



DEMONSTRATING PROGRESS

Innovations

IN WOMEN'S MENTAL HEALTH

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Acknowledgements

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Finally, we would like to recognize the dedication and courage of all of the women who participated in the projects and provided interviews about their experiences. We hope that the work contained in this report will offer some advancement in the treatment and support of women who struggle with mental illness.

Executive Summary

This report describes four, innovative, mental health demonstration projects designed specifically for women with chronic and persistent mental health problems in four different communities in British Columbia. These programs were funded through a one-time initiative of the British Columbia Ministry of Health Services (formerly the British Columbia Ministry of Health) and co-ordinated and evaluated by the British Columbia Centre of Excellence for Women's Health over a two-year period (2000-2002).

Each of the projects presented here was designed to address some aspect of the needs and concerns of women with serious mental illness. Two of the projects involved peer support: one of these allowed women treatment options (including the option to access alternative medical practitioners) in order to explore the role of treatment choice in women's healing; the other involved the redesign of a traditional peer support program in order to respond to the unique mental health needs of women more effectively. Both of these projects were designed and led by mental health consumers and each explores the implications of this design with respect to building capacity and leadership among women as a critical component of empowerment and maintaining wellness.

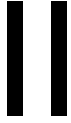
The other two projects involved trained mental health professionals in running programs for groups of women who are particularly marginalized. In the first instance, a unique group therapy program was designed for women with co-existing mental illness, developmental disabilities and histories of sexual abuse. In the second, women with mental illness who were mothers of young children participated in a group process called "Theraplay" that provided a safe, supportive environment to explore and enhance their relationships with their children.

The evaluation of each of the projects suggests that

demonstration models, although limited in their ability to address the long-term needs of women with mental illness, are useful for testing and evaluating innovative programs. Further, demonstration projects can help build the evidence base with respect to what kinds of programs are most useful for women with serious mental illness. In the *Demonstration Projects Initiative* we learned that women-specific peer support programs can provide important kinds of information and social support to women with mental illness that women do not experience in co-ed support groups. The data suggest that these groups play a role in assisting women to understand their mental illness and to navigate the mental health system, increasing the likelihood that they will receive the care they need. Additionally, we learned more about which therapeutic approaches are more useful for addressing traditionally neglected populations in mental health, specifically, mothers with mental illness who are actively parenting young children and women with co-existing developmental disabilities and mental illness who are experiencing the effects of sexual abuse. Finally, each of these projects revealed that consumer and community leadership and capacity building are important components of effective program development for women.

Each of the organizations that participated in these projects produced full reports and a more detailed

discussion of the particular mental health problems of the women participants. These are listed in the references to this report. Although the projects discussed here represent only one small step in ameliorating service gaps, it is hoped that our findings will help achieve the larger goal of developing more comprehensive mental health programming for women.



Introduction

To expand the knowledge of how to improve mental health outcomes for women who have been diagnosed with a serious and persistent mental illness, the *Women and Mental Health Demonstration Projects Initiative* provided one-time project funding through the British Columbia Ministry of Health Services (formerly the British Columbia Ministry of Health). Four innovative projects were funded that addressed gaps in the current mental health service system through collaborative partnerships and innovative program designs.

The British Columbia Centre of Excellence for Women's Health coordinated the *Initiative* and hired consultants to develop and carry out appropriate evaluation plans for each demonstration project. The purpose of the evaluations was to assist in understanding which approaches worked best to support women with serious and persistent mental health problems.

Proposals were invited in these areas:

- improving mental health outcomes for women diagnosed with serious mental illness who have violence and trauma histories;
- improving mental health outcomes for immigrant and refugee women, women of colour and Aboriginal women diagnosed with serious mental illness;
- improving mental health outcomes for women diagnosed with serious mental illness in the forensic psychiatry/ prison system;
- improving mental health outcomes for women diagnosed with serious mental illness who are mothers; and
- peer support for women diagnosed with serious mental illness.

Women with serious and persistent mental health problems face a wide array of difficulties associated not only with the effect of their illness on daily living, but with the social circumstances that often accompany mental illness.

Four projects were funded and are discussed in this report:

1. **Theraplay for Mothers with Mental Illness and their Children**
Chilliwack Mental Health,
Chilliwack, British Columbia
2. **Improving Mental Health Outcomes for Women Diagnosed with Serious Mental Illness and Developmental Disabilities Who Have Violence and Trauma Histories**
Fraser Valley/West Coast Mental Health Support Teams, Vancouver, British Columbia
3. **The Whole Woman Project: Demonstrating the Role of Peer Support for Women Diagnosed with Serious Mental Illness**
Vancouver/Richmond Mental Health Network, Vancouver, British Columbia
4. **RESPECT (Research on Education & Support by Peers Enhancing Consumer Togetherness) Project**
Williams Lake Association for

Consumers and Families for Mental Health, Education, Services and Advocacy (WL ACME)/
Women's Contact Society,
Williams Lake, British Columbia

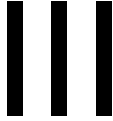
Specialized Programs for Women

A variety of provincial and national research reports on women and mental health have emphasized the need for specialized programs for women (e.g., Federal/Provincial/Territorial Working Group on Women's Health, 1993; The Women and Mental Health Working Group, 1993; Morrow & Chappell, 1999). These reports argue that the ability of the mental health system to address the social as well as the medical concerns that arise from women's mental illness is currently constrained by the predominance of bio-medical or "disease" models that do not adequately attend to the social problems and discrimination that often accompany mental illness.

Within the mental health system, only certain kinds of services are publicly funded. The emphasis for funded services is on psychiatric treatment, medication, and the monitoring of this

medication to reduce the symptoms associated with mental illness. Community-based mental health services do provide a wider range of services including advocacy, support for daily living and peer support. Many of these programs, however, do not have the knowledge or resources to provide specialized supports for women. Women-centred and feminist care models have generally not targeted their programs to women with the most serious mental health problems. The result is a gap in both service systems (mental health and women's services) with respect to addressing the needs of women from the chronically mentally ill population.

Women with serious and persistent mental health problems face a wide array of difficulties associated not only with the effect of their illness on daily living, but with the social circumstances that often accompany mental illness. Many of these women live in poverty, experience periods of homelessness and unemployment, have experienced physical and sexual violence, have co-occurring substance use problems, and have difficulties sustaining personal relationships with their families and their children. The stigma that continues to surround mental illness compounds women's difficulties and often leads to discriminatory treatment.



Women-Centred Care

Although not all of the projects featured here deliberately employed women-centred care models, most were guided to some degree by the principles of women-centred care, and/or contained elements from these models. An understanding of women-centred care is therefore useful as a starting point for exploring each of the demonstration projects.

Women-centred care models originally emerged from the women's health movement because of concerns that the health care system did not adequately address the unique needs and concerns of women (Doyal, 1998). Feminist health care providers and advocates have argued that in the mainstream medical system, women's needs are often invisible or subsumed within concerns for the needs of children, as in concerns about child poverty or fetal health. In contrast, women-centred models aim to value women as individuals, not only by the roles they often play in society as mothers, partners and workers.

Research by Barnett, White and Horne (2002) suggests that women-centred care is comprised of the following key elements: a focus on women, involvement and participation of women, empowerment, respect and safety. Further, they suggest that services that are women-centred should address the complexities of women's lives, include a diversity of women, integrate service delivery, respond to women's forms of communication and interaction and provide information and education. Women-centred care focuses on the participation, empowerment, respect for and safety of women.

