

Final Report
Building Resilient Families Action Research Initiative Project
August 30th, 2005

by
Nanaimo Family Life Association
1070 Townsite Road
Nanaimo, B.C. V9S 1M6

Contact Names: Kate Burns, Jane McKie
Telephone: 250-754-3331
Fax: 250-753-0268
E-mail: k_burns@nflabc.org
Report Author: Lisa Clarke

Submitted to:

Child Welfare Advisory Committee (CWAC)
Vancouver Island Strategic Investment Initiatives Fund (SIIF)
Queen Alexandra Foundation for Children

Acknowledgements:

Nanaimo Family Life Association's Board of Directors and the author of this report wishes to express their appreciation to the following for their significant contributions to the project:

- **Nanaimo Family Life Association staff:** Jo Ann Shillington, Building Resilient Families Project Counsellor; Jane McKie and Margit Larsen-Rogers, Program Coordinators; Nina Evans-Locke, Volunteer Clinical Supervisor; Wendy Pepperdine, Coordinator of Finance and Administrative Services; Morry-Lee Hall, Administrative Assistant; Mona MacLeod, Executive Assistant/Bookkeeper; and Kate Burns, Executive Director.
- **Malaspina University Research Team Members:** Professor, Dr. John Neville; and Research Students, Cindy Prior, Leslie Fletcher and Leah Brunet.
- **Community Partners:** June Harrington, Nanaimo Brain Injury Society; Christina Martens, Canadian Mental Health Association; Patrick Konkin, Child & Youth Mental Health, MCFD; Louise Maurakis and Maureen McGinley, Nanaimo Mental Health and Addictions Services, VIHA; Ron and Brett Plecas, Open Minds Open Windows; Shannon Wilson, John Barsby Community School & Caroline Iles, Georgia Avenue Community School, School District 68; Jorge McGladry, Citizen's Advocacy; Dione Vanice, Foodshare; Eileen Bennewith, Public Health.
- **Community Members & Businesses:** Rose McCulley; Gwen Boyd; ; Jennifer Wilson; Lynn Fraser, Coastal Community Credit Union; Alan Pudwell, Pudwell & Associates; ; Gordon Gamble, Focus Group; Kathleen Savory and Sharon DeLure, Savory & Associates; Evans-Locke Consulting; Runners of Compassion; Thrifty Foods- Longwood Station; Mid Island Co-op; Food Country; Costco; and Starbucks Coffee.
- **Supporting Families with Parental Mental Illness Provincial Working Group:** Special thanks to Desiree Blume and Dr. Robert Lees.
- **All the children, youth, parents and natural supports of families who participated in the Building Resilient Families Project. We wish you well, always.**

Table of Contents

1. Executive Summary.....	4
2. Project Outcomes:	
Goals.....	5
Identified Key Outcomes.....	5
Measured Service Target Outcomes.....	5
Anticipated and Actual Project Outcomes.....	6
Long Term Outcomes.....	7
3. Key Lessons and Learning:	
Collective Group Findings.....	8
Parent Group Feedback.....	10
Natural Support Group Feedback.....	11
Children & Youth Groups Feedback.....	12
Community Forum Participant Feedback.....	13
General Project Findings: Client Profile.....	13
Action Research Findings.....	13
4. Unexpected Events:	
Provincial Forum.....	15
Speaking Engagements.....	16
Community Forum.....	16
Low Referral Numbers.....	16
Group and Service Provision Modifications.....	17
5. Conclusions:	
Sustainability of the Project.....	17
Target Population that Most Benefited.....	18
Staff Observations and Conclusions.....	18

Appendices:

Appendix 1: **Supporting Families with Parental Mental Illness Forum
Collated Summaries of Collected Data**

1. Executive Summary:

The Building Resilient Families Project proposed to provide comprehensive support to families with significant parental mental health issues in the Nanaimo region. This was provided by offering psycho educational groups and support to the parents, youth, children and natural support people (ie: extended family members such as grandparents, neighbours & care-giving friends) of these families. An Action Research component was also an integral part of this project to increase community capacity and collaboration.

The adult group work involved increasing knowledge of the impact of parental mental illness, child development needs, parenting skill acquisition and advance planning for childcare. The groups for children and youth focused on helping them build their understanding of parental mental illness, build safety & coping skills and increase their resiliency (as indicated by research on protective factors).

The Building Resilient Families Project successfully implemented the work detailed in its proposal. Goals and anticipated outcomes were achieved in line with proposed project development, service provision and identified partnerships. Slight modifications to the original budget and services offered were required and made based on the lower than anticipated numbers that were referred and type of support services needed.

Several innovations to the project were undertaken to enhance the learning and outcomes that directly benefited our community and that of other communities in BC, particularly those in this region. These innovations included Project Counsellors and Community Partners organizing a special Community Forum to provide information and improve collaboration in Supporting Families with Parental Mental illness. It also included Project Counsellors accepting speaking engagements and providing consultations on Supporting Families with Parental Mental illness to Service Providers groups in this and other communities.

The project garnered a great deal of local interest from stakeholders and other interested parties, particularly from other researchers and mental health professionals. The increased level of community interest also resulted in a local commitment by Service Providers to develop a strategic plan around Supporting Families with Parental Mental Illness for the coming year. Another legacy of the project has been the establishment of an independently run ongoing Parent Support Group.

The project's research was done in partnership with Malaspina University. Focus groups were interviewed to collect qualitative data based on the project's goals. These findings supported outcomes identified by the group evaluations and post-test questionnaires.

2. Project Outcomes:

Goals

The overarching goals for this project were:

1. To prevent children of families where there is parental mental illness from entering Ministerial Care by assisting their families with:
 - advance planning, skill expansion, information sharing,
 - optimizing both natural and community supports, and
 - increasing awareness of parental mental illness and its impacts.
2. To use Action Research to improve relevancy and methods of practice as well as overall service delivery integration.
3. To reduce the stigma of mental illness.

Identified Key Outcomes

To achieve its key outcomes, specific expected results, such as service targets and anticipated project outcomes were identified from each element of the program and described in a *Building Resilient Families* (BRF) Logic Model in the original proposal. Staff and Malaspina University Researchers compiled outcome measurement data from pre & post-tests, focus groups, NFLA's standard formal program evaluations, as well as ongoing and continuous verbal feedback from participants during sessions (Action Research documented by staff).

