



CFAN Workshop Report 2009, plus Lessons learned from CAPHC 2009

This year's CFAN workshop was a powerful and practical session. The day was chaired by Sue Robins, and hosted by Robin England and Chuck Livingstone, a staff liaison and co-chair of IWK's Family Leadership Council. The costs associated with the meeting room rental, catering and AV were generously supported by the Canadian Association of Paediatric Health Centres (CAPHC).

Roundtable Introductions

Robin and Chuck began the day with the challenge: 'draw a picture of a tattoo you would get'...this led to a compelling roundtable introductions and icebreaker, where snippets of members' own stories were shared with the group.

Updates

Ten members gave local group updates. Glenrose, Stollery, London, McMasters, Sick Kids, Bloorview, CHEO, Roger's House, Montreal and IWK. The distributed handouts are posted in the local group information in the CFAN member's only site. (Reminder: User name: cfan. Password: member2009).
http://www.caphc.org/cfan_members/index.html

Donna Thompson

Donna Thompson, a skilled storyteller and parent advocate from Halifax, did a magnificent job of telling her family story while weaving in the importance of telling our stories to health providers. She distributed a reference list of stories about healthcare, and Donna's own story has been published in Privileged Presence which can be found on Amazon. Donna's reading list of Medical Literature is posted here on the CFAN site.
http://www.caphc.org/cfan_members/documents_partnerships/cfan/narrative_medicine_book_list.pdf

Sydney's Spot - Ann Hovey

Ann spoke in the first annual parent speaking spot, named Sydney's Spot in honour of CFAN Steering Committee member Ruth Hartanto's daughter Sydney.

Ann deftly drew parallels from her experience as a speaker in the business world to presenting her daughter's story to Grand Rounds at London Health Sciences Centre. Her creative approach to preparing to present to a large audience of medical professionals included examining risks and benefits to presenting family stories. Ann's CFAN presentation is found here.
http://www.caphc.org/cfan_members/docs/hovey_sharing_family_stories.pdf

Best Practices

This session was facilitated by Frank Gavin, and was documented by David Nicholas from the University of Calgary (Social Work). This was a chance for CFAN members to share their wisdom with other members about Advisory Council benefits, challenges and solutions. The transcript of the two hour

session will be posted on the CFAN website, and it is hoped that an article will be written about this discussion about Council best practices in Canada.

AGM

The annual report that outlines CFAN's work over the past year, and is found at http://www.caphc.org/partnerships_cfan_about.html. Of note, descriptions of volunteer opportunities within CFAN will be drafted, posted on the CFAN website, and opened up to the entire CFAN membership.

While the CFAN Steering Committee has a full slate of officers, all members are encouraged to start thinking about putting their names forward next year at the 2010 CFAN Workshop. Job descriptions and time commitment estimates for all the Steering Committee positions will also be posted on the CFAN website.

Next year's CFAN Workshop is in Winnipeg! We look forward to working with our Winnipeg connections to plan another successful and value-added workshop...

CAPHC Lessons Learned

We were very excited that three family members spoke at the Canadian Association of Pediatric Health Centres conference. Valerie McDonald, Joanne Ganton and Ian Brown, all parents of children involved in the health system, shined as speakers at the CAPHC conference. The three day conference included sessions on global action, and investing in early childhood. Valerie McDonald participated in the Youth Symposium and gave the important parent perspective of having a child involved with the health sector. Crystal Chin, a young adult delegate from Toronto who attended CFAN, also spoke at this panel and was very eloquent about the challenges involved with transitioning from child to adult services. Robin England did a fantastic job of moderating this session.

The motivational speaker was Frank O'Dea, founder of the Second Cup. He shared his story of triumphing over adversity as an alcoholic on the streets to becoming a successful businessman – with the underlying theme of: when all you have is hope.

Next up were breakout sessions. The 'Investing in Ability: Frameworks for Changing our Focus from Illness to Health' session was an explanation of a data collection tool created for children with chronic conditions that emphasized ability and health.

The breakout session on "Youth and Adults Working Together to Create Effective Transitions to Adult Care," unfortunately, had no youth or parents presenting together with staff on the panel. The three panelists did provide many practical tips and success stories as well as a case for the role usually overlooked primary care providers could play in transitions. One memorable nugget from the session: health professionals should ask about how things are going for the patient and family and wait for a response not at the end of an appointment when the family is half way out the door but at the very start of the appointment. This will help make it much more likely that the issues of greatest importance to the patient and family, including those related to transitions, are on the table.

Joanne Ganton provided a parent perspective on the panel addressing 'Populations at Risk – Are we as forward thinking as we should be?' In her moving presentation, she explained the challenges within systems of having a child with cerebral palsy, and was for many, the highlight session of the conference. Children from the inner city and aboriginal children were also presented as 'at risk' populations.

The final day of the conference was a lively World Cafe session. Presenters Mary-Jo Haddad (Sick Kids), Dr. Shoo K. Lee (Health Economist) and Ian Brown (parent and journalist) set the tone for small group breakout sessions and discussion around some key questions about re-examining assumptions about child health. The discussion was captured by the facilitators, and the theme of engaging and talking meaningfully to the 'users' of the child health system came up again and again.

What's next?

Feeling inspired and rejuvenated, CFAN has a long list of follow up items after Halifax. They include:

- Investigating support for a national youth network
- Posting 'volunteer opportunities' for family representation on national initiatives
- Opening up the CFAN Steering Committee meetings to ALL CFAN members
- Expanding our membership beyond children's hospital walls
- Strengthening our relationship with the Institute of Family Centered Care
- Looking into different ways of communicating, including e-newsletters
- Collecting CFAN Steering Committee information: on time and expenses spent on CFAN
- Connecting with the folks in Winnipeg to plan for CFAN 2010

Finally, the evaluation results from the CFAN Workshop in Halifax were collated by CFAN Steering Committee member Sherri Wuetherick, and are found

http://www.caphc.org/partnerships_cfan_workshops.html