An Environmental Scan:

Peer Support for Youth

with Mental Health Problems and Their Families

CANADIAN MENTAL
HEALTH ASSOCIATION

ASSOCIATION CANADIENNE
POUR LA SANTÉ MENTALE
BC DIVISION

Strengthening Family and Youth Voices Project

CMHA BC Division exists to promote the mental health of British Columbians and support people with mental illness. We do this through public education, direct services, community-based research and public policy work, as well as the support we provide to the 20 CMHA branches throughout BC.

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1 Introduction

This environmental scan was undertaken in partnership with the Canadian Mental Health Association BC Division's Strengthening Family and Youth Voices Project (Voices), the FORCE Society for Kids' Mental Health, and Kinex Youth Initiative, a program of the Self Help Resource Association of BC.

The project was sponsored by the Canadian Mental Health Association (CMHA), BC Division and funded by the Public Health Agency of Canada. CMHA is a national, non-profit, voluntary organization whose mission is to promote the mental health of all Canadians. CMHA BC Division carries out its mission through education, research, community development and advocacy. One of CMHA's core objectives is to promote and create innovative programs, which contribute to the recovery and community integration of persons with a mental illness.

The project goals were:

- To promote the participation in decision-making of families and youth who use child and youth mental health services
- To increase peer support networks across five pilot sites

Additionally, the project steering committee wished the pilot sites to learn from each other the best ways of facilitating peer support and to share that wisdom through documents such as this, as well as through a forum that was held at Simon Fraser University on February 9th, 2007.

The project took place from February 2005 to March 2007. It featured activities at the provincial level as well as community activities carried out by sponsoring agencies in five British Columbia communities:

- CMHA Kootenays Branch in Cranbrook
- The Child Development Centre in Kitimat
- Maple Ridge Community Services Society in Maple Ridge
- CMHA Cowichan Valley Branch in Duncan
- CMHA North and West Vancouver Branch in North Vancouver.

During the period of the pilot project, each of the sites was able to develop youth peer support activities and two of the sites were also able to develop family support groups.

Purpose of the Scan

Over the past few years, considerable momentum has been made in British Columbia regarding the development of peer support projects for youth with mental health challenges and their families. This scan intends to:

- Provide a baseline of peer support/mutual aid activities to be used as a tool in our joint and individual work to ensure that this momentum is not lost
- Gain an understanding of the barriers and opportunities that are relevant to family and youth peer support/mutual aid activities
- To determine the key provincial stakeholders and their respective roles in this area

What is Peer Support?

When the youth in the Voices project got together the day before the Voices forum, peer support seemed pretty straight forward: youth helping youth and parents helping parents.

The Self Help Resource Association in BC offers 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.*[1]

The main difference between self-help and peer support groups as articulated by the Association 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 peer support group. Like the self-help group, a support group connects people with common concerns but membership is usually more restricted and time limited. The groups that were formed in the Voices project according to these distinctions were peer support groups.

Peer support may be actualized through a variety of informal and formal strategies. Researchers describe three broad categories of peer-delivered interventions: self-help or peer support groups, participation in peer-run programs and the use of peers as providers of services and supports.[2]

❷ Why is Peer Support Important?

The evidence for peer support comes from the published literature, the children's rights movement and from the youth in the Voices Project.

Evidence from the Published Literature

After years of listening to consumers speak about how self-help groups have helped them, professionals have also recognized the effectiveness of self-help groups. In a landmark report on mental health issued by the US Surgeon General, the evidence for peer support was summarized this way:

> *As the number and variety of self-help groups has grown, so too has social science research on their benefit. In general, participation in self-help groups has been found to lessen feelings of isolation, increase practical knowledge, and sustain coping efforts. Similarly, for people with schizophrenia or other mental illnesses, participation in self-help groups increases knowledge and enhances coping. Various orientations include replacing self-defeating thoughts and actions with wellness-promoting activities, improved vocational involvement, social support and shared problem solving. Such orientations are thought to contribute greatly to increased coping, empowerment, and realistic hope for the future.*[3]

The 2006 report of the Standing Senate Committee on Social Affairs, Science and Technology, *Out of the Shadows at Last: Transforming Mental Health, Menatl Illness and Addiction Services in Canad*a, identifies the importance of shifting the orientation of the system from one centred around service providers to one centred around patients. Key to this is the adoption of a recovery value to mental health supports and services. The report identifies the value of peer support organizations in bringing hope and recovery to people living with a mental illness and their families.[4] The report acknowledges that this is a new area of research and findings are still emerging.

"Individuals receiving peer support at 18 months experienced fewer hospitalizations and fewer visits to the emergency rooms than a control group of non-members"

A recent evaluation report on peer support with families as part of the Community Mental Health Evaluation Initiative from the Centre on Addiction and Mental Health in Ontario identified that individuals receiving peer support at 18 months experienced fewer hospitalizations and fewer visits to the emergency rooms than a control group of non-members. The authors note that systems managers don't give self-help/peer support the recognition it deserves as a vehicle towards achieving recovery-centred mental health. [5]

Administrators, clinicians, youth and families are beginning to understand that to achieve recovery, youth must be involved in their own health care and services must be welcoming. Although the Voices projects found peer support first and then moved to community engagement, in Vancouver Coastal Health Authority, the Youth Mental Health Program found peer support emerging from youth and family engagement. The health authority wished to revitalize its services and engaged a group of youth to help comment on key elements of the transformation. The system managers partnered with Kinex Self Help Youth Exchange to brainstorm with youth ways to make mental health services more accessible and more effective for youth.[6] Peer Support groups were at the top of youth's list and are now being implemented. Additionally, the systems leaders are developing methods to reach out to youth and engage in dialogue about youth mental health issues. For example, the youth have developed a play called *Mirror, Mirror* which is about youth depression and suicide and it is currently touring various high schools throughout the health region.

