
Family to Family Connections

Evaluation Report

Family and Community Resource Centre
Southern Alberta Child and Youth Health Network

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Executive Summary and full report are available on the Family and Community Resource Centre's website: www.fcrc.sacyhn.ca.

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EXECUTIVE SUMMARY

This report presents the evaluation results of Family to Family Connections (F2Fc), a program operated through the Family and Community Resource Centre (FCRC) located at the Alberta Children's Hospital (ACH). This program has been made possible with seed funding provided by the Alberta Children's Hospital Foundation.

F2Fc offers one-to-one connection of a supportive family volunteer with a requesting family from across southern Alberta. The connection is between people who have been, or are going through, similar child health situations. An evaluation was conducted from October 2008 to January 2009¹ to better understand the successes achieved and challenges faced by the program in its early stages of operation and identify improvements that could be made to best meet the needs of requesting families. Data was gathered through 23 guided interviews with supportive and requesting families, a discussion group with 10 participants (eight F2Fc Advisory Committee members, five of whom are also supportive family volunteers, and two supportive family volunteers), telephone interviews with two members of the F2Fc Advisory Committee and background project document review.

This evaluation looked at successes and challenges in the early stages of F2Fc, as well as areas in which the program could enhance and expand. The findings of the evaluation validated many aspects of F2Fc, including the orientation process, efforts to raise awareness of F2Fc, support for supportive families, connections between families and positive outcomes being achieved. Recommendations that can be drawn from the findings are as follows.

Orientation for supportive families

- **Findings.** The orientation for supportive families helped to prepare them for their role in the F2Fc program, with only a few minor changes to the orientation being suggested. Supportive families indicated enhanced confidence levels achieved through the orientation session and by knowing about resources to which they can link requesting families.
- **Recommendations.** The orientation for supportive families could be strengthened by including some additional information in the orientation and by emphasizing to supportive families that the value to requesting families comes from the *impact* of a connection rather than the *frequency* of connections, i.e., frequency varies among families.

Awareness of F2Fc

- **Findings.** Requesting families are finding out about F2Fc from a variety of health care providers from several different institutions. Supportive and requesting families, and Advisory Committee members, validate the efforts of F2Fc in creating ongoing awareness of the program and suggest the additional strategies be used to increase awareness, i.e., encourage other organizations to post a link to F2Fc on their websites and enhance search engine optimization to heighten the profile of F2Fc on Internet

¹ Evaluation questions were finalized in June 2008 during the early stages of evaluation planning. The questions were written to explore the early phase of implementation.

searches. Participants in the discussion group validate the process of recruiting supportive families by working through health care providers. They also indicate that some health care providers question the value of family-to-family support.

- **Recommendations.** Efforts to promote F2Fc among families with children of special needs could be improved by continuing to raise awareness of the program among people who work with families of children with special needs (e.g., social workers, nurses, doctors, physiotherapists and other health care providers); continuing to promote F2Fc as a complement to what health care providers are already doing; ensuring F2Fc maintains a high profile as the provincial health care scene continues reorganization in 2009; encouraging other organizations to include an F2Fc link on their websites; and enhancing search engine optimization for F2Fc. It is also recommended that F2Fc continue efforts to strengthen relationships with health care providers and encourage requesting families to tell their health care providers how helpful they found the F2Fc connections.

Ongoing support for supportive families

- **Findings.** Supportive families feel strongly supported by the F2Fc Coordinator and FCRC, which appears to be integral to the success of F2Fc. Participants in the discussion group also felt there was strong support for supportive families and suggested F2Fc could explore ways to enhance the support already provided, e.g., informal gatherings of supportive families. F2Fc has already begun development of a secure and moderated online discussion forum for supportive families. Supportive families indicate that the clinical, professional and interpersonal skills of the F2Fc Coordinator contributed to their own sense of support. Participants in the discussion group saw opportunities to expand the role of supportive families and F2Fc has already begun to facilitate some of these expanded roles.
- **Recommendations.** Support for supportive families could be enhanced by exploring learnings around opportunities to keep supportive families engaged with the program; providing continued support by a highly skilled and knowledgeable Coordinator; and continuing with the development and implementation of the online discussion forum. It is also recommended that F2Fc emphasize to supportive families that the value to requesting families comes from the impact of a connection rather than the frequency of connections, i.e., frequency varies among families.

Connections between families

- **Findings.** Overall, connected families see themselves as being similar to each other and have found their communications to be successful and effective. While approximately half of the connected families felt they had enough contact, the other half felt they had too little contact, although this did not appear to lead to dissatisfaction in the connection.
- **Recommendations.** Connections between families could be strengthened by continuing to recruit supportive families to build a larger resource pool from which to draw similarities in connections.

Outcomes reported by supportive and requesting families

- **Findings.** Positive outcomes have been achieved for both requesting and supportive families regarding the provision of support, information and links to resources. Potential evaluation indicators can be found within these outcomes.
- **Recommendations.** It may be useful in the future to assess the extent to which these outcomes are being achieved through the following indicators: sources of support, information and resources accessed by requesting families; measurements of self-empowerment, self-efficacy and hope in requesting families; measurements of compassion satisfaction in supportive families; and points of community contact for supportive families.

Consultations with the evaluation team identified the following considerations for further data collection and program review: facilitating more feedback on orientation materials; finding out from families and health care providers about ideas for promoting F2Fc; keeping track of questions asked and support provided to supportive families; and checking in with families on a regular basis to inquire about perceived benefits and issues around their connections.

As F2Fc continues to develop, the program would benefit from continued consultation with ACH clinical areas and community providers to explore ways to further F2Fc as an augmentation to clinical intervention and discover how volunteers can support their work. In doing so, F2Fc can adapt to the ongoing needs of families within a shifting health care environment.

1/ INTRODUCTION

Family to Family Connections (F2Fc) is a program operated through the Family and Community Resource Centre (FCRC) located at the Alberta Children's Hospital (ACH). This program has been made possible with seed funding provided by the Alberta Children's Hospital Foundation. F2Fc offers one-to-one connection of a supportive family volunteer² with a requesting family from across southern Alberta. The connection is between people who have been, or are going through, similar child health situations. Supportive families share the unique perspectives they have gained through experience with many systems, including the health care system. The goal of the connection is to provide requesting families with information, support and links to resources.

"...another family's experience and strength gave me the courage..."

Excerpt from Family to Family Connections brochure

The first F2Fc connections were made in December 2007, although groundwork was being laid well before that time, e.g., project planning research conducted in 2005, Coordinator hired in February 2007, advisory committee formed in April 2007, orientation piloted in July 2007. Since its inception, F2Fc has oriented 16 supportive families and made 13 connections between supportive and requesting families.

The families involved with F2Fc are coping with a wide range of health, behavioural and family issues. To make a connection, the F2Fc Coordinator assesses a variety of factors—connections are not made specifically around diagnosis. Factors taken into consideration include age of child, stage of family life, behavioural challenges and school and community issues. Also considered are information needs around specific treatments and medical procedures and overall needs for information, resources and support, e.g., coping with a lengthy hospital stay.

1.1 Evaluation Purpose and Objectives

The purpose of this evaluation is to better understand the successes achieved and challenges faced by the program in its early stages of operation and identify improvements that could be made to best meet the needs of requesting families.

The F2Fc evaluation is one part of a comprehensive five-year multi-component FCRC evaluation. The FCRC provides universal access to comprehensive and reliable child health resources, support, information and education for families, service providers and community members and is one of the essential components of the Southern Alberta Child and Youth Health Network (SACYHN). SACYHN is committed to facilitating access to information as a way of building family and community care capacity across child-serving sectors.

² Hereafter referred to as supportive families.

