

CAPHC Family Advisory Workshops Post-mortem Report

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CAPHC Pre-Conference Session
Family Advisory Workshop
June 15, 2003
Hyatt Regency Hotel
Calgary, Alberta

A pre-conference satellite workshop was held on the Sunday preceding the CAPHC conference. All parent/family advisory councils at paediatric health centres across Canada were invited. Many advocacy groups and community support agencies in the Calgary area & across Alberta were also invited. A large advertisement ran 3 times in the Calgary Herald promoting the workshop to the general public.

Sessions held: (9:00am – 4:00pm)

1. Coordinating a Family/Parent Advisory Council
2. The relationship between Family Centred Care and Culturally Competent Care (Joint lunch session with Cultural Competency workshop)
3. Advocating for your child: Working together/collaboratively with health care professionals, with your child's best interest at heart – a parent/professional panel discussion (2 parents, 1 MD, 1 Clinic Nurse)
4. Canadian Family Advisory Network – next steps for national networking of FAC/PAC's; partnership with CAPHC; planning for Montreal 2004

Attendance:

34 attendees in total

5 CAPHC member hospitals were represented:

- Alberta Children's Hospital, Calgary
- The Hospital for Sick Children, Toronto (1 parent)
- London Health Sciences Centre (1 parent; 1 family advisory staff)
- Montreal Children's Hospital (2 parents)
- Winnipeg Children's Hospital (1 parent; 1 family centred care staff)

5 ACH Family Liaison Council members

7 Family/Parent Advisory Council members from other CAPHC member health centres

5 ACH/CHR staff members

5 Southern Alberta Child & Youth Health Network staff members

2 staff Peter Loughheed Centre, Calgary

1 parent Parents in Partnership for NICU/SCN at Foothills Medical Centre, Calgary

2 parents Paediatric Oncology Parent Advisory Committee at ACH

3 parents from the community

Gateways – special needs support agency

Learning Disabilities Association of Alberta

Children's Cottage Society/U of C Nursing

New Heights Learning Services - preschool

Sponsors:

Great appreciation and gratitude is extended to the individuals and organizations that assisted with the Family Advisory Workshop. They are:

CAPHC – promoted the Family Advisory Workshop in the CAPHC conference brochure and on the CAPHC website; provided the meeting room at the Hyatt; provided coffee & snacks throughout the day; flip charts

SACHYN (Southern Alberta Child & Youth Health Network) – sponsored a Family Liaison Council parent delegate to CAPHC & expenses for a parent from SACHYN to attend the pre-conference workshop; lunch expenses for all 34 workshop participants; provided SACHYN material for the delegate packages; managed the local registration process; transcribing flip chart notes from the workshop

Alberta Children's Hospital Foundation – design and production assistance for the Workshop brochure and newspaper advertisement; ran newspaper ad 3x in the Calgary Herald to create great exposure and awareness of the Family Workshop and the Family Liaison Council; folders, pens, pins for the delegate packages

Calgary Health Region & the Alberta Children's Hospital – organizing assistance for the conference; parent delegate attendance at the CAPHC Conference; production of Family Liaison & Workshop communication material; Thank You gift certificates to panellists; other miscellaneous expenses

Alberta Community Development – conducted a crash course in group facilitation for parent facilitators at the workshop

Organizing Committee:

Consultation and input on the topics and structure of the workshop was sought and provided by many of the Family/Parent Advisory committee members from across the country beginning Dec./02. The local organizing committee for the Family Advisory Workshop included participation from 10 parents plus a number of staff members from ACH. They provided assistance and input into planning the workshop topics, recruiting panellists and delivery of the workshop on the day.

Overall facilitation for the day was provided by a parent (J. Ganton, ACH Family Liaison Council co-chair). Facilitation of the afternoon panel discussion was facilitated by Debra Carnat, an ACH staff member. 4 parents were trained and facilitated the break out group discussions; parents & a SACHYN staff member provided assistance with the registration table.

Conference Follow-up:

Minutes and summary notes from all the sessions will be compiled and distributed to all attendees; CAPHC; and all family/parent advisory committees from across the country that were unable to attend. It is intended this material will also go onto the ACH Family Liaison Website, and possibly the CAPHC website, depending on content and format.