Evidence from the Children's Rights Movement

Some think that peer support is not just a mode of health care treatment but is a fundamental right for children. In 1991, the Government of Canada ratified the United Nations Convention on the Rights of the Child (UNCRC). The UNCRC affirms children's entitlement to fundamental human rights, including development, protection, participation and non-discrimination, and recognizes children's need for special care

and assistance in realizing these rights. The UNCRC states that:

- Families and communities are the natural environment for the development and well-being of children
- Parents have primary responsibility for the nurturing of children

■ The role of governments and communities is to support children and their families.

In 1996, the Government of British Columbia incorporated many of the UNCRC principles in Section 70 of their new child welfare legislation the Child, Family and Community Services Act (CF&CS Act). Section 70 of the Act) stipulates that children and youth in care must be informed of their rights and entitlements, in a manner that reflects their developmental level and assisted in addressing and resolving problems that arise when their rights are violated. It becomes the responsibility of the 'state as parent' to fulfill this role.

The Office of Children and Youth in BC has been exploring a strategy to operationalize ways to inform youth of their rights. See, for example, the review of Rights 2 Success implementation conducted in 2006 in British Columbia. [7]

Although not consciously driven by this legislation, two of the Voices groups explored the concept of rights and entitlements in light of current laws. As so many youth had experienced discrimination at the start of their illness, it was significant for them to get support to overcome this shaming and get on with their lives. It is likely for many of the province's most vulnerable youth; peer support is a first step towards being able to participate in a community workshop such as Rights 2 Success.

Research indicates that when children and youth are involved in their plans of care and decision-making that affects them, they are more motivated to

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achieve successful outcomes for themselves and their families.[8] They are more committed to the decisions and more likely to engage in services that are being offered. This concept of meaningful participation in decision-making was one of the two overarching goals of the Voices project.

Resiliency research identifies 'participation' as a protective factor that contributes to a young person's sense of competency, agency and belonging, which makes them less prone to depression and hopelessness.[9–13]

Within the field of children's rights, officials would argue that the UNCRC exists as a fundamental call to improve the health outcomes of youth by taking a more rights-based approach and encouraging and facilitating participation in care. The American reform of their youth mental health system situates youth empowerment and positive youth development at the centre of their systems of care projects. See, for example, the discussions on Youth Group Development's Youth Motivating Others through Voices of Experience (Youth MOVE) project website at www.tapartnership.org/youth/YouthMOVE.asp.

The BC Child and Youth Mental Health Plan identifies building community capacity as a target for 25% of the regional mental health budget but doesn't explicitly link building peer support as the vehicle to achieve this in quite the same way that is done in the American systems of care projects.

3 How Does Peer Support Fit within the Children's Mental Health Reform Process?

In the recent Senate Committee Report on mental health and mental illness in Canada, mental health was described as the orphan of the health care system, reflecting its lack of funding relative to other physical illnesses and conditions. To situate the work of this project even further, the Senate Committee called children's mental health the "orphan of the orphan," implying that while adult mental health services are poorly resourced, children's services are even more scantily resourced.[15] In this context, it is perhaps tempting to call peer support the orphan of the orphan's orphan—as it has been even more poorly resourced relative to clinical services.

The British Columbia Ministry of Children and Family Development stands out in Canada for its support of parental peer support via funding for the FORCE Society for Kids' Mental Health (FORCE) in the Child and Youth Mental Health plan but as other jurisdictions have indicated, though policy support and research evidence for family involvement in mental health services has been strong, implementation is a challenge.[16] The US literature on parent involvement in children's mental health care demonstrates an increase of self-steem among parents who are meaningfully involved in their children's care, better health outcomes for children and less reliance on institutional care as an option.[17]

Nationally, the hub of the family movement in the United States rests in the Federation of Families for Children's Mental Health (Federation), a 120-chapter organization with members nationwide. The Federation has provided leadership in promoting a "family-driven, youth guided" perspective on how best to improve services and outcomes. These approaches have been implemented and evaluated in over 29 demonstration sites with 52,000 youth. The findings from these studies are strong. Family-driven, youth-guided care reduces institutional placement, decreases hospitalizations and strengthens youth engagement in school and other activities of life.[18]

Having achieved these results, however, the Federation still reports in a recent environmental scan that implementing family involvement continues to be a challenge due to a variety of factors including the demands of parenting a child with mental health challenges.[19]

At the start of the Voices project, the senior staff, representatives from the FORCE, and the chair of the project steering committee traveled to Portland State University's Research and Training Centre on Family Support and Children's Mental Health to visit with researchers and practitioners and learn from their work implementing a family- and youth-centred approach.