What distinguishes women-centred care models from patient-centred care models is the assertion that the provision of health care has to be contextualized with respect to the social, political and economic situation of the people who are receiving care. Additionally, women-centred care recognizes that both sex (biological) and gender (social) differences between men and

women will impact on the health care needs of women and men. Thus these models recognize that men and women sometimes differ in the social determinants that impact on their health, in their patterns and experiences of illness, disease and mortality, in how they interact with the health system, and with respect to which programs and treatments ensure the best health outcomes for them.

It should be noted that gender is not static, unchanging or mutually exclusive. There are many forms of masculinity and femininity that men and women can exhibit, which makes gender a complex construct that interacts with other forms of difference in myriad ways (Courtenay, 2000). Given that women and men are not homogeneous groups, women-centred models of care must also take into account differences based on class, race, culture, ethnicity, sexual orientation, gender identity, age and ability. We know, for example, that some groups of women may be reluctant to access the health care system because of racism (Stout, Kipling & Stout, 2001; Bolaria & Bolaria, 1994; Browne & Fisk, 2001) and other forms of discrimination (e.g., against substance using women, women with mental illness, single mothers, elderly women).

Women-centred care focuses on the participation, empowerment, respect for and safety of women. It asserts that health care has to be contextualized within the social, political and economic conditions of women's lives.

IV

Women-Centred Mental Health Care

There is now a considerable body of literature that illustrates sufficient differences between the experiences of men and women to warrant mental health program planning and treatment that takes these differences into account. Although men and women do not vary in the overall prevalence of mental health concerns, sex and gender differences do exist in the types of diagnoses, in the development and course of mental illness and in access to and utilization of mental health services (Prior, 1999). Women are about twice as likely to experience recurring depressive episodes (Health Statistics Division, 1998) and anxiety (Howell et al., 2001) than men, while men are about four times more likely to have substance use problems or antisocial behaviours. Additionally, women are more likely to be diagnosed with eating disorders, panic and related phobias. While men have a higher incidence of completed suicide, women attempt suicide more often.

The social devaluation of women has an effect on their mental health. Women, even if they are in paid employment, continue to bear a disproportionate load of caregiving and family responsibilities and represent the majority of single parents. In Canada the average earnings of employed women remain substantially lower than those of men, and women, especially elderly women, single mothers and Aboriginal women, are more likely than men to live in poverty (Almey et al., 2000). Research has demonstrated a clear association between poverty and mental illness (Saraceno & Barbui, 1997). In turn the conditions of poverty often expose women to further harms and stresses. Although all women are vulnerable to physical and sexual abuse, women who live in poverty and who are socially marginalized are particularly vulnerable. Women's experiences of physical and sexual violence as children and as adults have a significant impact on their mental well-being (World Health Organization, 2001).

Women who are immigrants or refugees face particular stresses with respect to their mental health. Although there are many circumstances associated with psychological stress for all immigrants, (e.g., low income, language ability, unemployment, acculturation, barriers to education, older age, poor health, lack of social support), these affect men and women differently (Federal/Provincial/Territorial Working Group on Women's Health, 1993; Health Canada, 1999a). For example, social support has been shown to be of greater importance for women's mental health status, while work-related predictors are more relevant for men (Aroian, 2001).

Aboriginal women also face unique mental health concerns. The legacies of colonization and residential schools have resulted in cultural discontinuity and oppression in many communities that have been tied to high rates of depression, alcoholism, suicide and violence (Kirmayer, Brass and Tait, 2001). The under-utilization of mental health services by Aboriginal peoples may be the result of a combination of factors including lack of culturally-appropriate and non-racist services, lack of access to services due to geographical barriers and jurisdictional issues.

Sexual orientation and gender identity are also important aspects of mental health. Research has suggested that transgendered women experience high rates of violence and discrimination.

Lesbians and bisexuals have higher rates of suicide than the general population (Federal/Provincial/Territorial Advisory Committee on Population Health, 1996), often experience prejudice and discrimination due to their sexual orientation and are more frequently the victims of hate crimes.

Research suggests that men and women cope with stress and life events in different ways and vary in how they signal their distress (Health Canada, 1999b). These differences may have implications for diagnosis, treatment and service utilization.

Throughout Canada, women-centred mental health care models have been developed primarily in the form of specific programs for women. These programs may be freestanding or operate from outpatient or community-based services. Examples of the former include the Brief Psychotherapy Centre for Women, Across Boundaries: An Ethnoracial Mental Health Centre, both located in Toronto, and programs that serve women with mental health issues and substance-using problems like Sheway in Vancouver. Less common are programs designed specifically for women within existing hospital or community-based mental health programs such as the Aurora Treatment Program for substance-using women, and the Reproductive Mental Health Program at BC Women's Hospital and Health Centre and the Women and Psychosis program at the Centre for

Addiction and Mental Health in Toronto.

Beginning in the early 1970s women-specific services were developed throughout Canada and, although not specifically related to mental health, there are now a wide variety of women-serving groups and organizations. Some of these, such as shelters, women's centres and rape crisis centres, have played a critical role in assisting women who had experienced physical and sexual abuse, some of whom were misdiagnosed in the mainstream mental health system as having mental illness. Many of these organizations continue to support women with mental health problems in relation to the ongoing effects of physical and sexual violence. Additionally, in recognition of the limitations of dominant mental health paradigms for women, feminist frameworks for therapy and programs have been developed. Despite these developments, community-based women's organizations and feminist therapy remain inaccessible to many women, especially women with chronic and persistent mental health problems. The paucity of specific supports for women with serious mental illness has been well documented (e.g., Morrow, 2002; The Women and Mental Health Working Group, 1996).

Attempts to develop comprehensive models for women-centred mental health care, especially for women with serious mental illness, have been rare. Some researchers, however, have

outlined components of women-centred mental health care based on their understanding of the needs of women or have articulated best practices for the care of women (e.g., Federal/Provincial/Territorial Advisory Working Group on Women's Health, 1993; Morrow & Chappell, 1999).

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V

Challenges in Developing Women-Centred Care Models

The concept of women-centred care has been operative for some time. However, many challenges exist with respect to operationalizing and evaluating women-centred care models. One of the central challenges in these models is how to respond to the specific needs of individual women while attending to the specific needs of populations of women – Aboriginal women, women who are immigrants or refugees, women of colour, women with disabilities, women with mental illness and/or substance use problems, single mothers. In order for women-centred care to clearly distinguish itself from “patient-centred” care, it must maintain a structural/social analysis of gender, race, class, sexual orientation, age, ability and gender identity in the development and functioning of its programs. Women-centred care is not just about responding to individual needs; it is also about recognizing systemic oppression and its impact on the mental health of women. Despite this, in the literature on women-centred care there is a central focus on measuring quality of care with an emphasis on patient-provider interactions (e.g., Pittman, 1999; Weisman, Rich, Rogers, Crawford, Grayson & Henderson, 2000; Stichler & Weiss, 2000).

A further challenge for women-centred care models is to ensure that the needs of women’s children and supportive family members are also met. The needs of women are integrally linked to those of their children and models must reflect these connections without pitting the needs of children against the needs of women (Greaves, et al., 2002).

In the health and mental health fields, women-centred care has not been uniformly developed, effectively operationalized, or properly evaluated for health impact, qualitative and quantitative changes in health care exchanges and outcomes,

and for how it can support women's equality (Greaves, 1999; Doyal, 1998). Specifically, we do not know whether women-centred care models provide a higher quality of care than traditional models.