2/ METHOD

2.1 Data Collection

Data for this evaluation was gathered from four key sources:

1. Telephone interviews with both supportive and requesting families
2. Discussion group with members of the F2Fc Advisory Committee³ and supportive families
3. Program documents
4. Consultations with the evaluation team members

1. Telephone interviews

In October through November 2008, telephone interviews, of approximately 45 minutes each, were conducted with both supportive and requesting families by a member of the evaluation team at the convenience of the F2Fc families. The interviews followed a discussion guide prepared by the evaluation team (see Appendix A: Family Discussion Guides). Participating families provided informed consent to participate in telephone interviews (see Appendix B: Consent Forms). Notes were taken during the interviews and will be deleted after the finalization of this report.

Supportive families were asked questions about the orientation process, perceived support during the connection, experiences during the connection, the success of the connection and suggestions for improvement. Requesting families were asked how they became aware of F2Fc and about their initial contact experience with the Coordinator, experiences during the connection and suggestions for improvement.

2. Discussion group with members of the F2Fc Advisory Committee and supportive families

In January 2009, a discussion group was held with 10 participants (eight F2Fc Advisory Committee members, some of whom are also supportive family volunteers, and two supportive family volunteers). Two additional Advisory Committee members were interviewed by telephone as they could not participate in the discussion group. The F2Fc Advisory Committee consists of both health care providers and families (see Appendix B: Advisory Committee Terms of Reference). The discussion, facilitated by the research consultant and evaluation coordinator, was guided by a collaboratively designed discussion guide (see Appendix C: Advisory Committee Discussion Guide). The discussion guide probed for

³ Two Advisory Committee members could not participate in the discussion group so were interviewed by telephone.

deeper insights around ongoing support to supportive families, raising awareness of the program among potential requesting families, recruiting supportive families and how to involve supportive families in leadership roles.

3. Program documents

The evaluation also included a review of key documents on F2Fc, including the program brochure, Supportive Family Orientation Manual and materials related to the Southern Alberta Family and Community Resource Centre. These documents provided context and structure for the development of the discussion guides.

4. Consultations with the evaluation team members

The evaluation process was iterative in that evaluation team members provided feedback on data collected through interviews with families and a discussion with the Advisory Committee. This iterative process helps to generate recommendations and considerations for future data collection and evaluation.

2.2 Samples

1. F2Fc families

A total of 23 guided telephone interviews were conducted with families involved in F2Fc: 13 with supportive families and 10 with requesting families.⁴ Six of the supportive families had been connected with requesting families: two with two requesting families each and four with one requesting family each. One of the requesting families was connected with a family that had not been through the supportive family orientation. The evaluation team was unsuccessful in connecting with five other families involved in F2Fc, despite repeated attempts.

Children in the supportive families fell in to the following age categories: 2-5 years (n=6); 6-11 years (n=7); and 17-18 years (n=2). Children in the requesting families fell into the following age categories: newborn (n=1); 2-5 years (n=2); 6-11 years (n=2); 12-16 years (n=2); and unknown (n=1).

In the sample, areas of experience for supportive family included experience related to major life events (such as grief and loss of pediatric and adult family members, multiple births), specific care setting (neonatal intensive care unit, special care nursery, palliative care), family

⁴ Only nine separate requesting families are represented in the sample because, in one requesting family, both mother and father participated in separate interviews.

structure (blended families), professional training (counselor), and cultural background (multi-lingual and -cultural). Their experience related to children's health issues included allergies, autoimmune, congenital, endocrine and developmental disorders (including multiple related conditions), cancers, fetal conditions, palsies and sensory conditions, and accessing and coordinating educational and support services for their children.

In the requesting families, areas of concern related to children's conditions include autoimmune and developmental disorders, degenerative and gastrointestinal diseases, disease-related surgical interventions, brain development disorder, palsies and addictions. Areas of need related to setting included school matters and intensive care unit experiences. Areas of need for parents included accessing credible information, connecting with or coordinating supports, being involved in their child's care, coping with stress, keeping track of their child's information, balancing home and work life with their child's medical requirements as well as dealing with family and friends.

2. Advisory Committee

A total of 10 members of the F2Fc Advisory Committee participated in the evaluation: eight took part in a discussion group⁵ and two were interviewed on the telephone (because they were unable to attend the discussion group). Some Advisory Committee members are also supportive family volunteers.

The F2Fc Advisory Committee was formed in April 2007 to guide the development of this support to families. The 15-member committee includes five parents and seven professionals external to FCRC, as well as three representatives from FCRC, including the Coordinator, Manager and a child life assistant. The other professionals include two social workers from ACH (neurosciences and grief support), a caseworker from Family Support for Children with Disabilities (Children and Youth Services, Government of Alberta), the executive director of the Children's Link Society in Calgary, a nurse from ACH Urgent Care, Mental Health, and two educators (a school principal of a community elementary school and a vice principal at a specialized educational setting).

3. Evaluation team

The seven-member evaluation team included the FCRC Manager, SACYHN Evaluation Manager, SACYHN Evaluation Coordinator, FCRC

⁵ Two supportive family volunteers also participated in the discussion group so the total number of participants was 10.

Family and Youth Engagement Coordinator, a research consultant, research assistant (who is also a Family Support Specialist at the FCRC) and a graduate student.

2.3 Data Analysis

The research consultant reviewed all data sources to identify broad themes and sub-themes. Data was analyzed using qualitative methods, such as thematic analysis, and basic quantitative methods as required.

Themed datasets were shared with the evaluation team after the interviews and the discussion group to generate feedback and additional thematic insights. This circular, iterative process was integral to the narrative data analysis methodology.

Limitations

Potential limitations include interviewee/interviewer bias and small sample size, i.e., while almost all connected families were interviewed, the population from which to draw was small because few connections have been made to date.

The perspectives of Advisory Committee members may be limited by their roles on the committee and their personal experiences, i.e., Advisory Committee members are asked to provide input and broad vision to only specific aspects of F2Fc, not give overall direction; half of the Advisory Committee members who took part in the evaluation are also supportive family volunteers.

3/ DISCUSSION OF KEY FINDINGS

The findings from the F2Fc data analysis are presented here in relation to the orientation and ongoing support for supportive families, awareness of F2Fc, the connections themselves and outcomes reported by supportive and requesting families.

Suggestions are also made around potential areas for future evaluation of the F2Fc program.

3.1 Orientation for Supportive Families

Families interested in becoming F2Fc supportive families undergo a four-step process to become involved in the program: 1) conversation(s) with the Coordinator to commence the application to F2Fc and Volunteer Resources at ACH; 2) self-study of the orientation manual or materials; 3) participation in a six-hour orientation, which is co-facilitated by the F2Fc Coordinator and a Supportive Family Volunteer (see Appendix D: Supportive Family Orientation Agenda); and 4) being recommended by the F2Fc Coordinator and ACH Volunteer Resources that they become a supportive family for F2Fc.

Content

Helpfulness of Topics

All of the supportive families indicated the topics covered in the orientation session were helpful. Notably, the activity/topic cited most often as being most helpful was the role play around how to share experiences and respond in different situations. One supportive family remarked that the role play was “helpful and fun, which sparked enthusiasm.” Another identified the role play as valuable because it aided in learning about “your strengths and what you need to work on.” Also identified as most helpful was the video presentation on communication, in which they were shown “good and bad examples of optimal conversations.”

The volunteer orientation binder was mentioned by several supportive families as a particularly helpful tool and they anticipated it would be useful to find information for their requesting families. In addition, group discussions in which others shared their experiences were considered helpful in preparing for the role as supportive family.

[Orientation was] well organized, well thought out in order to prepare volunteers.

Supportive family

Got everything at orientation, handouts, pamphlets and can always go to the FCRC.