The project's goals were reviewed by the Research Team and further examined to ensure that past research and best practices supported each one. Resiliency was described as "the ability to cope effectively with adverse life conditions". Researched protective factors that can build resilience in families with parental mental illness were articulated and informed the design of outcome measurement tools utilized in this research project.

BRF staff and Malaspina University Researchers modified the terminology used in the pre and post tests to accommodate the needs of group members based on an Action Research initiative. Some project outcomes were thus measured based on the participant-informed modified indicators of success and measurement tools.

Unfortunately, insufficient quantitative data was available for analysis because of lower than anticipated numbers of group participants. Still, the qualitative research gathered from focus group interviews suggests the themes, trends and outcomes identified were congruent with the data gathered from the formal group evaluations, as well as pre and post test questionnaires. Based on the Malaspina University Team's findings, "It would appear that a client-centered, holistic approach to providing services to families and support networks of people with parental mental illness has been effective."

Measured Service Target Outcomes

Service target (in italics)- **Actual number of participants (in boldface)**

Family Triage

- *150 families will participate*- **38 families** were referred to project and participated in Triage Intake sessions

Modified Telephone or Individualized Support for Project Participants

- *0 Anticipated*- **26 families (46 individuals)** received Modified Telephone or Individualized Support (including 4 foster parents who had children participating in groups)

Group Sessions

- *24-36 children participating in group sessions*- **15 children participated**
- *24-36 parents participating in group sessions*- **18 parents participated** (6 of these participated in Phase Two group)
- *24-36 participants in the natural supports group*- **14 natural supports** participated, including 4 foster parents

Action Research

- *6-7 focus groups*- **5 focus groups were interviewed by Researchers**
- *100 participants and 20 community service providers participate in Action Research*- **all 47 group participants provided ongoing Action Research feedback to staff; 60 service providers and 20 family members** also participated in the Supporting Families with Parental Mental Illness Forum and received information about accessing the final BRF Report.
- *100 British Columbia organizations receiving or downloading the final report*- **number undeterminable at this time** though 100 participants at Provincial Forum and the organizers of this event (Provincial SFWPMI Working Group) were given information about project, its research and contact information to access the final report.

Anticipated and Actual Project Outcomes

Project Outcomes were evaluated utilizing several techniques, including the use of pre & post-test questionnaires, focus groups, telephone interviews and NFLA's standard formal program evaluations. Ongoing verbal feedback was also obtained using Action Research methods throughout the project from all participants documented by Project Counsellors.

In all five Focus group interviews were conducted; two with parent groups (total of 8 participants), two with natural supports (5 participants) and one with children/youth (two participants). An additional four telephone interviews were conducted by researchers for some of the participants who were unavailable for the Focus group meeting.

Formal pre & post test questionnaires and program evaluations were completed by 32 of the 35 participants who completed group (11 parents, 8 natural supports and 13 children/youth). Data gathered from these post-tests and formal program evaluation forms were used to determine the following outcomes.

At the end of the project the following outcomes were anticipated (*in italics*)-**attained (in boldface)**:

- *85% of parents report their family's resilience has increased as a result of group participation-* **91% of parents reported their children are now coping better and that they themselves know how to better help their children manage as a result of the project; 100% of parents self-reported an improvement in parenting skills and greater comfort in discussing their illness with their children.**
- *90% of children report their family's resilience has increased as a result of group participation-* **92% of children reported increased problem-solving abilities and hopefulness about their future; 77% reported knowing a lot more about their parent's illness and less confusion about it; 69% reported feeling more comfortable talking about their parent's illness, their feelings about it and asking for help when feeling upset about it; 92% said they would recommend the group to others and found the group helpful**
- *80% of parents tested report reduced difficulties with stigma of parental mental illness-* **100% of parents reported reduction of difficulties with stigma**
- *80% of group participants report less fear of parental mental illness-* **77% of children reported a slight reduction in their fear of their parent's illness**
- *80% of group participants report feeling less isolated-* **100% of parents and natural supports reported feeling less isolated**
- *80% of participants report an increase in the successful use of community supports-* **82% of parents and 75% of natural supports reported a significant increase in knowledge of support services and resources as well as the ability to access and use**
- *80% of participants report an increase in the successful use of natural supports-* **64% of parents reported they were now able to get needed support from family and friends**
- *80% of participants who are natural supports to families reported increased awareness and pragmatic approaches to be effective in their role-* **88% of natural supports reported an increase in their ability to be helpful to their family and believed their family is now coping okay or better**
- *50% of participating community services report they have increased knowledge related to improving service delivery as a result of this project. 25% of participating community services report improved service delivery and/or practices as a result of this project.* -**100% All completed Supporting Families with Parental Mental Illness Community Forum Evaluations indicated attendees had increased their knowledge related to service delivery and best practices**

In Addition to the initial project measures, the following was also reported:

- 100% of participants who completed the sessions reported they found attending the groups helpful, over 90% reported attending groups as very helpful and all but one (who didn't know anyone else with a parent living with mental illness) would recommend the groups to others.
- BRF also provided numerous case consultations with Service Providers working with families with parental mental illness and offered 9 Adult Offspring support and information about resources available to them.

Long Term Outcomes- presently undeterminable

- *Decrease in the number of children of families with parental mental illness placed in Ministerial Care,*
- *Decrease in negative intergenerational impact of mental illness on children of participating families, and*
- *Best Practices are moved forward in British Columbia.*

Collective Group Findings

The research findings in this project suggest that **providing comprehensive support to family members strengthens these families and increases the likelihood that the families' and particularly the children's resiliency will be increased.** It also reduced the likelihood of long term negative outcomes by developing the protective factors earlier research indicated is needed by these children. Focus group interviews provided the quotes from participants contained in this section.

All BRF Focus Group participants, post test questionnaire respondents and formal group evaluations reported an increase in resilience. Across the groups participants described significant changes in behaviour, knowledge, attitudes, perceptions and skills. These included:

- feeling a greater sense of well-being and **ability to cope with mental illness**

One grandfather who was attending the Natural Support group stated, "Our first meeting saw a great outpouring of emotion as we openly told of the reasons we were there and how hopeless the future appeared to us. After a few weeks the tension very much eased as we became comfortable with our group and that all was not lost or hopeless....We have learned to pace ourselves, to set priorities so we are not washed out ourselves and therefore able to be objective and of use to our families. We have also learned where to seek help if we need it after the

group finished. The descriptions of the various mental illnesses, symptoms and resources are very valuable... Our group has been given avenues to help the parents and their children accept the situation, ways and means to try to live a practical, useful and some semblance of happiness and normal family life."