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VI

Evaluation of Women-Centred Care

It is recognized that traditional evaluation models have some limitations with respect to women-centred care. For example, methodological approaches to evaluation research tend to focus on predefined outcomes (morbidity, mortality, and compliance with health professional recommendations) rather than processes (Weiss 1998; Denzin and Lincoln, 1994). Additionally, measures and indicators are limited in terms of what they can tell us about quality of service and outcome of treatment and often overlook sex and gender implications (McGrady & Rayek, 1993). Although many health care evaluation schemes do get client input, this input is usually limited to “client satisfaction” forms that are unable to tell us much about women’s experiences as they go through the care system and/or what would be quality care for women. Thus researchers have argued that evaluation should include more nuanced and complex measurements that would assess the identified goals of the client (Oakley, 2000).

Further, conventional models of evaluation do not always take into account the ethical ramifications of instituting an evaluation. One example is the use of control groups, which is clearly inappropriate when evaluating programs that are addressing women in crisis. However, no suitable substitution for this model has been developed or tested. The result is that the development and evaluation of women-centred care has, in general, been limited by the lack of appropriate evaluation models and methodologies.

Evaluators for the *Women and Mental Health Demonstration Projects Initiative* used a combination of traditional evaluation methods in conjunction with methods designed more specifically to evaluate the women-centred components of the projects. This allowed the evaluators to draw conclusions based on well-known evaluation methods, as well as to experiment with different methods in order to make suggestions

about their usefulness in evaluating women-centred care. The material presented here should not be held up as definitive models of women-centred mental health care or women-centred evaluation, but rather should be seen as one effort in the ongoing development of women-centred mental health care theory and practice.

VIII

Demonstration Projects

A. Peer Support and Alternative/Complementary Therapy Models

Two of the projects that were supported through the *Women and Mental Health Demonstration Projects Initiative* involved the development of peer support models for women with chronic and persistent mental health problems. In one case, the RESPECT project, this meant the redesign of a traditional peer support model called “BRIDGES”. In the second case, the Whole Woman Project involved both peer support and education, and support for women to choose the kind of treatment they felt would be most helpful to them, including access to alternative/complementary kinds of care to assist them in managing mental illness symptoms and in maintaining wellness. These included massage, counselling, Reiki and nutritional counselling.

Peer support and self-help have long been recognized as key components of recovery and of maintaining wellness for people with mental illness (Mowbray & Tan, 1992; Carpinello, Knight & Jantulis, 1992; Trainor, Shepherd, Boydell, Leff & Crawford, 1997). Indeed, throughout Canada peer support is now recognized as an integral component of the mental health system (e.g., B.C. Ministry of Health, 1998). The success of peer support appears to lie in the breaking of isolation by sharing similar experiences and learning self-advocacy skills. Peer support models for women that include a consciousness-raising component (e.g., of women’s social positioning) continue to be popular within the feminist movement and have often provided models for programs developed elsewhere, including in the mental health system.

While the literature on the efficacy of alternative and complementary therapies other than counselling is still in its nascent stages, many consumer/survivors of the mental health

In the RESPECT Project, consumers led the project but the local women’s organization took on all the administrative duties, enacting a partnership model that was mutually beneficial.

system request access to such treatments and others report that these therapies help to ameliorate symptoms (Across Boundaries: An Ethnoracial Mental Health Centre, 2001). Further, some research suggests that spiritual and traditional healers may especially play a role for some groups of women (Morrow & Chappell, 1999).

Consumer leadership of projects is now recognized as an important component of healing and maintaining wellness (Trainor et al., 1997). Earlier literature focused on helping mental health consumers access money to develop projects and exploring the role consumers should play in mechanisms designed to influence mental health policy development. Consumers in Ontario pushed this thinking further when they began to develop their own businesses independent of any support from the mental health system (Church, 1997). In both of the projects described below, consumers led the development and implementation of the programs. In the RESPECT Project, consumers led the project but the local women’s organization took on all the administrative duties, enacting a partnership model that was mutually beneficial. In the Whole Woman Project the initiative was entirely consumer-led.

In the evaluation of both of these projects, discussion about the experiences of the group leaders is examined, as are the kinds of challenges that can arise in consumer-led projects.

The RESPECT Project

Women’s Contact Society and Williams Lake Association for Consumers and Families for Mental Health, Education, Services and Advocacy (WL ACME).

This information is drawn from the report, RESPECT...Find out what it means to me. Final Project and Evaluation Report, by Anne Burrill and Lynda Dechief, July 2001. This report is available from the Women’s Contact Society in Williams Lake.

Project Background

RESPECT stands for “Research on Education & Support by Peers Enhancing Consumer Togetherness”. The RESPECT program was designed collaboratively by a local women’s centre (Women’s Contact Society), the local consumer-survivor organization (WL ACME), staff of the local Mental Health Centre and Northern FIRE (Feminist Institute for Research and Evaluation). Their aim was to provide 16 weeks of peer support and education for women with serious and

chronic mental health problems.

The key component of the project was to redesign a traditional peer support program originally developed in the United States called “BRIDGES” (Building Recovery of Individual Dreams and Goals through Education and Support) Peer Support Program, so that it would speak specifically to the needs and concerns of women. Originally developed in Tennessee by consumers, this program was introduced in B.C. by the British Columbia Schizophrenia Society. Initial reports from consumers in Williams Lake suggested that the BRIDGES program had helped people manage their illness and their lives. Despite its success, the BRIDGES program did not have the capacity to address some concerns that were either specific to women’s bodies (e.g., the interaction of female hormones with psychiatric medications, the concerns of women during pregnancy and childbirth) and/or arise out of the social experiences of women’s lives (e.g., women’s concerns about parenting and caregiving, the impact of violence on women, women’s disproportionate poverty). Thus the project leaders felt that if the BRIDGES curriculum were redesigned using a women-centred framework, it might be able to respond better to the specific issues that women with serious mental illness experience.

The program was situated in the Cariboo Region, a rural area (Williams Lake) that comprises several small

towns and has the highest rates of mental health hospitalizations in British Columbia (10 per 1000). There are about 400 referrals to the Williams Lake Mental Health Centre each year, half of whom are women (Burrill & Dechief, 2001). It is important to note that there are no psychiatric care facilities in Williams Lake, so people experiencing acute psychiatric crises have to leave the community to get services. Crisis stabilization services are available, but they are difficult to access unless one is familiar with one’s own illness and able to make plans for getting support before the crisis occurs. The lack of local services means that once people are in treatment they are often isolated from their communities and their sources of support.

Some members of WL ACME had participated in a focus group as part of a research project conducted by the British Columbia Centre of Excellence for Women’s Health in 1998 and had cited the need for local education and peer support programs. Women in the focus group indicated they wanted women-only peer support spaces. These factors motivated WL ACME to partner with the Women’s Contact Society to design this peer support project. The project was led by consumer/survivors but supported by the women’s centre, which handled the administration of funds for the project and offered a place for the group to meet. The goals and objectives of the project were to:

- provide women with information about their illness;
- teach participants about their medications and side effects;
- help women develop peer support relationships;
- help women create personal wellness and crisis management plans; and
- provide an opportunity for the women to develop leadership, research and program development and evaluation skills.

The leaders of the project took a participatory action approach to the development of the program and its evaluation. One of the key goals of the project was to empower the members, through their participation in the research and design process, to continue to develop innovative programs for women and assist them to compete for service funding.

Project Description

The project involved a review of the BRIDGES curriculum and an identification of the ways in which women's issues and needs are subsumed under gender-neutral approaches to peer support. Changes to the curriculum included identifying and explaining why a women-centred approach to peer support might be useful to women and identifying issues that, although not always unique to women, might have a different impact on women than on men (Appendix B

and C in Burrill & Dechief, 2001). For example, the redesigned curriculum dealt with women's experiences of violence, women's self-esteem issues, and the stresses caused by women's multiple roles as mothers, partners, caretakers and paid workers. In recognition of the diversity among women, issues related to racism, homophobia and socioeconomic status were also addressed. Further, the curriculum paid special attention to mental health problems that most effect women, such as depression, anxiety and personality disorders, and addressed what is currently known about the interaction of psychiatric medications with female hormones. Attention was also paid to the unique struggles of women living in rural and northern communities, such as coping with isolation. Women were also connected to a wider range of support options in the community (e.g., women-serving organizations).