Supportive family

Orientation topics identified as being helpful were:

- Providing support without giving advice
- Maintaining confidentiality
- Security considerations
- Sources of services and information, e.g., FCRC

Information Gaps

While most supportive families identified being provided with all the information they required at their orientation, a few offered suggestions for new information they would like to see included or explained in greater detail. The following suggestions were made by one supportive volunteer:

- More guidance on optimal ways in which to share personal experiences
- More information about how often to meet with requesting families
- Greater emphasis on the importance of continuing education for supportive families, e.g., increasing knowledge base through workshops and seminars
- Greater clarity around where to park and whether to sign into the volunteer lounge

Very few supportive families identified topics they considered to be 'least helpful' (i.e., most supportive families said all topics were helpful). Least helpful topics were:

- Process and background information on how the program developed
- Portions of the video on communication that did not relate to the role of supportive families

It was acknowledged by a few of the supportive families that some aspects of their role would be "learn as you go," i.e., they anticipated learning more about what to expect from requesting families as they gained experience through the connections.

Supportive families seemed aware that, if they required further information, they could ask the F2Fc Coordinator.

[The orientation] well defined your role. But until you get a requesting family, something may come up that hasn't been discussed. You can't cover everything in an orientation.

Supportive family

Understanding of Roles

Roles of Supportive and Requesting Families

All of the supportive families indicated having a clear understanding of their role in the F2Fc program. This was illustrated by the comments they

made about sharing experiencing, setting boundaries, referring to resources and handling the connection process:

- Sharing experiences (e.g., families talked about being an active listener, providing support without advising, asking open-ended questions, avoiding making judgments)
- Setting boundaries (e.g., families talked about maintaining confidentiality and avoiding giving personal information unless comfortable doing so)
- Referring to resources (e.g., families talked about being a source for resources)
- The connection process (e.g., families talked about the supportive family making the first contact with the requesting family after being contacted by the Coordinator, the importance of understanding the requesting family and their situation)
- How to handle long distance connections via the telephone

On the whole, supportive families expressed an understanding that requesting families were looking for support and information and would be connected with a family that is going, or has been through, a situation similar to their own.

Notably, almost half the supportive families recognized that generalizations could not be drawn about what exactly to expect from requesting families and that connection experiences were likely to be different each time. As one person stated, "The requesting family role, we went through it a bit, but can't be clear on role until you get a requesting family. You can't generalize." Another identified that the role of the requesting family was "learnt along the way."

My role was to connect with a person on the same level or similar situation. I was the light at the end of the tunnel for the requesting families.

Supportive family

Sharing Experiences

For the most part, supportive families appeared to be well informed about how to share their experiences and understood what would constitute inappropriate sharing. Most often they referred to the importance of giving support and not giving advice to the requesting families in response to the evaluator's questions about sharing experiences. They understood that it was desirable to tell the requesting family what they (the supportive family) did and felt in their own situation with their child. One supportive family explained that in their connection, "We shared our family experience and what we have gone through...Not only been specific to the orientation; [we have drawn from] our personal experience as well."

A number of supportive families also mentioned the importance of having a positive attitude while being realistic at the same time, e.g., "Don't say

everything is going to be okay because it may not turn out okay." Finally, another learning, described by supportive families, was to avoid over-sharing, i.e., supportive families were encouraged to share a moderate amount of information in the beginning until a relationship develops, after which more information could be shared if desired.

Approximately half of the supportive families remarked that the role playing activity and video were helpful in building their understanding of how to share their experiences, e.g., "focused on supporting the family without giving advice or counseling," "was within a comfortable environment to help you open up," "taught you to never put yourself in their shoes and don't tell them what to do, just listen," and "taught... never say I know how you feel."

Raising Awareness of and Linking to Resources

Most of the supportive families felt the orientation raised their awareness of the resources that requesting families might find useful. Several noted they were aware of additional resources through their own experiences with their children. The one supportive family who said they "could not remember" about the resource information in their orientation said if they required information, "I know I can always call [the Coordinator]."

The F2Fc Coordinator was seen as a primary source of information, both in the past and in the future. A number of supportive families indicated they would call the Coordinator if they required any information related to their connection.

Examples of useful resources identified by the supportive families included the following:

- FCRC in general and the FCRC library specifically
- Social workers on various units (Coordinator can provide this information)
- Family Support for Children with Disabilities
- Educational programs and resources
- F2Fc orientation binder, which provides contact information for organizations that requesting families might find helpful.

[The orientation] explained how we can share...how we coped instead of telling them what to do.

Supportive family

KEY LEARNINGS: ORIENTATION

- The orientation for supportive families helped to prepare them for their role in the F2Fc program, with only a few minor changes to the orientation being suggested.
 - Supportive families indicated enhanced confidence levels achieved through the orientation session and by knowing about resources to which they can link requesting families.
-

3.2 Awareness of F2Fc

Awareness of F2Fc is generated in the community and health care settings in numerous ways, e.g., promoting the program through formal and informal means within ACH, building relationships with health care providers, networking with community agencies that provide support to families with children with special needs, communicating through school communities and developing broad community involvement that mirrors the representative structure of SACYHN. Generally, requesting families find out about F2Fc through their health care providers and other contacts in the hospital and in the community. Supportive families usually are recruited through health care providers and allied health professionals.

Potential Requesting Families

Most requesting families were made aware of F2Fc through contact with health care providers, specifically the following:

- Social work: ACH, Foothills Hospital, Society for Treatment of Autism
- Public health nursing: postpartum nurse at home visit
- Paediatric Neurology: ACH
- Physician and physiotherapist (told a requesting family about FCRC after being asked by the family member, and FCRC told the family about F2Fc)

The program is fabulous and we were connected so quickly. I am thankful to [the Coordinator] and the program.

Requesting family

Two requesting families were approached directly by the F2Fc Coordinator: one while at ACH and one while participating in another program, i.e., Parents in Partnership at the Foothills Hospital. One requesting family said they found out about F2Fc either on the internet or through FCRC.⁶

A few families, both supportive and requesting, spoke during their interviews of a need for greater awareness about F2Fc. They validated the efforts already taken by F2Fc to raise awareness in the community and health care settings (described above) and offered suggestions for additional promotion strategies:

- Encourage other organizations to post a link to F2Fc on their websites, e.g., schools, groups that provide information and support to families with special needs children.
- Enhance search engine optimization, i.e., increase the likelihood F2Fc would appear near the top of lists on Internet searches.

Within ACH, ensure that each of the clinics...are really aware and reminded of the program. When people become aware of something, they may, over time, forget that it exists.

Advisory Committee/Supportive Family Discussion Group

⁶ Family could not remember through which of these two sources they discovered F2Fc.

Comments at the discussion group indicated some health care providers question the value of family-to-family support and may be concerned about supportive families giving advice. They recommended that F2Fc continue its efforts to strengthen relationships with unit managers, social workers, physicians, nurses and others, as they are the prime referral source for F2Fc. They also suggested that requesting families be encouraged to tell their health care providers how helpful they found their F2Fc connections. In addition, they supported the ongoing efforts by F2Fc of using storytelling as a strategy to illustrate the positive impact of connecting with other families.

[Among some health care providers] there seems to be a fear that supportive families will provide the wrong information.

Advisory Committee/Supportive Family Discussion Group

Potential Supportive Families

Members of the Advisory Committee responded to questions about raising awareness of F2Fc among potential supportive families so more supportive families could be recruited into the program. Committee members validated that one of the most effective ways to identify and recruit supportive families was to work through social workers, physicians, nurses and others on the units at ACH (lines of communication must maintain appropriate confidentiality). As one committee member explained, "They know families well and know where they are at in their journey and if they feel in a place where they are able to give back, if they have enough energy for their own support and to support others." In order to recruit supportive families in this manner, committee members felt it was necessary to focus on developing relationships with social workers, physicians, nurses and others to build trust in the program and keep F2Fc "at the front of their minds."

[F2Fc] is not about families replacing professionals. It is a whole different role.

Advisory Committee/Supportive Family Discussion Group

Committee members also validated that it is helpful when F2Fc notifies health care providers when a requesting family has a very specific need for which they would like to connect with a supportive family, e.g., to discuss family experience around a particular medical procedure.

A final suggestion was to implement a volunteer recognition component to communicate to supportive families how much their help is appreciated, e.g., informal coffee breaks with the Coordinator, formal recognition at F2Fc events. This action might help sustain volunteer engagement and enhance long-term retention.