A family friend further stated, "By the time I actually left the (Natural Support) group I was actually able to laugh about some of the stuff... I now know I can't fix her (mother with mental illness who attended Parent Group). I just have to help her...(Group) has made it easier for me to talk to her. I can say you're talking really fast or moving around really fast. Are you okay? Let me help you with this or let me take the boys. Group has made it easier to do that without her feeling like we are completely taking over and running her life for her...Even her youngest son (who was attending Children's Group) is really starting to understand. He has made some comments about mental illness and he seems to understand exactly what the illness is."

- an increase in their **ability to effectively manage feelings and communicate**, particularly anger and frustration which had been a source of ongoing stress within the family

One parent whose ten year old son was attending the group said, "About halfway through my son's group sessions, I was having a really bad day. We were arguing when he suddenly left the kitchen and went to his bedroom. A few minutes later I went in and saw him sitting on his bed with the teddy bear he had been given in group on his lap. I asked him what he was doing and he said he was talking to his bear about his troubles and how he felt rather than arguing. He said this is what he was taught to do in group and he asked me to leave his room. My son would never have done that before group. He is coping so much better and we can really talk now."

- **a greater understanding of mental illness**, its impact on their family and how they could pull together more in the face of illness

A family friend who attended the Natural Support Group stated, "I was able to come to the group and get answers to questions I had about how to handle different situations that had arisen when my friend is unwell. I also received very helpful information on how to handle different situations with her children. I have gained a lot more techniques to help my friend and her kids."

One child reported, "The most important thing I learned is to remember that my mom's mind can play tricks on her and it's not her fault. And it's not my fault that she has a mental illness, either. It just happens sometimes to people."

- **the lessening of the stigma** associated with mental illness through the groups' discussions, as well as the atmosphere of acceptance in groups and at the Community Forum that was attended by Service Providers and family members

One parent stated, *“I didn’t realize before coming to the Parent Group how strong a bias I had about other people with mental illness. I was judgmental and made a lot of assumptions. It was quite a revelation to realize I had to work through my own prejudice. I was guilty of perpetuating the stigma even though I have a mental illness myself. Since attending group I’m more open, accepting and less willing to isolate myself.”*

One grandmother stated, *“I never really discussed my daughter or her illness with anyone in the past seven years. I always felt it was private and the group helped with that a lot. I understand a lot more because of group.”*

A summary by the qualitative researchers further described, *“Some of the main themes that arose from our interviews with the parents, supports and children’s groups were: the roles of the facilitators, current fragmentation of services in the community, shared experiences and reduction of isolation, the belief in the ability of self to change, a reduction of stigma, connection with other community resources, empowerment and an increased sense of hopefulness in the ability to cope and deal with the effects of parental mental illness.”*

Parent Group Feedback

Parents in the Parenting Groups believed that the groups had many benefits. They believed the primary reasons the groups helped them achieve their parenting goals were:

- the focus was first on parenting instead of “mental illness” (**family focus**) and this reduced the stigma and made it easier for participants to talk openly because they were all there for their kids first
- facilitators used a **strengths-based** approach instead of focusing on deficits and this led parents to experience **a greater sense of empowerment** and hopefulness
- support was evident and congruent throughout their contact with the project (staff were available in group, by phone and for occasional one to one debriefing) so if anyone was having a bad week they had someone to call and get real practical help
- the structure of the groups helped with building connection, establishing a safe & respectful atmosphere and that was conducive to real learning
- the participants gained a significant increase in knowledge of how to help their children cope and the skills to do so, especially through the groups’ emphasis on **promoting effective strategies for parenting, self-care and feelings management** (ie: check in and personal process was encouraged)
- participants felt their concerns and feedback were heard, understood and acted upon by facilitators (**action research component ensured flexibility to meet needs**) and this meant that their concerns mattered and were truly important

- interacting with others facing similar struggles validated their own struggle, as well as reduced their sense of isolation (increased their sense of belonging)

Quotes from the Parent Groups Focus Group included the following:

“My son didn’t understand meds and emotions. With the door that was opened by the program he was able to ask lots of questions and I answered. He now has a lot of knowledge that I could not have got across without this group. He didn’t know what questions to ask...Before he would run and hide whereas now he asks: Mom are you alright? Do you need any help? Is there anything I can do? Things have turned around a lot...My son is not as angry and mad at me for not being there all the time...I think we have a better understanding and communication now. He was very, very lonely before. He really didn’t know how to put himself out there but now (the Project Counsellors) have shown him some tools he can do himself. When I’m in a mood he can re-establish his feelings for himself. He’s just there more, more than he used to be...Since the second or third group he comes home and shares with the other kids (siblings) what he’s learning about mental illness.”

“Through this I’ve learned a lot of things. There are other people out there like myself. From the educational component we learned about growth and development. When you don’t have a mental illness as compared to when you do things are much different. This (group) made me really aware that I can change how I’m doing things and use different ways of coping. I’m now using those skills...I’m learning to have more patience and letting my boys know why I need time out, why I need quiet when I’m sensitive to noise. Before group they didn’t know why I was acting like I was. I didn’t know why I was acting like I was. Everything was just chaos. So now it’s put more into perspective for me. Over the last 12 weeks I’ve been able to see why I’m like the way I am. I can see also why my children are the way they are as well and why they respond to me the way they do. It’s because of my illness, so it’s taught me a lot.”

“I’m agoraphobic, don’t like to leave my house, couldn’t leave my house but I’m here. I’m going out more which is a real tribute to the group because of this commitment I’m forced to go out more: 12 weeks. I’m much calmer than the first day I started here. The first day I was jumping out of my skin. I’m driving now. My dad agreed to go to the Natural Support Group if I went to the Parent Group so that did it.”

Natural Supports Group Feedback

The Natural Supports (kith and kin of the family such as grandparents, friends, spouses and ex-spouses) also reported that their groups were helpful. Their feedback identified the following additional benefits:

- the freedom to talk openly about how their loved one's illness has impacted their life and their concerns for their family provided them with an **increased sense of hopefulness** and healing
- **an increased awareness** of the parent and children's struggles
- **a significant increase in their knowledge and ability** of how they might better help/support the family, particularly during times of relapse
- **an increase in their ability to communicate** with family members
- **an increased knowledge of resources** and systems that allowed them to better advocate for their family's needs

Further quotes from the Natural Support Focus groups interviews included:

“Our relationship is now better than before group...My daughter is now more willing to listen...I think my daughter and I would have come to loggerheads, we were heading in that direction. It was going to be a parting of the ways eventually. I think the group has really helped the process. We're far from giving up.”

