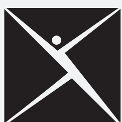
Strengthening Family and Youth Voices

Project Evaluation Report


CANADIAN MENTAL HEALTH ASSOCIATION
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BC DIVISION

Strengthening Family and Youth Voices Project

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Strengthening Family and Youth Voices: Project Evaluation Report

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Introduction

The purpose of this report is to present an evaluation of the Strengthening Family and Youth Voices project. It begins with a background section which provides an overview of mental health issues for youth and families in BC. The report then describes the project, its goal, objectives and evaluation method, followed by the evaluation findings. The report finishes with a summary of project outcomes, observations and 'lessons learned.'

While some people think evaluation is an objective, value-free activity, others think the effort is always subjective and that it is best to disclose one's orientation. The author of this report subscribes to the latter view. With this in mind, here is a brief introduction: I am a family member of someone with a serious mental illness, a parent of two youth 14 and 18 years old and the former Mental Health Advocate for BC. I think the work of this project is critically important, as I understand from my experiences that strong family and consumer voices are vital to effective services and recovery. My mission in working with this project was to provide supportive feedback so this work could continue to develop and flourish.

Background

"Approximately 150,000 of BC's one million children and youth have clinically significant mental disorders–an estimated rate of 15%"

The Strengthening Family and Youth Voices project was a population mental health project sponsored by the Canadian Mental Health Association, BC Division (CMHA) and funded by the Public Health Agency of Canada. The project took place from February 2005 to March 2007. The project featured activities at the provincial level as well as work with sponsoring agencies in five communities around BC. All of the participating local agencies except CMHA North and West Vancouver Branch had existing contracts with the Ministry of Children and Family Development (MCFD) Mental Health Services Program to provide outreach and support to youth with mental health concerns.

Child and Youth Mental Health in BC

Researchers at the University of British Columbia have concluded that approximately 150,000 of the province's one million children and youth have clinically significant mental disorders—an estimated prevalence rate of 15% based on six studies with comparable populations.[1] Every year, approximately 13% of the estimated 150,000 eligible children and youth receive services from the formal mental health system in British Columbia.[2] Youth might also receive some form of mental health service from school district psychologists and counselors, private practice family doctors, pediatricians, and psychiatrists, as well as provincial services such as Maples, BC Children's Hospital or the Interior Health's Regional Youth Mental Health Service located in Kelowna. Additionally, community agencies such as the groups participating in this project are contracted by MCFD to provide outreach to youth and families or to provide psychoeducational groups on specific topics such as children who witness abuse.

Two years prior to the commencement of this project in February 2003, the government of British Columbia released a five-year plan to improve mental health services for the province's children and youth.[3] Three key elements of the plan are:

1. **Improving services.** The budget for Child and Youth Mental Health Services (CYMH) increased by $12.7 million in the 2005/06 fiscal year. In 2007/08, the budget will increase by $14.25 million. Of that, $10.2 million (or 13% of the total Child and Youth Mental Health operating budget) is dedicated to developing Aboriginal CYMH services between 2006 and 2008. To provide increased services to clients, more than 100 new staff were added in 2005 and 83 new staff will be added this fiscal year.
2. **Building family and community capacity to care for children.** A variety of strategies were suggested including:
   - Providing mental health consultation to existing early child development, primary health care, school, recreation, and other community programs and organizations involved with the healthy development of children and families
   - Supporting and educating families and promoting the full participation of families in all aspects of planning for children's health, well-being and development

- Working with community organizations and institutions to address the social determinants of health, build resiliency, and reinforce protective factors in order to be supportive of children and families experiencing mental illness
- Providing increased collaboration and resources, facilitating the development of mental health programs for Aboriginal communities based on their individual cultures and needs, as well as ensuring Aboriginal children have full access to culturally-competent programs and services in the broad children's mental health system
- Reaching out to other cultural groups that under-utilize services

3 **Addressing youth at risk.** While there is a lack of research on the prevalence of mental disorders among Aboriginal, immigrant and refugee children and youth in British Columbia, there is compelling evidence from related studies that rates of anxiety and depressive disorders are likely much higher than that estimated for the general population of children and youth in the province.[4] The evidence also suggests that there is a higher prevalence of anxiety, depressive, learning, behaviour, and substance-related disorders among high-risk youth. Canadian census data indicate that the populations of Aboriginal, immigrant and refugee children and youth are growing as a proportion of the total population of children and youth in British Columbia. Without a concerted effort to improve access to mental health services for these young people, it is anticipated that they will become increasingly disproportionately represented among those with unmet mental health needs.

Canadian Mental Health Association's Unique Perspective

CMHA BC Division has a unique perspective that advocates for families and people with a mental illness by emphasizing the importance of community support and the voice of consumers and families. CMHA BC Division is a provincial non-profit agency with branches in many BC communities. In the period leading up to the Child and Youth Mental Health Plan, MCFD funded CMHA to carry out a consultation with families and youth in relation to their experiences and expectations from the new mental health plan.[5] In the process of this consultation, the issue of the need for more meaningful involvement of family and youth with mental health challenges was raised. In beginning stages of this project, the project sponsor, CMHA BC Division, put out a request for applications to its branches and other agencies that provide youth mental health services to be considered as one of five pilot sites.

Project Description

Project Goals and Objectives

The project goal, as stated in the project logic model (see Appendix A) and approved at the September 2005 Provincial Steering Committee meeting, was:

> *"to promote the participation of families and youth who use the Child and Youth Mental Health services in decision-making and increase their networks of support across five pilot sites."*

At the September 2005 Provincial Steering Committee meeting, this goal was further elaborated to include interest in learning from the experiences in the pilot sites so that these concepts could be better implemented in the future. In other words, the project was taking concepts already proven to improve child and youth mental health, and learning how to implement these academic-based concepts in the real world. The evaluation questions changed from "Is this improving outcomes?" to "Is the concept being implemented in a way that is faithful to best practices?" and "What is working to help and what are barriers?".

The project objectives were:

- To build multi-sectoral collaboration for family and youth support and involvement locally through the development and ongoing support of five local broadly representative advisory bodies
- To strengthen or develop peer support/mutual aid networks of families of children and youth with mental illness in five pilot communities within the first full year of the project
- To strengthen or develop peer support/mutual aid networks of young people with mental illness in five pilot communities within the first full year of the project
- To increase child and youth mental health service provider knowledge in the area of family and youth involvement in treatment decision-making in five pilot communities within the first full year of the project
- To increase child and youth mental health service provider knowledge in the area of family and youth peer support/mutual aid within the first full year of the project
- To identify opportunities for, and barriers to, family and youth mutual aid/peer support and youth and family involvement in treatment decision-making in each of the five pilot communities within the first full year of the project
- To increase young people's self-reports of involvement in treatment decision-making in five pilot communities by the end of the second year of the project
- To increase families self-reports of involvement in treatment decision-making in five pilot communities by the end of the second year of the project

Project Structure

The province-wide project was hosted by Catharine Hume, the Director of Policy and Research for Canadian Mental Health Association's (CMHA) BC Division. A provincial project coordinator was hired to provide provincial-level coordination with the project sites and the child and youth mental health system. Nancy Pike fulfilled this role from March 2005 to May 2006 and Jennifer Sweeney from June 2006 to March 2007. Nancy worked three days per week and Jennifer worked two days per week. Tina Bilns, a Master's student in social work from Dalhousie University, joined the project as a practicum student from September to December 2006 to research cross-cultural issues in child and youth mental health.

The project sponsor and provincial project coordinator met on a regular basis with the Ministry of Children and Family Development's Regional Transition Managers and the Provincial Director of Children and Youth Mental Health to exchange information on this project and other related activities. In March 2006, the project also invited these managers to a daylong education session of increasing family and youth participation in mental health presented by Barbara Friesen and Janet Walker, two researchers from Portland State University's Research and Training Centre on Children's Mental Health and Family Support (www.rtc.pdx.edu).

On a quarterly basis throughout the project lifespan, the project sponsor convened a Provincial Steering

Committee chaired by Jean Moore, a CMHA Board member, and attended by a variety of professionals with experience in child and youth mental health. Family members from the FORCE Society for Kids' Mental Health, the British Columbia Schizophrenia Society, and Mood Disorders Association also had places at this table. One youth from the Mood Disorders Association attended several meetings but her attendance was not sustained on an ongoing basis.

As of January 2007, the five local sites in the project were Maple Ridge Community Services, CMHA Kootenays Branch in Cranbrook, Kitimat Child Development Centre, CMHA North and West Vancouver Branch and the CMHA Cowichan Valley Branch in Duncan. One of the original sites withdrew from the project in March 2006 after struggling with mobilizing immigrant community families to participate in the project. CMHA North and West Vancouver Branch replaced this site in April 2006. This CMHA branch worked with an immigrant population on the North Shore.

The five local sites had resources to support a local site coordinator for seven hours per week, which was extended to eleven hours per week in February 2006 with an upward amendment from the Public Health Agency. Different sites chose to resource the project differently. Most chose to expand the hours of already employed youth outreach or family counselors to take on this new task. Some communities ended up using two (Maple Ridge and Duncan) or even three staff (Cranbrook project and the Kitimat youth group) to facilitate the youth groups. The Ministry Mental Health Team Leader in Kitimat dedicated three hours per week of staff time to participate in their youth group. The family self help group, SPOCK (Supporting Parents of Challenging Kids) that was formed in Cranbrook had a volunteer parent leader and was supported by the local project coordinator through monies to buy study books and DVDs.

Evaluation Process

The evaluation method used in this study could best be characterized as developmental. The evaluation began with the development of a logic model (see Appendix A). The intent of the evaluation process was to gain information about the project as it was being implemented to assess process and impact relative to the logic model, give feedback on progress and learn about key implementation issues as the project evolved.

The evaluation inputs included:

- Attendance at the provincial steering committee meetings for the project and periodic comments on project progress
- Attendance at some of the pilot site coordinators meetings
- Access to the quarterly project reports to Public Health Agency of Canada
- Interviews with the project coordinators and project sponsor
- Two visits to the participating sites to conduct focus group sessions. The evaluator visited four of the five sites in the first round of visits, as one of the sites was in the process of withdrawing from the project and was not able to meet. While we hoped that baseline participant data could be collected at this time, this was not feasible as the groups were still forming. During the second round of site visits, the evaluator visited all five of the pilot sites. Structured focus groups were conducted with the Project Advisory Group, the Youth Group and where there was one, the Family Group. The focus group questions are included as Appendix B
- Web surveys on the effect of participation on individuals and what they liked and disliked about the group they were involved with were developed and implemented in the fall of 2006. Separate surveys were developed for the project coordinators, the family group members and the youth, and are provided in Appendix C
- Attendance at the project dissemination forum held February 9, 2007 in Vancouver.

The evaluation outputs were:

- Attendance at quarterly steering committee meetings to give feedback on the process of the project to allow for deeper understanding of project concepts and support mid-stream correction
- An interim report delivered to the steering committee on March 18, 2006 used to help the group assess where the project(s) were going and to define some major mid-stream corrections in April and May 2006. The main actions recommended to strengthen the project are included in Appendix C
- This project evaluation report

3 Youth Support Activities and Outcomes

Youth Peer Support Groups

The project logic model envisioned that all sites would develop youth peer support groups and that each group would undertake a project. Further, the project leaders envisioned that as a result, youth would experience an increased sense of self-efficacy or confidence, reduced isolation, and increased involvement in their own mental health care. Further, it was anticipated that each youth group would undertake some form of community activity. How did the project fare?

As the project moved into its third quarter, the project sponsor connected with the Self Help Resource Association (SHRA) in BC who offered the following definition of self-help:

> *"Self-help and peer support are strategies to help individuals connect to other individuals with common concerns or shared experiences."*[6]

The main difference between self-help and support groups as articulated by SHRA is that a self-help group may be facilitated or co-facilitated by someone with the concern and is more independent from the formal service system. In contrast, a paid person working in an agency usually facilitates a support group. Like the self-help group, a support group connects people with common concerns but membership is usually more restricted and time-limited.

Four groups had similar membership (youth aged 13–16) drawn from similar sources (outreach and Ministry of Children and Family Development (MCFD) caseloads and high school friends) and the site coordinators worked in similar ways (unstructured support groups). On this basis, I combined the comments from the surveys and focus groups from Kitimat (eight youth), Maple Ridge (four youth with one absent member), Cranbrook (four youth with one absent member) and Duncan (five youth with three absent members). This represented a total of 23 youth who all participated in a youth support group. The groups in Cranbrook, Kitimat and Maple Ridge had participated for approximately ten months from February to December 2006. The Duncan group had met for seven weekly sessions between late October and December 17, 2006. The Kitimat and Cranbrook groups met weekly with no hiatus over the summer and Maple Ridge took a summer break.

The project on the North Shore involved youth in more of a psycho-educational program. The project was time-limited and professionally facilitated. The reason the group needed more of an educational focus was that the agency did not have a pre-existing relationship with MCFD nor youth outreach contracts and so had no ready flow of interested youth through their pre-existing services. The group, organized and recruited in partnership with the school district, was billed as a learning activity linked to 'text anxiety' rather than as a support group, even though the youth I met gained mutual aid and support from their participation. The youth in these groups were also less clinically involved than the support group members discussed above.

All sites developed youth groups, although it took nine to twelve months from the date of the project funding for the majority of groups to come together. While local coordinators in conversation described each site as different, based on the above definitions,[7] four could be classified as support groups and one could be classified as psycho-educational group. The description of the groups and the results of the December 2006/January 2007 focus groups are summarized in Appendix D with direct quotations from the youth, organized into themes.

Health Outcomes

The project leaders wanted a before/after comparison to assess the impact of the groups on youth. This kind of evaluation model presumes there is consensus on the kind of group the project coordinators were developing, a clear understanding of theory behind the group and groups with individuals with similar levels of 'exposure' to the intervention. Because it took the project longer to organize the groups than anticipated and the models were different, the timing of the evaluation and the vulnerability of the participants did not permit before and after measures.

What follows are survey responses reported by participating youth in December 2006, looking back on the impact of the project. A total of 24 youth contributed to the survey responses. I included the responses from the Duncan group even though in comparison to the other groups they had much less time in the group (two versus an average of ten months).

- **Satisfaction:** 82% of the youth surveyed were extremely satisfied with their group. Every focus group contained numerous positive comments about the groups.
- **Reduced isolation:** 67% reported relating better to others and 67% felt they were part of a community
- **Self-confidence:** 75% of the youth surveyed reported increased self-confidence as a result of participating in their group. Many in the focus groups reported this increase in confidence as well.

Increased Participation in Decision-Making

One of the goals of this project was to set out to find ways to increase youth participation in their own health care. At the one-year point, there was very little discussion of this goal and how youth in groups might reach it. It seemed that the way this discussion was arrived at was by providing a safe place for vulnerable youth to first get support and feel better about themselves and then to want to take action about their self-care. The final step in this sequence was action to advocate for better care for others.

From the survey with youth, a number responded with discussions of the meaning of participation:

- *"Participation means you offer your hand or your words to the people who need it."*
- *"Participation means equally sharing the responsibility of the project with anyone else and also being able to speak an opinion and have it be respected and do the same for others."*
- *"Participation is when someone helps out a program or a person. They can participate in many ways in the group."*
- "*Participation means being involved in a community and I think this is very good to do."*

While youth clearly understood what participation meant, in the focus groups they were not able to articulate whether or not they increased participation in their own care. The Duncan group identified that the very fact they had learned about mental illness, stress and coping readied them to participate more actively and cope with present and future mental health challenges.