KEY LEARNINGS: AWARENESS OF F2Fc

- Requesting families are finding out about F2Fc from a variety of health care providers from several different settings.
 - Supportive and requesting families, and Advisory Committee members, validate the efforts of F2Fc in creating ongoing awareness of the program and suggest the additional strategies be used to increase awareness: encourage other organizations to post a link to F2Fc on their websites; enhance search engine optimization to increase the likelihood F2Fc would appear near the top of lists on Internet searches.
 - Participants in the discussion group suggest F2Fc continue to recruit supportive families by working through health care providers and allied health care professionals.
 - Participants in the discussion group indicate that some health care providers question the value of family-to-family support and recommend that F2Fc continue its efforts to strengthen relationships with health care providers and that requesting families be encouraged to tell their health care providers how helpful they found the connections.
-

3.3 Support for Supportive Families

Following orientation and during the course of their connections, supportive families receive ongoing support and supervision from the F2Fc Coordinator. The coordinator orients volunteers to the role, facilitates connections, monitors and supports connections, provides opportunities to debrief after interactions with requesting families, assists with closing connections and facilitates leadership development, e.g., coaching volunteers to co-facilitate at presentations (see Appendix E: F2Fc Coordinator Roles and Responsibilities).

Involvement with F2Fc

All of the supportive families felt they were supported by the Coordinator throughout the connection, although it should be noted that only half of the supportive families had actually been connected with a requesting family by the time of their interview.

Supportive families provided very positive feedback about the program Coordinator, recognizing her as a source of information on family resources as well as coping with broader issues, such as child abuse. One supportive family remarked on the close communication they had during the course of their connection, e.g., “We were the first families to be matched up, so [the Coordinator] was very interested in the progress. We stayed in close contact throughout the connection.” One discussion group participant, who expressed appreciation for the program and the efforts of the Coordinator, felt the Coordinator had limited time to dedicate to F2Fc and might require an assistant in the future.

Several supportive families remarked on the Coordinator’s approachable, respectful manner and easy availability. Comments about the Coordinator included, “If I didn’t know the answer or the resource I could call [the Coordinator] and she would do the leg work,” “Always there for questions and brainstorming various approaches,” “Very knowledgeable person,” “Very open and supportive”

All of the supportive families acknowledged that the Coordinator’s involvement increased their confidence level, with several giving specific examples. One supportive family said, “[The Coordinator] called to see if I had anymore questions because I was leery about connecting with a family because I was uncertain of my listening skills.” Another supportive family gave the example of having to make a “cold call” and “[The Coordinator] was the go-between and made it comfortable. [The Coordinator] was the mediator.” A final example was explained in this way, “I talked to her about my fear of saying it’s going to be ok. She then made me feel comfortable when I went to meet the family initially.”

[the Coordinator] is always there for answers and advice. She is very understanding, and made sure I can handle what has been given. I felt no fear. She gave good supportive feedback.

Supportive family

The program is fabulous and we were connected so quickly. I am thankful to [the Coordinator] and the program.

Requesting family

[The Coordinator] was very available and not being intrusive at all.

Supportive family

Supportive families indicated that the following factors helped to increase their confidence level:

- Receiving ongoing support from the Coordinator
- Being given different examples, pointers and tips on what to say
- Being encouraged to practice communications skills, such as through role playing
- Knowing they could trust the Coordinator to respond appropriately if a connection was unsuitable

You can always call [the Coordinator]. We are not alone.

Supportive family

Involvement with Other Supportive Families

Most of the supportive families said they felt supported by other supportive families. Several indicated it was during their orientation that they developed relationships. As one person explained, “We had a common purpose and shared the same enthusiasm.” They cited the following factors as contributing to their sense of support: sharing experiences, practicing listening skills, learning to listen to others and hearing different perspectives. The picnic, which took place later, was also mentioned as an opportunity to get together and regroup.

I feel my story was big, but there are worse things that others have experienced. Their bravery made me say I can do it.

Supportive family

Three supportive families felt the support from other supportive families was limited, generally because they had little contact following the orientation.

Participants in the discussion group talked about the importance of debriefing after interactions with requesting families and, when they “feel a need to talk,” they contact the F2Fc Coordinator. They felt there was strong support for supportive families and suggested F2Fc could explore ways to enhance the support already provided, e.g., look at the possibility of informal gatherings of supportive families in a community location. Several participants mentioned that they enjoyed being with other families at the F2Fc picnic.

Consultation with the F2FcCoordinator revealed that an online discussion forum for supportive families has been designed and next steps for implementation are underway (see Appendix C: Advisory Committee Terms of Reference). An online discussion forum would provide a secure, private, moderated method for volunteers to interact.

Expanded Role of Supportive Families

Advisory Committee members offered several suggestions as to how the role of supportive families could be expanded beyond their one-on-one connections with requesting families:

- Participate in “coffee times” on ACH units to connect informally with other parents of children with special needs
- Participate in online discussion groups with other parents of children with special needs
- Participate on other ACH committees that have parent representation, e.g., Ethics Committee, Family Centred Care Committee

Consultation with the F2FcCoordinator revealed examples of expanded roles for supportive family volunteers already occurring:

- Parents attend tea time at the Neonatal Intensive Care Unit at Foothills Hospital once a month
- Parents from F2Fc participate on committees for two conferences in 2008-09.

KEY LEARNINGS: SUPPORT FOR SUPPORTIVE FAMILIES

- Supportive families feel strongly supported by the F2Fc Coordinator and FCRC, which appears to be integral to the success of F2Fc.
 - Participants in the discussion group also felt there was strong support for supportive families and suggested F2Fc could explore ways to enhance the support already provided, e.g., informal gatherings of supportive families. F2Fc has already begun development of a secure and moderated online discussion forum for supportive families.
 - Supportive families indicate that the clinical, professional and interpersonal skills of the F2Fc Coordinator contributed to their own sense of support.
 - Participants in the discussion group saw opportunities to expand the role of supportive families (e.g., participation in family coffee times in hospital settings and participation on committees outside of F2Fc); although they cautioned that their volunteer time is limited. F2Fc has already begun to facilitate some of these expanded roles.
-

3.4 Connections Between Families

The F2Fc Coordinator connects supportive and requesting families based on family similarities and requesting families' needs. Typically, the families connect through one to four phone calls over two months, although the number of contacts varies from family to family.

Initial Contact

When the requesting families first contact F2Fc, they arrange to meet with the Coordinator to talk about their family and their needs for information and support. All requesting families reported that this introduction to the program was a positive experience. For example, one requesting family stated, "We connected on the phone, then in person. I felt comfortable and relaxed." Another commented, "[The Coordinator] was perfect. Asked when we can meet each other and then she came to our home."

It was a difficult time and she was very respectful. She gave us the information we needed and then gave us our space.

Requesting family

Similarity Between Supportive and Requesting Families

Most of the requesting families indicated that, in general, they had similarities to the supportive family, both between the adults and between the children. While two requesting families felt they did not have similar experiences to the supportive family, one identified that they were "both moms." Most of the parents involved in the connections are mothers.

The few requesting families who felt their children did not have similar needs or experiences to their supportive family generally remarked that despite differences in diagnoses, they had other similarities, e.g., "different diseases but both lifelong." One requesting family said the connection was dissimilar because their child had a rare diagnosis.

Similarity between children and families was seen by seven of the nine requesting families as a necessary factor for the connection to be successful. As they explained, similarity allows families to "know how to help and what to say" and provide "resources and different ideas on how to advocate" for the child.

The only supportive family to identify a lack of success with their connection was related to the requesting family looking for a more exact match. Another supportive family, while they considered their connection to be a success, found they needed to do a lot of research on the rare diagnosis of the child in the requesting family and would have appreciated being provided with more information prior to the first contact, or provided with a reliable 'one-stop' information source like the

The most important for the connection to be successful is that there are similar experiences that have happened.