Family Advocacy Workshop Participant Feedback

1. What aspects of today's workshop did you find most beneficial?

Interaction with people, both parent & professional who want to improve healthcare for kids & their families;
Being aware of Family Advisory Council; understanding what area I can contribute to;
Morning session on parent councils exchanging ideas;
Morning group; learning what other hospitals are doing;
The discussion; the facilitation of the small groups by parents!
The different experiences & ideas that the participants shared with each other for each of the discussion topics;

2. What aspects of today's workshop did you find least beneficial?

Too short a time frame; great discussion; if there is a second session or some follow-up I would like to participate;
By-laws and admin notes;
Too much structure in small group session in terms of the 2 questions that were asked;

3. If we were to plan other Family Advocacy workshops in the future, what recommendations would you have for improvements or other component to include?

Make the session a little longer; this one (afternoon panel discussion) was hard on the facilitator;
Seating that allowed us to face each other; FAC/PAC presenters on projects that worked and that didn't
To pursue further the use of parents as leaders & facilitators among a group of professionals > this strategy in itself educates professionals about parents' capacity and help to generate more respect & credibility;
Funding sources for initiatives; Evaluation approaches; Building a community network of resources;

4. Any other comments?

I appreciated the opportunity to be here!
Invite more people!
You folks did a fantastic job!
Please pay attention to the "Southern Alberta Child & Youth Health Network" > your participation with its work would be invaluable!
I appreciated the opportunity to participate and I intend to share the discussion points with other members of the Board of Directors (Children's Cottage Society)

5. Would you like to receive any additional information about the Family Liaison Council at the Alberta Children's Hospital or becoming a member? Please specify.

I would like to know what the FLC is and how I could help give something back to the system that has given me my daughter back!
Yes
Design information on the new hospital (London Health Sciences Centre)
Yes I would like to receive additional information about the council as well as membership information. I intend to share the information with the Children's Cottage Society.

Additional comments also received by parents and family council representatives:

- Excellent Family Advisory Workshop; with this as a pre-conference workshop in the CAPHC brochure it was much easier (than in past years) to request and obtain the funding support from our hospital to send parent reps to CAPHC
- Parent attendance at the full CAPHC conference was very valuable and interesting
- Would like to see more family participation in full plenary sessions
- Would like to have more time to learn in detail about particular projects from other Family Advisory Councils
- Would like to see CAPHC partner with FAC/PAC's to further enhance awareness and education of Family Centred Care at our institutions
- Pre-conference workshop was a very valuable time

**Canadian Association of Paediatric Health Centres (CAPHC)
Pre-Conference Family Advisory Workshop
Afternoon Session Summary
June 15, 2003**

“Advocating for your child: Working together/collaboratively with health care professionals, with your child’s best interest at heart”

Thirty-four parents and health care providers from across Canada spent an afternoon participating in both a panel discussion and smaller breakout groups. Participants discussed the importance of developing positive collaborative relationships between parents and their child’s health care providers.

Panelists:

Jason Mutschler – parent from Medicine Hat; young daughter with Down Syndrome; member of SACHN Steering Committee and Parent & Youth working group.

John Cuthbertson – parent of teen battling Leukemia and other health challenges; member of ACH Parents Advisory Committee for Pediatric Oncology

Andrea Pritchard – nurse clinician at ACH Hemophilia and hematology clinics; Masters student; chair of Child Health Nursing Research Initiatives committee

Dr. Andrew Wade – pediatric nephrologist and Director of Dialysis at ACH; Assistant Professor of Pediatrics at UofC

Facilitators:

Debra Carnat – Dept. of Social Work at ACH

Joanne Ganton – co-chair Family Liaison Council at ACH

Additionally, 4 parent volunteers led and facilitated the breakout group discussions.

What facilitates collaborative relationships between parents and child health care providers?

- Using a multi-disciplinary team approach with parents as team members
- Having good communication with the child’s doctor
- Well informed parents
- Parents being heard and respected
- Parents having information
- Having a second meeting after diagnosis to review what was said initially
- Meeting other families whose children have the same diagnosis/condition
- Learning from others
- Accepting extended family members as part of team – including family in case conferences
- Having a main contact to pull things together for the family
- Experts asking what parents want/expect
- When parents are active members of their child’s health team
- Asking questions and making copies of documents
- Having appropriate information before making decisions
- Maintaining a positive outlook
- Recognizing success and looking for alternatives when faced with setbacks in treatment
- Professionals using and suggesting the use of outside groups and other families
- Keeping relationships with out-of-town families “seamless”

- Working with families who aren't able to advocate for themselves

What hinders collaborative relationships between parents and child health care providers?