During the focus group discussion with the site coordinators and their advisory groups, a number of concrete examples identified how this was starting to happen in the experiential world of the pilot sites:

- **Developing mental health literacy.** In order to participate more actively in one's care, one has to understand how the body and mind works. The Duncan group explored the science of stress and the sympathetic and parasympathetic nervous systems. They learned the signs and symptoms of depression and anxiety and how to cope. They felt this was the beginning of preparing themselves to meet mental health challenges if they should occur.
- **Transparency to the mental health counselling process.** One new mental health therapist talked about how he worked to help youth understand what the mental health counselling process was about. He felt youth were so anxious coming into treatment that the therapist ought to lay out his or her method. For example, the treatment process has three steps: first, assessment, usually by asking questions and observing the person, then diagnosis according to internationally derived criteria for mental illness, and finally, a treatment plan based on the assessment and diagnosis. He said once he explained this to youth, they felt much more relaxed and able to participate. Some were even relieved that there was in fact an explanation for how they had been feeling and what the therapist would do to help. He agreed that it was hard to participate if you didn't know what the process was, and he hoped his colleagues might learn how to make their clinical process more transparent and inviting to youth. Clearly this is not a consistent outcome of the project, but it is an indication that the dialogue on involving youth is starting.
- **Youth coming into treatment.** Because of the stigma and discrimination associated with mental illness many family doctors and even family members are reluctant to suggest the young person needs mental health counselling. In the safety of the support groups of this project and albeit in a totally emergent manner, youth in each group did learn about mental illness, the signs and symptoms and available treatments. In one group one individual was referred to treatment and went. In the North Shore psycho-educational group, three youth asked for more intensive help and were referred to treatment.
- **Youth understanding medication treatment.** The youth in focus groups said quite a bit about this: *"I have learned a lot about meds. I have another source for information to weigh my options. I learned that emotions could have chemical effects."* Youth

needed to talk about the different medications they were prescribed and the effects of some. Even being able to call the drug by its correct name was empowering towards self-management. In one group, a youth disclosed how she had stopped taking meds and when she realized how challenging it was to come off and start again, she asked for group support in taking her pills. This was clearly an ongoing process as one youth simultaneously mentioned he was stopping his meds with this father's support and clearly the group would be providing support to monitor how he was doing and whether or not this worked for him.

- **Youth understanding self-harm and options for healthy coping.** One girl described how she learned her coping mechanisms for stress were just hurting herself and others. With the help of the group she learned safe coping mechanisms. Another youth described how learning to knit helped to deal with her depressive thinking. Another girl got information on self-harm and suicide for her 'friend.'
- **Youth understanding the power of support.** One youth described, *"I know someone who needs help. He got even more messed up. The only time he feels normal is when he drinks. He has bi polar illness. He told me he would try to kill himself. We talk pretty regular."* Another youth reflected, *" I feel like I belong more. I can talk about my mental illness and share my stories".*
- **Youth advocating for other youth.** Another part in the continuum of participation in care is moving from self-care and mutual aid to advocacy. The Cranbrook group was able to do this. It seemed that it began with discussions about youth rights and youth friendly services. The youth gave an award to the coffee shop where they met for being youth friendly. Several months later, they decided to do a video postcard of the youth friendliness of youth related services in their communities. And in December 2006, they created a Teens 4 Teens website (www.freewebs.com/teens-4-teens) with links to helpful resources as well as a chat room on everything from teen suicide to sexual orientation.

Youth Outreach Projects

The project logic model and the focus of the first project coordinator put quite a bit of emphasis on the groups working on a project and not all groups got to the point of producing a project. In fact, coordinators and youth in the various sites over time came to understand that the project was the support group. One youth described their major accomplishment as forming their group, going on to say that *"many groups start but don't gel."* As one youth summed it up:

> *"I hounded this office so they would start a support group. I saw a huge discrepancy between which kids got help and how the youth were supported to view certain situations. A lot of time the youth are isolated with their problems and think they are the only one who feels that way."*

The pattern of self-help mutual aid observed in the projects of Cranbrook and Duncan was *"learn about it and then turn around and teach it to your peers."* The youth in these focus groups were very specific about the power of teaching something after you had learned it in youth friendly language. Youth expressed strong values for community peer-led service. The impact literature on self-help describes a helper benefit where the helper benefits by reaching out rather than receiving service.

- The youth in Cranbrook did develop a youth-friendly survey and produced a video about this. They also developed their own brochure to promote their group and created a website.
- The youth in Kitimat, with the aid of one of the group facilitators, made a film about their group, then had a family and friend viewing and planned a community viewing.
- The youth in Duncan developed a logo and a poster for a stress management workshop they offered on Dec. 17, 2006. The workshop was intended for their peers to celebrate the group's learnings about stress and how to cope. One adult who attended said it was very accurate and full of youth-friendly examples. The workshop was very well received by the 25 to 30 youth who attended.
- The youth in Maple Ridge did not come to making a project. This may have been due to the discontinuities resulting from the turn over in project coordinators. In any case this should not tarnish the results of the group because first and foremost, the youth in focus groups discussed the value of the group in terms of the support it provided, not the external activities they produced.
- The youth on the North Shore decided quite spontaneously to do a survey of fellow youth and take it to their Mayor. This project idea arose because they were discussing depression and how

there was nothing to do in their community. They then wondered if their peers felt like this and, if they came up with some ideas for improvement, whether or not their Mayor would respond. This group developed a number of outreach projects within their school—a presentation on depression to grade 10 students and a presentation on test anxiety to grade 8 students, for example—mainly because each of the participants was committed to doing some community outreach to achieve Career and Personal Planning credits for their project.

Advice to Others Starting a Group Like This

One cannot underestimate how important giving and gettng support and making friends were to these youth. In every group, youth talked about how lonely and isolating their experiences with mental illness had been and how important it was to be in a group where peers respected and cared for each other. Even the youth in the Duncan group, who were recruited from a less high-risk population, commented on the importance of the safety and support created in their group. I saw this manifest in youth who listened to peers and reflected back concern (e.g, "Aren't you setting the bar a bit high for yourself?"), youth who brought cookies to share with the group, youth who struggled to organize a New Year's gathering, and youth who encouraged others to take leadership roles in projects. This happened because the coordinators were able to orchestrate a safe place for discussion where youth could enjoy friendship, fun, good food, a ride home and, when they were ready, a place to pitch in and work on a group project.

One of the things that emerged was that every group (Kitimat, Cranbrook, Maple Ridge and Duncan) had a youth mentor who provided an original point of contact for the coordinator, and who worked to encourage other youth to join. While the project didn't consider this in the first phase, it is good to know that often by finding one young person who 'gets' the concept of a support group, others will join often at the suggestion of this youth mentor.

The groups gave consistent advice about the importance of the meeting location, food, good conversation with opportunities to learn, and transportation home. They thought six youth was the optimum group size. And group rules were also considered a given, although it was equally important for the youth to develop those rules as a means of creating their unique social space.

- The youth made several comments about a safe attitude: *"Create a place where it safe to talk." "Listen to us and take action about what we say." "Create a trusting environment." "Make it safe to talk about what we want to talk about."*
- The youth made comments about location: *"The best place to start a group is at the high school." "I really liked meeting in the KRC (a local coffee shop)." "The neutral environment was good." "A relaxing safe place. Anywhere but a government office."*
- The youth made many comments about the value of food for their sessions: *"Food is really important." "Food made it comfortable."*
- The youth made several comments about the necessity of youth led discussions: *"Let conversation happen. Keep the quality of the conversation high. You feel important if people listen to you." "You have to be willing to put yourself out a bit. If you give some, you get some." "Keep the peer to peer learning going." "Teens feel more comfortable going to other teens for help."*
- Youth thought it was important to have a chance to share what they were learning. After meeting with the five groups, there seemed to be a cycle of learning something and then wanting to share what they learned with other teens. It happens at the group's own pace and doesn't seem to have to be forced because when youth get to the point of valuing what the group has given them, and seeing others without their unique knowledge, the urge to share is quite spontaneous. This happened in the project via a web site in one group (set up literally over night at no cost), via individual presentations at school for several individuals and via a community workshop on stress for another group
- In some areas providing transportation was important. *"Rides home helped."* This may depend upon the community and the ages and needs of the youth involved. The youth in Duncan thought it important that they were responsible for their own transport. One person said it demonstrated their commitment.
- All groups discussed the group size: *"Our group was 8 people and though I would never refuse anyone, six might be optimum." "Matters to a point."* Every group agreed it helped when they were all from the same school but when there was someone else wanted to come, it didn't bother them to add another person. Coming from the same school could also help if the youth wanted to process something that had taken place at school.

- Group rules were an important part of some groups and not for others. One group developed quite a long list of group rules that emerged as the group met difficulties in their discussion (for example, "no negativisms"). It seemed a way of learning to have a successful conversation. As many of the youth were already in the system and/or had experienced hurtful comments in relation to their diagnosis, confidentially was very real to them. *"Confidentiality is really important." "This group rocks. Everyone is totally confidential."* Other groups seemed quite comfortable with no rules beyond confidentiality and a loose agenda that began with sharing.

Youth Psycho-Educational Group

The West Vancouver group recruited seven to nine youth in grades 10–12 to meet to talk about test anxiety. They met over five 2½-hour sessions. Seven students were newcomers to Canada. The students earned Career and Personal Planning (CAPP) credits for attending, which was a clever way of turning a deficit (test anxiety) into a reward. While the coordinator developed a rough outline of each of the five sessions, she also allowed youth to explore topics that they were interested in and make their contribution in a way that used their skills. The group met at the local high school immediately after classes finished.

The coordinator chose this group strategy with the support from the district psychologist who also helped in distributing the flyer promoting the group to the district schools via his network of school counselors. The sponsoring agency did not have a pre-existing relationship with the local MCFD team and found it difficult to connect with them, so the partnership with the school district was particularly encouraging as a place to start and continue.

Health Outcomes

- **Satisfaction:** 71% of the group was somewhat satisfied. In all cases, the reason for this reservation was the limited number of sessions. Youth felt it was hard to build trust by meeting every other week and for only five sessions. One commented, *"Stress is continuous, why isn't this group?"*
- **Self Confidence:** The group did not note any impact on their well-being, as they did not feel they met for sufficient number of sessions to change habits. They were quick to add that they did learn some useful things and they valued the discussion. It just didn't have time to 'stick.'
- **Reduced isolation:** Again, the group did not feel they had sufficient time to experience an impact and in addition, these were not students who experienced the shame and discrimination experienced by those with labels.

Increased Participation in Decision-Making

Again, the group was not a clinical group and they did not meet for long enough to consider self-care. That said, they did decide to develop a survey on opportunities for youth engagement and are planning to meet with the Mayor. Two of the youth also volunteered to teach a parenting class (to parents) with the group facilitator.

Advice to Others Starting a Group Like This

The biggest piece of advice was to meet weekly for a shorter time over a longer period of time. Youth needed time to develop trust. Other things that are important are:

- The advisory group and the youth thought it key to let youth drive the group learning process: *"What is important is that we are all interested in being here. No one was forced to be here." "Everyone contributed/not just Lida." "We made up group guidelines together."*
- As with the other youth groups, these youth emphasized the importance of creating an environment of trust: *"We could say what was on our mind (about stress and anxiety) where as we can't say these things anywhere else." " Every week I got to trust people more." " I learned how to trust someone."*
- The youth valued the excellent facilitation job of their coordinator: *"Lida was a great help. She let us ask questions and I felt very comfortable."*
- The fact that the group was convenient to youth was important. Their meeting for the majority of the youth was in the school they attended and right after classes.

- The group valued the provision of food at each session: *"Food comes first. Then the group." "More pizza."* On the practical side, a coordinator noted that the youth wouldn't have had the mental focus to do a 2½-hour session after school until 6 pm unless they were fed. Additionally, some youth did not have extensive social skills in English, so food provided and informal way for this to happen.
- The youth valued learning useful life skills: *"We learned useful things such as relaxation that actually worked to make me feel better." "Every session we did practical relaxation techniques. It made me understand myself better." "I now have the knowledge [to understand anxiety] but not always the time to implement it. It is useful knowledge but sometimes at a critical point, I just can't pull it out. My stress management is not yet a habit." "The survey empowers us to help others. It gives us a purpose. We are doing something to help the community." " I presented a workshop to grade 8 students on test anxiety."*
- Various group members talked about how the group grew their self-confidence: *"It is taboo to speak about emotions. But I now know there are others out there who feel the way I do." "When you know something [about these feelings you get], you don't feel so helpless."*

4 Family Support Activities and Outcomes

Establishing family self-help/support groups was one of two key activities in this project. The envisioned outcomes were that families would report increased self-efficacy and involvement in care, could identify local resources and experience less isolation. Unfortunately not all pilot communities were able to develop a group. The reasons for this were varied. In one case, it was hard to recruit parents to a support group but the same agency was able to recruit parents to join a psycho educational group for parents of youth with mental illness, so clearly there were some parents who wanted to be in some type of group within their network. In another site, two parents were recruited but the group failed to achieve a sustained critical mass. This same site had staffing changes in June and in October 2006, so it is hard to know what would have happened had their been continuity of local site coordination. In a third community, family was operationalized as parent and child and dyads were signed up to participate in a psycho educational group on life skills run by a local psychologist.

Despite these challenges, three sites did manage to create family support groups. They are all quite different so making comparisons on the impact between groups would not be a meaningful exercise. Accordingly, the experiences of these groups are presented as case studies and the reasons for joining the group, the purpose of the group, and the impact of the group are discussed as well as descriptions of the impact on participation in decision-making. Finally, each case study report includes a description of advice to others starting a group such as theirs.

Case Study 1: Parent Support in Cranbrook

Cranbrook is the one community in the project who managed to develop a parent self-help group in the classic format one might understand as a self-help group. The group was entirely composed of parents who had a child with mental health challenges and a family member facilitated the group.

The Cranbrook group began Dec 2005 with the youth worker at the host agency asking a parent of one of her clients to consider getting involved in the Voices project. The youth worker knew that the mother had good organizing skills (she was an outreach worker with a local parish) and that her daughter was on the road to recovery. The parents were also supported by a visit from the two parent leaders of the FORCE who suggested they might find it useful to work through the book by Ross Green called *Parenting the Explosive Child*. This book is the basis of the inpatient behavioural management techniques used in the new Interior Health adolescent unit in Kelowna. The mother had a group up and running by March 2006. She told me:

> *"Our purpose in having the group was recognition that there was a high level of frustration between parents and professionals. Parents didn't feel heard. Because my husband and I have fought the battle for our daughter for the past seven years and now have some peace, we can advocate for others. Parents feel blamed by professionals. Seventy five per cent of the time the professionals were wrong. It was not the parent's fault the kid was behaving in a particular way. We named our group SPOCK, standing for Supporting Parents of Challenging Kids."*

The group met every two weeks for three hours at the Lutheran church in Cranbrook. Membership was open and there were two sets of families in neighboring towns who were considering establishing their own support groups with support from this group.

Reason for Joining the Group

All parents who joined the group self identified as having challenging children and wanting a safe place to get support for doing the right thing for their children.