Supportive family

FCRC.⁷ Only one requesting family identified the success of their connection as being “in-between” (i.e. not successful but not unsuccessful) and attributed this to an inexact match.

Two requesting families made specific suggestions to increase similarity in connections as follows:

- Recruit more supportive families from outside Calgary to meet the needs of requesting families who live outside Calgary
- Build a broader network of families so “it is less personal than being connected with only one family”

Communication Between Families

Interpersonal Interaction

Overall, supportive families were seen by requesting families as being easy to talk to, supportive and understanding. Interpersonal factors of supportive families that requesting families felt were important included a positive approach, a non-judgmental attitude and an ability to understand their situation. In one connection, the relationship has developed so strongly that the two families have become “really good friends.”

[Supportive family volunteer has been] very easy to talk to and has been very supportive. She has been through the same experience.

Requesting family

Several of the requesting families acknowledged that their contact with the supportive families has been minimal and, as such, were unable to comment further on those interactions.

Method and Amount of Contact

Method of contact

While telephone and email were the most common methods of contact between families, in-person contact has occasionally occurred and was identified by one requesting family as an important success factor. This requesting family said that, without in-person contact, their relationship “would have fizzled out...sitting face to face has made it work.”

Amount of contact

At the time of the interviews, six of the supportive families had been connected with requesting families (two had been connected with two

⁷ The F2Fc Coordinator facilitates information provision and connections between families and the FCRC on an ongoing basis, e.g., following the Advisory Committee discussion group, the F2Fc Coordinator had already arranged an in-service by a health care provider for a supportive family volunteer who required specific information.

requesting families and four had been connected with only one requesting family). Families were asked in their interviews whether they felt their number of contacts was too few, too many or just enough.

Of the six supportive families who had been involved in connections, half felt they had “just enough” and half felt there were “too few” contacts. The reason for having “too few” connections was explained by one person as related to their being too busy with other responsibilities.

Of the nine requesting families, four felt they had “too few” contacts and five felt they had “just enough.” Despite some requesting families indicating “too few” contacts, most requesting families indicated the amount and type of contact they received met their needs.

Several requesting families identified reasons for not making more frequent contact, such as:

- Too busy to call
- Had difficulty connecting with their supportive family
- “Haven’t really made too much of an effort to connect with them”
- Too occupied with their child in hospital to connect as much as they would have liked

One requesting family noted that they have started meeting in-person with their supportive family and plan to have their children meet each other soon.

It is worth noting that one supportive family expressed feelings of guilt over not calling the supportive family as much as they would have liked. This being the case, it is possible there could be other families who felt similarly but did not express this to the interviewer.

KEY LEARNINGS: CONNECTIONS BETWEEN FAMILIES

- Overall, connected families see themselves as being similar to each other and have found their communications to be successful and effective.
 - While approximately half of the connected families felt they had enough contact, the other half felt they had too little contact, although this did not appear to lead to dissatisfaction in the connection.
-

3.5 Outcomes Identified by Connected Families

F2Fc connects families who have been, or are going through, similar child health experiences. Supportive families share the unique perspectives they have gained through experience with many systems, including the health care system. The goal of the connection is to provide requesting families with support, information and links to resources.

Outcomes Related to Requesting Families

During the course of the interviews, it became apparent that outcomes for requesting families had been achieved in the areas related to increased access and support, enhanced feelings of control and confidence, and strengthened sense of hope. These outcomes, and a selection of quotations that illustrate them, are as follows.

Outcome: Increased awareness and access to support, information and resources

“For teenagers there is not a lot out there. I don't think we could of gotten this support anywhere else.” (Requesting family)

“I was able to connect the requesting family to a USA organization with families who had the same disorder. I also connected them to a local Alberta community resource in regards to the developmental aspects.” (Supportive family)

“I didn't know how to get support before. Now I know resources.” (Requesting family)

“This is a unique program that is more convenient than other support groups.” (Requesting family)

Outcome: Enhanced sense of empowerment and self-efficacy

“The requesting family told me they felt empowered by me sharing my experience and they feel they have more power in terms of their child's care.”

“It's been inspiring and I would love to give back one day once we are more settled.” (Requesting family)

Outcome: Strengthened sense of hope

“Helped me feel more confident and how the future will look.” (Requesting family)

“Confused at the beginning with my child's recent diagnosis. Family volunteer was reassuring, and helped show what the future holds for my child.” (Requesting family)

“Initially the family was terrified and unsure of the future. As time progressed they felt they were not alone.” (Supportive family)

The program is great. I hope it continues. It gives you someone to turn to.

Requesting family

We benefited from it, by talking to someone who already went through it. Then we didn't feel alone, we could relate. A friendship has evolved.

Requesting family

The first person I have met with a child with special needs.

Requesting family

Outcomes Related to Supportive Families

During the course of the interviews, it became apparent that outcomes for supportive families had been achieved in the areas of enhanced sense of compassion satisfaction and increased community connectedness. These outcomes, and a selection of quotations that illustrate them, are as follows.

Outcome: Enhanced sense of compassion satisfaction

“Feel that this is really purposeful and well intentioned. I am happy to put my time into this.” (Supportive family)

“It provides a two-way benefit for the volunteer and requesting families. It is very fulfilling.” (Supportive family)

“Helping makes me feel good.” (Supportive family)

“ I like the idea of volunteering and giving back.” (Supportive family)

Outcome: Increased community connectedness

“Being able to meet various people to hear their stories made me realize I'm not alone.” (Supportive family)

“I wanted to help and the group is growing and expanding, it is working really well. Working together as a community.” (Supportive family)

“I feel a part of something.” (Supportive family)



KEY LEARNINGS: OUTCOMES IDENTIFIED BY CONNECTED FAMILIES

- Positive outcomes have been achieved for both requesting and supportive families around the provision of support, information and links to resources.
- Potential evaluation indicators can be found within these outcomes, e.g., sources of support, information and resources accessed by requesting families; measurements of self-empowerment, self-efficacy and hope in requesting families; measurements of compassion satisfaction in supportive families; and points of community contact for supportive families.



...a lot of credibility. It expands what the ACH does. Helps families that are desperate to connect to other families to see hope. It stays true to supportive family volunteers that see children as part of the human mosaic and not for their deficits.

Supportive family

With time and growing as it gets bigger the program can only get better.

Supportive family

I am looking forward to helping another family.

Supportive family

4/ RECOMMENDATIONS

The findings of this evaluation validated many aspects of F2Fc, including the orientation process, efforts to raise awareness of F2Fc, support for supportive families, connections between families and positive outcomes being achieved. This evaluation looked at successes and challenges in the early stages of F2Fc, as well as areas in the program that could enhance and expand. Recommendations that can be drawn from the findings are as follows.

Orientation

The orientation for supportive families could be strengthened by:

- Emphasizing in the orientation for supportive families that the value to requesting families comes from the *impact* of a connection rather than the *frequency* of connections, i.e., frequency varies among families.
- Providing information to supportive families about continuing education opportunities.
- Emphasizing the information already included in the orientation related to parking.

Awareness of F2Fc

Efforts to promote F2Fc among families with children of special needs could be improved by:

- Continuing to raise awareness of the program among people who work with families of children with special needs within the health care system and in the community, e.g., social workers, nurses, doctors, allied health care professionals and other health care providers (strengthen relationships with health care providers, increase and repeat distribution of information and make use of existing communication channels).
- Continuing to promote F2Fc as a complement to what health care providers are already doing.
- Ensuring F2Fc maintains a high profile as the provincial health care scene continues reorganization in 2009.
- Encouraging other organizations to include an F2Fc link on their websites and enhancing search engine optimization for F2Fc.
- Continuing efforts to strengthen relationships with health care providers and encouraging requesting families to tell their health care providers how helpful they found the F2Fc connections.