The Women's Contact Society and WL ACME carried out the project jointly. Groups began on January 10, 2001 and ran for 16 weeks (three hours per week). Participants received an honorarium each week to assist them with transportation and childcare costs. Participants were recruited through a pamphlet designed by WL ACME, which was distributed to community organizations and individuals who had contact with women with serious mental illness. Letters were also sent to physicians in the area, with a copy of the pamphlet enclosed. Project team members made presentations to local service providers. In the end, seven

women, including two Aboriginal women, completed the program, all of whom had different diagnoses and were at different stages of wellness. The program culminated in a “graduation” ceremony at which the women who had completed the group were celebrated for their accomplishments.

The research team was composed of four consumer members of WL ACME, the Executive Director of the Women’s Contact Society, a staff member and therapist from the Cariboo Community Health Service Society Mental Health Centre, two research consultants from Northern FIRE and an external evaluator. The First Nations Hospital Liaison Program Coordinator, who was invited to participate in the team, was unable to make a commitment to the project because of time constraints. One of the key features of this collaboration was that it supported the consumer members in leading the project and made adjustments to the project timelines when members became ill and needed time-out or additional supports.

Evaluation

Using the principles of participatory evaluation (Health Canada, 1996) the consumer leaders and project coordinator were involved with the evaluator and the research consultants to develop the evaluation plan and the indicators of success. In this approach to evaluation the process and outcomes were seen as interconnected. A key

feature of the evaluation was to find ways to develop success indicators that recognized the limitations of traditional evaluation indicators and the need to tap into a variety of data sources for assessing the usefulness of the group. Several evaluation tools were employed using multiple perspectives—the perspectives of the research team, the project leaders and the participants. Ongoing data collection methods were used; data were collected from a variety of sources at a number of different points throughout the project. All of the sources of data were qualitative and were aimed primarily at understanding the meaning and impact of the group on the women participants.

It was originally hoped that a control group, as in a regular BRIDGES program, could be run concurrently to compare women participants’ experiences in each group. This would have enabled the evaluator to indicate whether women experienced the women-centred curriculum differently than the generic, co-ed BRIDGES curriculum. Unfortunately, at the time of the study the research team was unable to enlist enough participants to form two groups. Consumer/survivors come to Williams Lake from a number of smaller communities in the area and participation in programs is affected, particularly in the winter months during which time the RESPECT program was offered. Notwithstanding the absence of a control group, it had already been established, prior to this project, that

women in the community desired women-only peer support programs, suggesting that generic co-ed programs like the BRIDGES model would not be able to meet the needs of all women.

The following materials were used to evaluate the project:

- Participants submitted weekly feedback forms. These forms helped to assess the relevance of the knowledge they were gaining through the group.
- Participants kept journals to record their thoughts about the group and to chart their self-development.
- The leaders and the project coordinator also kept journals to record their thoughts about the group process.
- At mid-term, the project team led a participatory workshop with the group participants to check in and make any adjustments needed to the curriculum or running of the group.
- A “mapping connections” activity was conducted twice during the program to look at what kinds of connections, social support and access to healthy environments that participants had gained through their participation in the group.
- Participants completed a goal-setting exercise at the beginning of the project and returned to consider whether their goals and objectives changed and/or began

to be met over the duration of the project.

- At the end of the project, a focus group was held to assess the participants’ experience of the group.
- A one-month reunion of the participants was held in order to consider whether participants were able to carry out their goals, and to assess barriers and supports for achieving the goals.

In assessing the success of the project a number of indicators were drawn up, including:

- increased participant knowledge about her diagnosis and about coping with her illness;
- provision of a safe, supportive environment for participants to discuss important issues in their lives;
- increased participant self-esteem, personal strength and skills;
- decreased participant isolation within the community;
- increased participant ability to form goals and take the steps to meet them;
- increased knowledge, skills and self-esteem of the project’s leaders;
- positive impact on the organizations involved in the projects.

The evaluator wanted to determine if the group’s women-centred curriculum helped women feel more confident in their knowledge about their mental illness and

The evaluator wanted to determine if the women felt empowered to form new life goals and to take steps to achieve them, and what impact the group had on the four women, consumer/survivors, who developed and led the group.

its treatments; if the women felt empowered to form new life goals and to take steps to achieve them; and what impact the group had on the four women, consumer/survivors, who developed and led the group and who were at a different stage of wellness than some of the participants.

As indicated, the data collected from a variety of sources were qualitatively analyzed on an ongoing basis through regular check-ins with group leaders and participants. This participatory/collective analysis was used to continually improve the program and to deal with challenges that arose. Data collection and analysis were thus reciprocal processes.

Evaluation Outcomes

The outcome of the evaluation suggests that the group was very successful in meeting its stated goals and objectives. The evaluation indicators suggest that both the education and empowerment goals of the project were met. With respect to education, the women participants reported that they left the group with a better understanding of their illness, the side effects of

medications and what they individually required to maintain wellness. Women also reported a better understanding of the specific challenges that women with mental illness face. One of the offshoots of this was that some reported being able to better cope with their illness and to stabilize more quickly after a period of illness. Women also reported a better understanding of how to navigate the mental health system and a better understanding of their rights within the system.

With respect to empowerment the group process itself helped women to feel more confident about themselves and less anxious about participating in the group discussions. For some women, this assisted them in their lives outside of the group. Women reported that they had more positive connections with others, in part because of the safety and support they experienced in the group. One key aspect to attaining this safety was the role of the consumer group leaders who modeled the guiding principles of the group in their behaviour. This modeling included actively soliciting feedback from the group members along the way and shifting the activities to respond to the

needs of the women. With respect to setting personal goals and being able to begin following through on these goals, women reported feeling more focused, better able to manage their time and more hopeful that they would reach their goals. One woman was able to begin working again, two women were taking steps by the end of the group to leave abusive relationships and several became engaged in advocacy about mental health issues in their community. Another indication of the positive role the group played for the women was that the women decided to keep the group running past its initial end date (the group now meets once a month at WL ACME) and discussed how they might support the development of more women's groups in the community.

The four project leaders, all of whom were consumers, also reported positive outcomes as a result of their involvement in the development of the project and the running of the group, and described the positive learning and increased confidence that resulted. Like the participants in the group, the leaders also described making changes in their

lives as a result of their involvement in the group, including seeking other forms of employment and establishing new contacts and relationships. Leaders reported a deeper understanding of how mental illness affects women and a better understanding of how to apply a gender analysis to mental health issues. Further, throughout the project the leaders developed research skills, including knowledge about proposal writing and ethical review processes. They also learned how to design peer support curriculum and reported that they felt they had gained better problem-solving, communication and teaching skills.

Two of the leaders were admitted to hospital shortly before the project was scheduled to begin. It is unclear whether the pressures of preparing for the group played a role in these women's illness, however, both were able to rejoin the project when they were well and both went on to be successful leaders of the group. Although the leaders and participants strongly supported the leadership role of consumers in the group, the leaders felt that the occasional participation of mental health

The women participants reported that they left the group with a better understanding of their illness, the side effects of medications and what they individually required to maintain wellness.