> *"I came because it was not professionally led so I knew I could talk about issues I face in confidence and not be judged."*

At the start of the project the group leader did substantial advertising: an ad in the local paper, free listings in local papers and brochures that were delivered to local service providers to give to parents. Some people indicated that they learned about the group from the ads, while others heard about the group through personal contact with the group leaders at local parent workshops or through friendship circles. One parent reported health care professionals recommended her to the group.

Purpose of the Group

The group identified two main purposes to their group:

1) **Support.** SPOCK exists to support parents without judgment (this came up a lot because many parents had been significantly blamed for their children's disorders). Said one parent, *"I could voice an opinion and not have it put in my child's file."* Several parents had identified that early on in their child's journey towards official diagnosis, their parenting techniques had been identified as the problem. One told a painful story of having to charge her son in the forensic system in order to obtain necessary services.

2) **Education.** To educate parents on parenting techniques and learn what services are available. *"We needed to 'learn the ropes' about assessment/diagnosis/treatment/follow-up/parenting challenges/youth services in our community and in the province."*

Impact of the Group on the Parents

When asked how being in the froup had helped them, parents replied in terms of support, specific skills, resources and advocacy:

- **Support from others in the 'same shoes.'**

  "*This group is a 'sounding board' to deal with the stress of raising a challenging child and get help from others."*

  "Every parent that comes here has hit a roadblock but there is also a parent in the group that has gotten around it. We open doors for others."

  "This group's informal nature creates the safety and comfort to share our concerns and gain peer support. If the structure of the group were less independent and more formal/more government run or affiliated, it would be less appealing and less comfortable. It would seem like it wasn't providing something very different from the formal supports we are accessing in the community and the very necessary, informative, stress relieving, healing, support system and environment that it does."

  "When you can vent a bit here, then you don't go off half cocked with the professionals."

  "It showed me things could be worse. My situation is not half as bad as I thought."

  "We just talk. You have to understand that with kids who act out you have no one to talk to because the Ministry might think you were losing it and take the kid. It is a real threat against seeking help because some days you do feel like throttling your kid and you don't. You just feel that way and need to talk to someone."

- **Learning specific parenting techniques**

  "I learned specific parenting techniques [through inspirational speakers and videos] to better support my child and my self."

  "I learned better ways of approaching my child particularly in dealing with melt down."

  Several parents were critical of the advice on parenting they received from the formal system, as most of the workers in these programs are single, young women, with limited training and no parenting experience themselves. People also talked about getting parenting advice designed for parents of children up to six years old when they needed help with teens. This appears to be a resourcing issue, where the people paid to do parenting support don't have training in parenting issues for youth. Additionally, while there were professionals who had training in youth-specific strategies through the Kelowna Adolescent Unit, since there wasn't a mechanism to transfer these skills to parents, gains were often lost in the transfer of settings from hospital to home. One parent described how her daughter with bipolar illness had to train the parents on how the hospital handled her 'melt down.' The group spent several sessions working through the book, *Parenting the Explosive Child* and also acquired a DVD set demonstrating the behavioural techniques described in the text. They are now following *The Total Transformation Program*, a twelve-week parenting program by James Lehman.

- **Learning about health care resources.** People talked about learning about the regional child and adolescent mental health centre, and three families in the group ended up getting their youth referred there for assessment, diagnosis and treatment.

  "The local GPs don't feel comfortable making medication changes so when things 'heat up' with my

son, I needed to know who to see to get the meds adjusted."

Other parents learned how to get specialized support in the school system. Many parents described going through a variety of behavioural supports —from private counselors, to the outreach counselors at CMHA, to the family support counselors at Summit Community Centre—until they found the help they needed. One mother, whose son was currently in the youth forensic system, bemoaned the absence of timely resources when she needed them and the way the formal system had blamed her for being a bad parent to her challenging youth.

- **Learning about educational resources.** Parents described how frequently youth with challenges were gifted through primary school only to arrive at high school and have the rubber hit the road with results that varied from failure to being medically excused from school. It was nothing short of amazing to hear the story of a youth who two years previously was excluded from school and marginalized, and this report card cycle where the youth was described as attending school regularly on her own and achieving all As and Bs. The parents discussed learning how to approach teachers ("not like a defensive or aggressive or demanding mother bear") what to ask for, what student services might be available and which schools and school staff might be more responsive. Another parent said, *"It is still frustrating dealing with the school system but getting better. My son has been medicated since grade 1 and he is now in grade 6. Every year I have to repeat the story…this is who he is, this is what works and …they still don't do it. But now I get support not to be a raving lunatic mother."*

  "The elementary school is running the Friends program and that is helpful as anxiety is the most common thread leading to explosion but the high school teachers are not aware or involved in Friends (so I still have to work to educate my son's teachers)."

- **Learning how to advocate for their child and how to feel confident that they are receiving the best care.**

  "Our family was caught in between a diagnostic conflict with a pediatrician saying our daughter had one diagnosis and a child psychiatrist saying she had another. It required us learning about the medical treatment process, the different possibilities and making a decision as to which specialist is best trained to deal with our child."

  Being able to talk with other parents with youth with one of these two conditions helped them to make sense of the conflict they experienced when the professionals were not willing to collaborate to reach consensus on a treatment plan. The facilitator also commented on the inspiration they had from the two visits from members of the FORCE, a provincial family group. They learned from them about ways to open doors to advocate for change.

Increased Participation in Decision-Making

Parents in this group definitely got support to be more involved. First of all, they developed the language and understanding to be involved in the assessment, diagnostic and treatment process. They also gained an understanding that professionals in different sectors often don't communicate well with one another and that if you want results you have to advocate for your family to get the necessary collaboration. For example, one parent had their daughter sent to the new youth mental health facility in Kelowna. It took three months to get the basic report and six months to get the full report to the treating doctors in the local community. When told by her family doctor that he didn't have the necessary information, this parent wasn't afraid to call up and ask for the report and make it clear that the good work done by the regional centre would be undone without timely follow-up.

The group followed the *Parenting the Explosive Child* book developed by psychologist Ross Greene and used in the Kelowna Youth Mental Health facility but they were frustrated that the inpatient staff didn't train the parents to do the quieting in the same manner as they did. But members of this group wrote the Kelowna program and suggested it would be good to train the parents too especially when this facility operates on the basis of a 'one time only' admission policy.

The formal government treatment system offers no opportunity for client or family feedback on an ongoing basis. It is encouraging that the new treatment centre in Kelowna sent a feedback survey to the parents whose youths had used this service. The non-profit agencies that support this project are required to do client feedback as a condition of the accreditation process. The absence of feedback loops with government services seems to be a challenge as without any regular quality assessment feedback and problem solving, things can heat up in an already hot situation between parents and the formal system.

Advice to Others Starting a Group Like This

The discussion was summarized by the comment from one parent:

> *"Call our facilitator and learn what she does. Read our brochure. Attend and see for yourself: it is a great group with great learning taking place. Make up brochures promoting your group at many locations around the community. Be sure the group's organizational structure and affiliations are clearly stated and understood by members and remind them occasionally."*

When asked the what made the group work for them, group members responded:

- *"Laughter"*
- *"The great facilitation."*
  I asked how much time Liza spent and she said, "A lot." She does research. She also prepares a bi-weekly agenda. She takes support calls from individuals. *"We have a standard format that includes chitchat, an inspirational reading, an educational part and then discussion of a weekly challenge and how the parent resolved it."*
- *"Not a clinical setting; Informal setting, nothing stuffy."*
- Confidentiality that is rigorously observed, i.e., no cameras or no documentation of the discussion. *"We know that the information that comes here stays here. It is a small town and this is important."*
- Resources such as free space, money for snacks, and money for printing brochures.

Case Study 2: Parent Support on the North Shore

The North Shore pilot site was asked to explore cultural issues in parent support. The local CMHA hired an Iranian woman with a master's degree in counselling psychology to develop a support group for parents with youth with challenges. In her wisdom, this site coordinator knew that she could only convene a group of parents within the context of culture and that given the stigma of mental illness and the fears of new immigrants to Canada, a group focusing exclusively on parents of youth with challenges would not find many members. She found in her approach to this subject matter it was better to use the phrase 'emotional challenges' rather than 'mental illness.'

The group of sixteen women met weekly at the CMHA branch office from May 20 to July 22, 2006. They then took a summer break and recommenced meeting from September 16 to December 18. The group began with three mothers in the counselling practice of the project coordinator who were experiencing challenges in parenting children with emotional difficulties. These three women then contacted other women they knew who were Iranian newcomers to Canada and wanted to learn about parenting children and youth with emotional challenges. Referrals also came from the multicultural health worker at the Health Authority. Three men had attended a few initial sessions but it seemed that in their cultural framework, the work of parenting and problem solving was the work of women. The few participating men dropped out within the first few sessions. Membership was a bit flexible but towards the last few months, the numbers were static at 16.

The group met for two and a half to three hours. Their sessions were conducted in Farsi and all of the participants were new comers to Canada. While the site coordinator developed an initial agenda for the group following the STEP (Systematic Training for Effective Parenting) Program, later sessions were developed as members of the group identified things they wanted to learn or skills they had to contribute. Each week, there were handouts given on the topic under discussion and each week, individuals were given a parenting 'assignment.' In addition each week, participants learned supportive self-care techniques such as relaxation breathing and systematic relaxation techniques.

Reason for Joining the Group

The group identified that they joined for one of three reasons: the coordinator had referred them, a friend told them about it, or the multicultural family worker told them about it. They made the following comments:

- *"I know Lida. I am a new immigrant to Canada. This is a new culture and I need support in parenting."*
- *"It is hard to be an immigrant. There are so many problems and I tend to withdraw into my problems. I have no experience in parenting. (Here) I get specific ways to handle my problems. I came from Iran to Toronto to here. I have two young kids and I felt so alone."*

Purpose for the Group

The group identified that their purpose was to learn about parenting, to get support and to learn things to help others. They made the following comments:

- *"I am meeting a group of people from whom I can learn a lot about parenting. This is meaningful."*
- *"This group is safe for me. I can share my problems"*
- *"I learn things to help others. This summer when I went to Iran I was able to help my relatives with their kids. I could see my problems much better."*
- *"I learn things. I found out last week I don't listen to my kids."*
- *"This class has three components: personal, social and family."*
- *"I like the ways we engage in intellectual discussion."*

Impact of the Group on Parents

The group worked to provide support for newcomers to Canada, mutual aid for self-care and problem solving and specific skills in parenting. They made the following comments:

- *"I am meeting a group of people who I like a lot."*
- *"This kind of feeling is not every day."*
- *"I have been in Canada three years. Everyone in this group gives me motivation to know I can get there."*
- *"I stopped trying to be super mom and started trying to help myself."*
- *"This place is safe for me. This is my home. I share my problems."*
- *"I can see the problems with my kids better."*
- *"I have more self confidence."*
- *"I am calmer."*
- *"I come here with happiness. I wait for the day. (It is) hard to be an immigrant with so many problems."*
- *"I see some of my daughter's problems as related not to her but related to my mood."*
- *"I get specific ways to handle my problems with my kids and I get results."*
- *"I learned there is not only one way to look at things."*
- *"I have learned to be firm and loving in my parenting and to see Canadian parenting through the Iranian point of view."*
- *"I have learned how to work with my child better. (I have learned) to move from an authoritative style of parenting to a more logical consequences style."*
- *"I am learning to let my children make their own choices and not feel so strongly I have to make all the decisions for them."*
- *"I was learning a new way to be with my children in a new country and it was very positive. I switched from the authoritarian style to the logical consequences method."*

Increased Participation in Decision-Making

The group was not able to discuss this question, as they did not focus on mental illness per se. But it is notable that three members of the group of sixteen had children in the formal treatment system and in this group received support and learned coping skills.

Advice to Others Starting a Group Like This

The women really liked their group and were so infectious about its power, that they were distressed at the prospect of it finishing. Since the last session, they have created the Iranian Women's Association; two group members took facilitation training and continue to meet on a rotating basis at different women's homes. It would seem they have become a self-help group. They didn't really respond to the question about how to give others advice, their answers continued to relate to how wonderful the group experience had been and how much better they felt at parenting and being in Canada. In the closing moments, one woman relayed that her Canadian friend wanted to know why there weren't groups like this for Canadian women.

Case Study 3: Parent Support in Duncan

The Duncan pilot site experienced some frustration in their journey towards developing parent support. Early in the project, they connected with a local psychologist who offers a program to parents and youth called Inclusive Leadership. While it was a well-received local educational and experiential group, it was also not a form of self-help or mutual aid that the project leaders could relate to for reasons of the one-time aspect of the program and the cost to participate. At the end of June 2006, the local site coordinator and agency director were encouraged to take more of a support group approach.

The coordinator also worked as a clinician in the eating disorders treatment program at her host agency. She decided to do a workshop with her therapist husband with family members who had eating disorders. This approach was unique as it involved both the husbands and the wives. The participants in this workshop then agreed to volunteer to support new parents who were coming into the eating disorders treatment system.

The program was well received but was more of a peer support/buddy program where new parents could talk to experienced parents on the telephone as the need arose. The other identifying feature of this program was that it was disease-specific.

The parent support component of this group were not available to meet in a focus group and the message I received was that they had performed their service by helping others but now their own children had grown up and moved on and they did not wish to have an ongoing relationship with the project.

5 Insights from Site Coordinators and Community Partners

I worked to get information about the local site activities through reviewing minutes of coordinators meetings, personal interviews and a structured focus group during the two site visits and through a web-based survey. The site coordinators were extremely proud of the groups that emerged under their leadership and their survey answers below provide some food for thought.