Support for Supportive Families

Support for supportive families could be enhanced by:

- Continuing to provide support from a highly skilled and knowledgeable Coordinator.
- Exploring learnings around opportunities to keep supportive families engaged with the program, e.g., informal monthly gatherings of supportive families.
- Continuing with the development and implementation of the online discussion forum for supportive families.
- Emphasizing to supportive families, on an ongoing basis, that the value to requesting families comes from the *impact* of a connection rather than the *frequency* of connections, i.e., frequency varies among families.
- Continue to explore and offer opportunities for supportive families to participate in parent gatherings as partnerships with ACH units develop; in online family discussion groups and ACH committees.

Connections Between Families

Connections between families could be strengthened by:

- Continuing to recruit supportive families to build a larger resource pool from which to draw similarities in connections.
- Continuing to consult with health care professionals to implement this support as a complement to their clinical work.

Outcomes Identified by Connected Families

Positive outcomes have been achieved for both requesting and supportive families regarding the provision of support, information and links to resources. It may be useful in the future to assess the extent to which these outcomes are being achieved through the following indicators:

- Sources of support, information and resources accessed by requesting families.
- Measurements of self-empowerment, self-efficacy and hope in requesting families.
- Measurements of compassion satisfaction in supportive families.
- Points of community contact for supportive families.

5/ FUTURE CONSIDERATIONS

Data Collection and Program Review

The F2Fc evaluation is one part of a comprehensive five-year multi-component FCRC evaluation. Consultations with the evaluation team identified the following considerations for future data collection activities and program review related to F2Fc:

- Orientation: Facilitate a focus group in which supportive families, who have had experience with three or more connections, review the orientation materials and identify aspects that could be revised or enhanced.
- Awareness of F2Fc: Ask requesting families how they heard about F2Fc.
- Support for supportive families: Keep track of questions asked and support provided to supportive families.
- Connections between families: Check in with families on a regular basis to inquire about perceived benefits and issues of connections. Focus on the impact of connections rather than the frequency, e.g., ask, "What is different for you now compared to what you think it would have been like without F2Fc."
- Further enhancement: Ask health care providers how this support could enhance their clinical work, how to increase referrals of requesting families and how to build relationships with potential new supportive families in their particular resource area.

As F2Fc continues to develop, the program would benefit from continued consultation with ACH clinical areas and community providers to explore ways to further F2Fc as an augmentation to clinical intervention and discover how volunteers can support their work. In doing so, F2Fc can adapt to the ongoing needs of families within a shifting health care environment.

APPENDICES

Appendix A: Family Discussion Guides

Appendix B: Evaluation Consent Forms

Appendix C: Advisory Committee Terms of Reference

Appendix D: Advisory Committee Discussion Guide

Appendix E: Supportive Family Orientation Agenda

Appendix F: F2Fc Coordinator Roles and Responsibilities

Appendix A: Family Discussion Guides

Questions for Supportive Family Volunteers

Note to interviewer: The following is a semi-structured interview guide. Depending on the interviewee's responses, it may not be necessary to ask all the questions and/or to ask them exactly as they appear on this page. Please document any changes to your line of questioning. Verbal consent obtained: |

As I mentioned, this interview is being conducted so that I can learn more about your experience in F2Fc to date. The first few questions are about your experience in the orientation.

1. I'd first like to get a sense of the extent to which you feel that the orientation prepared you for your role as a Supportive Family Volunteer.
 - a. Were the topics covered in orientation helpful? *Probe: In what ways? What were the most helpful topics? What topics were least helpful?*
 - b. Did the orientation give you a firm understanding of your role and the role of Requesting Families? Please elaborate.
 - c. Did the orientation help you to understand how to share your own experience with the Requesting Families? Please elaborate.
 - d. Did the orientation increase your awareness of resources that might be useful for the Requesting Families and how to link families to these resources?
2. Now, I'd like to get a sense of the support that you may or may have not received throughout the connection.
 - a. Do you feel you were supported throughout the connection by the Coordinator? In what ways?
 - b. Did the Coordinator's involvement help to increase your confidence in supporting the Requesting Family? In what ways?
 - c. Do you feel you were supported throughout the connection by the other Supportive Families? In what ways?
 - d. Was there any type of support or information you needed but did not get? Please elaborate.
3. Now I'd like to ask you about the connections you have been involved in to date.
 - a. How many families have you been connected with so far?
 - b. Was the contact with the family/families mainly through:
 - i. Telephone?
 - ii. In-person?
 - iii. Email?
 - iv. Other?
 - c. In general, was the number of calls, emails or visits:
 - i. Too few?
 - ii. Too many?
 - iii. Just enough?
 - d. Overall, do you feel that the connection(s) was/were successful? *Probe: If "yes", ask: In what ways? If "no", ask: Why do you feel that the connection(s) did not work?*
4. How has the experience in F2Fc impacted you to date? *Probe: Has the experience impacted you positively and/or negatively in any way? Have you benefited in any way by participating in F2Fc? If so, how?*
5. Would you like to make any additional comments about F2Fc?

THANK YOU VERY MUCH!!!

Questions for Requesting Families

Note to interviewer: The following is a semi-structured interview guide. Depending on the interviewee's responses, it may not be necessary to ask all the questions and/or to ask them exactly as they appear on this page. Please document any changes to your line of questioning. Verbal consent Obtained: |

As I mentioned, this interview is being conducted so that I can learn more about your experience in F2Fc. The first questions are about your awareness of F2Fc and your experience in being connected with a Supportive Family Volunteer.

1. First of all, I would like to get a sense of your initial contact experience with F2Fc.
 - a. How did you find out about F2Fc? *Probe: Did someone refer you to F2Fc? If so, who?*
 - b. Would you like to make any comments about your initial contact with the Coordinator?
Probe: Was the initial conversation with the Coordinator a positive experience? In what way?
2. Now, I'd like to ask you about the type and amount of contact you had with your Supportive Family Volunteer.
 - a. Was the contact with your Supportive Family Volunteer mainly through:
 - i. Telephone?
 - ii. In-person?
 - iii. Email?
 - iv. Other?
 - b. In general, was the number of calls, emails or visits:
 - i. Too few?
 - ii. Too many?
 - iii. Just enough?
 - c. Did this type and amount of contact meet your needs?
Probe: If not, from your perspective, what would have worked better?
3. Now, I'd like to get a sense of the extent to which you feel that your situation was similar to that of the Supportive Family Volunteer, and how important it was – from your perspective – for your situations to be similar.
 - a. Thinking back to your contact with the Supportive Family Volunteer:
 - i. Do your children/youth have similar needs and/or experiences?
 - ii. Do you and the Supportive Family Volunteer have similar life experiences?
 - iii. Are you and the Supportive Family Volunteer the same gender?
 - iv. Was the Supportive Family Volunteer easy to talk to, supportive and understanding?
 - b. What do you think was most important for the connection to be successful? *Probe: Something that we just discussed? Something else?*
4. Did participation in F2Fc allow you to receive support that you would not have been able to get somewhere else?
Probe: Did participation in F2Fc help you understand the situation facing your family? Help you to cope? Did F2Fc help you in meeting your immediate information needs? Did you receive emotional support from the Supportive Family? Did you feel you were linked to the FCRC?(Did F2Fc help reduce your isolation? Decrease your anxiety? – These are just some possible outcomes but probe for others)
5. Do you feel that the connection was successful? *Probe: If "yes", ask: In what ways? If "no", ask: Why do you feel that the connection did not work?*
6. Would you like to make any additional comments about F2Fc?

THANK YOU VERY MUCH!!!

Appendix B: Evaluation Consent Forms



CONSENT FORM – Supportive Family Volunteer Evaluation

Family to Family Connections (F2Fc) provides a universal opportunity for families to share the unique perspectives they have gained through experience with many systems – including our health care system - in order to provide valuable support to Requesting Families. The purpose of this interview is to better understand how F2Fc is doing in its first few months of operation and what improvements can be made. Your participation in this interview will provide valuable insight as you are experiencing F2Fc first hand. Your feedback will be used to guide the staff in improving F2Fc in order to ensure that the needs of the Supportive and Requesting Families are met.