The Research and Training Center was established in 1984 with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), US Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, and US Department of Health and Human Services. The Center is dedicated to promoting effective community-based, culturally competent, family-centered services for families and their children who are, or may be affected by mental, emotional or behavioural disorders. Barbara Freisen and Janet Walker also visited the Voices project and conducted workshops on family-centred care for the project staff and Ministry Regional Transition Managers. There was a lively discussion of family involvement at these sessions as individuals worked to understand what family- and youth-centred involvement really means.

In British Columbia, a research base for the evidence to support family involvement has been slow to evolve. The Children's Mental Health Policy Unit who has to date provided strong evidenced-based reviews of clinical procedures to the Ministry of Children and Family Development's Mental Health Plan has as of yet not included a research focus on family or youth engagement or peer support.[20]

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4 Method of this Scan

A team of researchers carried out this scan: Elise Kipps and Romi Chandra from Kinex Youth Exchange, Keli Anderson from the FORCE Society and Nancy Hall, an independent consultant. Research activities included:

Identifying Regional Work

Jean Moore, Chair of the Voices project steering committee sent letters to all Health Authority CEOs, school superintendents and Ministry of Children and Family Development regional executive directors inquiring about peer support activities in their region for youth with mental health challenges and their families. Nancy Hall collated the responses provided to the Canadian Mental Health Association BC Division. A copy of the letter is included in Appendix A.

Interviewing Stakeholders on Youth and Family Peer Support

Researchers from the FORCE and Kinex phoned a minimum of five individuals in key positions within each of the five geographic regions of the child and youth mental health system to inquire about peer support activities for youth with mental health challenges and for their families.

Examining the Research

Nancy Hall performed a scan of published literature and 'grey literature' on peer support for youth with mental health challenges and their families in Canada.

The work was carried out between January and March 2007. In addition to the above listed researchers, Catharine Hume from CMHA BC Division and Brian Copley, a consultant working with the Ministry of Children and Family Development, provided input and discussion on planning the project and carrying out the analyses. Nancy Hall facilitated a summary meeting with the research team, then wrote the final document.

5 Findings

The findings of the environmental scan are first discussed according to their source: identifying regional work, interviewing stakeholders on youth peer support and on parent peer support.

Regional Review

The Chair of the Voices project steering committee, Jean Moore, sent letters to all of the health authority CEOs, school superintendents and regional executive directors of the Ministry of Children and Family Development, inquiring about peer support activities for youth with mental health challenges and their families. Overall, three health authorities, one Regional Executive Director and twelve school districts replied. This is not a representative sample that would allow statistical calculations, but it did fulfill our goal—to get a flavor of what is going on. We apologize in advance if we have inadvertently left someone or some program out. Our aim was to provide a snapshot within a discrete period of time.

The responses from the school districts indicate that teachers value the role of peer support and, indeed, most high schools in the province have a peer counselling program for one-on-one support to youth who seek help. A number of psycho-educational programs are described, such as the PARTY program which focuses on taking a class to a local trauma room to see first hand the impact of impaired driving, and the ACE program which is an industry training program for high school students and may involve a number of specific initiatives that utilize youth helping youth.

The McCreary Society was also identified as doing peer support work. Upon investigation though, the McCreary Society staff go into communities to work with the results of their youth health survey. The overlap is significant, however, as youth in these surveys have consistently identified mental health issues among the top youth health needs to address. There is clearly an opportunity to work with youth mobilized by the McCreary Society staff to create a youth self-help group.

Some school districts employ peer support for a variety of mental health issues. For example, School District 33 in Chilliwack offers a group for parents with anxious kids, Parenting Practically (for dealing with behaviours resulting from a mental illness), a group for resiliency for kids, Kids In Control (for kids of parents with mental illness), and GUESS (for teen girls feeling stressed). However, the degree to which youth and parents determine the agenda of these groups, or if there is time for mutual aid outside of a fixed educational agenda, is not known.

Some school districts cited the Friends program as an example of peer support, which it is to some extent. Friends is a mental health promotion program imported from Australia where it has been proven to improve coping with anxiety by teaching kids about mood, feelings and friends. However, designed as a preventive program, the target group for Friends is kids who don't yet have mental health challenges. It may well be that as the Friends program deepens its implementation, and there is less stigma associated with seeking help, more youth may be diagnosed with mental health challenges and more school settings may wish to develop support groups such as those currently being offered in Maple Ridge. There is clearly an opportunity to increase connections with the school system to provide peer support to address issues that may arise out of the Friends implementation.

Some health authorities employ peer support and youth engagement strategies extensively. For example, Vancouver Coastal partnered with Kinex to engage youth in making youth mental health services more youth friendly. This dialogue resulted in a number of changes including the establishment of peer support groups, hiring of youth counsellors and producing a play about suicide to facilitate dialogue among high school students by high school students. Northern Health has a Youth Outreach Team that employs youth counselors for youth mental health issues. The Early Intervention Program (EPI) in Fraser Health Authority uses peer support groups for both parents and youth experiencing their first psychotic episode. Unfortunately, peer support as part of the EPI program is not routine—although the official EPI care map would include, as policy peer, support as part of an EPI Program. [21]

The responses indicate that while there are some great local examples in a few settings, there are a limited number of province-wide peer support programs available specifically for youth with mental health challenges.