Site Coordinator Survey Responses

Key Actions to Increase Support and Participation for Families

In answer to the question, "What have you come to understand the key actions to increase support and participation for families?" site coordinators replied:

- *"Many of our families are facing multiple barriers therefore the key action to increase participation is relationship building. This can be a slow process and therefore at times frustrating. These families need time to get comfortable and in Maple Ridge there has been a change, which has further complicated connections."*
- *"Sharing their common difficulties. Sharing success stories and peak experiences Sharing information and resources. Empowering one another. Overcoming feelings of isolation and shame. Learning together to focus on what they have rather than what they don't. Using the supportive energy of the group to voice their opinions and take steps to get what they want."*
- *"Following are some of the key points that community members have identified: more mutual aid groups needed for parents of youth experiencing difficulties; decrease wait lists for Child & Youth Mental Health Services; identify and clarify what Ministry is doing what, for example Child & Youth Addiction Services, Ministry of Children and Family Development (MCFD) or the health authority—there is a lot of confusion in this area both by service providers and families."*
- *"Reduce stigma and increase awareness of mental illness. Groups with consistent meeting times/locations, with transportation available. Information and pamphlets. Connection with facilitators."*

Key Actions to Increase Support and Participation for Youth

In answer to the question, "What have you come to understand the key actions to increase support and participation for youth?" site coordinators replied:

- *"In order to answer this question I spoke to the youth and the resounding answer was trust and relationship building."*
- *"Following are some of the key points that community members have identified: definitely a peer support/mutual aid group is needed to support youth, learning together to focus on what they have rather than what they don't (is very important), and using the supportive energy of the group to voice their opinions and take steps to get what they want."*
- *"Normalizing psychological disturbances, establishing hope and emphasizing that they have the power to change their situation for better, demonstrating to youth that their ideas and participation are needed and extremely important, showing respect for their autonomy, accommodating fun and exciting activities, identifying and highlighting their strengths."*
- *"Group consistency of meeting times/location, having transportation available, acceptance"*

Project Success Factors

In answer to the question, "What have been the main factors contributing to the initiative's success?" site coordinators replied:

- *"Safe space for youth and families to speak."*
- *"CONSISTENCY!! Meetings are always Thursdays, same time/same place. Snacks, youth 'buy-in,' parental support, having two facilitators—they can pick up much more from the youth as well as covering if a facilitator is away or sick."*
- *"The amount of information shared through the* Strengthening Family and Youth Voices Coordinators Manual *was an initial contributing factor, the desire of youth and their families to participate, already-established CMHA relationships with youth, their families and community partners."*

- *"Accessibility and openness of provincial coordinator as well as meetings and conferences that were organized; leadership quality and generous support of Katie Hughes; passion and dedication of people involved in the project was inspiring; knowledge of group facilitation and group dynamics helped the group develop a sense of ownership, cohesiveness and loyalty; strong connections with community and service providers.*

Project Challenges

In answer to the question, "What were some of the challenges that you faced?" site coordinators replied:

- *"Progress has been slow but consistent. I would not say that there has been a challenge for me as a new coordinator."*
- *"Staff changes both locally and provincially -Identify goals that are appropriate for this project -Time allotted to work on this project."*
- *"Relationship with MCFD team leader. Accessing youth community and opening dialogue about mental illness."*
- *"Getting parents to come out, [dealing with] parents' thoughts of 'fix my kids,' and 'it's their problem,' parental mental illness can be a factor of fear of socializing with others, differing mental health issues may hinder participation (for example, parents or youth with Asberger's, OCD, bipolar and how they may not connect)."*
- *"Clients have multiple barriers and have various support systems in place and therefore have limited time."*
- *"Staff changes, miscommunication about appropriate project goals, scheduling issues with local steering committee, continuity of project during summer holidays, trying to gain community support when this is not a sustainable project."*
- *"Stigma around mental illness, short-term funding and project—the project needs deserves more time to be well established and accepted in the community, lack of relationship with MCFD."*
- *"Stigma associated with anything mental health, energy of youth participants, lack of time on youth's part to follow through on practicing activities (puppet play, for example), lack of energy of parents."*

Lessons Learned

In answer to the question, "What lessons can be derived from your local project's experience over the duration of the project?" site coordinators replied:

- *"What I have learnt in the time that I have been doing the project is that if we truly allow the youth and the families to take the initiative and help them to strengthen their voices then we have to have so much more time. Stigma and bad education as to how to deal with clients with mental health Issues is a huge problem and it seems almost disrespectful to try and complete something of this magnitude in such a short period of time. Clients often have low self esteem and have had multiple challenges, if a project cannot be completed at a particular site it will be one more thing that clients will feel they have not achieved or managed to do well."*
- *"There is a want and a need for this kind of work. The community contacts are important. The project has a low cost to no cost location. Having a youth 'champion' participate was great."*
- *"My thoughts on this are to keep clarifying the processes and goals of any similar future endeavors. To further realize the healing possibilities found in mutual aid /peer support gatherings. I learned the importance of not working in isolation."*
- *"The group was homogeneous in respect with intellectual and educational level and this made goal alignment easy within the group. This element also kept the interest level high and helped members to feel understood and remain connected. It also helped them develop relationships outside the group meetings The safety level and trust was high among group members because after the first two sessions we closed the group and members felt comfortable sharing their stories. Group homogeneity also helped sustainability."*

Support Group Focus Group Responses

During the period December 2006 to January 2007, I met separately in a focus group at each site with the project coordinators, the executive director of the sponsoring agency, other staff who were involved in the project and where there was a partnership with the Ministry of Children and Family Development (MCFD) team leaders and or staff who participated in the project. It is significant that in Kitimat (arguably the smallest community in the project), the MCFD team leader gave three hours per week of the newest youth counselor to the project.

My aim was to meet with the project advisory group but not all groups were able to convene this advisory function. Two of the three support group facilitators were able to meet regularly with the sponsoring agency and the MCFD Team leader. One of the groups was able to build a strong connection with the Director of Student Services for the local school district. This was a helpful connection although the limited time of the coordinator meant that the collaborative advantage of this partnership wasn't always realized.

Community Feedback

In answer to the question, "What feedback have you received about this youth group?" advisory group members responded in extremely positive ways. Every site noted that teachers in their community liked the group, as there is a place to refer youth with behavioural challenges other than Ministry of Children and Family Developmenmt offices, which is sometimes seen as too drastic a step for some parents or youth. The following are direct quotes from the focus group question:

- *"Youth really love to be in this group. They say they don't have a forum to talk with other kids. They describe themselves as 'geeks.' One parent of a youth in our group has been particularly positive. She phoned and told me this is the only thing her son does each week outside of school."*
- *"The kids really love the group. It is a safe environment and an opportunity to have fun."*
- *"Youth really like the group. I heard stories of how they were bullied at school and how welcome they felt here."*
- *"The staff in the child development centre really notices that the youth are comfortable and happy coming here."*

Success Factors

In answer to the question "What contributed to your youth project working?" advisory group members responded around the following points:

- The different groups valued transportation to and from the group differently. One group responded: *"The 'clinic in the car' was incredible because I would hear kids talking to each other without me directing things,"* while another found that *"It worked that youth had to make their own way here."*
- All valued food at the meetings.
- Three communities noted their pre-existing relationships with youth at risk through Ministry contracts enabled things to get rolling: *"Partnership with CDC, the local high school and MCFD was important."* The one community that had full collaboration from Ministry staff (a worker helped to co-facilitate the group on a weekly basis) achieved the largest group with the most vulnerable youth.
- Marketing was important. Three communities drew up flyers to distribute to the schools, clinics and community agencies.
- All communities had a youth mentor who promoted the group and got buy in from other youth. This was not anticipated in the beginning as a key strategy.
- All communities noted the importance of trust and confidentiality in operating their group: *"Trust kept our group going. The youth are very good at supporting one another."*
- All groups noted that meeting in a non-government office was preferred by youth.
- All groups noted the value of empowerment education expressed in quotes as follows: *"Letting youth learn about something [such as stress management] and then supporting them to teach others via their workshop." "Kids know what they need and our job was to let them go at it." "This project hit the nail on the head. Kids don't feel heard."*

Value of Support Groups Within the Continuum of Support

In response to the question, "Did the project add to the continuum of supports for youth in your community?" all groups replied in the affirmative. The following direct quotes give further details:

- *"A definitive yes. We [MCFD] can't duplicate what is here. It is informal; fun and the learning comes from peers. In Mental Health the treatment model that we use is only good if you have a follow-up support group. Older kids in our community with mental health issues previously had migrated to church based youth groups but this was difficult for them as participation in this sense comes with an agenda."*
- *"A definitive yes. We [MCFD] can do the assessment and treatment but then we need to reintegrate youth into the community and help kids problem solve normal teen-age issues such as 'How to ask a girl out on a date?' The group helped the kids disconnect from the therapist as the sole source of support and learn to look for support and friendship from peers. We can't do that from where we sit."*
- *"Our kids [MCFD] are more vulnerable than the youth who might go to a community youth centre. Most often they have been made fun of or labeled and their self-esteem is battered. Some have experienced abuse. It is good to have a place for them to go to just be kids."*
- *"We [a community agency] are funded by MCFD to do psycho educational groups, which are fine, but this provides an opportunity for kids to heal and grow with a sense of their own power. I saw distinct phases in the evolution of self-help in the group. First is the blaming and finger-pointing phase. Kids really need to blame someone for something that has happened to them outside of their control. The first voice that joined our group was almost always anger. And it was best to listen to it and move on. The second phase was telling your story and actually being heard. The third phase was creating change. Some of our kids are now thinking about how things could be better for other kids in the same shoes".*
- *"I would like to see more groups for older kids from 17–18 [MCFD]. Perhaps doing expressive work such as film, plays or music. We are looking for services to support youth in the transition to adulthood. We have a protocol with adult mental health in Northern Health, which is difficult to achieve. Seventeen year olds don't fit into the adult clubhouse as many of them are still working their way through high school."*
- *" We [a community agency] have youth outreach but we have no support groups for youth. We offer community education quite regularly for adults but not for youth. The response to the workshop on stress management told me there is interest in learning more."*
- *"There are lots of groups for youth that are activity based such as sports teams. There are no groups in this area. This was a good group because it had flexible boundaries and wasn't tightly defined as to who has a formal diagnosis or not. It was up to the youth to define their issues. This was good. [MCFD]"*

Increased Participation in Treatment Decision-Making

In response to the question, "Did the project work to get youth involved in their own care?" the project advisors were generally positive that this had happened. Youth got to this place after passing through the self-help/mutual aid phase and maturing from anger and acting out to information seeking and self-care. It is important to note that the youth are not all in the same system. For example, some receive care from an MCFD team, others see a family doctor, some go to Terrace to a pediatrician and others see a fly in psychiatrist, others still receive care from an adult mental health program. The diversity and scarcity in this system makes it even more important for youth to learn to advocate for themselves. The following direct quotes relate to this question:

- *"We did get there if you think about teaching peers about stress and emotions as involvement in your own care. Additionally, our group came up with a long list of mental health/mental illness topics they wanted to learn more about which we would like to support. Learning about these kinds of things is the first stage to personal and group action."*
- *"We did get there [expressing surprise]. A couple of clients disclosed in the group that they had a mental illness and talked about what they do to get help such as go to their family doctor or see A. or R. [the two therapists in the MCFD office]. That was really big [to do that in a group]."*
- *"Youth are also asking for support. For example, last week one of the kids had a meltdown—another youth asked for support in taking her medication as she recognized that coming off and starting again was too hard for her."*
- *"We work to take the mystery out of mental health treatment. I explain to youth what I do in therapy. I explain that I have to do a mental status assessment*

that will help me make a diagnosis and from that draw up a treatment plan. Making this transparent to them is really important. One kid recently said to me: 'Now I know I am not crazy…there is a reason I feel this way.' Another kid in the group session relayed how he was more in charge of his life and how the medication gave him a steering wheel in his life."

- *"We did get there. In our coffee house chats we talked about rights of the person 'served' and the idea of 'youth-friendly' places. The youth then went from giving the coffee house owner a certificate for being a youth-friendly business to developing a video assessing the youth-friendliness of local businesses and support services for youth. Through this video youth were coming to the point of identifying a vision for how youth should be treated by service providers and local businesses."*

Challenges

In response to the question, "What challenges did your project present?" the following issues were identified:

- Human resources issues were well known to the project as one site withdrew and another two sites experienced workers leaving half way through the project. *"It is difficult to hire workers on such a part time basis. We were lucky to have youth workers already in place so that we could simply add additional hours. We wouldn't have found someone good very easily at 11 hours per week."* The pay scale for workers was also a problem. *"The unionized rate for this work should be $26/hour. The project paid between $16–18/hour. We stretched the rate to $20/hour but still it was less than what MCFD pays for their other projects."*
- The level of resourcing for each of the local sites was also a challenge. Initially the project was funded for a seven hour per week local coordinator in each site and in February 2006, increased to eleven hours per week. Still even with the additional hours, limited time on the job meant it was difficult to follow-up with queries that might arrive anytime throughout the week.
- Local site coordinators indicated that it was challenging at first to figure out what the project planners wanted. One site coordinator summed it up: *"The initial mandate of the project (youth asset mapping, positive youth development) that focused on creating a group to do a project was too broad. In the end, understanding that the project was the group helped me."* The work of the last six months of the project addressed this and created some clear 'recipes' for starting youth or parent support groups.
- Group development was also a challenge. Groups took time to form and sometimes one group fell apart before a second and stronger group emerged.
- Giving youth power was seen as a challenge for some coordinators. *"This worked because we followed youth's lead but it also opened up some potentially controversial areas. If youth disclose certain things and if you do your job, which is to listen and let them problem solve, it can come back to you. The more you let the youth run with it; the more successful the group will be. But it takes courage to let it go."* This comment was made in the context of a youth who initiated discussion as to whether "If I had too much to drink and I had sex, is that rape?"
- Group inclusion/exclusion criteria were also a challenge to some workers. This issue shifted through the project. Originally, there was a thought that the youth might all be from the formal system. Then people recognized that:
  a) the formal system encompasses many providers so not everyone would be known to MCFD or the providing agency,
  b) due to reasons of stigma youth might not initially be out about whether or not they had a diagnosis, and
  c) participation should be voluntary, kids should be able to self refer and self disclose their issues at their own rate.

  It seemed however that one might want to consider group age because there is a difference between 12–14-year-olds in comparison to 15–19-year-olds.
- Group size was also a challenge: *"The group [of eight youth] is large for the energy of the kids. Six kids might be better, but given there are eight we would not send anyone home. Still, at this point the group facilitators are challenged to include additional members."* Group size also varied by age and mental health challenges of the groups.

Psycho-Educational Group Focus Group Responses

On December 5, 2006, I met with the North Shore Advisory Group which consisted of the local project coordinator, the executive director of the CMHA North and West Vancouver Branch, the School District psychologist and the multicultural worker from the Health Authority. This site joined the project in May of 2006, and the Advisory Group was very proud of what had been accomplished given this short time frame and the experiences of the other sites.

Community Feedback

In response to the questions "What feedback have you received about this youth group?" the advisors replied:

- *"I am thrilled [with this group]. There is a huge gap between the high school counselors who try to see the kids at risk and those kids who are experienced real signs of anxiety and depression. The closest we get to help a kid with serious mental health challenges is to refer them the formal MCFD services. We know many kids and or families don't go. They don't consider themselves 'wackos' and the thought of the psychiatric system seems too stigmatizing."*
- *"I had calls from two parents of youth in the group. Both said they have been really waiting for something like this to happen. Both felt the group gave their kids courage to see what they experienced (anxiety) was normal and there were people who might help. Both parents were given the contact info for the MCFD child and youth service. One child had social anxiety disorder; the other had learning disabilities and severe anxiety associated with this."*

Success Factors

In response to the questions "What contributed to your youth project working?" the advisors identified a number of things:

- *"Our 'back door' strategy was key."* The project approached youth about a subject that was something concrete to most high school students: 'test anxiety.' Test anxiety is something everyone experiences and is different than a mental illness, which can be perceived as something that 'geeks' have.
- *"Having a great internal champion, a senior leader in the school counselling system who was able to connect with his colleagues who in turn could promote the project with their students via personal contact and the poster helped us immensely. Without this partnership CMHA wouldn't have been able to get to the youth."*
- Developing a poster helped spread the word: *"The poster the project developed was youth friendly and spoke in language that promised to put youth in charge."*
- Convening the group in a non-clinical location also contributed to lessening the stigma associated with seeking help for your nerves. Two-thirds of the students came from West Vancouver Secondary, where the group was convened. As the sessions were held after school, this eliminated any transportation problems for the majority.
- Because the students were engaged into a pilot project designed to help other students lessen test anxiety and each student had a role to play in the workshop format, the district psychologist arranged for the students to get Career and Personal Planning credit for participating in the group.
- Group homogeneity with regard to grade level was important. Although the students had diverse cultural backgrounds, the fact that they were recruited from grades 10–12 presented a degree of homogeneity that helped to make the group work.
- The empowerment facilitation style of the coordinator was important. The coordinator is an experienced group counselor. She set out with the goal of youth engagement in learning rather than a lecture format. So, for example, the group defined what test anxiety felt like rather than the coordinator telling the group what anxiety is. She also seized the repeated complaints that youth have no opportunities for fun in the community and engaged the youth in an action research strategy to approach the Mayor about policies that limit opportunities for healthy youth development.