Women felt more comfortable talking about issues that they might remain silent about in co-ed groups, such as sexuality and experiences of sexual or physical violence.

professionals as guests to discuss certain topics would be a helpful addition to the group. Suggested guests included a psychiatrist knowledgeable about drug side effects and women, and a counsellor specializing in suicide prevention.

All of the participants and all of the leaders indicated that the group's women-only design, which specifically took into account how women's life experiences differ from men's, afforded them a comfort and a degree of safety that they had not always experienced in co-ed groups. Women indicated that they felt valued as women and that this feeling led to greater comfort in being able to talk about issues that they might remain silent about in co-ed groups, such as sexuality and experiences of sexual or physical violence.

The Whole Woman Project: Demonstrating the Role of Peer Support for Women Diagnosed with Serious Mental Illness

Vancouver/Richmond Mental Health
Network
Vancouver, B.C.

The information in this section is drawn from The Report of The Whole Woman Project: A Project of The Vancouver

Richmond Mental Health Network
written by JoAnna Carson, April 2000.
*The report is available through the
Vancouver Richmond Mental Health
Network.*

Project Background

The Whole Woman Project was initiated by consumer/survivors from Vancouver/Richmond Mental Health Network (the Network). The Network is a peer support, consumer-run organization for both women and men. It has a history of running women-specific peer support groups and peer support groups for specific ethnoracial communities such as Aboriginal, South Asian, and French Canadian. The Network was founded in 1992 and provides peer support, referrals and information for people who are using or who have used the mental health system. The Network also engages in community outreach and produces a newsletter called "The Bulletin". Working from an empowerment framework, the Network provides support to consumers and fosters capacity building through active involvement in the organization. Often acting as an advocacy organization, the Network has a commitment to address the social determinants of mental health (poverty, discrimination, and

homelessness) and to speak out against abuses in the mental health system. It is also committed to encouraging consumers to become less dependent on the mental health system; it does so by providing education about alternative programs and treatments for recovery and maintaining wellness.

In 1994/95 the Network ran a program called “Pathways to Healing”, which was designed to help consumers access treatments outside of the conventional mental health system. The success of the program was, in part, the impetus for the Whole Woman Project. Another impetus was an ongoing interest by the Network in the development of a “safe house”. The idea of the safe house arose from the Network’s experience with consumers, especially women, who have had experiences of trauma and abuse and have found it difficult to get the support they need from conventional mental health services. A safe house would provide a residential facility where women could work on their issues related to mental illness and trauma in a safe, supportive environment.

Consumer peers would run the safe house. Residents would include access to alternative and complementary forms of treatment such as counselling, massage therapy, and acupuncture. At the time of the request for proposals for the *Women and Mental Health Demonstration Projects Initiative*, the Network decided that submitting a proposal for the Whole Woman Project would provide an opportunity to implement and evaluate the safe house, peer support, alternative and complementary therapy model they had been developing.

Project Description

The Whole Woman Project was designed to test the efficacy of combining peer support, education/skill development and access to alternative therapies to promote the well-being and empowerment of women with serious mental health problems. The Whole Woman Project was guided by the belief that respect for women’s knowledge and choices are key elements of recovery and maintaining wellness. The specific goals of the project

The Whole Woman Project was designed to test the efficacy of combining peer support, education/skill development and access to alternative therapies to promote the well-being and empowerment of women with serious mental health problems.

were to:

- provide a safe, non-judgmental space for women;
- provide women with options and choices about what kinds of therapy and treatment they thought would be most helpful to them;
- provide a space where women could come to see themselves as “whole women”, that is to move from having a “patient” identity to understanding themselves outside of the lens of discrimination and stigma to see their own potential as women; and
- contribute to the development of a safe house for women.

An empowerment framework was used to guide the group, which encouraged women to take responsibility for their recovery and create goals to assist themselves. It was hoped that women would develop closer networks with peers, learn more about a variety of treatment options and find solutions that worked for them. Additionally, the group was designed to assist women to better understand the impact of discrimination and stigma and the unique effects of mental illness on women.

The project coordinator and committee worked with a variety of professional consultants to develop the educational modules that would guide the project. Professional consultants were chosen for their extensive experience in working with women with mental illness.

Educational modules included discussions about body image, self-esteem, violence against women, self-soothing behaviours, anger, conflict management, nutrition and about the effects of discrimination and stigma on women (i.e., sexism, racism, classism, homophobia). The modules also provided an introduction to the concepts of holistic health care and holistic therapies.

Peer support workers were hired to facilitate the groups. There was some fluctuation in who played these roles because two peer support workers dropped out of the process for personal reasons and needed to be replaced. In the end, two peer support people remained for the duration of the project. The original project coordinator also experienced difficulties and eventually resigned her position. An additional peer support worker was then hired and the three peer support workers shared the duties of coordination.

Participants were recruited through flyers; a screening interview was conducted with each interested participant. Ten women participated in the group, which ran for five months. The program did not attract a racially diverse group of women and it was concluded that better outreach was needed to attract women from diverse communities. The evaluators' participant profile revealed that the participants were well educated; however, their mental and physical health problems

generally precluded their involvement in the labour force. Only one participant had a job and this was part-time. All of the women were either on disability benefits (80%) or social assistance (20%). The majority of the women (90%) were not in a partner relationship and six of the participants were mothers (primarily of adult children). Four of the six mothers had had to give up custody of their children. Many of the participants had serious health problems (e.g., rheumatoid arthritis and osteoarthritis), half of the participants had had past alcohol and drug problems, and 30% were currently smokers. Half of the participants were taking psychiatric medicine: 80% anti-psychotics and 60% anti-depressant medicines. None of the participants had used hospital services three months prior to the project and four had already seen alternative health care practitioners in the past.

The group combined peer support meetings with the presentation of educational modules and facilitated access to alternative supports. Each participant was assigned a peer support worker to contact between meetings if needed; each woman was also paired with another participant in a “buddy system” to increase support.

In order to access holistic therapies, each participant was given a letter of introduction that could be given to an alternative practitioner. The letter described the Whole Woman Project

and the billing system that the Network had set up to pay holistic practitioners. In this way, once women had gained knowledge about alternative therapies, they were able to independently approach practitioners they wanted to work with. Each woman was allocated \$600 that could be used toward her choice of holistic therapies. One of the problems that arose was that practitioners were reluctant to bill the Network, which meant that some of the time women had to cover payments themselves and get reimbursement through the Network, and/or cash advances were handled by the peer support workers who had to accompany women to meetings with alternative practitioners or buy the recommended products for them. This added unexpected administrative tasks to the project and added to the workload of the Network.

Evaluation

The evaluation and the subsequent report, Evaluation of the Whole Woman Project, were conducted and written by Nancy Poole and Monika Chappell, July 2001.

The evaluation methods were designed to:

- provide a profile of project participants and the changes in key life areas that they experienced over the course of the five-month project that may have impacted on their participation;

By the end of the Whole Woman Project, 33% of participants had reduced their use of psychiatric medications and 88% reported considerable physical health improvements.

- determine if and how the project activities as a whole made a difference in the well-being and empowerment of the participants ;
- determine the impact of, and women's satisfaction with, the peer support aspect of the project, the skill building workshops, and the use of alternative and complementary therapies; and
- determine the feasibility of offering such services in the context of a safe house.

The first goal was evaluated by requiring each participant to fill out short profile forms at the beginning and end of the project in order to track any major life changes that would have an impact on the woman and her experience of the group. In order to determine if and how the project activities affected women's well being and empowerment, a measurement called *The Consumer Constructed Empowerment Scale* was used. This 28-item scale was developed with input from consumers and pilot-tested with self-help programs in the United States (Rogers et al., 1997). It was developed to measure the personal construct of empowerment as defined by consumers of mental health services. It measures dimensions of empowerment such as self-efficacy,

self-esteem, power, change, anger, and group/community action. This tool was administered at the outset and at the end of the project. Additionally, feedback forms were used after each session, self-reports were solicited through a focus group at the end of the project and an "art expression" exercise was used in order to elicit responses for women who were less comfortable with verbal expression. The project leaders kept journals, which were examined by the evaluators. An electronic survey was also sent out to the project leaders (two responded) and to the external workshop facilitators (one responded).