“(The Natural Support Group) gave me a better perspective from the person with the illness, the resources available and need for a back up plan (advance planning for child care)...I noticed a huge difference after the second time she (my friend) had been to the (Parent) group. She didn't sound hopeless anymore. She sounded hopeful, optimistic and she was excited...Her actions have started to make more sense to me...I learned what kind of things are stressful for her and she's way better now at recognizing her limitations...The groups have just made helping my friend with mental illness a whole lot easier.”

“Before group I was feeling lost, hopeless...We were hoping to learn more about mental illness, how to help the grandchildren cope. There was an openness in the group. It helps; humour helps; we look forward to getting out, checking in and venting...The best things about it was getting out, meeting with people, laughing, friendship, discussing issues. I enjoyed the course. I didn't think that I would as much as I did. It helped.”

Children and Youth Groups Feedback

The benefits identified by the Youth and Children's Groups were:

- the format of group and connection to peers with similar family experiences or concerns made group safe and fun to attend
- the children found talking about their feelings, the highs and lows of their week initially challenging but later very appealing and comforting
- most felt **a reduction in their fears and stigma about their parent's illness**
- **a significant increase in the children's ability/willingness to ask for help** when they needed to was noted in the research findings

Parents and Natural Supports of the children in group provided facilitators with feedback as well:

- Parents said they witnessed some significant differences in their children including **the increased ability to manage feelings** such as anger; knowing what to do when a parent was not well; and how to “self soothe”. Most also reported their children looked forward to group each week and had increased life skills.

Community Forum Participant Feedback

The BRF Project learned from Community Forum participant feedback that consumers and their families felt:

- the chief barrier to gaining support and strengthening their families is the **lack of understanding and specific support for parenting with a mental illness** that deals directly with the impact of one upon the other (mental illness on parenting and parenting on mental illness)
- **the lack of parental mental health education available** to Natural Supports was a barrier to accessing ongoing support from them
- **the stigma of mental illness reinforces the isolation** of these families
- **the lack of and significant need for better community service integration**

3. Key Lessons and Learning:

Action Research Findings

The project was anchored in an Action Research approach, so that while services were delivered, staff and participants were continuously involved in identifying and documenting their experiences and learning, which was then incorporated both into the program design to improve services, as well as collected for dissemination to interested stakeholders.

Action Research findings were numerous and included:

- a consumer-friendly redesign of the project brochure to generate more referrals and reflect the strength-based focus of the project (ie: pathological terminology used such as mental illness was replaced with mental health challenges)
- increasing networking to promote the project in community
- utilization of media and speaking opportunities to decrease stigma of parental mental illness throughout the duration of project
- modification of referral and group intake process to accommodate client need (ie: Referring Service Provider calling Project Counsellors with referral info so they could make initial contact with client, meet client in community rather than at office for intake and have more one to one sessions if desired by client to increase comfort level and likelihood of client’s participation)

- redesign of the group pre and post tests into more accessible user-friendly terminology
- Continuous modifications to group curriculum resources (“*Supporting Families with Parental Mental Illness Provincial Training Tool Manual*” and “*I Wish You Well, Always: A Workbook for Children of Parents with Mental Illness*”), handouts and methodologies taught were incorporated into group design and structure for each successive group session as well as next group series based on participant feedback determining the usefulness of each session’s resources, educational components and personal relevancy of information
- Revision of weekly educational agenda to fit in pertinent components and simplify material to fit group need/ability to comprehend and assimilate
- Increased weekly focus in all groups on feeling identification and management skills (utilizing Feeling Card tool) to normalize feelings; increase insight into personal process; increase level of group intimacy & support; focus on strengths; encourage meaningful discussion; develop strategies and utilize tools to release stress
- Provision of additional anger management skills training component for all groups and additional child behavior management strategies for adult groups
- Increased focus on self-care/nurturing/soothing and coping skills
- Increased focus on identifying strengths, victories (goal achievement) and weekly goal-setting
- Provision of more practical information ie: community resources, disability forms and budgeting with a limited income
- Provision of additional information on mental health diagnoses, symptoms and treatment (ie: checklist of panic attack symptoms to normalize reactions)
- Provision of a younger children’s group (5-9 year olds) and modification of the project’s curriculum and workbook activities for this group
- Expansion of weekly group session time for parent group to cover material and meet needs for process (from 2 hours to 3- 3 ½ hours)
- Establishment of a reduced group size cap for parenting group to a maximum of 8 participants in order to reduce overwhelming anxiety of group members (this cap was actually never utilized as low number of referrals did not require)
- Encouragement of telephone support/check in of participants with facilitators during stressful times between group sessions
- Provision of debriefing after group to members experiencing high level of stress
- Increased focus on managing stress and boundary work with natural support group to decrease sense of burden and learn how to effectively cope while helping children and parent
- Expansion of time dedicated to grief and loss issues for natural supports group
- Separation of foster parents from natural supports group due to differences in needs
- Provision of one to one, family & telephone support sessions, as well as school and community case conferencing support for parents, children and natural supports including foster parents with children in their care attending group
- Provision of resource information for Adult Offspring contacting project staff

- Organizing and provision of a Community Educational Forum on Supporting Families with Parental Mental Illness to reduce stigma and increase community capacity.

General Project Findings: Client Profile

The typical client family profile accessing services from this project included the following characteristics:

- The family is headed by a Caucasian mother who is a single parent and the primary caregiver of her two children aged between 5 and 12. She sought out services in this project to learn to parent more effectively while at the same time learning to cope with her own mental illness.
- The mother has been diagnosed primarily with Bi Polar Disorder but also has received at least one other diagnosis such as an Anxiety or Personality Disorder.
- The mother does not work outside the home. The family survives on this parent's disability income, living in poverty.
- The mother has one natural support that assisted with childcare during crisis.
- The mother has been hospitalized at least once for psychosis or depression in the past two years.
- The mother is quite high functioning, had a later onset of illness, an above average IQ and some post secondary education.
- The children have some contact with their father, usually weekend visitation.
- The parent and natural support are concerned about the behaviour and psychological impact of the parent's mental illness on at least one child in the family.
- The mother, one of her children and one natural support attended project groups.