Value of Psycho-Educational Groups Within the Continuum of Support

When asked, "Did the project added to the continuum of supports for youth in your community?" the advisors uniformly replied in a positive manner. The executive director of CMHA North and West Vancouver Branch is working with the school district to offer groups in all three district highs schools next year.

Increased Participation in Decision-Making

Although the group was not a 'clinical' sample, it did get youth involved in understanding their body/mind relationships. It also prompted three youth to seek professional help.

Challenges

The challenges involved the lack of MCFD at the table, the limited number of project coordinator hours and the limited amount of time to pull off the project given this sites late start. The site coordinator expressed frustrations at running a group such as this and only being able to meet every other week.

6 Provincial-Level Activities and Outcomes

At the provincial level, the project sponsor and project coordinator engaged in a number of activities designed to both develop the knowledge base for the project and promote supportive policy development and communication about the findings and activities of the project.

Developing the Knowledge Base of the Project

Besides the mandate of building family and youth capacity in the Child and Youth Mental Health Plan, the project leaders were guided from three specific knowledge bases. A binder was developed for the coordinators and an online file cabinet was created on the project's Yahoo group website. The areas of knowledge are:

1) **A Framework for Support.** This analysis developed by the Canadian Mental Health Association (CMHA) lays out the determinants of mental health, which include, but are not limited to formal mental health services.[8] It places self-help, family and community support as key ingredients to achieve positive mental health. It also discusses a knowledge resource base, which describes knowing about mental health and mental illness, including professionally derived knowledge as well as cultural and personal knowledge. From this framework, the experience and knowledge of youth and family who have 'been there' is considered complimentary to and different from professionally derived knowledge.
2) **The BC Office of Children and Youth.** The project coordinator came to the project fresh from doing a practicum at the Office of Children and Youth that was particularly directed towards increasing the participation of youth in the service and support system. This literature focused on Arnstein's "Ladder of Citizen Participation.'[9] Additionally, Dulcie Fernandez, an Associate Child and Youth Officer, served on the Project Advisory Committee. This influence meant that while some might ask for the evidence base that involving youth and family in youth mental health care makes a difference, the Office of Child and Youth would suggest that participation is a right according to international conventions such as the UN Convention on the Rights of the Child. During the duration of the project, the Office produced a number of issue papers that were relevant to the project's mandate and can be downloaded from the Office's website at www.gov.bc.ca/cyo.
3) **Portland State's Research Centre and Training Centre on Family Support and Children's Mental Health.** At the start of the project, the project sponsor, provincial coordinator, steering committee chair, and two representatives from the FORCE visited Portland State University's Research Centre on Family Support and Children's Mental Health (www.rtc.pdx.edu). The US federal Substance Abuse and Mental Health Services Administration funds Portland State to operate a regional training centre designed to carryout multi level research on child and family mental health issues and to build capacity to take best practices to scale. The initiative is one of several regional centres to support the national Systems of Care initiative. The concept of youth and family participation has been a key ingredient in the large-scale American Systems of Care projects dedicated towards improving children's mental health services. Despite best practice writing suggesting the need for increasing family and youth involvement in Canada (e.g., the BC Child and Youth Mental Health Plan), there is no equivalent federally funded training resource in Canada. The service in Portland works to increase youth and family involvement and extends across a continuum from participation in clinical care, to community self-help and mutual aid to community supports. Much of the program theory behind this initiative derives from the research-based work provided by this training centre to the project. In March 2005 an educational session was convened with project representatives, MCFD's Regional Transition Managers, and representatives from Portland State University's Technical Assistance Program on family involvement in mental health care.

Developing Family and Youth Capacity

In the last quarter of the project, the project leaders connected with Kinex Youth Exchange of the Self Help Resource Association of BC and together developed an approach towards capacity-building for self-help and peer support. Additional funding was secured to contract with Kinex to provide two workshops in each of the five pilot communities between January and March 2007. The first workshop was designed for young people and was focused on exploring and developing leadership skills among young people engaged in the project and beyond. These workshops were variously received. In some communities attendance was limited, in other

communities the core group of the youth support group participated and participating youth reported increases in their ability to work in a group and use different methods for thinking about problems (for example, theatre, free drawing, etc.). The second workshop was designed for adults working with youth and focused on how to better engage young people in decision-making. This 'adult ally' workshop was a relatively new concept for Kinex, so the project gave the organization an opportunity to try out some of the concepts they wanted to promote to facilitate positive youth engagement. Again, the participants in the actual workshop commented variously on the success of the workshop in achieving its aims. However the longer-term benefits of these pilots are quite evident, as Kinex has been invited back to participate in three regions to provide staff training in positive youth engagement and being an adult ally.

Developing Supportive Policy

During the life of the project, policy-development activities of the project included:

- Both CMHA and the FORCE attended a special April 2005 visioning session convened by the MCFD to explore family capacity-building in the province.
- Quarterly meetings with the Provincial Advisory Committee for the project. The key roles for this committee were identification of policy and funding barriers, identification of sustainability issues, key informants advice to the project, and helping to ensure long-term support of local family and youth involvement initiatives.
- Quarterly meetings with the Director of Child and Youth Mental Health and the Regional Transition Managers from all regions of the province. During these meetings, the project coordinator gave regular project updates as well as discussed emerging policy issues in relation to family and youth self-help and participation in decision-making.
- Regular meetings with the FORCE, a provincial association of family members who were funded by the Ministry to provide a focus for family support and give family input into policy development. CMHA ended up contracting with the FORCE to develop a guide to establishing parent support.

Developing Project Communications

During the life of the project, provincial communications activities included:

- Development of a Yahoo Newsgroup for the project coordinators. Over time, the group of coordinators decided that they preferred teleconferences in contrast to asynchronous communication. This was partly because they all worked such limited hours and often on different days of the week, so asynchronous communication became disjointed and often out of date.
- Development of an unsuccessful funding application to CIBC to develop an online support for parents with children with mental Illness. Part of this proposal development involved a contract with the FORCE to identify pre-existing online parent support using Health On the Net Foundation's accreditation criteria (available on their website at www.hon.ch/HONcode/Conduct.html).
- Development of a graphic identity and three project newsletters describing project activities that were circulated widely throughout the province. A final newsletter highlighting the provincial forum was also produced.
- Development of three legacy documents: *Youth Helping Youth: fostering peer support as part of the youth mental health services continuum, Peer Support Guide for Parents of a Child with Mental Illness,* and *An Environmental Scan: Peer Support for Youth with Mental Health Challenges and their Families.* These are available from the CMHA BC Division website at www.cmha.bc.ca.

Knowledge-Transfer Activities

The project leaders convened a project forum on the emerging role of peer support and mutual aid in child and youth mental health on February 9, 2007 at Simon Fraser University, Harbour Centre. The forum was designed to tell the stories of the pilot sites and the impact of peer support for young people and families and then to add to the stories by highlighting other peer support activities in the province. Through the work of the forum planning committee, the project was able to attract prominent government officials and community leaders to participate in the day. The host and moderator for the day was Kathryn Gretsinger. The Minister of Children and Family Development, Honourable Tom Christensen, gave the opening address and, after viewing the program, adjusted his busy schedule to listen to the presentation by the youth. Stan Williams, a young

aboriginal man who is participating in the transformation at the Ministry for Children and Family Development and leading the Youth Advisory Committee to increase the voice of youth in services delivered by the ministry gave the keynote address. Christy Clark, who is currently a journalist and social commentator, gave the closing address. There were 147 participants in the forum including many young people, families and service providers, primarily from the Ministry of Children and Family Development. Participants were asked to provide evaluations of the forum on the day and were also sent a web-based survey approximately one month after the forum to assess its impact.

Selected feedback received from forum participants:

- *"I thought the conference set-up was flawless, and I no longer sit in awe when young people take ownership of an issue and speak out. I've learned through experience that that's just the way they are when they have the right kinds of support—very, very capable."*
- *"The thing is that what happened was so powerful, I am having trouble on my own summarizing it.*
- *"I saw youth in the projects grow."*
- *"I saw parents in the project grow."*
- *"I saw parents get tuned into the project (Kitimat)."*
- *"I saw government funders grow."*
- *"Mostly, I also saw wide acceptance of the power of peer support from a variety of people who worked in the field."*
- *"The forum was really well organized and it showed everyone was there with all their heart and soul...was very nice to be a part of it. Thank you all."*
- *"I have to say, I am so very proud of the 'little pilot that could' in Kitimat and everyone that was involved, so I look forward to moving forward with further plans. Thank so much to the CMHA for giving us this opportunity!!"*
- *"After the forum, "I brought the information back to my employer and made suggestions regarding peer groups being developed in our middle and high schools"*
- *"I am making sure that all individuals that I come into contact with through my position, has an opportunity to tell their story. It isn't about my agenda and gathering all the facts first."*
- *"At a rudimentary stage of developing a parent self help/peer support group for our community…hope to have this operating in the next year. Engaging other professionals in discussion of youth peer support."*

Impacts of Provincial-Level Activities

The impacts of these activities can be discussed at three levels: the knowledge base, the policy context and getting the word out.

The Knowledge Base

The knowledge base for the project was an area of controversy. Local coordinators were asked to consider the SEARCH Institute's Developmental Asset Framework and to consider how to map their community's youth friendly resources. An early stage deliverable of the project was an asset map of the community. They were asked to look through the lens of appreciative inquiry where one emphasized what was working for youth. Unsure about what they were supposed to deliver, coordinators expressed frustration. Though each project site prepared a local asset map, in reality, meaningful participation came through the 'back door' after vulnerable youth (usually from the worker's outreach clients or from the MCFD therapist's case load) had come together in a support group and dealt with fundamental barriers to meaningful participation, such as hurt from discrimination or isolation experienced in their school secondary to being labeled with a mental illness.

In retrospect, as one of the major outcomes of the project at the local level were family and youth self-help/support groups, it may have made things simpler to provide the local coordinators with some definitions and process guides to establishing a self-help group. These guides can be found on the internet through the Self Help Clearinghouse, both American[10] and Canadian.[11] The BC-based Self Help Resource Association—which joined this project during the last seven months of the project to build more capacity in the area of youth participation—also has a number of resources detailing how to develop support groups.[12] The project has developed their own support group 'how-to' guides as legacy documents, which are available through CMHA BC Division. With these resources available, hopefully the confusion discussed above need not be repeated.

Another area where the project contributed to the knowledge base was in the area of cultural approaches to family and youth mental health. In the spirit of a pilot project, the planners chose an agency that provides services to immigrants and refugees. They hoped that the worker there would reach out to families or youth and begin a group. They also hoped that the provincial coordinator would help build the links to the mental health service system, as this agency was not already networked. The worker tried reaching parents through a letter for students in the local high school to take home, but was unable to get more than one family to respond. Shortly after this effort, this site withdrew from the project in March 2006. The general consensus, supported by the literature, is that immigrant and refugee families find it difficult to respond to requests to voluntarily present oneself as having a child with a challenge.

In the second go around at this issue with another agency, a counselor from within the Iranian community was recruited to start a family support group. While the same issues of fear of disclosure were present, she presented the group as a support group for parenting rather than a support group for parents of challenging youth. The newcomers group was very successful and though many of the 16 participants were women with no youth at risk, the three women with labeled children found much support and normalization for dealing with their parenting challenges and for adapting to life in their new country. This same worker went into the local high schools and again using a 'back door' strategy was able to recruit twelve youth to join a bi-weekly group on 'test anxiety,' and through that psycho-educational strategy was able to support three immigrant youth to seek out more intensive support.

The Policy Context

This is difficult to evaluate as there were no new concrete family or youth friendly policies adopted by the service system during the tenure of this project but there were concrete actions in the right direction and through dialogue the understanding of support and meaningful participation began to take place. The technical assistance centre at Portland State has been in operation since 1984, so the ideas of giving family and youth a place at the service provider table are well established and generally understood. It is likely it will simply take time for providers to have a clear understanding of the concepts behind this project. And it is likely that families will have to continue to advocate for their place in the provision of care and support to their children. The Federation of Families for Children's Mental Health, a 120-chapter organization with members nationwide, discusses this issue in a recent report.[13] The Federation has provided leadership in promoting a 'family-driven, youth-guided' perspective on how best to improve services and outcomes. Its influence comes from the thousands of families and youth across the country who speak out as service users, family members, and advocates.

It was significant that the project participants were able to present their findings to the Minister of Children and Family Development and the Special Youth Advisor for the Ministry as part of the project forum on February 9, 2007. The youth and family members learned how to present their case in front of a room of policy makers and service providers in a thoughtful and engaging manner. They were supported in doing so with excellent facilitation from the Kinex Youth Exchange staff at the Self Help Resource Association. This wouldn't have been possible at the start of the project.

The cumulative effect of the project and the project forum was such that each of the pilot site host agencies are now in negotiation with the local MCFD offices around continuation of the project. This represented significant progress from where the project began. And at least one of the sites has confirmed funding to continue with the youth support group.

Getting the Word Out

Despite initial resistance, the project was successful in getting the word out both among government officials and among the community. Further, the project developed key partnerships between CMHA, Kinex and the FORCE, which will continue to provide momentum. Finally, the project developed a number of legacy documents that document how to start a peer support group for youth and for parents of youth with mental health challenges.

7 Discussion and Conclusions

This project set out to create family and youth self help/support groups in five different communities plus bolster this work with a variety of activities at the provincial level. It also aimed to learn from their experiences so as to keep the innovation going.

Every pilot site developed a youth group with some more characterized as support groups and others more characterized as psycho-education groups. One support group graduated to be a self-help group.

Outcomes Matched Against Objectives

In concluding this report, it might be helpful to reference the accomplishments against the project objectives for a final comment.

The project objectives were:

- To build multisectoral collaboration for family and youth support and involvement locally through the development and ongoing support of five local broadly representative advisory bodies.
- To strengthen or develop peer support/mutual aid networks of families of children and youth with mental illness in five pilot communities within the first full year of the project.
- To strengthen or develop peer support/mutual aid networks of young people with mental illness in five pilot communities within the first full year of the project.
- To increase child and youth mental health service provider knowledge in the area of family and youth involvement in treatment decision-making in five pilot communities within the first full year of the project.
- To increase child and youth mental health service provider knowledge in the area of family and youth peer support/mutual aid within the first full year of the project.
- To identify opportunities for, and barriers to, family and youth mutual aid/peer support and youth and family involvement in treatment decision-making in each of the five pilot communities within the first full year of the project.
- To increase young people's self-reports of involvement in treatment decision-making in five pilot communities by the end of the second year of the project.
- To increase families self-reports of involvement in treatment decision-making in five pilot communities by the end of the second year of the project.

From this lens, the following conclusions van be made:

Collaboration

The project built multisectoral collaboration for family and youth peer support in varying degrees in the pilot sites. Some groups were very successful while others were not able to build a project advisory group. The communities in which this was done, however, have had a stronger basis from which to negotiate continuing funding for youth peer support in particular. In the end, the sectors where collaboration was key were between the host agency, the Ministry of Children and Family Development (MCFD) Mental Health Team Leader, and a representative from the local school system. In the pilot sites where this collaboration was able to come to the table, the youth projects showed more sustainability. The project also built multisectoral collaboration for family and youth peer support at the provincial level, through networking with the FORCE, Kinex Youth Exchange from the Self Help Resource Association, CMHA and MCFD staff. The Environmental Scan produced at the end of the project, was a particularly strong tool for building shared mental models of peer support and its place in the continuum of existing youth and family services.