Youth Peer Support Scan

During a three-week period in Feb/March 2007, Romi Chandra from Kinex contacted 38 individuals working in community-based agencies, health authorities and the Ministry of Children and Family Development to talk to them about the presence of peer support in their service. Seventeen individuals were actually interviewed within the allocated time. Generally speaking, very few examples of peer support groups were found in operation. The further North the researchers ventured, the fewer peer support programs were found. Some factors contributing to this include: access to funding, knowledge of various peer support models, lack of agencies to partner with, and lack of youth to request peer support due to the isolation and marginalization that comes with diagnosis.

The most noteworthy observation from this scan was that there were minimal activities focused specifically on peer support for youth. Many of the calls to the key informants could not cite any youth peer support but were very proud of the peer support programs in the adult mental health service. While the concept of peer support had permeated the adult mental health service culture in the form of peer support workers, the concept had not permeated the youth mental health service culture.

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Strengths

CMHA Branches

Many CMHA branches around the province offer peer support programs. While these programs predominately target adults, the concept of peer support is vigorously embraced. Peer support in the adult mental health context, tends to manifest as a peer support worker who is an individual who works alongside the treatment team. Extensive training is offered to mental health consumers interested in becoming peer support workers. These trainings include orientation to the concepts of self-esteem, adjusting to changes in life, grieving, relationships, wellness, boundary setting, mentorship, anger and stress management, crisis management and alcohol and drug prevention. However, it needs to be noted that the focus is on adults with serious and persistent mental illness and not on youth who are newly entering the treatment system. The training offered to peer support workers does not offer training in addressing the unique needs of youth.

Other Non-Profit Organizations

Organizations such as the Mood Disorders Association and the BC Schizophrenia Society, funded through the health authorities delivering adult mental health services, seemed to be very in tune with the concept of peer support. Mood Disorders Association alone offers over 50 self-help support groups across the province and over ten special interest groups including faith-based, ethnocultural, language- and age-specific groups. They had begun one support group for youth called Moving Beyond, but the funding for this group had lapsed and with it, facilitation and membership.

Networking Between Agencies

With fewer resources available in rural areas, the mental health community seems to have built a very strong network, notably in the Interior. Agencies in one health service delivery area offer an annual conference, which rotates between three towns in the area. When contacting services for purposes of this scan, many individuals contacted were eager to offer suggestions regarding other agencies or people who could offer additional insight to this research. That said, the individuals were not themselves networked with youth-serving agencies.

Challenges

Stigma for Youth

Communities are still dealing with the stigma that is associated with mental illness, especially among youth. Many youth programs aimed at building strengths and resilience seem to be project based. In one case, the youth who was running a program moved to Vancouver to access better services, leaving their community without youth programs. School-based projects seem to be popular but they are often community development or psycho-educational type programs without a specific focus on peer support for youth with mental health challenges.

Funding

All programs indicated that it would be quite difficult to offer peer support programming without funding. Regions varied in the amount of honoraria paid to adult peer helpers. The challenge regarding funding is that the peer helping model has been operationalized as a job for individuals, whereas the peer support group model could be offered at a much more economical rate.

Hospitals

Hospitals seem to be the major place for peer outreach in rural communities. Many adult peer support workers spent much of their time offering hospital visits to individuals who are acutely ill, with little time for the strengths-based focus of peer support groups. Shifting this focus to a community-based group specific to the strengths of youth is a challenge.

Decision-Making Process

Some agencies excelled in involving people with mental illness in decision-making, while others were struggling to apply the best strategies. Again, it was the adults who benefited from being involved in the decision-making process. One agency had an adult mental health consumer on their board of directors while for other groups, the peers set the agenda for the ongoing peer support meetings. It needs to be clarified that peer support workers predominately offered one-to-one support versus running actual peer support groups (Mood Disorders Association and BC Schizophrenia Society are the exceptions).

Travel

Travel expenses were a key challenge for peer support workers in offering their services. Often, peer support workers didn't have access to vehicles, the expenses or the means to get to various locations. It is notable that in peer support groups for other conditions such as breast cancer, peers are creating online communities that eliminate the need for travel, which might be a method for overcoming the costs associated with travel.

Parent Peer Support Scan

Interviewers contacted senior administrators in the five major MCFD regions of the province and asked about contacts in their areas. Similarly, contact was made with the mental health agencies that form part of the BC Partners for Mental Health and Addictions Information.

The type and number of parent support groups relates to the history of government funding and the strength of individual parents in certain communities.

Historically, groups to support attention deficit disorder have been in existence for many years now with successful chapters in Vancouver, Abbotsford and the North Shore. A group exists in Castlegar to support parents of children with fetal alcohol spectrum disorder (FASD). Groups for parents with children with autism spectrum disorder are emerging around the province in communities such as Vancouver, the Comox Valley and Cranbrook. The autism support groups for parents have been particularly active in advocating for improved care for their children and youth. However, they do not see autism as a mental illness and therefore tend to distance themselves from generic mental health support groups.

There are also some volunteer parent support groups that have emerged around the province. The Dynaparent group in Maple Ridge is one of these groups.

MCFD funds contractors to deliver the Strengthening Families Program (SFP).[22] SFP is a nationally and internationally recognized parenting and family-strengthening program for high-risk families. SFP is an evidence-based family skills training program found to significantly reduce problem behaviors, delinquency, and alcohol and drug abuse in children and to improve social competencies and school performance. Child maltreatment also decreases as parents learn more effective parenting skills. This program is offered in the Sunshine Coast/Squamish District and in the Northern Region.