Evaluation Outcomes

Participants

The short profile forms that were filled out at the beginning and end of the five-month project revealed several noteworthy changes in the women's use of alternative services (alternative to crisis and/or inpatient services). Thirty-three percent of participants had reduced their use of psychiatric medications and eighty-eight percent of the women who completed the group reported considerable physical health improvements (e.g., having more energy, feeling calmer, less disordered eating). Thirty-three percent had used

other supportive services as a result of their involvement in the group (e.g., mental health team workers, a dual diagnosis program, a Buddhist retreat). With respect to changes in employment, one woman had begun a vocational program but found that her symptoms (related to past abuse) kept her from continuing. One woman was about to complete 100 prerequisite volunteer hours related to a course at one of the colleges and was able to do some volunteer work.

Throughout the program, women also faced important life challenges that may have directly or indirectly affected their experience of the group and the alternative treatments that they used. For example, the living arrangements of 44% of the participants had changed, 33% of the women reported deterioration in relationships with friends or children and one woman was dealing with sexual harassment from an ex-partner. Additionally, one woman was diagnosed with cancer during the course of the group and another woman contracted pneumonia.

With respect to participants' reports of how the project affected them, the *Consumer Constructed Empowerment Scale* was used both at the outset of the project and at the end. The initial test revealed that the women in the group were already quite empowered, coming into the project with an overall average score of 3.12 out of a possible 4 (range 2.76-3.71). This score compares as only

slightly lower than that of college students (3.16) but considerably higher than that of patients in a state hospital (2.29) (Rogers, et al., 1997). All but one woman improved her score according to this scale, with women reporting the most improvement in self-esteem and feelings of power. The area that showed least improvement was that of community activism, but this was not a formal component of the group. Women also reported on their feelings of empowerment in the focus group; in particular, women reported feeling more empowered in their interactions with care providers. Despite these positive results women also reported challenges, especially with respect to physical health and the ongoing regulation of their lives through the mental health system.

With respect to changes in knowledge and skills that the participants gained from the educational modules, the women overwhelmingly (80 to 100%) reported that they enjoyed them and found them useful. Especially useful were the sessions on nutrition, research and holistic therapies. Women reported that the supportive learning environment and the opportunity to share information with other women during these sessions were also really important to them.

With respect to reported health changes as a result of the use of alternative therapies, women indicated many changes in their health status. Although a variety of alternative therapies were used (including aromatherapy, naturopathy, EMDR therapy, cranial sacral massage,

acupuncture, Tai Chi), interestingly, the majority of women chose nutritional therapies and reported changes in nutritional habits that increased their energy and decreased symptoms of illness.

It is difficult to fully assess the role that alternative and complementary treatments played for women in the Whole Woman Project, in part because the project was too short for any long-term follow-up regarding this. Another difficulty is in knowing what to attribute women's self-reports of change to: was the change the impact of alternative treatment, better knowledge about specific mental health problems, peer support, or some combination of the three? Despite this, women in the group and the group leaders all highly valued the alternative treatment component of the Whole Woman Project. Women reported many changes in their physical and mental health status, which they attributed to the treatments they pursued. Additionally, they demonstrated a deeper knowledge about the interconnections between their physical, mental and spiritual health as a result of the project. Studies suggest that people's satisfaction with their care is heightened if they play a role in decision making (Wensing, Jung, Mainz, Olesen & Grol, 1998). The fact that women were able to exercise this kind of choice, regardless of income, may have been a major factor in their reports of positive effects in this project.

The value of mutual aid and peer support was affirmed by the participants. Much of this support took place within the context of the information/skill development sessions. Participants, however, were critical that the peer support sessions had not been fully implemented; that is, that the educational sessions were the main focus. They felt that group (rather than one-to-one) peer support sessions should have been more of a focus throughout the project.

Participants were sensitive to changes in project leadership and felt the impact of the changes with respect to peer leaders leaving. In particular, the fact that this also caused financial difficulties with respect to paying for alternative therapies meant that many women had trouble getting reimbursed in a timely manner. They recommended that peer leaders be better screened to ensure their ability to provide peer support and lead groups and that a better infrastructure be set up to run this kind of project. In general, participants recommended a more organized and coordinated approach to the project's three components and emphasized that they wanted a strengthening of the peer support component and more assistance in choosing and evaluating alternative therapies. Even with these limitations, however, they supported the continued testing of the project model on an outpatient basis and agreed this model might be useful in the context of a safe house.

Participants also spoke about how the information they received from the group and their holistic practitioners was not always consistent with their treatment by psychiatrists. In particular, as women learned more about their illness and the side effects of the medications they were on, they began to demand more from their psychiatrists with respect to possible alternatives to the drugs they were on.

Providers

The facilitators and peer group leaders all felt that the project had had an overall positive impact on participants. In particular they pointed to the alternative therapies as being the most useful for women. Their negative comments were focused on the project management and lack of consistent leadership. They also felt that more assessment expertise and group facilitation expertise were needed. Finally, they indicated that the participant recruitment process could have been better, especially to recruit more diverse groups of women and to be sensitive to the needs of diverse women.

The project leaders felt that the program would work well in a residential setting, but suggested that it be offered over a longer period of time on an outpatient basis, with more opportunities to integrate the material. There was also a suggestion that the additional support of a trained trauma therapist might be useful.

In conclusion, it is clear that the project had favourable outcomes for this group of relatively stable and educated women. It is not clear whether the group would have had the same outcomes for a group of women with more extensive issues or more severe illness, or whether the women who participated would be able to sustain the benefits they reported.

B. Professional Assisted Models

In this section, two projects are described that involve the development of specific therapies for women. In the first instance, a group treatment program was developed for women who have co-occurring mental illness and developmental disabilities and are also survivors of sexual abuse. In the second instance, a therapy program was designed for women with mental illness who have small children to assist them in developing relationships with their children. These projects differ from the two peer support projects previously described in that they involve mental health professionals in the design and delivery of the two programs. However, in keeping with the principles of women-centred mental health care, both projects actively involved the consumer populations they were working with in order to solicit their input. The two projects shared a common goal of addressing the needs of populations of women who have often been marginalized in traditional mental health care treatment.

Improving Mental Health Outcomes for Women Diagnosed with Serious Mental Illness and Mental Retardation/Developmental Disabilities Who Have Violence and Trauma Histories

Fraser Valley/West Coast Mental Health Support Teams
Vancouver, B.C.

The information in this section is drawn from the report Improving Mental Health Outcomes for Women Diagnosed with Serious Mental Illness and Mental Retardation/Developmental Disabilities Who Have Violence and Trauma Histories by Kim Burton, which is available through the Fraser Valley/West Coast Mental Health Support Teams, Vancouver, B.C..

Project Background

This project was initiated by the Fraser Valley/West Coast Mental Health Support Teams to address particularly vulnerable populations: women with development disabilities, mental illness and histories of sexual abuse. The Fraser Valley/West Coast Mental Health Support Teams are specialized interdisciplinary teams staffed by a mental health nurse, a mental health worker and a health care worker. Prior to this project the teams had identified that the needs of their clients with co-occurring mental illness, developmental disabilities and sexual abuse histories were not being fully met by the teams or by other organizations in the community.