Family Peer Support Group Development

The challenge to build peer support networks for families with children with mental health challenges in the first year of the project was realized in three communities by the end of the second year. Each of the pilot sites focused on building youth peer support initially because that was the agency's basis for involvement in the pilot project (they were already providing youth mental health support services). Since they did not necessarily

offer family mental health support services, the family groups were that much harder to start. It was also very evident that parents with a child with a mental health issue felt very stigmatized and it was difficult for them to come forward and participate in a group.

The project did experiment with different ways to develop parent peer support. For example, while Cranbrook was able to source a particularly vibrant group with the aid of a key parent volunteer who had been through the various stages of crisis and recovery and could offer comfort and support to meet up with others. Duncan experimented with a parent buddy system where parents who had been through the crisis period were trained to provide phone support to individuals on an as needed basis.

Youth Peer Support Group Development

The challenge to build peer support networks for youth with mental health challenges in the first year of the project was realized in five communities by the end of the second year. On reflection, this might have happened faster if project leaders had been clearer at the start of the project as to what they expected. Starting with increasing meaningful participation didn't necessarily lead to peer support, whereas starting a peer support group first did lead to increasingly meaningful participation once the group was ready. The initial desired activity was actually a peer support group and there are a number of 'recipes' on how to do this. Regardless, the local site coordinators were eventually successful; the power of the peer support for youth was realized in all pilot communities and their knowledge was shared through a project publication.[14]

Collaborative Treatment Decision-Making Training

The pilot communities were challenged to increase health service provider knowledge in the area of family and youth peer support in treatment-decision making in the first year of the project. There were a variety of reasons for this. First, the health service providers were involved in their own service transformation relative to the implementation of the Child and Youth Mental Health Plan, so they had there own priorities to realize. Even though, in most cases, the number of staff in participating MCFD offices increased, increasing peer support was not a named priority. There was, however, strong policy support for increasing family peer support through direct funding to the FORCE, a family self-help organization. At the end of the project, the MCFD had implemented a Youth Advisory Council and hired Stan Williams, a special advisor, to champion the issue of meaningful youth involvement. This bodes well. There is now a policy foundation to implement meaningful youth involvement. The participation of the Ministry's Regional Transition Managers in a day workshop with staff from Portland State's Research Centre and Training Centre on Family Support and Children's Mental Health also helped to provide a vision for the idea of 'family-driven' and 'youth-led' mental health services as it is operationalized in the United States.

Peer Support Facilitation Training

The objective of increasing child and youth mental health service provider knowledge in the area of family and youth peer support/mutual aid was not realized within the first full year of the project. However, it was difficult to measure objectively as the project did not have access to local government mental health service providers who would agree to be surveyed. Also, only two of the pilot sites had staff who remained consistent through the two years of the project making any kind of numerical comparison of limited value. Practically speaking however, it was obvious from the interviews in each community that this result was achieved by the second year of the project. The project facilitators learned what they had to do to facilitate peer support with youth with mental health challenges—several of the groups realized it was more effective to have more than one person facilitating in case individualized support was needed. Realizing this objective was supported by work both inside and outside the project, indicating this is an idea whose time has come. In the last half of the project, with additional funding from the Public Health Agency of Canada, Kinex Youth Exchange was hired to put on workshops on increasing youth peer support and youth engagement in the host communities. The achievement of this objective was evidenced by the successful experiences of Ministry mental health staff with the local pilot site groups and by the moving testimonies at the project forum in February 2007. The fact that a number of regional youth mental health programs (notably Vancouver Coastal and Fraser) are moving towards youth involvement and are beginning or have already installed their own peer support programs for youth is encouraging. It is also encouraging that Kinex Youth Exchange has been sponsored by the Ministry to work with adult allies in the Northern and Interior Regions to build capacity for meaningful youth involvement.

Identifying Barriers

The objective of identifying opportunities for, and barriers to, family and youth mutual aid/peer support and youth and family involvement in treatment decision-making in each of the five pilot communities was not realized within the first full year of the project. In the youth groups, by the end of the second year discussions on this were beginning to happen within the context of support groups. For example, the group in Kitimat talked about the steps in the treatment process. Most, if not all, providers understand that the treatment process begins with assessment and diagnosis leading to a treatment plan, but to a youth and his or her family these steps are all new information and not usually made so transparent with consequent anxiety about all the questions involved. In the one very successful parent support group in Cranbrook, the group members demonstrated active understanding of peer support and mutual aid and the barriers and enablers towards participating more actively in their youth's treatment. Ironically, their own discussions about the high emotionality of raising a child with a highly stigmatizing illness in the context of very limited services, gives a clue as to perhaps why families are not more welcome in the treatment decision-making process. One aspect of family involvement that was not openly discussed at the start of the project that became quite visible among families in the evaluation was the need to participate openly in the young person's school program in order to get the youth the necessary supports to succeed. The peer support group in Cranbrook provided an excellent opportunity for parents to discuss barriers to accessing the needed supports and strategies to make the education and health systems work for them.

Increasing Youth Involvement in Treatment Decision-Making

The objective of increasing young people's self-reports of involvement in treatment decision-making in five pilot communities by the end of the second year of the project was realized. It was reported in the focus groups with the youth groups. It was reported in the surveys and it was reported in the testimonials at the Forum. It seemed that involvement in treatment decision-making came out of peer support. Peer support provided confidence, the understanding that the individual was not alone and the possibilities of choices towards recover. This resulted in an activated patient.

Increasing Family Involvement in Treatment Decision-Making

The objective of increasing family member's self reports of involvement in the treatment decision-making in five pilot communities by the end of the second year of the project was realized in two of the three communities where families were involved. Curiously, family members from a community where there had not been any success in starting a family group reported enthusiasm for the concept once introduced to it by other self-helper parents. When the parents attended the Forum to chaperone their children and talked to the other parents engaged in peer support who were presenting, the non-involved parents realized the power of family involvement and peer support and left the meeting wanting to start their own group. This again speaks to the infectiousness of peer support.

Serendipitous Outcomes

Community health development work is not always straight ahead. Some outcomes are anticipated and others arise because innovation occurs or other situations change that influence the project's direction. This project had several serendipitous outcomes:

The Voices Forum

At the start of the project, the project planners had not anticipated convening a significant provincial conference on peer support especially one that involved youth and their families traveling from their host communities but as the plans for the Forum developed, it became clear that the whole effort would be meaningless without youth present to tell their stories. The story telling by youth formerly marginalized by their diagnoses was remarkable for its honesty, clarity and recovery orientation. While it was anticipated to involve youth, it was unknown until the youth arrived if a forum would work to evoke the youth stories. The other theme about the Forum that was remarkable was the inclusion of innovation from other youth and family oriented mental health programs in the province such as presenters from the Early Psychosis Program in South Fraser

and Vancouver Coastal health Authority's play on youth depression *Mirror, Mirror.* This was important as often numerous players fighting against one another for the limited funds characterize the field. An indicator of the impact of the work of the project was the commitment of the Minister of Children and Family Development to attend the meeting to give a key note address and stay and hear the youth presenters. There were also some unanticipated synergies in the forum that deserve mention. The projects in the local sites carried out family and youth events separately with very little cross over. It was moving to observe the youth listening to parents tell their stories about parenting a youth with a mental health challenge and vice versa. The anecdotal comments were that youth had never thought about what their parents were feeling because their own issues were so all encompassing. It was also moving to see young people journey to the Forum from other communities and jump up on the stage and describe their own experiences in starting peer support. Finally it was inspiring to see parents coming to the meeting as chaperones of their youth who were participating in a group and joining up with other parents as they considered the possibility of starting their own group.

The Environmental Scan of Youth and Family Peer Support Groups

At the start of this project, the FORCE, CMHA BC Division and Kinex Youth Initiative of the Self Help Resource Association were not working together although the priorities of these three provincial organizations were similar. By the end of the project, youth from Kinex were conducting workshops with youth and adult allies from the site communities and staff from the three organizations were involved in conducting an environmental scan to inform their respective policy and practice. It would have been easy for CMHA as the lead contact for the grant with the Public Health Agency to work by themselves but they chose not to do so. These partnerships have since expanded to include the Ministry of Children and Family Development staff in the regions and the work to further peer support is stronger because of these emergent partnerships.

Legacy Documents

This report makes no secret of the fact, that at the beginning the local sites found it challenging to operationalize the goals set by the project planners. Learning from this confusion, CMHA chose to create two legacy documents to support other parents and youth allies in beginning peer support groups for youth with mental health challenges and/or their parents. Because of this project, the way forward will be easier. The focus on group support is particularly important as peer support in the adult mental health world, tends to focus on a peer support worker doing one on one outreach to someone with a mental illness. The youth in this project were quite adamant about the power of being in a group where others had experienced the same shaming and bullying and learning how to recover together.

Media Coverage

The project did not set up to create a public dialogue on the power of peer support but the presentations at the Forum were so powerful that one of the facilitators who is a broadcaster arranged for a local CBC radio host to interview two of the youth about their involvement in peer support. This was followed by a half hour interview with the same two youth on a national CBC radio program, *Sounds Like Canada*. The project coordinators could not have wished for a better dissemination strategy than to have the issues of peer support for youth with mental health challenges discussed by youth on radio shows with thousands of listeners. Indeed the feedback to the show's producers indicated that the listeners were impressed and saw a need for more of these types of groups.

The post-project climate for family and youth peer support is not optimal but it is moving and growing. The climate for meaningful involvement in decision-making regarding their own care, is also moving but likely can be characterized as having further to go. Some of the clinicians involved in the project showed skills in making the system more transparent and in enabling active participation. This was through simple things such as educating parents and youth of the steps involved in the clinical process ranging from assessment, diagnosis and treatment.

The Fraser Region in the Ministry of Children and Family Development has shown leadership in developing family and youth feedback process in an attempt to strengthen and improve the service system. The project coordinators hope this good work will be disseminated throughout the province as central to having a voice in your own care, is having a confidential means to give feedback about service quality.

Lessons Learned

The Provincial Steering Committee revised the original goals to include a knowledge transfer type goal. They thought it important that the project engage in reflective practice so as to help others implement this kind of work in the future. In this kind of developmental evaluation where the evaluator has an ongoing conversation with the project staff, it is important that the lessons learned come from the staff of the project as these are the lessons that will stick. What follows are lessons learned by the project sponsor.

What Worked to Make the Project a Success?

- **Youth peer support across all pilot sites was a significant factor towards achieving the project goals.** Although varied from site to site, each site was able to successfully engage young people in peer support initiatives. The power of peer support became evident to local coordinators and sponsoring agencies and built a strong commitment to working with young people in different ways across the pilot sites. Additionally, at the beginning of the project, youth involvement in decision-making and in peer support initiatives was not explicitly identified by the Ministry of Children and Family Development as a priority. Through exposure to this project and due to a shift in MCFD leadership, among other factors, this area became more of a priority in the child and youth mental health area over the course of the project.
- **Family peer support in two pilot sites was also significant.** In these sites where family peer support initiatives were strong, participating families identified many positive impacts of connecting to other families in a peer support context. Through the Forum, the power of family peer support was strongly articulated with an anticipated outcome of more family peer support initiatives in other pilot sites.
- **Forum.** The project forum in February 2007 was a significant success and provided a strong momentum for ongoing work in this area.
- **Pre-forum gathering.** Involving young people, families and local coordinators in a pre-forum gathering created a very strong sense of team and belonging. The power of the youth, family and coordinator panel presentations at the forum was a direct testament to the value of bringing people together and working with them to craft their key messages and presentations. Although not appreciated by some of the adults, the facilitation by Kinex worked to help the youth to participate comfortably the next day.
- **Partnerships.** Partnerships with MCFD, the FORCE and latterly Kinex were critical to the success of the project in a variety of ways. The MCFD partnership in particular proved to be valuable as the project increasingly was seen to be a resource particularly in the youth peer support area.
- **Being responsive to pilot site requests/concerns.** It is important in this kind of project to be responsive to local requests/concerns. The project made a number of adjustments throughout the course of the project in response to local feedback including: Involving a local coordinator on the provincial steering committee, minimizing reporting requirements and clarifying evaluation processes.
- **Engaging Kinex.** Kinex provided significant support in the development of the project forum and pre-forum gathering. Kinex had a wealth of relevant knowledge and experience and although the project engaged them later than would have been ideal—their involvement certainly worked for the project.

What Didn't Work?

- **Human resources.** Changes in provincial and local coordinators during the course of the project created unexpected challenges. Some of the changes that the project encountered included the change of one project site to a new agency for the second year, two different coordinators to manage one local youth project, and three changes in a local coordinator over the course of a few months in another site. The provincial coordinator who had been involved in the developing the conceptual framework of the project left a little after one year, which also created a challenge. Of the initial five project sites, only two maintained the same coordinators throughout the course of the two-year project making it very difficult to create a sustained sense of team. In all but one case, local coordinators left the project due to family demands or illness. It was also difficult to hire workers on such a part-time basis. In all sites, these hours were included as part of existing staff roles rather than hiring outside the agency.

- **Resourcing for local coordinators.** Initially the project was funded seven hours per week and in February 2006, increased to eleven hours per week. Still even with the additional hours, limited time on the job meant it was difficult to follow-up with queries that might arrive anytime throughout the week. Every successful group ended up partnering up with at least one or two other adults to act as co facilitators. When asked about this the coordinators said it was important to have two people in the group especially if one person needed individual attention, then the other could keep the group going. Additionally, it made things less pressured on the one site coordinator especially given vacations and time away due to family illness. Another site commented that it was important to have youth outreach workers who were skilled in working with youth do this work.
- **Youth Involvement in provincial project decision-making.** Involving Kinex in the project had a significant impact on the project forum and pre-forum gathering. Kinex, however, was clearly a group that should have been involved in the beginning of the project, as their participation would have contributed significantly to the project as it was developed and implemented in the first year. The project attempted to engage young people in the steering committee yet was not successful.
- **Developing family support groups across all pilot sites.** Family support groups proved to be more difficult for the project sites than the youth groups. Parenting children with mental health issues often leads to isolation. These groups required a parent to spearhead the group or a well-connected parent in a cultural community. Creating trusting and caring relationships among parents and families may require a different skill set than facilitating a youth support group. This is likely to include direct experience with the mental health system as a family member, or people who have walked the same path.
- **Family and youth participation in decision-making.** As the groups took longer to form than expected, focused strategies to increase youth and family involvement in decision-making were not being developed or implemented at a local level as originally proposed. There were anecdotal stories of individual group members having increased confidence in having a voice and this theme likely would have emerged more strongly given more time in the project.
- **Conceptual clarity.** The project coordinators were provided with a great deal of information at the beginning of the project and struggled with what was perceived as a 'top down' direction. Once the models of self-help/mutual aid were clarified with documents and experience with the groups, the groups began to flourish.
- **Initial Cross-Cultural Site.** The steering committee provided important guidance in terms of suggesting that the project seek out at least one explicitly cross-cultural site. Once the decision had been made to approach a cross-cultural site, the project did not apply the site selection criteria to the site and therefore did not do an adequate assessment of the areas that might require additional support in this particular context.
- **Local advisory committees in some pilot sites.** Some of the project sites had difficulty in setting up local advisory committees. The reasons for this were varied and included lack of time in the schedules of busy people and an overall shift in project based funding for health and social services that require project advisory groups. Some of the projects operated without a committee, while others operated with small committees who had frequent contact with the site coordinator.
- **Limited engagement of pilot sites in decision-making.** The project had multiple layers including local advisory groups, a provincial steering committee, a provincial and local coordinators, an external evaluator and a supervisor to the provincial coordinator. In these layers, there were not sufficient ways to involve local sites in provincial decision-making. Although attempts were made at various points in the project, additional and consistent mechanisms needed to be developed to help ensure a stronger sense of team across the pilot sites and to help ensure that the project was fully informed by the communities involved.