MCFD also funds, through staff at the Maples provincial tertiary youth mental health facility, a parenting education program called Connect. This program is a 10-week psycho-educational program with a scripted curriculum and is centred on attachment theory.

At the provincial level, there are a number of groups who are funded to provide support for vulnerable parents. Depending upon their funding stream, they receive differing amounts of provincial funding. These groups include:

- **Parent Support Services of BC**[23]
  These generic parenting support groups were originally funded to provide support to parents with children who were potentially in child protection situations, and to prevent child abuse. A central office coordinates a network of support groups run by volunteer facilitators throughout the BC regions, but there is nothing specific to child and youth mental health.

- **SNAP (Special Needs Adoptive Parents)**[24]
  SNAP seeks parents with children with special needs to become resource parents to other adoptive parents. They assist with a wide range of issues including adoption, grief, loss, FASD, attachment issues, learning disabilities and much more. Parent-to-parent contact is done mainly through telephone or email.

- **In Your Grasp**[25]
  This website (www.snap.bc.ca) offers information for foster and adoptive parents, but no face-to-face support groups. The BC Federation of Foster Parent Associations (BCFFPA), the Adoptive Families Association of BC (AFABC), and the Federation of Aboriginal Foster Parents (FAFP), have combined their resources and expertise to create a regional and provincial database of available community resources.

- **Parents Together Program**
  This is a provincial program for parents with children with conduct disorder issues. It is delivered through the Boys and Girls Club in BC. Contactors offer the program around the province for parents experiencing problems with their teenagers. Parents meet weekly in small groups with a facilitator who assists them in identifying problems and charting a course of action. Minimal registration fee. Funded by MCFD. Community service clubs and fundraising efforts through Boys and Girls Club.

- **Family Support Institute of BC (FSI)**[26]
  The FSI supports parents with children with developmental disabilities. FSI supports a network of resource parents around the province who provide one-on-one support to parents coping with a child with challenges. Children and youth with mental health concerns and concurrent mental illness tend to receive mental health care through the specialized mental health teams for concurrent disorders operated by the health authorities. FSI is supported by a grant from Community Living British Columbia. FSI and the FORCE recently collaborated to produce a guide for families coping with the dual diagnosis of a mental illness and a developmental disability.

- **BC Schizophrenia Society (BCSS)**
  BCSS offers a Family-to-Family psychoeducational group for family members with adult children with schizophrenia. These time-limited groups are offered in various regions around the province. There are no specialized groups for parents with youth with psychotic illnesses.

- **Early Psychosis Initiatives**
  In 2001, the Ministry of Children and Family Development and the Ministry of Health supported the development of early intervention programs for psychotic illness in youth aged 14–25. The clinical leadership for the initiative was in Fraser Health and represented a collaboration of funding between MCFD and the Fraser Health Authority. Other health authorities received small grants to provide community education to gatekeepers (teachers and police) about early warning signs of psychosis. Since that time only Fraser Health (adult mental health) has been able to develop a health authority-wide early psychosis program and the fidelity to the original model has slipped according to a 2005 review of programs around the province. Both Fraser Health and Vancouver Coastal Health (Vancouver Health Service Delivery Area) have youth support groups and parent support groups for parents of youth who are newly diagnosed with psychotic illness. They also offer psycho-educational groups to teach parents about the illness, treatment and recovery options. Although the initiative was once province-wide, it now has distinctly regional and local programs.

- **Provincial or Regional Hospitals for youth with mental health needs**
  The interviewers contacted individuals in hospitals around the province who provide specialized mental health care to children and youth (BC Children's, Prince George Regional, Kelowna Adolescent Treatment Unit, Victoria General and Northern Cariboo Memorial Hospital in Williams Lake) but none provide support groups for parents.

- **Tourette's Foundation**
  The Tourette's Foundation supported a parent support group for parents with youth with Tourette's syndrome in Comox but after the funding ceased, the group was turned over to two volunteers with no supports and the group was dissolved.

- **FORCE Society for Kids' Mental Health (FORCE)**
  Recently, the FORCE has been funded through the Child and Youth Mental Health Plan to support the development of parent support groups for parents with children with mental health challenges. Groups exist in the Sunshine Coast, Victoria, Abbotsford, Surrey, Tri-Cities and Penticton. Groups are in the planning stages in New Westminster, Chilliwack and Vancouver. The FORCE will be convening a provincial conference of their members in May 2007.

Interviewers also contacted MCFD offices in the macro-provincial regions but none were able to identify parent support groups for parents with youth with mental illness other than the groups identified above.

The Voices project attempted to seed parent support groups in five pilot site communities and were only able to develop two groups. There were a variety of hypotheses as to why this was so. The first was that the sites were recruited because they were already active in providing youth outreach so it was an easy stretch to ask those workers with contacts to start a group. The second relates to the challenges faced by parent leaders. For example, one site recruited a parent leader whose child was later sent to the provincial tertiary facility for a prolonged stay and her energy then was devoted to traveling to visit with her son who was receiving care outside her home community. Another reason given by service providers was that parents with a child with mental health challenges face a long wait for services, so when they finally get to a professional the concept of joining a peer support group is a 'hard sell.' Yet another reason given was the systematic bias of seeing parents as part of the problem and the lack of willingness to engage in open-ended group work with parents when the service providers know that there will more than likely be a lot of anger and grief in the discussion. Interview data from the Voices evaluation indicated that after being in a peer support group, parents were better able to participate in their child's care in a more logical and less emotional manner.