Depending on your responses, the interview should take approximately 45 minutes to complete. You will be asked questions about the orientation process, whether you felt supported during the connection, the nature of the connection, the success of the connection and any suggestions you may have for improvement. Your participation in the interview is voluntary. You are free to withdraw from the interview at any time or skip questions that you do not wish to answer. There are no right or wrong answers; we are only looking for your opinion. The interview is confidential and only the interviewer will have access to the transcripts.

Please feel free to ask any questions you have about the study at this time or any time during the interview.

Lastly I would like to take this opportunity to thank you for taking time out of your busy schedule to participate in the interview and assist us in ensuring that F2Fc is meeting the needs of families.

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this interview, and 2) agree to participate in the interview.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this interview at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature: _____ Date: _____



CONSENT FORM – Requesting Family Evaluation

Family to Family Connections (F2Fc) provides a universal opportunity for families to share the unique perspectives they have gained through experience with many systems – including our health care system - in order to provide valuable support to Requesting Families, such as you. The purpose of this interview is to better understand how F2Fc is doing in its first few months of operation and what improvements can be made. Your participation in this interview will provide valuable insight as you are experiencing F2Fc first hand. Your feedback will be used to guide the staff in improving F2Fc in order to ensure that the needs of the Supportive and Requesting Families are met.

Depending on your responses, the interview will take approximately 45 minutes to complete. You will be asked questions about how you became aware of F2Fc, your initial contact experience with the Coordinator, the nature of the connection, your experience with the connection and any suggestions you may have for improvement. Your participation in the interview is voluntary. You are free to withdraw from the interview at any time or skip questions that you do not wish to answer. There are no right or wrong answers; we are only looking for your opinion. The interview is confidential and only the interviewer will have access to the transcripts.

Please feel free to ask any questions you have about the study at this time or any time during the interview.

Lastly I would like to take this opportunity to thank you for taking time out of your busy schedule to participate in the interview and assist us in ensuring that F2Fc is meeting the needs of families.

Signatures (written consent)

Your signature on this form indicates that you 1) understand to your satisfaction the information provided to you about your participation in this interview, and 2) agree to participate in the interview.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this interview at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature: _____ Date: _____

Appendix C: Advisory Committee Terms of Reference

Family* to Family Connections Advisory Committee Terms of Reference

January 22, 2009 draft revision

PURPOSE of ADVISORY COMMITTEE

The Family to Family Connections Advisory Committee will actively promote and provide ongoing support to Family to Family Connections.

MISSION

Family to Family Connections (F2Fc) provides opportunities for families to share information, network regarding practical resources and to support each other. The core activities of Family to Family Connections are to recruit, orient, and support one to one connections between Supportive Family Volunteers and Requesting Families.

VISION OF FAMILY TO FAMILY CONNECTIONS

Family to Family Connections provides a universal opportunity for families to share the unique perspectives they have gained through experience with many systems in order to provide valuable support to requesting families.

GUIDING PRINCIPLES OF FAMILY TO FAMILY CONNECTIONS

Family to Family Connections

- Believes that parents are the experts on their child's needs;
- Values families' beliefs and cultural backgrounds;
- Supports family care giving and decision-making;
- Respects child, youth and family choices;
- Builds on individual and family strengths;
- Encourages transparent sharing of information and decision making;
- Promotes family involvement in planning, delivery and evaluation of care
- Believes connections should be as natural as possible.

ROLES AND RESPONSIBILITIES

1. Through an overall balance of family and professional voice, provide expertise and experience to make recommendations for the development, implementation and operations of Family to Family Connections. This includes but is not limited to:
 - Orientation and screening processes.
 - Marketing (awareness, promotion and recruitment) to *Network* partners, AHS staff, families and service providers in the community
 - Policies and procedures
 - Changes required based on evaluation outcomes or other feedback.
 - Pilot development & provide rotating monitoring of a closed electronic discussion board for this committee per privacy guidelines developed, with Supportive Family Volunteers, to exchange thoughts, ideas, and updates on topics relevant to their role. This forum will be open to Supportive Family Volunteers, Family members and Advisory Committee Members.
 - Identify priority areas of action to begin and advance the growth and development of Family to Family Connections. This will be achieved by the Coordinator bringing forward key elements of the work plan to the Advisory Committee. The Advisory Committee members will provide direction on the work plan with prioritization and formulation of short and long term goals to be achieved.
2. Identify and refer potential Supportive and Requesting Families to assist with the commencement of this support.
3. To encourage family leadership in order that the growth of the Family to Family Connections remains sustainable.

* The word 'family' in this context refers to children, youth, parents, and caregivers.

ADVISORY GROUP MEMBERSHIP

Desired minimum representation includes, but is not limited to:

- Family Representatives (6+)
- Family and Community Resource Centre (2)
- Child Health/Children's Services program representatives (4)
- Volunteer Resources, ACH
- Community Organizations (2)
- Education Representative (1)

An overall balance of family and professional voices is desired.

PROCESS

1. Meetings will be held approximately quarterly, from Sept 2008 to Sept 2009 and then re-evaluated. Subsequent meetings may be called as required and/or if the terms of reference require revision. Tentative meeting dates set: January 22, 2009, April 23 2009 and June 18, 2009.
2. The advisory group meetings will be co-chaired by a Supportive Family Volunteer in good standing and the Family and Youth Engagement Coordinator. The Co-chairs will be supported by a Vice-chair role, who will be a Supportive Family Volunteer in good standing. All committee members are able to bring forward agenda items for the committee's review.
3. Copies of minutes and program materials are maintained by Coordinator.
4. Working groups will be developed as identified with the Advisory Committee and the Coordinator.
5. Ad hoc consultation and communication will be sought from ACH programs/services and community organizations as indicated (e.g., Alberta Health Services Family Centred Care Portfolio committee within Calgary's Child and Women's Health and Specialized Services); SACYHN evaluation coordinator; Diversity Coordinator; physicians and others as identified)
6. Terms of reference will be reviewed by October 2009.

REPORTING/ACCOUNTABILITY

The advisory group will report through the chair(s) to the Manager of the Family and Community Resource Centre.

December 17, 2007

Draft revision January 22, 2009

Appendix D: Advisory Committee Discussion Guide

1. Our evaluation indicates that F2Fc is a valuable program for families of children with special needs. How can we make more people aware that the program exists, i.e., health care providers in different clinical areas, new families who could benefit from the connection (requesting families)?
2. As F2Fc grows and includes more requesting families, there will be more time pressures placed on existing supportive family volunteers. Can you talk about this? Could you share some of your experiences with time pressures and offer suggestions on how we could recruit more supportive family volunteers to help meet this growing demand? When looking to serve more requesting families, what issues should we pay attention to when recruiting more volunteer families?
3. When we have volunteers involved in the program, it's important they get all the support they need to fulfill the role. What has been your experience with receiving support, i.e., what types of support have been really important to you, where could you have used more support? What types of things would make it more likely that you would stay involved in F2Fc for the long-term? What types of things could make it less likely that you would stay involved?
4. In what ways could supportive family volunteers expand their role, e.g., participate in coffee time discussions, take on leadership positions on other committees?
5. Do you have any other comments to make?

Appendix E: Supportive Family Orientation Checklist

1. Orient the volunteer according to the Volunteer Role Description to include:
 - The purpose and objectives of the program.
 - The vision and mission of SACYHN & the Family & Community Resource Centre (FCRC)
 - The FCRC service components and team relationships including the invaluable role that volunteers play in the overall service delivery model.
 - Discussion of supervision/communication and reporting procedures with Family to Family Connections, and the FCRC to ensure clarity of roles, responsibilities, and back-up.

2. Contacts by Supportive Family Volunteers occur initially by telephone, or face-to-face on-site at ACH with Requesting Families. Contact thereafter is as negotiated among the families.

