers whose experience on advisory bodies ranged from very little to quite extensive (e.g., up to 15 years). In a few cases, individuals who initially had been parent volunteers had subsequently assumed staff positions at their facility. There was representation from across Canada with the exception of a few provinces and the territories.

3.0 Questions asked

The following questions were posed to the group by Frank Gavin:

1. Why do we join Advisory Councils?
2. What are the benefits of having an Advisory Council?
3. What are challenges that Advisory Councils face?
4. How do we achieve success and maintain momentum?

The results were recorded by David Nicholas on flip chart paper, transcribed by a Research Assistant at the meeting, and also recorded by a tape recorder. The following sections outline the group's responses to each question, compiled from the three transcriptions of the discussion.

3.1 Why do we join Advisory Councils?

The answers to why we join Advisory Councils fell into two different themes: *to contribute to others or the system, and to improve our own or our families' lives.*

Reasons associated with *contributing to others or the system*, included such considerations as: addressing health care issues and challenges (including system breakdowns and concerns), improving or optimizing environments, seeking to be a voice for families.

Reasons that related to *benefits to our own or our families' lives* included considerations such as: proactively addressing concerns and thus alleviating feelings of helplessness, giving back to the facility, in the process of helping others also helping one's own family in navigating the system, gaining insight into how the system works, obtaining information on how to help others, and relationship building i.e., making connections and forging 'community' with others. Participants largely hoped that their involvement in, and contribution to, a family advisory body would make a positive difference for the pediatric health care community including their own child and family.

3.2 What are the benefits of having an Advisory Council?

The benefits and achievements of having an Advisory Council were plentiful. They fell into seven categories.

Much of the discussion touched on how councils can effect a significant **change in the perspective** of individual staff members and of the institution itself. The altered perspective sometimes results in or takes the form of **greater compassion** while at other times it helps build the case for **better patient-care processes**. Family stories are particularly compelling not only for **making the case for change** but in **indicating the direction the change should take**. Sometimes very specific problems can be highlighted and practical solutions identified because families are readily available. Family members of councils can also play **indispensable and unique roles in advocating** for programs and for the health centre with the rest of the public and with governments. Members of councils can also play such roles in **educating students and staff** in both formal and informal settings.

3.3 What are the challenges to having an Advisory Council?

Participants listed a number of **practical or logistical** challenges (e.g., extended and complex recruiting process, finding common times to meet, lack of child care availability, difficulty involving families who live at a distance, insuring adequate representativeness among families, etc.). More formidable challenges seemed to be **attitudinal or grounded in institutional or professional culture** (e.g., fear of criticism, fear of loss of control, sense of self-sufficiency, "us vs. them" attitude, etc.). Parents also identified **parental fears, attitudes, and expectations** (e.g., fear or previous experience of tokenism, "us vs. them" attitude, unrealistic expectation of how fast change can happen, etc.).

3.4 How do we achieve success and maintain momentum?

Finally, the Best Practice Discussion ended on a high note, with a lively discussion about what strategies worked and were successful for Councils.

Several participants noted the necessity of **sustained support from and involvement of senior leadership, alignment of council goals with institutional goals, explicit expectations of / role clarity for council members, accountability and progress measures that are regularly applied, and ongoing succession planning for family leaders.** Some participants noted the advantages of different ratios of staff and volunteer members and of different leadership models. There was general consensus that **attention to what may seem like "little things"** (parking, meals, beginning and ending meetings on time, showing appreciation, providing promised material or information, etc.) mattered a great deal.

Conclusions

1. It is important for parents who are thinking of joining or who have already joined advisory bodies to reflect on their reasons for joining, to assess their level of commitment and their ability to fulfill the responsibilities of their membership, and to assess regularly their individual contributions to the work of the council, asking "am I serving or sitting."
2. Recruiting, training, and mentoring new members and nurturing potential new leaders must be ongoing priorities.
3. Councils as a whole should set realistic short-, medium-, and long-term goals (aligned to some significant degree with those of the organization) and should regularly measure their progress toward achieving those goals.
4. Parents should be encouraged and trained--at least partly by other parents--to contribute their experiences and stories in appropriate settings, especially educational ones.
5. Parent and staff members of advisory bodies should be encouraged to identify whatever attitudes or expectations they may have that could limit or undermine the work of the council.
6. While no single formula or model seems to offer itself as the best one to use when deciding on the proportion or number of staff and parent members of councils or on a particular leadership structure or reporting relationship, the ongoing direct involvement and support of senior leadership within the organization is crucial to the advisory body's success.
7. The regular identification of logistical barriers to the participation of members and the work of the council and efforts to remove those barriers, i.e. paying attention to the little things, can make a substantial difference to the health and effectiveness of a council.