Strengths

- Family peer support is acknowledged in policy and in practice.
- Funding from the Child and Youth Mental Health plan to the FORCE has given policy support and resources to develop family support groups for parents with child and youth with mental health concerns.
- The FSI is a strong provincial network of parents with children and youth with developmental disabilities. The resource parent model seems to work very well and parent volunteers connect at the provincial level to learn and network on a semi-annual basis.
- MCFD already funds psycho-educational programs for parents with childhood mental illness through the Strengthening Families program and the Connect program.

Challenges

- Many leaders in the child and youth mental health field understand the value of peer support but there is some confusion as to what the term really means. Some understand the 'peer' aspect and the need for focus on support, while others understand a group of peers taking a course to be equivalent to peer support.
- While Ministry staff and contractors currently support psycho-educational programs for parents with children or youth with mental health challenges, these groups are time limited and there is not an automatic referral from psycho-education programs to peer support provided by groups such as the FORCE.
- Paying for parent peer support group leaders is an area of controversy. Some regions recognize the effort required to foster and maintain a support group, while other MCFD regions are not in support of paying parents for their volunteer labour. However, in the adult mental health service system, paying an honorarium for peer support leadership has been established as a precedent.

6 Observations

The environmental scan tells us that peer support in British Columbia for youth with mental health challenges and their parents is a growing phenomenon. As with any innovation, it is also struggling to find its footing. What follows are some summary observations that could be made as a result of the environmental scan.

Strengths in the Current Environment

There is growth in interest in peer support in the mental health field in Canada. A national review of mental health services in Canada conducted by the Standing Senate Committee on Social Affairs, Science and Technology sees peer support as an essential tool towards creating a recovery-oriented mental health system. The report also notes that challenges in the current system include becoming more user-friendly and letting parents and youth come to the planning and evaluation table with health professionals. The federal government has recently announced funding for the Mental Health Commission of Canada, currently chaired by former senator and lead author of *Out of the Shadows at Last,* Michael Kirby. There appears to be an increasing appreciation for the value of peer support on the national horizon. Support for this comes from national policies in the UK, the US and Australia, where family and user involvement across the age spectrum receives stronger support than in Canada.

The Ministry of Children and Family Development (MCFD) has a strong policy commitment within the Child and Youth Mental Health Plan towards funding parent peer support via its investment in the FORCE Society for Kids' Mental Health (FORCE). With this support, the number of parent support groups are growing. Fraser Region in particular has a regional strategy to foster parent peer support groups. The focus of these groups is on parent support for childhood mental health challenges. It is assumed that the support needs of parenting a child with mental health challenges are similar regardless of the specific diagnosis.

MCFD funds a number of parent peer support programs through different budget lines. For example, the Parent Support Society sets up support groups for parents with kids with any kind of challenges in local neighbourhoods. This is done as a preventive strategy to build capacity and prevent apprehension of challenging kids. The Ministry also funds, through Community Living British Columbia, the Parent Support Institute. The institute has limited staff to develop a network of volunteer resource parents to provide one-on-one peer support to other families with children with developmental disabilities and challenging behaviours.

Kinex Youth Initiative of the Self Help Resource Association of BC has become actively involved in working with system managers to foster peer support for youth with mental health challenges. Recent work with Vancouver Coastal Health Youth Mental Health Services is an example of this. Kinex is also scheduled to carry out an Adult Ally Workshop for Youth Peer Support with MCFD workers in the Interior and Northern Regions.

The division of Mental Health Services into adult services (provided by the health authorities) and child and youth services (provided by MCFD) creates artificial boundaries for youth in particular and peer support may help bridge this discontinuity. Many youth with serious mental illness are not yet ready for the adult system and in turn, the adult system does not have youth-friendly services. In the evaluation of the Voices project, service providers observed that peer support groups can be a valuable bridging tool as youth transition to the adult system and change service providers.

The MCFD has a strong policy commitment towards developing youth voice. The appointment of Stan Williams as the Special Advisor on Youth, and the creation of a Youth Advisory Council for the MCFD will provide a positive climate for expanding youth peer support.

The school systems—through collaboration with MCFD and the FORCE for the Friends program—are developing an increased sensitivity towards youth mental health challenges. While Friends is a preventative program, it is also likely to provide awareness of the need for follow-up support for mental illness as a legitimate health need and the concurrent value of peer support. The Voices Peer Support Program in West Vancouver school district found an enthusiastic response (a group of ten students came forward within a week of the announcement of the program) for peer support groups for test anxiety. The school district is planning to carry on with six of these groups in the next school year in partnership with the Canadian Mental Health Association's North and West Vancouver Branch.

Peer support is acknowledged as a best practice within the adult mental health system and presence of an informal provincial network of self-helpers may be helpful to youth or family groups starting out. Notably, the Early Psychosis Program in Fraser Health Authority has peer support programs for parents and youth. Vancouver Coastal Health also has a commitment to peer support for parents and youth. In all health regions, peer support workers are a distinct part of the adult mental health service system and it is generally acknowledged that peer support plays a vital part in the recovery of a person with a serious mental illness. It may be seen as a challenge that peer support in the adult mental health world is operationalized as one-on-one support rather than the experience of a peer support group. In the Voices evaluation, youth in every pilot site consistently mentioned the normalizing experience of being in a group and knowing you were not the only one feeling this way.