3. Review the following in addition to the general hospital procedures already covered in the General Orientation Session for new volunteers and reviewed in the Volunteer Handbook given to each volunteer:

Covered by Volunteer Resources

- General Orientation**
 - DVD/ Information Technology and Information Privacy Awareness Video (16 minutes)
 - Confidentiality agreement
 - Infection Control - Hand washing
 - Emergency Code Procedures
 - On-site check-in with Volunteer Works/Volunteer Lounge information
 - ID Card application

SUPPORTIVE FAMILY ORIENTATION WORKSHOP Covered by Family and Youth Engagement Coordinator

- Family to Family Connections Orientation:**
 - Skills and resource information required to begin/maintain role of Supportive Family Volunteer.
 - Commitment/Accepting or declining a match
 - Parking
 - Safety, Location of Match and Boundaries
 - Photo/Media Consent
-
4. Resource materials and forms to be given/completed with the volunteer at interview:
 - Interview with Family and Youth Engagement Coordinator. Assessment regarding suitability, interests and information collected for the purposes of connecting.
 - Consent/Waiver signed and copy given to prospective volunteer about info collected and location of matches.
 - Family to Family Connections, "Volunteer Manual for Supportive Families".
 - ACH Volunteer Resources Application form (yellow folder) containing:

- Police Check form with 2 pieces of ID copied, one of which must be government photo ID.
- Child Intervention Record Check Form with instructions for completion if applicable
- Two names and phone numbers for references obtained from volunteer; at least one must be checked. Check referred to VR depending on situation.
- Occupational Health Assessment / Immunization Record.
- A.C.H.'s Volunteer Resources will advise Family to Family Connections (F2Fc) when above requirements are completed.
- Recommendation regarding suitability for F2F Connections and ongoing connections will be finalized between the volunteer and the F2Fc Coordinator and provided to Volunteer Resources.

This is to acknowledge that orientation has been completed for the F2Fc role description and that all of the above points have been covered with the new volunteer:

	PRINT NAME	SIGNATURE	DATE
Family & Youth Engagement Coordinator			
Co-facilitator, Volunteer Parent <i>(if applicable)</i>			

This is to acknowledge that I have received orientation as a Supportive Family Volunteer within the Family and Community Resource Centre and that I fully understand the responsibilities of this position.

	PRINT NAME	SIGNATURE	DATE
Volunteer Supportive Family			

<p>For Coordinator Use:</p> <p><input type="checkbox"/> Date Supportive Family Orientation Completed _____</p> <p><input type="checkbox"/> Photo consent?</p> <p><input type="checkbox"/> Certificate mailed? _____</p> <p>Date of form review: Dec 10, 2008</p>
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Appendix F: F2Fc Coordinator Roles and Responsibilities

Job Description: Family & Youth Engagement Coordinator, Calgary Health Region

(Note: 70% of this position is dedicated to the role of F2Fc Coordinator)

CLASSIFICATION TITLE:	PROGRAM FACILITATOR
Site:	ACH
Department/Program:	Southern Alberta Child & Youth Health Network (SACYHN)
Title Of Direct Supervisor:	Dual Report: -Manager, FCRC -Calgary Region Network Manager
Bargaining Unit:	HSSA
Date:	February 15, 2005

POSITION SUMMARY:

Reporting to the Manager of the Southern Alberta Family & Community Resource Centre (FCRC) and the Calgary Region Network Manager for the Southern Alberta Child & Youth Health Network, the Family & Youth Engagement Coordinator is primarily responsible for the development and implementation of the Parent to Parent Support Service and the ongoing coordination of the SACYHN Child & Youth Advisory Council (CAYAC).

KEY RESPONSIBILITIES:

PARENT TO PARENT SUPPORT – 70%

- Develops and implements a service delivery model that operationalizes the *Network's* commitment to Family Centred Care, as recommended and described in the Parent Connection Service Development Report (August 2005).
- Develops a matching and screening process for “requesting parents” with “supportive parents”
- Develops a collaborative working relationship with clinical staff across the Child & Women’s Health Portfolio who will be consulted regarding program implementation and potential matches in their areas which may include creating matches for parents across southern Alberta..
- Creates referral mechanisms for those clinical areas that have already identified an interest in the centralized program and develops advertising and marketing strategies for those areas that are unaware of the program’s existence.
- Creates and implements a recruitment training process for “supportive parents’ and provides ongoing supervisory responsibility for parent matches.
- Provides ongoing resource and support to “requesting parents” as their life circumstances and family situations shift and change.
- Creates a centralized database/registry to maintain and update parent information, compile program statistics, and track participation rates and program evaluations.
- Establish a working partnership with Volunteer Resources regarding hospital orientation for volunteer “supportive parents”.
- Develop an evaluation process to track outcomes for the service.
- Collaborates with other components of the FCRC Community Education Service including the Parents in Partnership Education Series which will provide an informational and educational resource both for “supportive” and “requesting” parents.
- Explore the further potential of implementing parent support groups as an extension of the Parent to Parent Support Service, in concert with the Community Education Service and through the use of Telehealth technology across southern Alberta.

Child & Youth Advisory Council – 30%

- Assumes the lead for arranging, organizing, coordinating, and facilitating the regular Child & Youth Advisory meetings 5 times per year in addition to the periodic “one off” opportunities that often come the Council’s way.
- With the input from SACYHN staff and CAYAC members, assumes responsibility for creating meeting agendas and coordinates and manages distribution processes for Council business.
- Assumes the lead for coordinating and encouraging recruitment strategies including personal connections across southern Alberta and the possibility of face to face presentations.
- Maintains personalized connections with all Council members and/or CAYAC Coordinators in other regions in the *Network* over the course of their involvement with the CAYAC.
- Communicates and negotiates with potential stakeholder groups who may be seeking consultation with the Council.
- Encourages partners within the *Network* and Calgary Health Region to become proactive in seeking input from children and youth.
- Develops and maintains working relationships with key adult contacts in all southern Alberta regions who assist in supporting CAYAC members from those regions to participate in regular council meetings and “one off” opportunities.
- Organizes, chairs and facilitates all CAYAC Planning Meetings.
- Assumes the lead on attending to the numerous maintenance and housekeeping activities required to sustain the Council and those involved in regular CAYAC meetings.

SUPERVISION:

RECEIVED DIRECT: MANAGER, FCRC
 : CALGARY REGION NETWORK MANAGER
 :
 : INDIRECT MANAGER, FAMILY & COMMUNITY RESOURCE CENTRE
 : DIRECTOR, SACYHN
 GIVEN: DIRECT: VOLUNTEER PARENTS
 : INDIRECT
 :

QUALIFICATIONS:

EDUCATION: • Masters Degree in a Health Related Discipline with experience in direct child, youth & family care. Bachelors degree with 3 – 5 years of experience in direct child, youth & family care may be considered.

EXPERIENCE : • Program development and implementation skills required.
 : • Demonstrated commitment to Family Centred Care is required.
 : • Demonstrated ability to engage and work with youth is required.
 : • Experience and skills working with a wide range of service providers including other health regions, internal regional programs, other child serving sectors including community based agencies.
 : • Knowledge of evaluation and outcome measures is an asset.
 : • Experience in advertising and marketing is an asset
 : • Experience with Youth Councils or other groups is an asset.
 : • Experience with Parent Support groups is an asset.
 : • Knowledge of videoconferencing technology is an asset.

KNOWLEDGE , SKILLS, AND ABILITIES: • Excellent communication skills including ability to connect with a wide range of individuals.
 : • Excellent time management, priority setting skills and ability to work with little supervision.

- Demonstrated excellence in team work.
- Good understanding of child health community resources.
- Direct knowledge of ACH programs and services is an asset.
- Direct knowledge of other child serving sectors is an asset.

CONTACTS:

INTERNAL: Physicians, program and service managers, clinical staff and service providers, and families across Southern Alberta.

EXTERNAL: Southern Alberta Child and Youth Health Network.
Key CAYAC contacts from across SACYHN
Parents whose children are receiving service throughout SACYHN