Research has documented the particular needs of this group of women, as well as the high proportion of women in this population who have been sexually abused (Sobsey & Mansell, 1990; Nosek & Howland, 1999; Masuda, 1992; Waxman, 1991). The interconnections between early childhood trauma and mental illness have been widely discussed in the literature (Harris, 1997; O'Donohue & Greer, 1992). Poverty, communication difficulties and social marginalization can make it very difficult for this group of women to access programs for abused and assaulted women (e.g., transition houses, shelters, women's centres). Further, beliefs that people with cognitive challenges are unlikely to benefit from therapeutic treatments, and the fact that there is little research or understanding about what kinds of treatments are effective for this population, are additional barriers (Burton, 2001).

Project Description

The main objective of this project was to improve the mental health outcomes for women with developmental disabilities who have been diagnosed with serious mental illness by directly addressing their sexual abuse histories, through group work and the development of individualized treatment plans. Further, by drawing on other mental health and anti-violence organizations in the community, it was hoped that this project would augment the existing

service system and ultimately result in a wider range of support services for this group of women.

Referrals to the project were made through the regular intake process of the Fraser Valley/West Coast Mental Health Support Teams and by contacting other organizations in the community that offer services to diverse groups of women, such as Aboriginal women's organizations, women's centres, shelters and community centres. Some of these organizations already had established relationships with the Fraser Valley/West Coast Mental Health Support Teams, but others were contacted for the first time during this project. The service providers from these organizations were solicited to provide input directly to the project based on their knowledge about the needs of the women they serve. This information was gathered through a questionnaire and used to inform the program development.

At the outset women who were referred to the program were invited to take part in an assessment for participation in the group. Assessment tools included:

- a structured interview to determine the participant's goals for the group;
- the *Global Assessment and Functioning Scale* (GAF) to determine behaviour and functioning pre- and post-treatment;

- the *Clinical Global Impression Scale* (CGI) to assess severity of mental illness (extremely ill clients were not recommended for group counselling);
- the *Aberrant Behaviour Checklist* (ABC) was used to assess caregivers' perceptions of the kinds of problem behaviours the women had and how they experienced these in their community;
- an adapted *Post-traumatic Stress Disorder Scale* (PDS) was administered to see if women were experiencing post-traumatic stress symptoms. This tool is not designed for persons with developmental disabilities. A modified version was used with women who required assistance with comprehension and communication;
- the *Play It Safe Game* (Blue Heron Productions, 1998) was used to gain information about a woman's knowledge of safe and unsafe situations and safety strategies;
- women were invited to create a sandtray at the beginning and end of the group. *The Sandtray Categorical Checklist* (Grubbs, 1997) was used to look for signs of strength, progress, working through or integration.

Supportive family members and workers were also invited to this assessment in order to understand the project and its goals better. Comment and suggestions

from these support people were welcomed throughout the project. Women were informed of their confidentiality and client rights and understood that they could leave the group at any time. From this process 12 women were invited to participate.

All of the participants had been diagnosed with a developmental disorder (in the mild to moderate range), with a serious mental illness (e.g., depression, dysthymia, anxiety, obsessive compulsive disorder, and bipolar disorder) and all met the criteria for post-traumatic stress disorder. All of the women who participated had either documented histories of sexual abuse or were suspected of having been abused according to past documentation. In addition, three women had diabetes, two had cerebral palsy and one had early symptoms of Alzheimer's.

The women were from diverse cultural, ethnic and socio-economic backgrounds (five of the participants were from minority ethnic and racial groups) and ranged in age from 26 to 47. Many of the women struggled with issues related to poverty, including access to housing (one woman moved into a supportive living situation over the course of the project) and especially access to transportation (this project took place during a bus strike). The degree to which women required assistance from other people varied; for example, many women were accompanied by their support workers to the group and some

needed assistance with daily living activities (e.g., going to the bathroom, reading and walking). Two women were being assessed as to whether they required more support as a result of physical disabilities.

The group leaders were highly experienced mental health workers who had expertise in the area of developmental disabilities, mental illness and sexual abuse. The group leader was a registered clinical counsellor and the co-leader was a mental health nurse. The group took place at the Fraser Valley/West Coast Mental Health Support Teams' offices and women were encouraged to interact socially through the provision of breaks with drinks and snacks. The treatment offered by the group included providing the women with the option of getting one-to-one support from group leaders. Women were especially encouraged to use one-to-one support to discuss their experiences of abuse.

Three groups of five, four and three women were run for a period of 10 weeks. Women were asked about what they wanted to accomplish in the group. Their goals and experiences with service delivery were used to guide the group process. A number of different modalities were used in the group including sand play, art, music, games, books, videos and discussion. Current knowledge about the impact of trauma on women's self-perception, attention, and relations with others was applied to

Psychoeducational approaches that promote personal safety were used in sessions where women were able to safely talk about their sexuality and interpersonal relationships.

assist women to develop coping skills to reduce the intrusive effects of trauma and to prevent revictimization. For example, women were helped to develop containment skills, affect management skills and breathing and relaxation techniques to reduce stress and enhance self-control. Further, psychoeducational approaches that promote personal safety were used in sessions where women were able to safely talk about their sexuality and interpersonal relationships. Feminist frameworks for understanding abuse and for empowering women were used in the sessions. In some instances, women were given the support and advocacy they needed to deal with current situations of abuse. For example, one woman was still seeing her ex-husband out of fear he would withdraw child support and maintenance payments; she was helped to understand her legal rights and was given permission to draw boundaries.

Community education was an important part of this project. Women in the group gave their support people (family, friends, other mental health workers and professionals) information about trauma and abuse that they had learned in the group sessions, which included facts about sexual abuse, risk factors,

prevention, what to do when someone discloses abuse, and the development of protocols. In addition, a forum was organized that brought together service providers in the community, women with mental illness and developmental disabilities and their supportive family and friends to share knowledge and discuss concerns about the needs of abuse survivors in this population.

Evaluation

The groups were evaluated in a number of different ways. Qualitative information was gathered through follow-up interviews with the women, who were invited to speak about what they found most useful about the group and were encouraged to carry over the skills they had learned into their day-to-day lives. Additionally, a structured interview was conducted to see whether the women had attained the goals they had set for themselves. Finally, each of the tools administered at the beginning of the group (e.g., *Global Assessment of Functioning*, *Clinical Global Impression Scale*, *Aberrant Behaviour Checklist*, *Post-traumatic Stress Diagnostic Scale*, the *Play It Safe Game* and *The Sandtray*) were also administered post-group.

The community survey was also

evaluated, as were the answers to four questions that were posed to participants in the community forum.

Evaluation Outcomes

Three distinct themes arose from the qualitative information that was gathered from the women participants: identification and belonging (53%), sex education and abuse prevention (28%), and affect management (19%). Women reported that the group broke their isolation and gave them a sense of a community with the possibility of lasting friendships, that they now had more information and personal resources with respect to sexuality and abuse prevention and, for some, that they had learned new social skills (e.g., use breathing and stress reduction exercises rather than crying or yelling). The structured interviews revealed that the top three goals for women were to make friends and share feelings, know how to protect one's self and feel good about one's self. All of the women reported attaining and, in many cases, exceeding these goals. Analysis of women's strong desire to feel good about themselves, however, did not reveal very many comments directly suggesting that the group affected women's self-esteem; rather this was suggested indirectly through women's comments about their feelings of belonging and having gained knowledge and skills about abuse prevention and affect management.

The small size of the groups meant that

the quantitative measures could not be statistically analyzed. However, the results from the various assessment tools suggested that women had improved psychological, social and occupational functioning and suggested a decrease in severity of mental illness. For example, pre-group mean scores fell within the "moderately ill" range while post-group mean scores fell in the "borderline mentally ill" range.