Through the Strengthening Family and Youth Voices Project, the Canadian Mental Health Association (CMHA), BC Division has raised awareness within the organization provincially about the value of peer support for families and youth with mental health challenges. There is now fertile ground for this work to continue throughout CMHA, provincially. All of the pilot site youth groups are currently negotiating for continuing support from MCFD and one of the five pilot sites will continue with a youth peer support group for parents with childhood mental health challenges. Two of the parent support groups started by the Voices project will continue with their own means.

Challenges

Convincing individuals to seek support of others is still hampered by individuals' fears of having a highly stigmatized condition and the community repercussions of this diagnosis among their family members. Hopefully, the developmental work associated with the school-based Friends program, among other initiatives, will lessen this sense of shame.

The Voices project and its collaboration were time-limited. It will be a challenge to maintain the collaborations between FORCE, Kinex and CMHA beyond the project, without a common vision and funding to work on collaborative projects.

BC is just finishing the roll out of an extensive five-year plan to improve mental health services for children and youth. However the gains are challenged by the elimination of specific leadership for mental health within the Ministry. This means that regions will individually determine if peer support is a priority. It also means without provincial standards for peer support, extensive work will have to be done at the regional level rather than at the provincial level.

Many leaders in the child and youth mental health field in BC understand peer support to be a good thing, but there is some confusion as to what the term actually means. Some understand the youth helping youth (or family helping family) aspect of peer support, while others see any educational group for youth or parents as being peer support. This is not meant to say this is an either/or situation but that peer support belongs on the continuum of services beside the more structured educational approach.

The ongoing sustainability of parent-led peer support groups is a challenge. Many of the parent leaders are currently stretched to their limits with a heavy volunteer load and meeting the needs of a youth with challenges. Different MCFD regions have different policies on paying parents for their volunteer group leadership role. This should be reconciled.

Youth peer support is not anchored in provincial policy or practice. The Voices Forum showed that peer support is a powerful force in the recovery from a serious mental illness and with the appointment of a new provincial youth advisor, Stan Williams, we can hope that peer support will grow from its current fledgling beginning. Kinex's work with Vancouver Coastal Health Authority's Child and Youth Mental Health Program shows that youth can be engaged and can make meaningful changes to make services more youth friendly and ultimately more effective. Currently, all of the groups are in discussion regarding ongoing support from MCFD but at the time of writing, only one of the five Voices project youth peer support groups will be funded by MCFD in the next fiscal year.

There is still a fear of the 'family voice' among many service providers. This may be held over from the days before mental illness was understood to be a definable illness and instead interpreted as an offshoot of bad parenting. It may also be that mental health services have operated in an environment of high demand and low level of resourcing, so that clinicians had little time for feedback discussions with

family members, accelerating their frustrations. At any rate, currently, to our knowledge, only the Fraser Region has a system in place for soliciting family feedback about service quality within the context of continuous quality improvement. This tendency towards seeing the family as the cause of the problem was also echoed by the American consultants from Portland who had to consistently provide training around the benefits of family-driven and youth-directed care.

Providing parent or youth peer support in rural and northern areas is a challenge for a variety of reasons, including small numbers of people who live far apart and lack of local role models. Another factor is that MCFD services in the Northern Region are contracted to a private agency, Interconnect, who does not see a place for peer support in their mandate. The Teens 4 Teens group from the Voices project in Cranbrook found a ready audience for their peer support discussions via web-based discussions. Thus distance is both an opportunity and a challenge.

Although peer support is growing there is also a tendency to see the commonality as being the mental illness—when diversity may be the commonality that brings individuals together. For example, youth with mental health challenges who are from culturally diverse backgrounds and questioning their sexual orientation may be more comfortable in a support group for questioning youth.

In order to foster youth peer support, there needs to be support for training youth co-facilitators. Currently there are no training opportunities for youth to facilitate mental health-related peer support groups while there are training opportunities for peer support in the adult mental health world.

In order to grow the practice of peer support, there needs to be research into the contributions of families and peers in the recovery process. Currently, there is little research in this area in BC. Peer support is not seen as a valued area for knowledge development. This need for research was also recognized in *Out of the Shadows At Last*.

Opportunities

The value of an environmental scan is to determine where the openings for change are and where strategic partnerships can be leveraged to create a collaborative advantage. The researchers involved in this environmental scan offer the following opportunities:

The FORCE, Kinex and CMHA BC Division developed a good partnership for peer support while working on the Voices Project. This positive experience may lead to additional collaborations. The Voices Forum in February 2007 created a provincial momentum among families, youth and service providers. The interviews on local and national CBC radio with two youth in Voices peer support groups created much interest in peer support as an effective strategy for mental health recovery.

Although fostering peer support in rural and remote regions was identified to be a challenge, it may be that online communities could be created as with other chronic conditions. Currently, BC Cancer Agency is piloting online support groups for young women with breast cancer in BC. CMHA began to explore the possibility of creating an online community for parent support with the Voices project but was unable to operationalize the interest due to funding and time limitations.

The FORCE has scheduled a provincial workshop on Kid's Mental Health on May 8. The new federal Mental Health Commissioner is scheduled to attend and give a keynote presentation. He may be able to give further profile to the importance of peer support.