- Poor communication between families, their *team* and outside health care providers
- Applying labels such as “difficult” and “non-compliant” to families
- Lack of access to basic health information and education
- Lack of follow up and information
- Poor bedside manner
- Parental guilt when genetic problems are identified
- Families responding to diagnoses by back lashing
- Lack of access to appointment times
- Knowing how much information to provide to families
- Not being able to ask stupid questions of professionals
- Receiving conflicting information re. diagnoses
- Openness, or lack of, with professionals
- Treating providers with a lack of respect (includes all staff – cleaning, porters, students, etc.)
- Not being open with thoughts and concerns (results in internal feeling of discontent that can result in poor communication and lack of projected respect for providers)

Strategies to build positive and collaborative relationships between parents and their child's health care providers:

- Educating staff and families about what family centred care is and isn't
- Developing family faculty programs
- Having brochures for families
- Talking with families upon hospital admission about mutual expectations and including the family when developing both care and discharge plans
- Staff adapting to learning styles of families
- Respecting families as being experts on their own child and family
- Getting to know families and not judging them
- Using available resources and seeking out information
- Being persistent
- Being a good listener
- Speaking up: health care professionals and parents aren't mind readers.
- Building trust and acknowledging misunderstandings, mistakes and weaknesses
- Asking families how they want to receive information ie. when, how much, what, who else can be present
- Requesting a second opinion
- Using resource centres
- Having parent network / space for parents to meet and/or be alone and use resources
- Finding most appropriate ways to communicate ie. email, phone face-to-face, teleconferences
- Understanding and clarifying roles of team members
- Understanding family context
- Providing bridging between families and professionals (family support)
- Asking families what is important to them (this validates everyone's role)
- Transition Planning – needs change over time
- Using appropriate language – simplify explanations where necessary
- Connecting families together both informally and through advisory groups
- Interdisciplinary coaching to understand collaborative relationships and family centred care

- Communicating with doctors and nurses through email
- Professionals who are flexible
- Having someone else (another parent/support person) attend appointments
- An accessible whole health care team
- Acknowledging that the diagnosis is a family affair
- Training for parents to provide support to other parents

Child health care providers can help make parents and children feel like valuable members of the health care team by:

- Treating each child with respect – including the both the child and parents in the discussion
- Taking time to answer questions – getting back to families with answers when necessary
- Having proper supports on hand during meetings for important procedures or decisions
- Being willing to repeat answers for families
- Recognize that lay people do not have medical degrees
- Explaining treatments – even small procedures
- Taking time to listen to parents and children
- Being patient with families
- Recognizing sleep deprivation and its effects. Allowing for some grumpiness.
- Realizing that people go through wholly unpleasant experiences with little or no preparation for what they are being faced with

Families can help by:

- Maintaining an upbeat attitude
- Being open and honest with concerns and feelings
- Recognizing and thanking people who provide exceptional service and treatment
- Asking someone's name and remembering it when you see them the next time
- Taking an interest in how someone does their job. Asking for an explanation on how a process works or why things are being done. Professionals like to explain their work

Report on CFAN Meeting, June 2003

On Sunday June 15th at the end of the all-day Family Advisory Workshop (a pre-conference event that was attached to the annual conference of The Canadian Association of Paediatric Health Centres and made possible by CAPHC) the following representatives of hospital-linked family advisory bodies met to discuss the status and future of The Canadian Family Advisory Network (CFAN):

- Joanne Ganton, Co-Chair, Family Liaison Council, Alberta Children's Hospital (jganton@telusplanet.net)
- Debra Raoufian, Co-Chair, Parents in Partnership (NICU Parents) Alberta Children's Hospital (raoufian@shaw.ca)
- Ardis Cheater, Co-Chair, Family Advisory Committee, Winnipeg Children's Hospital (webuild@mts.net)
- Joanne van Dyck, Co-Chair, Family Advisory Committee and FCC Advisor, Winnipeg Children's Hospital (jvandyck@hsc.mb.ca)
- Danica Rose, Family Advisory Council Liaison, Children's Hospital of Western Ontario (Danica.Rose@lhsc.on.ca)
- Nancy LeBlanc, Member, Family Advisory Council, Children's Hospital of Western Ontario (LRstarr@aol.com)
- Frank Gavin, Associate Member, Family Advisory Committee, Hospital for Sick Children (frankgavin@rogers.com)
- Beverley Fields, Co-Chair, Family Forum, Montreal Children's Hospital (beverley.fields@muhc.mcgill.ca)
- Anne Usher, Member, Family Forum, Montreal Children's Hospital

Earlier in the day, as part of the larger group, in the sessions on starting and maintaining effective advisory groups, on cultural competency and family-centred care, and on advocacy. In the morning session especially we provided updates on each group's current activities, accomplishments, and challenges (i.e. difficulties).