4. Unexpected Events

Provincial Forum

BRF Counsellors were invited to attend a Provincial Forum on Evidence Based Practices in Supporting Families with Parental Mental Illness in December 2004. (This was a Five year follow up to a previously held Forum.) BRF Counsellors did a poster session in which almost all 100 attendees were provided with more information on the project. This was a very successful endeavour and generated a tremendous amount of interest in the research this project was to provide.

Speaking Engagements

BRF Project Counsellors were asked to speak in other communities to provide information and education on supporting families with parental mental illness to Service Providers Groups (comprised of staff from Adult Mental Health, Child & Youth Mental Health, Child Welfare/Protection, Family Support Services, Canadian Mental Health Association and other potential collaborators). BRF staff did this in four regional communities, as well as spoke with and shared its research with professionals in several other BC communities.

Community Forum

BRF Counsellors became the primary organizers of a Community Forum for Service Providers and Families to help our community in better Supporting Families with Parental Mental Illness. This was well attended (80 participants) by parents and family members, local Service Providers and a few from other communities on Vancouver Island. The Forum's Keynote Guest Speaker from the Supporting Families with Parental Mental Illness Provincial Working Group provided information on the current research in this area.

The proposed project outcomes that involved increasing the knowledge of community service providers to improve community capacity, collaboration and service delivery integration for this population were greatly enhanced by this Forum (Appendix 2). It has led to a commitment from service providers to attend a follow-up meeting to establish a committee that will develop a strategic plan designed to attain the goals identified at the Forum. These goals were largely informed and paralleled the work done throughout the BRF project. Monies needed to put on this Forum were re-allocated from within the project as noted in the Amendment Report submitted to the CWAC (Appendix 3).

Low Referral Numbers

Referrals to the project were significantly lower than anticipated in the BRF Proposal. Initially, on the recommendation of the BRF Advisory Committee, staff greatly expanded their networking and focus on advertising the project in the community. NFLA constantly sought ways to continue maintaining a high profile of the project, including continuously contacting potential referral sources and re-presenting information on the project. Media opportunities and fund-raising efforts were also utilized. Staff presented information to and later joined the Mental Health Advisory Committee to attend monthly meeting with this group, as well as attending the Adult Mental Health and Addictions Services monthly networking lunch.

When referrals remained low, BRF Staff attempted to identify the reasons for this by asking potential referral sources and families. The staff in the project were led to believe that the lower than anticipated numbers of referrals to the project were impacted by its "short term" project status versus an ongoing established program; the insular and

“confidential” nature of the Adult Mental Health system; fear from negative past experiences of families with the system or stigma; and in some cases a lack of parental readiness to engage in this type of service. Families suggested that Service Providers may have been hesitant to inform and refer families to this service due to the stigma or lack of awareness of the family’s needs.

Group and Service Provision Modifications

For the second series of groups there was not sufficient enrollment of Natural Supports to warrant a group. As a result, Counsellors provided **more individualized services** to willing Natural Supports of families who were attending the other groups as well as other family members. This also proved beneficial as all reported feeling helped and supported.

In the third and final series of groups there was not enough parents with mental health issues signed up for the proposed group. At the request of some parents who had attended one of the other series, the curriculum was expanded and a **“Phase Two” Parenting Group** was offered. This was well-attended and involved connecting parents directly with other services in the community by bringing in Guest Speakers as well as holding groups at other program sites.

Since the end of the final intake period for groups, six more families have connected with BRF Counsellors for support. Several calls have also been made by local professionals who stated they believed there was **an ongoing need for this service** and were very disappointed to learn that continued funding was unavailable.

5. Conclusions

Sustainability of the Project

Feedback and data collected from the local Forum suggested a great deal of concern about losing the momentum of interest in this area generated from the Forum and the Building Resilient Families project. As an example of the commitment to the Action Research component of the project, a community follow-up plan was developed. **The Forum planning committee agreed to host a meeting in September to explore strategic planning around Supporting Families with Parental Mental Illness in our community for the coming year.**

Another legacy of the project has been the **establishment of an independently run ongoing Parent Support Group**. This group is being run by six members of the Phase Two parent group. These mothers felt the support they experienced in group was very valuable. They wanted this ongoing group opportunity to maintain gains achieved in increasing their family’s resiliency and their own sense of wellness.

Target Population that Most Benefited

Staff concluded from their experiences in the project that Mothers with Bi Polar illness and their families benefited most from group attendance. Their needs for complicated advance planning were minimal as most had psychotic symptoms of their illness under control and rarely required hospitalization to re-stabilize their health at this point in their lives.

Staff Observations and Conclusions

BRF Counsellors believe the success of any program for this population is dependent to a large degree on incorporating the elements largely identified by the parents' groups. Best practices involved **utilizing a strength-based and family focused approach** that embodies respect for the parent and their family. All groups emphasized and encouraged expression of feelings and the sharing of each member's personal process. This sharing was a first for almost everyone involved in the BRF groups. Many parents and natural supports noted how different and valuable this single element in the group format was when compared to Mental Health and other groups they had attended.

Staff learned from project participants that **best practices acknowledge the internal resources these families possess; focus on building hopefulness, parental empowerment, mental health knowledge; and emphasize the promotion of skill-building, specifically in the areas of developing effective strategies for self-care, feelings management and parenting.**

Staff also learned that participants needed to know their concerns and feedback were heard, understood and acted upon by facilitators. The **action research component of this project ensured flexibility** to meet these needs and would benefit any future programming efforts.

Feedback from the group also indicated the necessity of holding each series of groups in a closed homogenous structure to encourage intimacy and enhance the learning of participants in a safe environment. Family members also anecdotally reported that children and youth quickly built trust in the facilitators as all groups benefited by having the same two counselors facilitate all of the groups. Staff had wondered if it would have been better to have all groups running at the same time each week with other counselors facilitating each group but participants thought this would have more disadvantages without the connection of facilitators between all the groups.