Advice to Others Starting a Project Such as This

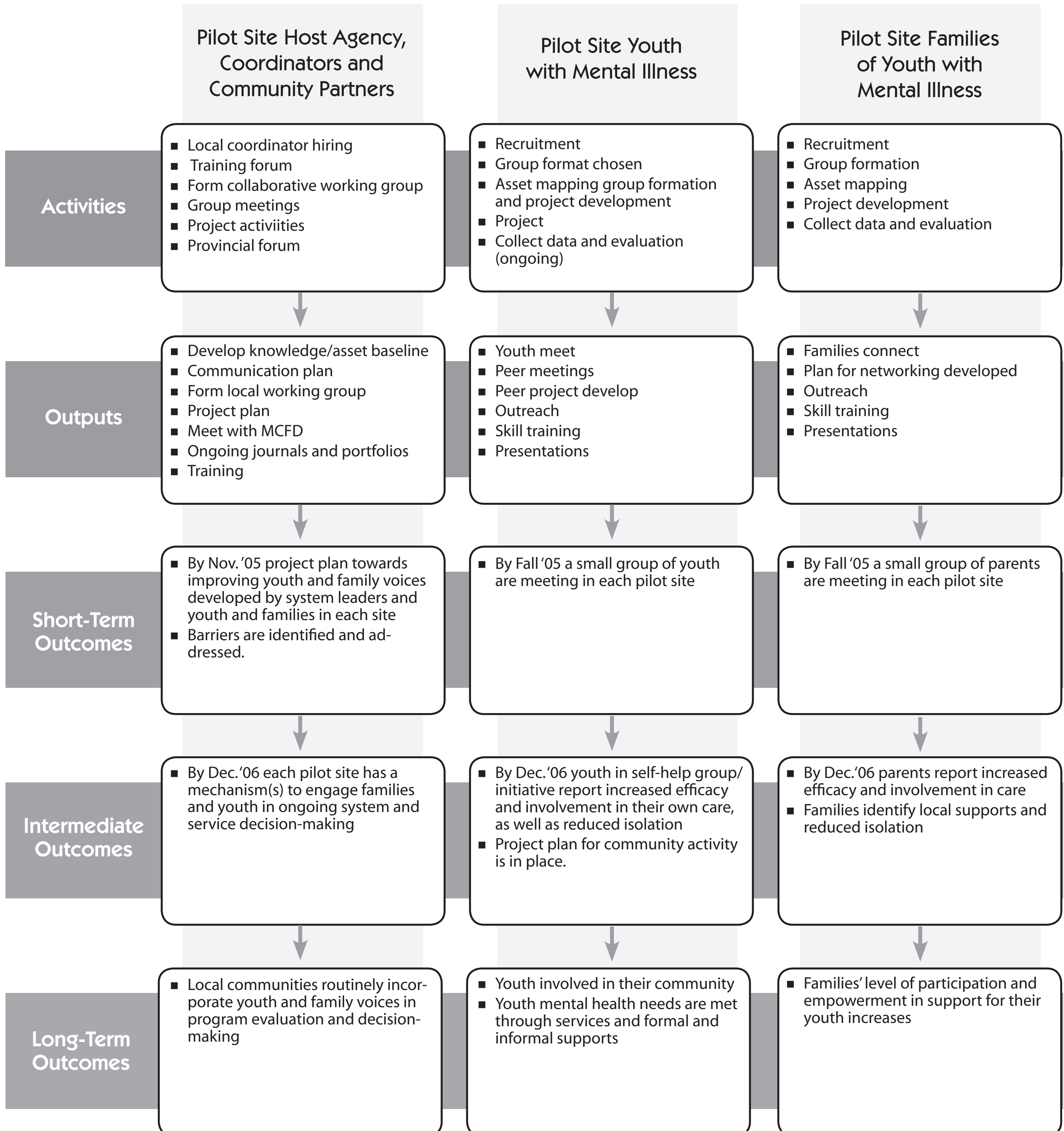
- Take time to ensure that key people such as project sponsors, external evaluators, provincial and local coordinators, and steering committees have a common and consistent understanding of the goals, objectives and conceptual framework of the project from the beginning.
- Ensure that all key resources are identified at the beginning of the project and engaged in the project as appropriate.
- When pilot sites have limited time, it is important to simplify the tasks and focus on those.

- Be as clear as possible about the expectations of local site coordinators over the course of the project—organizing and participating in the Forum predictably took a significant amount of time and this time needed to be planned for.
- Explicitly link the local initiatives to the provincial activities to increase the sense of being part of a larger movement.
- Clarify roles and responsibilities of a multi-layered project and ensure that pilot sites are linked to provincial steering or advisory committee in an ongoing way.
- When engaging cross-cultural communities or pilot sites, ensure that there is sufficient flexibility in the project to be responsive to the needs of these communities and identify additional supports that may be needed to help ensure success. In the case of this project, actively connecting the original multicultural organization to the local Ministry of Children and Family Development office and working with them to develop a strong partnership throughout the project may have helped to support the project's success.
- Build in opportunities to ensure project learnings have impacts on the organizations themselves. For instance, the project could have included a site visit with pilot site Board of Directors to discuss youth and family involvement in decision-making and strategies to build or strengthen this involvement at the organizational level.

Appendix A
Logic Model

Project Goal

Our goal is to promote participation of youth who use Child and Youth Mental Health services and their families/caregivers in decision-making and increase their networks of support across five pilot sites.



Appendix B
Focus Group Questions

Advisory Focus Group Questions

Youth Component

1) What is your youth project? Describe who, how many, what, when and where.
2) What feedback have you received from youth and/or parents of youth who were involved?
3) What contributed to the youth peer support/mutual aid project working?
4) What were challenges that the project faced?
5) Do you think the project added to the continuum of supports for youth in your community? If yes, what is the unique contribution of your project?
6) If you were starting again, what would you do differently?
7) When you look ahead, do you see an ongoing role for this form of peer support/mutual aid in your community? If yes, what would be the ongoing role? If no, why not?
8) Are there resources to support the ongoing continuation of the group?
9) The project's second goal was to increase decision-making in youth's own mental health care. While most groups did not formally reach this activity in the project, were there examples of impacts in this area? If not, what are the issues, if any, that need to be addressed in this area? Do you have any ideas about how youth involvement in their own treatment decision-making can be strengthened?

Family Component

1) What is your family project? (Describe who, how many, what, when and where)
2) If you do not have a family project, what were the barriers to developing one?
3) What are possible ways to overcome these barriers?
4) What feedback have you received from families that were involved? From service providers? From youth?
5) What contributed to the family peer support/mutual aid project working?
6) What were the challenges that the project faced?
7) If you were starting again, what would you do differently?
8) Do you think this project added to the continuum of supports for families in your community? If yes, what contribution do you think the project made?
9) When you look ahead, do you see an ongoing role for this form of peer support/mutual aid in your community? If yes, what would be the ongoing role? If no, why not?
10) Are there resources to support the on going continuation of the group?
11) The project's second goal was to increase family decision making in their youth's own mental health care. While most groups did not formally reach this activity in the project, were there examples of impacts in this area? If not, what are the issues, if any, that need to be addressed in this area? Do you have any ideas about how family involvement in their youth's treatment decision-making can be strengthened?
12) How do you involve families and youth in the services you provide in your agency? On your board? In service feedback? In advisory capacities? In volunteering and job mentoring

Project Support

A project such as this involves more than setting up local projects. The next few questions address the quality of advice and support from the central office:

1) What support did your project receive that was helpful?
2) What support could have been better?

Youth Focus Group Questions

1) Reasons for joining the group:
   Let's start by talking a bit about your group. What brought you to join?

2) Purpose of the group:
   If you were telling someone about the group, what would you say is the reason this group exists?
   How would you complete the sentence: "I go to this group and we…"

3) Major accomplishments of the group:
   What is the major thing your group has accomplished?
   Describe a project or what you did—this could even just be having a place to hang out with others.

4) Learnings:
   What have you have learned as a result of being in the group?
   What have you learned that helped you?
   Can you give me specific examples from your experience?

5) Things that worked:
   What did you like about the group?

6) Things that didn't work:
   Is there something that happened in the group that didn't help you or that could have gone better for you?
   This is something you may wish to write me a letter about or speak to me in private after the group as I appreciate it may be difficult to hear. On the other hand, my experience is that groups learn from mistakes if given a chance. How about it?

7) Help with emotional issues:
   Can you tell me the biggest challenges you face in living with emotional issues?
   Has this group helped you cope with your emotional issues?
   Can you give me specific examples?

8) Help in dealing with others:
   Has this group helped you deal with others?

9) Participation:
   Part of this project that was set out, as a goal was to find out ways to increase youth participation in their own health care. Is there anything you learned in this group that has helped you do this?
   It could be something direct or it could be something indirect…like you feel more confident in general when dealing with adults.

10) Group experience:
    I want to now talk a bit about how you function as a group. What are the things that make this group a positive experience for you?
    I am interested in things that the coordinator and or group members do to make family members feel more welcome?

11) Group rules:
    Did your group have any rules for membership?
    For conflict mediation?
    For privacy and confidentiality?

12) Advice to others starting a group such as this:
    What advice would you give to other youth wanting to start a group like this?
    What worked to bring you in?
    What worked to make you stay?

Family Focus Group Questions

1) Reasons for joining the group:
Let's start by talking a bit about your group. What brought you to join the group?

2) Purpose of the group:
If you were telling someone about the group, what would you say is the reason this group exists?
Finish the sentence: "I go to this really neat group. I like it because..."

3) Major accomplishments of the group:
What is the major thing your group has accomplished?
Describe a project or what you did—this could even just be having a place to hang out with others.

4) Learnings:
What did you learn?
How has being in the group helped you?
Can you give me some specific examples from your experience?

5) Things that worked:
What worked about being in the group?

6) Things that didn't work:
Is there something that happened in the group that didn't help you or that could have gone better for you?
This is something you may have already described in the survey, which I have copies of or perhaps something you wish to discuss in private. On the other hand, my experience is that groups learn from mistakes if given a chance.

7) Help with emotional issues:
Can you tell me the biggest challenges you face in living with emotional issues?
Has this group helped you cope with your emotional issues?
Can you give me specific examples?

8) Help in dealing with others

9) Participation:
Part of the background to this project talks about the value of involving families in treatment decision-making. To what extent do you think this happens in your community?
Has this project equipped you to participate in your son or daughter's care in a more formal way? If yes, in what ways? If not, what are some of the barriers to this involvement? What would be some strategies for building this involvement?

10) Group Function:
I now want to talk a bit about how you function as a group. What are the things that make this group a positive experience for you?
I am interested in things that the coordinator and or group members do to make family members feel more welcome?

11) Group Rules:
Did your group have any rules for membership?
For conflict mediation?
For privacy and confidentiality?

12) Advice to others starting a group such as this:
What advice would you give to other parents wanting to start a group such as this?
What worked to bring you into the group?
What worked to make you stay?

Appendix C

Interim Evaluation Recommendations

An *Interim Evaluation Report* was delivered to the Steering Committee on March 18, 2006. Its goal was to help the group assess where the project was going and to facilitate mid-stream corrections with the provincial and local projects in April and May 2006. The main actions to strengthen the project that were identified included:

- **Acknowledge how far the project has come from its beginnings and celebrate the youth and family who have joined the projects in different communities.** The local communities working on this project deserve kudos for their hard work.
- **Clarify the role of the local community committee.** Discuss if it is a requirement for the project. If it is, provide some hands on support to those whose groups are having challenges in meeting this requirement.
- **Goal Statement.** The project participants should review the goal statement and make refinements as necessary. It may be that focusing on developing self-help groups is a manageable task for this project given its resources and competing priorities. (And not working to increase participation in youth's care). It may be that having a parent and/or a youth group operating is a target for each site. It would be good to clarify.
- **Logic model.** The project can now be more specific about what it wants to achieve and should consider revising the logic model. Perhaps it can be made simpler and less intimidating a document.
- **Learning plan.** The project coordinator has been working with the project site coordinators to develop learning plans in relation to key project activities and outcomes. It would be good to collect information on what was done and what kinds of supports really worked. The major tension here was whether the groups were doing community development with youth and families or implementing self-help groups according to the published literature.
- **Number of communities in the project and number of groups.** The project management group needs to decide on how to replace the one community who withdrew from the project. It would also be good to discuss whether community sites need to have both parents and youth self-help groups. It should be ok to have whatever the community needs right now, but it would be good to agree on this before the project finishes.
- **Timeline for project ending.** One of the most challenging things about a community development is the tension between supporting community development and working within a discrete timeline. The final reporting out of the local community projects would be one year from now and the leaders should be supported to find the balance between developing connections and supporting the groups to become as sustainable as possible.
- **Next evaluation cycle.** The current evaluation was spread over three months as local communities have been in transition and individuals have been unable to meet for a wide variety of reasons. This is likely too long a period. The next report will once again focus on the activities in the logic model and the different communities' progress in completing the activities. Additionally, communities should be supported to develop simple action surveys so they can assess what individuals learn and experience in their self-help groups. Given the rate of progress and the activities that are now in process both unanticipated and anticipated, the project evaluator, the sponsor and coordinator should sit down and revise the original evaluation strategy to line up with what is currently taking place.

Appendix D

Youth Support Group Focus Group Results

The focus groups took place between December 4–14, 2006. Each group was asked the same questions, responses recorded, transcribed and analyzed for common themes. I had planned to tape record the sessions but the confidentiality issues became so significant it was best for me to listen hard and write fast without a tape recorder. Where youth are quoted, quotation marks are used. Where the quote needed a piece of information to allow the reader to make sense of the statement, I added clarifying context information in closed brackets.

Group Membership

All of the group members were of high school age and most commonly between ages of 13–16 years. The gender break down was seven males and nine females. Only two youth missed the focus group meeting (one in Cranbrook and one in Maple Ridge). One site involved two youth from a neighboring First Nations Village. The majority of group members were inside the mental health system but not always. In every setting there was at least one youth in foster care or in a vulnerable family situation. In two sites, youth got support to get help from the formal support system. All could be considered vulnerable youth.

Reasons for Joining the Group

Consistently across groups, youth joined the group for three main reasons: peer mentors who facilitated access, youth outreach workers who facilitated access and youth looking for alternatives to find support in recovery. As young people facing challenges they also told me they were looking for something different that promised to be fun.

- Peer mentors in each site were young women who had already met the challenges of serious mental illness and were in recovery. From all sites, they seemed to know what would work because of what they had been through. These youth mentors were key enablers.

  "[An older youth] told me to."

  "[An older youth] told me about it."

- From all sites, some youth joined because of a preexisting therapeutic relationship with the youth outreach worker who also coordinated the local Voices project. In some sites MCFD therapists referred youth.