In the late-day session all agreed that, despite the difficulties of maintaining regular contact through the year and getting away from our real lives and to a yearly meeting, it was worthwhile to keep CFAN alive and to make it more functional in the future. In particular, the group decided to:

- form a steering committee (Joanne Ganton, Joanne van Dyck, Frank Gavin, and Beverley Fields) that will try to identify and contact all existing advisory groups in the various parts of the country and co-ordinate regional and national activities and projects;
- work with CAPHC to gain a presence on the CAPHC website where there might be links to each advisory group's website and where we might post news and information of general interest (e.g. information about September's Family-Centred Conference in Boston where Alyssa Sacks of Partners in Care in Vancouver and Debra Raoufian of Parents in Partnership in Calgary will be presenters); and
- work with CAPHC in preparing for the conference in Montreal in November 2004 where we hope both to have another all-day pre-conference workshop and to participate in a presentation that would be part of the program for all those attending the conference.

(Since the conference the value of the kind of networking that happened in Calgary has already become evident in the sharing of information between some Ontario-based advisory groups about changes, in the post-SARS world, to visitor's policies and the need to keep such changes consistent with family-centred care.)

Frank Gavin, Associate Member, Family Advisory Committee, The Hospital for Sick Children

Report on Patient Safety Meeting

On Saturday June 14th Joanne Ganton from the Family Liaison Council at Alberta Children's Hospital and I participated in a joint all-day Health Canada—Canadian Association of Paediatric Health Centres workshop on patient safety. Four officials from Health Canada and about twenty-five staff members from paediatric centres across Canada were the other participants.

The workshop grew directly out of a “Notice to Hospitals” that Health Canada sent last summer in response to the death by strangulation in IV tubing of a very young child in Edmonton. (There have been reports of many serious entanglements in such tubing and in monitor leads in both Canada and the U.S.) Of most concern was one of the notice's recommendations: “All hospitalized children who could possibly become entangled in a lead or tubing should be continuously observed by an adult or placed on a monitor.” Some said this wasn't practical; some said it might not even necessarily be effective. (Think for a moment about whether even the 24-hour presence of a parent would really constitute “continuous observation.”) There were also presentations and discussions about larger questions regarding patient safety that I, for one, found eye-opening.

By the end of the day the group hammered out the core elements of a new “Notice to Hospitals” that the Health Canada officials present agreed to take back to Ottawa for further feedback and final approval. Perhaps the item that will be of greatest interest to families is a recommendation that in developing each patient's risk assessment staff be required to collaborate with the patient's family. (Think of what each family could share about their child's sleeping habits, degree of restlessness, past responses to medication, ways of expressing anxiety, etc. and think of how useful it would be if families and staff could move beyond often unstated assumptions about how much time the family will be in the room, how familiar the family is with various procedures and equipment, how much the family can participate in the child's care, etc.) Joanne emphasized the need to keep the family of the Edmonton child fully informed about the new notice, the process in which it was developed, and the reasons for the changes.

In the more general discussion there was a suggestion that hospital staff be encouraged to report “near misses” related to patient safety and that each hospital have a clearly defined process for reporting such incidents—as happens in the airline and nuclear power industries. I suggested families too should be so encouraged and have a formal process identified whereby they too can report what seem to them to have been near misses.

The Health Canada officials present agreed to contact CAPHC promptly whenever a particular issue regarding paediatric patient safety arises, and I'm sure CAPHC will involve families in their response whenever such involvement seems warranted.

Joanne and I were happy to be invited to participate. We found the other participants receptive to our comments and suggestions, and we learned a great deal from them. Certainly we took away from the meeting a reinforced conviction that patients and families should be at the table when patient safety issues are on the table.

Frank Gavin
Associate Member, Family Advisory Committee to The Hospital for Sick Children