Staff noted that the research suggested that some children's fear of parental mental illness may not have been significantly alleviated through their participation in group (77% showed a slight decrease in fear). This was incongruent with the BRF Counsellors' experience of the children's groups and feedback from adults in the family. Staff wondered if perhaps the children experienced their fear as a normal healthy response to their parent's illness that altered their own stress level. The research question did not take into account that children may have become more capable of using inner resources such

as courage to combat its impact. BRF Counsellors were reminded that resilience is developed through exposure to risk rather than avoidance of stressful life events. “Courage is resistance to fear, mastery of fear- not the absence of fear.”

In hindsight, staff thought that the Community Forum should have been held closer to the beginning of the project start as it would likely have been more beneficial in several ways, such as quickly raising the awareness & interest in the community about the project, generating more referrals, working to immediately reduce stigma, decrease isolation and possibly attracting ongoing funding.

Lastly, project staff believe the benefit of reducing these families’ sense of isolation by attending group and **interacting with others facing similar struggles was invaluable** for the participants. Best practices incorporate a respect for the unique needs and ongoing struggles of each of these family members and encourage their healthy risk-taking to increase their sense of belonging. The sense of connection to and caring of community will ultimately build everyone’s resiliency in the face of most challenging mental health issues.

Appendix 1

July 5th, 2005

"Dear _____

Please find attached to this e-mail the Summary of Information collected at the local Supporting Families with Parental Mental Illness (SFWPMI) Forum held April 29, 2005. Due to the overwhelming interest and value of the small group feedback, we are sending the results of the Forum to all attendees and stakeholders in the community.

In order to ensure we do not lose the momentum of planning to better support these families, we are inviting **all interested community members to attend a meeting on Tuesday, September 20th, 2005 at 1 - 3pm.** The SMWPMI Forum Planning Committee will host this meeting **at the Health Unit - 1665 Grant Ave.** We hope to establish a committee at that meeting that will develop a strategic plan designed to attain the goals identified at the Forum. This committee would then meet to further develop the planning and implementation processes that would be announced during Mental Health Awareness Week in May 2006."

The Planning Committee
Supporting Families with Parental Mental Illness
Forum

Lisa Clarke and
Jo Ann Shillington
Building Resilient Families Project
Nanaimo Family Life Association
1070 Townsite Road
Nanaimo, B.C. V9S 1M6
250-754-3331

Christina Martens
Executive Director
Mid Island Branch
Canadian Mental Health
Association
1045A Terminal Ave
Nanaimo, B.C.
250-716-8823

Patrick Konkin
Program Coordinator
Ministry of Children and Family Development
Child and Youth Mental Health Services
#201 - 488 Albert St.
Nanaimo, B.C.
V9R 2V7
741-3600; 741-3648(fax)
Patrick.Konkin@gov.bc.ca

**Supporting Families with
Parental Mental Illness
Forum**

April 29th, 2005

**Collated Summaries of
Small Group Brainstorm and Discussion Session
and
Participant Evaluations**

Forum Planning Committee:

**Patrick Konkin, Team Leader, Child & Youth Mental Health, MCFD
Christina Martens, Executive Director, Canadian Mental Health Assoc.
Jo Ann Shillington & Lisa Clarke, Child, Youth & Family Counsellors,
Building Resilient Families Project, Nanaimo Family Life Assoc.**

Summary Notes:

During the afternoon at the Supporting Families with Parental Mental Illness Forum, 80 participants were divided into ten small groups for a brainstorming and discussion activity. Organizers tried to ensure that each group had a balance of family members and service providers. The groups were all asked to brainstorm four two part questions. These questions were designed to build awareness of the issues faced by these family members and identify what could be done/how service providers might better support these families. Several themes emerged on what participants felt was needed in our community.

Every group noted the increased need for communication and collaboration between professionals, as well as between professionals and family members. The concerns repeatedly heard throughout the day's discussions were that the family often experienced or perceived a lack of understanding, ongoing stigmatizing and absence of a collaborative "will" by service providers. The feedback also identified that almost every family member wanted the community of service providers to work from a family focused, strength-based approach to better support the needs of everyone.

The need for more community awareness of mental health and parenting issues faced by this population was also stressed in the feedback. Family members noted the need for ongoing education, information and various kinds of support for the parents, children, extended family and natural supports. A preference for educational, psycho-social support groups such as those offered through the pilot project, Building Resilient Families was also noted. In-home supports such as Family Counseling services, Respite care and Integrated Case Management involving all professional and natural supports was also desired.

One in four Forum evaluations was filled out and returned to organizers. The vast majority of evaluators also requested that the collated summary of the small group sessions be sent to them. Several groups reported that they were unable to get through all the small group questions in the time allotted or rushed through the last few. Participants expressed a lot of positive feedback and enthusiasm for this event but many also expressed concern that the needs identified at the Forum may not be addressed or steps to address these might not be implemented in our community.

Evaluations and documentation from small groups identified that participants were in solid support for another Forum to be held to develop more awareness and begin to work on a community implementation plan. Several also suggested mandatory professional training on working collaboratively should be implemented and a co-ordinator should be hired to improve service accessibility and collaboration in our community.

On a final note, the overwhelming impact of poverty on these families was reported by every small group. Without appropriate resources, the stress and risk factors are very high for the children of and parents living with mental illness: participants strongly recommended that preventative measures (programs and resources) be funded to build resiliency.

Small Group Brainstorm and Discussion- Collated Results

1. a) What is the impact of mental illness on parenting?

- A range of symptoms may be experienced depending on the degree of mental illness a parent experiences
- Effective parenting ability is diminished at times due to increased stress, anxiety, depression as well as the unpredictability of symptoms and their impact
- Parenting role is eclipsed by the illness: parent's focus is often on the illness rather than family especially during hospitalization
- Parents are not able to be a stabilizing influence and positive role model for children at times and may experience loss of control when others take over duties
- Parent may lack coping & life skills, self awareness and find recovery (learning to live with mental illness) difficult
- Parents may have difficulty with:
 - openly communicating/guiding children
 - helping children to understand/explaining illness to children
 - children becoming parentified care-givers for the parent and siblings (role reversal)
 - isolation, stigma and relationship breakdown (strain of single parenting)
 - ability to connect with others (ie: in regular/generic parent groups)
 - interactions with and getting support from spouse, extended family, friends
 - negotiating through conflict especially around divided loyalty issues
 - keeping sense of humour and building/teaching resiliency to children
 - substance abuse (trying to self medicate to solve problems)
 - violence, verbal abuse
- Parent may experience an overwhelming sense of guilt, incompetence and feel unable to balance the demands of child-raising or compensate in helpful ways
- Parents often fear sharing information with others or in asking for support because of perceived repercussions (ie: stigma, child protection fears)
- Parents may not know what support is available, be afraid to ask and lack important knowledge of healthy child-rearing practices
 - Parents often experience inability to work and financial constraints/ poverty including difficulties providing adequate housing, child care, education, extra curricular activities for children and self

- Entire family may experience ongoing grief, loss and anger over impact

b) What supports are needed for parents living with mental illness?