  "Amber, my youth worker told me about it."

  "Lori my outreach worker put it to me."

- *"I figured I would be good for this group as I have a mental illness and hadn't received helpful help."*

  "Being able to meet new people"

  "A free space to express ourselves."

  "I heard about it and decided to come. People shouldn't have to go through what I went through. People are really mean to people with mental illness."

  "Someplace to talk about mental illness and how we cope."

  "I missed the bus (and came to the group) and decided to come back the next week because it seemed like an art class."

  "I hounded CMHA so they would have a support group. I saw a huge discrepancy between which kids get help and how youth viewed certain situations. A lot of the time they are left to think they are the only one with problems."

Purpose of the Group

Consistently across groups, youth described the purpose to come and talk in a supportive place. The fact that was fun was important was mentioned in all groups.

- Youth described the groups as places to make connections and have fun:

  "A support group to talk about things."

  "To discuss things."

  "To talk about what is going on and problem solve."

  "To hang out and get support."

  "Kids helping other kids."

  "To do stuff."

  "It's fun."

- They also thought the groups helped connect youth to services and supports:

  "Anyone should be able to come. I know someone who really needs help. He says the only time he feels normal is when he drinks. I think he is bipolar."

  "To connect youth with services."

  "To learn things so we can teach others. Peer-to-peer is best, as we know what is going on. We have different language and understand our issues differently."

Accomplishments of the Group

One group started off by answering this question by saying the major accomplishment was even forming a group. It was his experiences that in the youth world lots of groups come together but few 'stick' the way their group did.

Consistently I met young people who were very excited about their group and its accomplishments. The outcomes that youth expressed varied along a continuum from self-help to mutual aid to advocacy, which is in keeping with the literature on self-help/mutual aid groups. I understood that at the start of the project, the project workers were looking for a project youth could do, but what the youth told me was their accomplishments were more in the area of having fun, meeting friends you could trust, getting support, having a sense of worth through helping others and not feeling alone. It seems the project was the group itself. Achieving trust with another person, having meaningful and safe conversations on topics of their choosing and having fun were major outcomes to these young people.

Learnings from the Group

I asked the youth, "What did you learn from your group?" The major learnings from the group and reported in all three groups were awareness of mental illness and how to cope, how to communicate better with others, how to feel more self-confident, how to access resources and how to problem solve daily living issues.

- **How to function as a group**
  The first learning and articulated by two groups but demonstrated by all was that they learned to function as a group.

  "We learned about trust and commitment."

- **Mental health literacy**
  At least two groups reported on learning about stress (signs, symptoms, techniques for management) and how stress influences mental illness and mental wellness.

- **Awareness of mental illness and how to cope**
  This was raised in various stories. The consistent experience of shame and discrimination needs to be noted. The site coordinators and their advisors also identified learnings in this area. They said it was significant that youth learned to ask for help in getting treatment, to disclose their diagnosed mental illness without feeling ashamed; to get group support for medication compliance and to get professional help with group support to learn about the different mental illnesses and their signs and symptoms. It is important to note that these learnings were not structured but emerged with help from the group leaders, as youth were willing to talk about it.

  "I am not the only one with a mental illness." This was said in each group by at least one person. It was often the conversation opener following my question, "What did you learn?"

  "We all became psychologists. We know what to do."

  "You don't want to be sad. You have a particular mask. (I learned) everyone has a mask. It takes a real person to be able to take off the mask."

  "How to not to bottle it up. Others are going through the same thing".

  "Constructive ways to channel my emotions: anything that will make you happy and not hurt you or others." This was followed by a group discussion of safe coping activities such as listening to music, surfing the net, playing music, drawing, etc.

  "Do healthy things to relieve stress."

  "I think by hearing each other out, by listening to our problems and then we find ways to cope with our problems. It is hard to see where to go by yourself."

  "Somewhere to talk about illness and how we cope."

  "I have stopped taking my pills with my dad's support."

  "I have learned a lot about meds. I have another source of information from which to weigh my options. I learned that emotions could have chemical effects."

- **How to communicate better with others**
  In every group, at least one youth talked about how important it was to learn to talk with others. The group leaders validated this and shared how they had to work to teach listening and respect for others in what was often a chaotic conversation. Anger management support was mentioned by at least two participants in two different groups. One group had quite a discussion about rights and it clearly had an impact on them. In two different groups, particularly fragile youth said very little (one drew pictures all the time) but given their extreme social anxiety, it was significant that they came to a social space once a week.

  "I learned how to listen better."

  "We learned how to open up and contribute to the group. Everyone was encouraged to make positive and inclusive communication."

  "I learned how to deal with my anger."

"I learned to express my feelings…Hey I am feeling this. Don't make me feel bad."

"During grade 5, 6 & 7, I used to fight a lot. Since then I haven't unleashed the beast. Medication gave me a steering wheel."

"I learned how to help others."

"I had problems with anger. I have been to several anger management groups but they didn't help. This group helped me."

"I learned to deal with emotional issues through talking it through with my friends."

"I have learned to help people close to me. What I should do to avoid being hurt."

- **How to feel more confident**
  In every group I met young people recovering from the negative effects of discrimination due to their mental illness and the negative impact of falling behind in school due to struggles finding the right treatment.

  "This group pushed me in my confidence. I am going to chef's training. I am manic-depressive. Everyone knew I had this illness. People judged me and shot my confidence down. I didn't go to grade 8. It shot my confidence."

  "You can't treat someone different just because they have a mental illness."

  "When I came here, I had the lowest self esteem. Now I have self confidence in being at school with other kids".

  "We learned about the fact that we have rights. I didn't know what that meant or that I had rights (in getting service)."

  "We learned to do what we wanted to do."

- **How to access resources and which ones are youth-friendly**
  "It is more comfortable to go to teens for help."

  "Teens are more likely to listen to other teens."

  "I had a bad history with MCFD and was afraid to go there."

  "These guys supported me to go there and drop off our brochures."

- **How to problem-solve**
  "We problem solve issues at school such as suicide in our friends or the way the principals handled two kids smoking drugs in the bathroom."

Things that Worked about the Group

One cannot underestimate how important making friends were to these youth. In every group, youth talked about how lonely and isolating their experiences with mental illness had been and how important it was to be in a group where peers respected and cared for each other. I saw this manifest in youth who listened to peers and reflected back concern ("Aren't you setting the bar a bit high for yourself?"), youth who brought cookies to share with the group, youth who struggled to organize a New Year's gathering, youth who encouraged others to take leadership roles in projects. This happened because the coordinators were able to orchestrate a safe place for discussion, a place for friendship and fun, a place with good food, a ride home and, when you were ready, a place to pitch in and work on a group project.

- **A place for safe discussion**

  "A free space to express ourselves"

  "We can talk about our feelings."

  "You feel you are heard and you are important".

  "This group actually makes me more hyper. Here I can let it all hang out which is a relief because when I am at school I have to hold it all in and it is exhausting. I can be myself here."

  "I am glad I came. (The group) made me feel happier and I can be myself."

  "Here people listen to me and having intelligent conversation makes me feel real."

  "I joined because it was sort of like an art class." In this group, three youth drew pictures during the whole focus group. It seemed like a way of focusing their internal expression in a way their illness often prevented them from focusing externally. No one in the group told them to stop drawing and listen. It was very safe.

  "I feel respected".

  "People go through a lot of things but talking about it can really fortify us." " We talked about what we wanted to talk about."

  "It's safe enough to ask question, such as 'Where would I go if...?'"

  "This type of conversation makes every day life flow easier. I know I have the group to fall back on (if I can't figure it out.)"

  "It is nice to have something to go to that I want to go to as opposed to something I have to go to."

  "Last year I was struggling with depression and there was nothing my own age for me to go to. Coming here makes it a lot easier to function."

- **A place for friendship**
  One focus group ended with a rousing game of five people 'Twister.' One of the quietest group members was a finalist in this game. I spun the wheel.

  "It's fun. We meet and know people better."

  "My friends".

"The people who came"

"Being able to meet new people."

"I have friends."

"Louisa and Lori are the only two adults who understand me."

"I get support."

"We have a lot of fun".

"When I moved here, I didn't know anyone. I didn't say anything in school for the next six months."

- **Food**

  "Food brings us together. Food makes us stay."

  "Food is a bonus."

  "Food calms me down."

  "I like the coffee."

  "Healthy food was really important."

- **Transportation home**
  In two of the groups, the youth made their way to the meeting location after school on their own but were given a ride home by the group leaders. In a third group, the youth were given rides both way. Youth in all groups mentioned the ride home to be important.

- **Having a project**
  This was inconsistent across groups and varied according to the size of the group, the duration of the group's life and the social skills of the group. The longest existing group with a small number of participants (five core members) seemed to naturally graduate to projects.

  One youth who had been through the mental health system commented that projects were important: *"I like the fact that we do things. I don't feel like some head case in a self-help group because you are crazy."* Another youth said, *"Projects got us involved and learning. I get a chance to use my skills and feel more confident and make our discussions more interesting."*

  After meeting for a year, one group had graduated to a series of activities: doing a survey of the youth friendly services in their town, setting up a website and volunteering at a community dinner to help less fortunate people. Other groups also developed their own projects:

  "We are making a film".

  "We learned about stress in our group and then organized a workshop for 25 peers so they could learn about what we learned about. No one teaches this stuff in school and it is really important."

Things That Didn't Work about the Group

There were very few, if any responses to this question or comments made in passing that indicated things hadn't gone well in each of the three settings.

What Advice Would You Give to Others Starting a Group Like This?

The groups gave consistent advice about the kind of location, the importance of food, good conversation with opportunities to learn and transportation home. They thought six youth was the optimum group size. And group rules were also considered a given, although it was equally important for the youth to develop those rules as means of creating their unique social space.

- **Attitude**

  "Create a trusting environment."

  "Listen to us and take action about what we say."

  "Make it safe to talk about what we want to talk about."

- **Location**

  "The best place to start a group is at the high school."

  "I really liked meeting in the KRC (a local coffee shop)."

  "The neutral environment was good."

  "A relaxing safe place. Anywhere but a government office."

  "This was a great trusting environment (referring to the house where the agency had its offices)."

- **Food**

  "Food is really important."

  "Food made it comfortable."

  "Food is important."

- **Let conversation happen**

  "Keep the quality of the conversation high. You feel important if people listen to you."

  "You have to be willing to put yourself out a bit. If you give some, you get some."

  "Keep the peer to peer learning going."

  "Teens feel more comfortable going to other teens for help."

- **Give youth a chance to share what they learn**
  After meeting with five groups, there seemed to be

a cycle of learning something and then wanting to share what they learned with other teens. This happened via a web site in one group, via individual presentations at school for several individuals and through a community workshop on stress for another group.

- **Transportation**
  Depending upon the community and the age of the youth, ome youth had no trouble showing up on their own and in fact, it seemed important to make the effort to get yourself there on your own steam.

  "Rides home helped."

- **Size of group**
  Every group agreed it helped when they were all from the same school. This was partly because sometimes the youth wanted to process something that had taken place at school.

  "Matters to a point."

  "Our group was eight people and though I would never refuse anyone, six might be optimum."

- **Group rules.**
  One group developed quite a long list of group rules that emerged as the group met difficulties in their discussion (for example, "No negativisms."). It seemed a way of learning to have a successful conversation. As many of the youth were already in the system and/or had experienced hurtful comments in relation to their diagnosis, confidentially was very real to them.

  "Confidentiality is really important."

  "This group rocks. Everyone is totally confidential."

  "We know what gets said in here, stays in here."

Appendix E
Youth Psycho-Education Group Focus Group Results

West Vancouver Group

The West Vancouver group recruited seven to nine youth in Grades 10–12 to meet to discuss over five- two and one half hour sessions to talk about 'test anxiety.' Seven students were newcomers to Canada. The students earned Career and Personal Planning (CAPP) credits for attending which was a clever way of turning a deficit (test anxiety) into a reward. While the coordinator developed a rough outline of each of the five sessions, she also allowed youth to explore topics that they were interested in and make their contribution in a way that used their skills. The group met after school at the local high school immediately after classes finished.

The coordinator chose this group strategy with the support from the District Psychologist who also helped in distributing the flyer promoting to the group to the district schools via his network of school counselors. The sponsoring agency did not have a pre-existing relationship with the local MCFD team and found it difficult to connect with them, so the partnership with the School District was particularly encouraging as a place to start and continue.

Reasons for Joining the Group

Youth joined the group for one of three reasons: peer referral, school credit or counselor referral.

- *"I got CAPP credits for attending"*
- *"[My friend] told me to come."*
- *"My school counselor told me to come".*
- *"She told me to come".*

Purpose of the Group

- *"We learn about depression and stress."*
- *"It's a good chance to talk. It is rare you get to open your heart."*
- *"It's a place to discuss the issues that you have."*
- *"How to improve youth life."*

Accomplishments of the Group

This group in addition to their five-session exploration into mental health, mental illness and coping strategies, decided that youth mental health was poor because of lack of anything to do with meaning. They decided to survey their peers on this thesis and present the findings to the mayor of the municipality.

- *"Doing the survey and presenting it to the mayor."*
- *"Getting experience with mental health concepts and strategies to manage stress."*
- *"Making a binder of our studies to support other groups doing what we did."*

Learnings from the Group

This group reported learning about the signs and symptoms of depression and anxiety and self-care coping strategies such as deep breathing and systematic relaxation. They learned about stress and how that affects one's nerves. They learned how to create a survey and advocate for change. They also learned that "I am not the only one who feels this way and naming that is a release of stress."

Things that Worked about the Group

- **Friends**

  "Making friends"
- **Youth drove the group learning process**

  "What is important is that we are all interested in being here. No one was forced to be here."

  "Everyone contributed/not just Lida."

  "We made up group guidelines together."
- **Trust**

  "We could say what was on our mind (about stress and anxiety) where as we can't say these things anywhere else."

  " Every week I got to trust people more."

  " I learned how to trust someone."
- **Good facilitation**

  Lida was a great help. She let us ask questions and I felt very comfortable."

- **Convenience**
  The meeting was at school and right after classes.
- **Food**

  "Food comes first. Then the group"

  "More pizza."

  The youth wouldn't have had the mental focus to do a 2½-hour session after school until 6 pm unless they were fed. And again, many of these "anxious" youth, did not have extensive social skills, so food provided the grease for this to happen.
- **Learning useful skills**

  "We learned useful things such as relaxation that actually worked to make me feel better."

  "Every session we did practical relaxation techniques. It made me understand myself better."

  "I now have the knowledge [to understand anxiety] but not always the time to implement it. It is useful knowledge but sometimes at a critical point, I just can't pull it out. My stress management is not yet a habit."

  "The survey empowers us to help others. It gives us a purpose. We are doing something to help the community."

  "I presented a workshop to grade 8 *students on test anxiety."*
- **Self-confidence**

  "It is taboo to speak about emotions. But I now know there are others out there who feel the way I do."

  "When you know something [about these feelings you get], you don't feel so helpless."

Things that didn't Work About the Group

Everyone generally agreed that five sessions every other week was too short: *"Stress is continuous. Why isn't this group?"* They suggested perhaps more frequent but shorter sessions might be better next time. They also thought there should be more marketing for the program as all youth could use these ideas.

What Advice Would You Give to Others Starting a Group Like This?

Their advice was a reprise of what they thought worked about their group with the provsion as above that they wanted more frequent shorter sessions (1½ hour).

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