

Canadian Family Advisory Network (CFAN)
Summary of 2004 Workshop
CAPHC Conference (Montreal)

Sixteen people attended all or part of the day-long workshop on Sunday, November 7th. The following groups were represented: The Family Advisory Forum at Montreal Children's Hospital, The Family Forum at The Children's Hospital of Eastern Ontario, The Family Advisory Committee to The Hospital for Sick Children, The Family Advisory Council at The Children's Hospital of Western Ontario, The Canadian Sickle Cell Society, and The Child Health Network of the Greater Toronto Area. Also participating were several staff members of The Montreal Children's Hospital, including a senior administrator, and a staff member from The Shriners Hospital for Children in Montreal.

From Vision to Practice: The Morning Session

The morning session was facilitated by Sharon Leslie from Montreal. We first participated in a visioning exercise in which, after choosing pictures that spoke to us about family-centred care, we identified core characteristics of family-centred care, shared brief narratives that exemplified family-centred care, and then discussed specific ways we could advance such care in our local settings. The representatives from the advisory bodies also shared brochures, annual reports, and information about particular projects in which they were engaged.

Dr. Rosenbaum's Presentation on Family-Centred Service

After a wonderful lunch provided by CAPHC and shared with participants in various other pre-conference sessions, we listened and responded to a presentation by Dr. Peter Rosenbaum, Co-Director, CanChild Centre for Research at McMaster University. From the announcement of the title of the presentation ("Family-Centred Service: Why Should I Care?") to the end of the ensuing discussion, all present were both engaged and enlightened. Dr. Rosenbaum defined and presented a conceptual framework of family-centred service, shared some recent research that links processes of family-centred service with outcomes, and then discussed the implications of the research.

Dr. Rosenbaum spoke of the value of a "non-categorical" approach to children with chronic health problems and their families. This approach is grounded in the evidence-based understanding that children with a wide variety of diagnoses and their families have many more needs and problems in common than they have needs and problems unique to the particular diagnoses. He also noted that families' adherence to advice and therapeutic protocols depends, at least to some extent, on how well clinicians respect, inform, and partner with families.

In the core of the presentation Dr. Rosenbaum presented evidence linking family-centred service with greater parental satisfaction, less parental stress, and improved child

behaviour. He also offered an illuminating challenge to the commonly-held notion that parents of children with disabilities experience a disproportionately high rate of marital breakdown.

Much discussion occurred during and after the presentation, and all present seemed to find it very stimulating. Slides from it should soon be available electronically.

Getting Down to Business

Finally, CFAN had a short, focused business meeting. Given that only four advisory bodies were represented, those present decided to make only modest, achievable plans. First, all agreed that CFAN should serve two purposes:

1. to facilitate communication between and among the various family-based advisory bodies linked to CAPHC member institutions; and
2. to act as a resource providing parent and family perspectives and expertise to CAPHC and other organizations trying to improve the health of children and youth in Canada.

The important point here is that CFAN doesn't exist primarily for its own sake but for the sake of the individual groups across the country either already in place or at some degree of being formed.

A new Steering Committee was selected: Erin Pearson of The Family Advisory Council at CHWO, Lisa Rosati-White from the Family Advisory Forum at Montreal Children's, Rosetta Cadogan from Montreal Children's and The Canadian Sickle Cell Society, and Frank Gavin from The Family Advisory Committee at HSC. All present also hoped that someone from western Canada will be able to join the Steering Committee in the coming months. Frank Gavin will act as Chair of the Steering Committee for the next year.

All present also indicated a desire to work with CAPHC staff to establish a permanent presence on the CAPHC website (www.caphc.org) and a mechanism to exchange information and ideas via the website.

Finally, everyone agreed on two areas about which they are most eager to share information and ideas: 1) our education programs for health care professionals and students and 2) family-to-family support programs.

New Contacts

During the course of the conference many of us met people from several paediatric health centres not represented at the CFAN workshop who, nonetheless, expressed considerable interest in our work and in fostering advisory bodies at their own institutions. We shared tips, strategies, and materials with them and hope they are able to

help add to a network that can, in turn, support local groups and champion family-centred care across the country.

Thank You

We are most grateful to The Hospital for Sick Children Foundation for providing a grant of \$2,000 that helped some of the parents who travelled to Montreal attend the workshop. Thanks also to CAPHC, especially its CEO, Elaine Orrbine, for constant encouragement and good advice. And finally thanks to our good-hearted hosts in Montreal, especially Anne Usher , who planned most of Sunday's activities, and Beverly Fields, who welcomed several of us to her home for a very convivial evening on the Monday.

Frank Gavin

Member, Family Advisory Committee to The Hospital for Sick Children
Chair, Steering Committee, Canadian Family Advisory Network.