- Family centered, strength-based approach from all supports
- Network of informal supports (family and friends) that were available before illness
- A range of formal supports including:
 - Individual and Family Counseling-specific Parent and Children's Groups focused on mental health issues and education ie: child developmental stages, information on ways of encouraging attachment
 - ongoing professionally-facilitated, peer-based Support Groups for parents with mental illness
 - Parent/Family Support Workers who visit in home and provide community programs
 - knowledgeable physician, psychiatrist, healthcare/medical staff who are sensitive and responsive to the needs of patients with mental illness for more time, understanding and respect (less stigmatizing)
 - Mental Health Outreach Service Workers
 - Clinical support and education around medication (ie: bubblepacks, completion of disability forms & Rx forms to cover costs of meds)
 - Practical, dependable Support Workers for help with daily living skills (ie: keeping appointments, maintaining order, developing assertiveness, using positive discipline strategies)
 - unique, versatile Respite and Child Care Resources to meet the individual family's needs
 - School Counsellors who can interface with school system (ie: help teachers recognize child cannot always be sent home for disruptive behaviour as it causes further problems)
 - Mentors, Legal Helpers and Advocates to help parent navigate through systems and build bridges to other supports (formal & informal)
 - Financial Advisor to help with banking, budget and tax preparation
- Professionals to use understandable language "plain speak" and not assume literacy
- Financial resources to address needs for affordable child care, respite care, safe, adequate housing, recreation & extra curricular activities for all family members (ie: special summer camps)
- Food banks and Grocery stores that provide delivery
- A community
- Increased community awareness/education about mental health issues
- Mental Health Education and Sensitivity Training of Financial Assistance Workers
- Parents often need help in educating their spouses, extended family members and friends about mental illness and the special challenges parenting with a mental illness presents to them (ie: Parents need Professionals to take the time to build relationship with their supports)

- Specific pre-natal program for people with mental health issues

2. a) What is the impact of mental health, child welfare and other governmental systems on parents with mental health challenges?

- Often these systems create a negative impact and once involved with a family they create more divisiveness/defensive stance by family members
- Parents fear child protection apprehension/removal so don't go for help/support, don't fully disclose their situation/needs or wait until crisis to reach out (Apprehension can increase trauma experienced through illness)
- Parents find workers sometimes have pre-conceived judgmental stigmatic attitudes (ie: don't understand real client needs or (dis)abilities and may view parent as "the problem")
- Family may feel disempowered by systems: System is unresponsive and discouraging at times when help is sought in a proactive manner by a parent/family (dealing with gate-keeping function/mandate barriers can create "burn out" for parent and their natural supports)
- Systems can be inflexible and unwilling to meet client needs (ie: for home visits instead of "sterile" office settings)
- Services and agencies are inundated/overloaded with requests and limited resources so these parents & children often fall through the cracks (gaps) or endure unreasonable waitlists that put them at further disadvantage
- Services are often fragmented, lacking flexibility (program criteria too rigid), constantly changing and it's difficult for family members to navigate the maze of systems and services or understand the parameters & limitations of each service (ie: what they can't provide, who can fill that need or where services overlap)
- Frequently there are communication barriers between services and providers that add to problems in the family (ie: confidentiality creates a barrier to collaboration even when it's in the family's best interests)
- Services can be in competition for funding so not refer or work collaboratively with other agencies, provide information or build bridges
- Authority creates barriers
- Involvement with systems can bring a "breakthrough" for family when support need is viewed as "normal", empowering, expectation of support is met and positive changes occur within family and family relationships

2. b) What supports are needed for their children?

- Improved co-ordination of services so all needed ones are accessible and provide family-focused, strength-based support (ie: hire or appoint a Community Co-ordinator)

- A relationship with a healthy adult to encourage attachment and foster connection (ie: healthy involved adult family and friends)
- Safe place to talk about what's going on- openness, education & support (Children need repeated invitations to talk and people to listen attentively and responsively to what these children know they need)
- Individual, Group and Family Counselling
- Both natural, peer and professional support groups (ie: like BRF)
- Prevention education (instead of just “intervention for acting out” kids)
- Age appropriate information and education on mental illness (ie: not their fault, how it effects parent)
- Age and issue specific skills training (ie: stress, anger management and grief education)
- Parenting safety net/Child care safety plan or Action Plan with contingency plans if family fail to act asap
- Children need basic needs met during parental mental illness relapse
- Permission to ask for help when needed (ie: with teachers/counselors at school)
- Access to information via school system to prevent stigma/stereo-typing (ie: More teaching and talking in elementary school about mental health concerns and awareness of issues to normalize like diabetes, development of Buddy system)
- Normalizing of situation (ie: hospitalization) and “Family friendly” hospital setting for family visits
- Ways to keep children in the home and out of system/foster care such as Nurse/Social Worker/Family Support Worker providing in home and outreach services
- Various types of respite care- appropriate, least disruptive- including access to and financial resources for safe child-minding, nurturing day care, pre-school programs
- Recreational programs & activities that provide positive experiences and take stress off parent & family (ie: camps and more community supports)

3. a. How would you improve collaboration /co-ordination of services?

- **Establish a team, then address confidentiality, standards and trust**
- **Get permission to exchange and share information/ideas, communicate with everyone who needs to be involved in supporting the family, then communicate!**
- **put the client first**
- **all team members need to come from Family focus strength-based approach**
- **establish a team right away at onset of parent's mental illness**
- **hold regular Integrated Case Management, case conferences, integrated case management and joint collaborative team meetings – CYMH and Adult MH and Addictions, and MCFD (get and give regular updates, make regular opportunities for networking)**

- empower a coordinator/case manager for collaborative services (encourage clients to case manage: client needs to be involved in partnership)
- develop common goal setting plans (goals common across services)
- practice role plays on teamwork and collaboration
- professionals need to educate themselves or be taught how to do collaboration/involvement with family and professionals
- stop making assumptions about level of empowerment of parent (can be compromised by mental illness)
- provide training for family
- family priorities need to come first – will need to learn how to determine those
- provide families with services directory / map / service providers info (like in the phone book) including when, where, what, and why
- professionals are becoming specialized so people can only get help on certain issues (ie: Mental Health workers don't work on parenting concerns)
- holding more of these forums- forums are good
- provide support at home
- funding for home and children
- support groups and non-profits really needed
- team involvement in advance planning for when parent ill
- use school counselors and natural resources
- do more research, speak out for more resources and involve politicians

3. b. What would you like to see our community do to better support these families?