Kinex is scheduled to provide training in Youth Engagement with MCFD Staff in the Interior Region, the Northern Region and the Vancouver Coastal Region. The initial collaboration with Vancouver Coastal Youth Mental Health Services and Kinex has produced positive results and good news travels fast!

CMHA BC Division and its branches have an opportunity to increase the profile of youth and family involvement in it is activities. Currently there are no youth involved at the Board level and this presents an opportunity to walk the talk of youth engagement.

Currently MCFD has two psycho-educational parenting programs for parents of youth with a mental illness: the Connect program and the Strengthening Families program. As these are specific, time-limited programs, and are often run in communities with ongoing support groups operated by the FORCE, there exists an opportunity to link the graduates of these programs to FORCE support groups. Again, the opportunity would be to see these different interventions as part of a continuum of service and not in competition.

Currently the Child and Youth Mental Health Plan is in the final year of hiring of new staff. There continues to be an opportunity to persuade new staff of the power of peer support through the orientation meetings. The FORCE representatives already participate in these meetings. CMHA and Kinex could ask to attend and give a briefing on the power of youth peer support.

Fraser Region has a particularly strong approach towards fostering peer support among youth and families. This is true with both the MCFD Services and the Fraser Health Authority Services. It may be that this leadership from within the system can be leveraged to provide support to other areas of the province to give peer support a chance.

Moving Forward: What Next?

It is hard to specify what might be next, but at the same time, each of the agencies involved in this scan have specific projects lined up to foster the peer support agenda further. The thing about self-help and peer support is that they are infectious. And once one has moved beyond one's individual issues, a focus on making it easier for others is natural.

While the provincial child and youth system is in the midst of yet another transformation—with uncertain leadership for youth mental health services—the language of resiliency and strengths-building services is part of the current system transformation and is also the language of self-help and peer support. CMHA, Kinex and the FORCE are working to find a place in this new system in the absence of a provincial-level mental health services champion. Policy indicates that 30% of the regional service budget should go to building capacity. Peer support builds capacity, but whether it will receive priority above psycho-educational initiatives remains to be seen.

Federally, the policy landscape is very supportive of peer support and user involvement. If the communities can come together and create the right pressure for funding a national mental health strategy, there is more than likely a place for peer support.

In the meantime, with or without funding, peer support will soldier on because of the very power of peer support. It is unstoppable because, simply put: "helping you helps me." People who have 'been there' will reach out regardless of the funding to support this activity. Some will thrive, some may burn out, and still others will have their lives transformed. Slowly but surely British Columbia is moving towards a future where mental illness is less feared, stigma is less of a reality, treatment is more accessible and support to get on with life more available to all.

The challenge identified in this scan is that peer support needs assistance from the system to be effective and to minimize the burnout and fatigue that is so easy to surface among its leaders who by the very nature of the mental health challenges in their families may be stretched to their limits of coping.

Appendix A
Letter to Decision-Makers

January 2007

Dear

I am writing to you on behalf of the Canadian Mental Health Association's Strengthening Family and Youth Voices Project. The Strengthening Family and Youth Voices Project is a 2-year project funded by the Public Health Agency of Canada. The focus of the project has been on developing peer support/mutual aid for young people with mental health issues and their families in 5 communities in British Columbia. [The project has been working closely with the Ministry of Children and Family Development.]* We have also been working closely with the FORCE Society for Kid's mental health and KINEX, the youth arm of the Self-Help Resource Association of BC. All three of our organizations are committed to promoting self-help/mutual aid for young people and families impacted by mental health issues.

The learnings from our project sites and from other related peer support/mutual aid activities, will be highlighted at our February 9th provincial forum "Strengthening Family and Youth Voices" which is designed to explore the emerging role of peer support/mutual aid in the area of child and youth mental health. For more information about the Forum or to register, please visit www.voicesbc.org.

We recently were able to secure funds through the Public Health Agency of Canada to conduct an initial environmental scan of existing peer support/mutual aid activities which impact on the mental health of children, youth and their families in BC. The intent of this environmental scan is to gain an understanding of existing initiatives in this area as a first step to identifying opportunities for collaboration.

To this end we are writing to you, to request that you provide us with information about the number and type of peer support/mutual aid activities currently underway within your region which impact on the mental health of children, youth and their families and, where possible, contact names for these initiatives. We would ask that you provide this information to us by February 21st via email to chume@cmha.bc.ca.

For the purposes of this scanning process, we are defining peer support as:

- Support through opportunities to learn new coping skills and new means to approach or improve personal situations
- Are unique, offering the kind of support that one can only get from others who share similar experiences
- Are about helping people to help themselves
- Can be done one-on-one or in groups, in person, by telephone or online.

We know that there are many peer support activities related to the mental health of children, youth and families and would very much like to include these initiatives in our environmental scan. The scan results will be shared with respondents and will be available on our website, www.cmha.bc.ca by early Spring 2007.

Thank you very much, in advance, for your attention to this matter. We look forward to your response. If you require any additional information, please feel free to contact Catharine Hume, Director of Policy and Research either by phone at 604-688-3234 or by email chume@cmha.bc.ca.

*Included in letters to Health Authority CEOs and Regional Executive Directors, Ministry of Children and Family Development

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