- provide family focused strength based approach, early interventions and supports
- collaborate, advocate, clarify roles of service providers
- foster collaborative relationships
- discourage agencies from “bunkerism”
- educate people about what's available in community
- hold focus groups- ongoing, regularly and incorporate consumers in boards and Community Planning committees
- provide community education about mental illness, programs and availability
- build public awareness- public campaign i.e. AA
- educate kids at school forums (start at young age to decrease stigma)
- teach people how to advocate (family members, friends, community)
- develop family center – combo paid and trained volunteer core to provide outreach and central support for families
- hold Pro-D days where MH professionals get updated and have to take refresher courses
- educate foster parents and employment assistance workers about mental illness and its impact
- provide supports before needed (ie: prior to looking for employment)
- provide more resources, services (ie: subsidized housing for families with p.m.i.)

- **funding assisted transportation, respite – childcare, extra \$ for day clubs, camps**
- **take pressure off very young moms**
- **provide in home parent support**
- **support children to develop natural activities – friends, join clubs, teams**
- **offer support groups for children**
- **ongoing programs like BRF and others like it i.e. BCSS's Family to Family**
- **advocate for foster care / respite when needed**

4. a. What would you do to foster collaborative relationships between families and professionals?

- **educate professionals about collaboration as part of their training**
- **learn about family**
- **build professional awareness of client's needs for social interaction**
- **get decision makers involved, teach mutual respect and decrease stigma**
- **talk about positive aspects of professional involvement (family service program)**
- **address fear and support for all as soon as possible and help people find a role**
- **teach people to be better parents**
- **keep open mind instead of making judgment –accept people where they are at**
- **help family develop understanding of family system- their own mobile**
- **be clear about confidentiality**
- **check with family and encourage them to invite others of their choice (be aware of power differential between system and family)**
- **have family members meeting and get family on board- sharing info**
- **facilitate collaboration with family and natural supports**
- **empower family to make their own choices (give as much power to family in decision making)**
- **bring people together both socially and professionally on ongoing basis**
- **lay people and health care providers working together (not us and them mentality), have group meetings and build in some fun**
- **have outreach workers check in periodically, make, maintain connections**
- **collaboration between professionals**
- **trust roles of each individual**
- **remove fear of removal**
- **have forums for support; workshops and integrated team work**
- **provide emergency education for mental health workers**
- **provide transportation**

4. b How could you respectfully invite, include and involve families and natural supports into collaborative case management?

- **ask what family wants- respectfully invite – just ask**

- client wants to be asked and establish who is there (confidentiality)
 - be inclusive and respectful- be in partnership with- don't rush through a timeline or come with a second/hidden agenda
 - understand sometimes families are not ready to accept available supports at time offered so work with flexibility week to week
 - form/re-establish relationships between families and natural supports
 - teach assertiveness, build trust and positive relationships with all involved
 - educate family members about collaborative case management (invites should be part of the advance plan)
 - respect families are the experts on themselves
 - establish coordinator/case manager who is visible in the community and can support the above, perhaps a family support worker
 - use support groups, advocate being part of a team and build in some fun
-

Forum Participant Evaluations- Collated Results

1. How was this Forum helpful to you? Please be as specific as possible.

- Helped build my awareness of services, understand what's out available and how services can collaborate/work together (13 responses)
- Opportunity to network (8 responses)
- All of the information/education provided- increased my knowledge (7 responses)
- Realized importance of providing Family Support (5 responses)
- Increased awareness of needs of families with parental mental illness (5 responses)
- Group discussions very informative (2 responses)
- Discussion of research, resiliency factors, strength-based approach was helpful (2 responses)
- Speakers provided important insights (1 response)
- Discussing barriers very helpful

2. If you were presenting this Forum, what would you do differently?

- Nothing different (5 responses)
- Make more time for brainstorming, discussion groups (5 responses)
-specific suggestions inc. longer day, extra day, fewer topics/questions
- No response to question (5)
- Include more family perspective/testimonials (ie: from a youth) (2 responses)
- Have participants wear nametags with agency name on them (1 response)
- Increase time and depth in describing pilot project & its research (1)
- Provide handouts from Guest Speakers (1)

- **Remind people that they need to pay for parking at venue (1)**

3. Do you have any suggestions for future Forums or other activities to follow up this Forum?

- **No response to question (3)**
- **Include more time for group work with nonjudgmental recorders to empower all participants (3 responses)**
- **Hold a huge interagency/community/public Forum, including politicians, school personnel to educate, reduce stigma, support families and implement true collaborative practices of team working on common goals (2 responses)**
- **Include consumers on provincial standing committee (1)**
- **More consumer input on a committee or another Forum (1)**
- **Train service providers to build specific skills- how to teach families coping strategies (1 response)**
- **Have more Adult Mental Health representation (1 response)**
- **Plan for new funding (CYMH, Adult MH should fund & develop) (1)**
- **Grow & develop major themes gathered at this Forum (1)**
- **Offer more info on research with adult offspring (grown children) (1)**
- **Open floor for half hour rather than group work (1)**
- **Offer ongoing parenting and children's groups (1)**

4. Would you be interested in having the collated small group information from the Forum sent to you?

- **Received 20 written requests for collated information.**

Collated by:

**Lisa Clarke and Jo Ann Shillington
Building Resilient Families Project- 2005
Nanaimo Family Life Association
1070 Townsite Road
Nanaimo, B.C. V9S 1M6
Tel: 250-754-3331 Fax: 250-754-0268**

The Forum Planning Committee will host a meeting on Supporting Families with Parental Mental Illness in the Fall of 2005. We hope to address the needs identified at the Forum and continue determining our direction in developing a collaborative, sustainable support plan to be implemented in our community. All interested community members are invited to attend this meeting. Please contact Lisa Clarke at Nanaimo Family Life for more information.