Women in the group had had a range of experience with sexual and physical abuse. Eleven women reported physical assault by a family member or someone known to them, nine reported sexual assault by a family member or someone known to them, eight reported being sexually abused before the age of 18 by someone five or more years older, four reported being sexually assaulted by a stranger, two reported life-threatening illness, one reported torture and one reported physical assault by a stranger. The results of the *Post-traumatic Stress Diagnostic Scale* (which is meant to measure PTSD symptoms as defined in the DSM-IV) suggest an overall decrease in PTSD symptoms for the women, especially with the phenomena of "re-experiencing" abuse (e.g., "flashbacks" to the traumatic experience).

The *Play It Safe Game* (Blue Heron Productions, 1998) is useful for obtaining information about women's knowledge of safe and unsafe situations and safety strategies. Most of the

women demonstrated increased knowledge about safety at the end of the group.

Women's sandtrays were qualitatively compared before and after the group using *The Sandtray Categorical Checklist* (SCC) to assess for signs of strength, progress, working through and integration. Some of the sandtrays suggested an increase in internal ordering toward the centre of the tray, a potential indication of personal development.

Overall, the results of the evaluation suggest highly positive outcomes for the women who participated. The group process helped women to feel less isolated and provided a space where they could comfortably address their issues related to experiences of sexual abuse. Some women who had received counselling prior to the group felt that the group experience consolidated their learning, which allowed them to decrease therapeutic support and/or to use continued support to improve their social and occupational functioning. It was suggested that group "refresher courses" could be given to allow women to practice the skills they had learned and to continue the development of self-capacities and systemic supports.

Finally, larger group sample sizes and control groups must be used in the future to determine effectiveness and if the results from this evaluation can be replicated and extended beyond this

group of women.

The community survey that was distributed prior to the start of the group to assess the knowledge of providers in the community, suggested limited understanding of the issues faced by women with developmental disabilities who are sexual abuse survivors. At the end of the community forum, participants were asked four questions to determine what information had been most useful, whether or not the information had affected their thinking, and what actions they might take in their agencies as a result of their participation in the forum. The results suggested that participants found the forum very valuable in providing information about abuse and how to support women. Participants reported that the forum provided a space for service providers to get to know each other and reinforced a sense that everyone should be supporting women abuse survivors. Participants reported increased knowledge about sexual abuse issues and this population of women; they also reported a better understanding of how group therapy can be useful for these women.

Most significantly, results suggest that organizations were willing to provide more information and support to their clients on these issues. For example, some participants said they would be able to run a similar group for women while others felt they could encourage connections between women abuse survivors more informally. Some

participants said they were committed to getting more information about the issues through research and by identifying available resources for treatment. Finally, suggestions were made to follow up with the women who had participated in the group in order to see if they retained the benefits gained.

Theraplay for Mothers with Mental Illness and Their Children

Chilliwack Mental Health, Chilliwack, B.C.

The information in this section is drawn from the report entitled Theraplay, Assisting Mothers with Mental Health Issues in their Relationships with their Children, by Marion Fallding, available through the Chilliwack Mental Health Centre.

Project Background

This project was meant to address the needs of mothers diagnosed with mental illness and their children by providing a therapy program that would improve the relationship between these mothers and their young children (ages 4 to 9).

Mothers with mental illness face particular challenges with respect to parenting, related both to the impact of their illness on their ability to parent (Hamilton, Jones & Hammen, 1993; Oyserman et al., 1994) and on the social conditions and discrimination that face mothers with mental illness (e.g., single-parenthood, poverty, the belief

that they cannot be good mothers). For example, women are more likely than men to seek psychiatric help and thus come under particular scrutiny by the mental health and child welfare systems if they are mothers or expectant mothers (Mosoff, 1997; Mowbray, Oyserman, & Ross, 1995). Many women are afraid to seek help and support for fear that they will be closely scrutinized and/or that they will lose custody of their children.

Each of these factors suggests that specialized supports are needed for mothers with mental illness to form close attachments to their children. Theraplay is a specific form of therapeutic intervention to assist mothers to meet the primary needs of their children through experiences that enhance the mother's self-awareness, self-esteem and trust (Jernberg, 1998). In an experiential setting under the guidance of a trained therapist, Theraplay focuses on both the needs of the mother and the child for:

- nurturance (e.g., activities that are calming and soothing where both mother and children feel loved and valued);
- structure (e.g., activities that teach boundaries and a sense of trust and security);
- stimulation (e.g., to facilitate learning and adaptation to change); and
- challenge (e.g., to address issues of competence through activities that will increase self-esteem, self-confidence and a sense of

competence).

Project Description

This project was conducted in Chilliwack, B.C., a small rural city. Clients were also drawn from the neighbouring community of Abbotsford. Mothers with mental illness with children between the ages of four and nine were recruited through Adult Mental Health, Child and Youth Mental Health, Public Health, the B.C. Schizophrenia Society (which has a specialized program for children of parents with mental illness), the Ministry of Child and Family Development, family physicians, and a pre-school program for children. Advertisements were also placed in local newspapers. Through these methods, 13 dyads of mother and child were recruited for the 12-week program. One group participant left before the group began just after she had completed the pre-test, stating that the stress in her life was too great to commit to the program. Two other women left the group after it started, one after the fifth session because she felt the group was not suitable for her and one towards the end of the sessions when she was hospitalized. A fourth mother missed about half of the sessions due to depression and feelings of being overwhelmed. The remaining nine dyads attended regularly. Although women attended the group with only one child, some of the women had other children as well.

The women in the group had a variety of diagnoses including depression, post-partum depression, anxiety, bipolar disorder, borderline personality disorder, disordered thinking with paranoia and attention deficit disorder. Many of the women described the fathers of their children as also having mental or emotional problems that impeded the fathers' relationships with their children. Many of the women were separated and the degree to which the fathers of their children were involved in parenting varied; some reported their children had good relationships with their fathers and others related that their children did not have good relationships with their fathers.

Evaluation

Three questions guided the evaluation.

1. Is Theraplay effective in enhancing the mother's relationship with the child?
2. Is Theraplay effective in reducing the mother's stress in parenting?
3. Is Theraplay effective in reducing the child's problematic behaviours?

Qualitative and quantitative measures were used in the evaluation, including pre- and post-structured interviews, a tool used to measure a mother's self-reported attitudes toward parenting and their child (i.e., the *Parent-Child Relationship Inventory* (PCRI) (Gerard, 1994), the *Marschack Observational Interview* (Jernberg, 1998), which provides

information about the mother-child relationship, the *Parenting Stress Index* (Abidin, 1995) which identifies stressors that are experienced by parents, and the *Child Behaviour Checklist* (Achenbach, 1999), which identifies the child's problematic behaviours.

Pre-group interviews suggested that women were experiencing various degrees of difficulty in the mother-child relationship. For example, women reported being impatient with their children, having difficulty relating to their children, conflict with their children, difficulty setting limits, feeling guilty, communication difficulty and feelings of inadequacy. All of the women reported that their mental and emotional difficulties impaired their relationships to their children. The *Parenting Stress Index* also indicated that this group of women had higher than normal stress in their lives.

Although not all women reported that their children had problem behaviours, those who did reported that their children had poor social skills, hyperactivity, aggression and attention and learning problems. Some women also reported that their children were having difficulty as a result of witnessing the abuse of their mothers by their ex-partners or because of problems with the children's fathers. At least one woman spoke about how her child was taking out anger on her.

Evaluation Outcomes

As in the previous example, the sample size of this group was too small to permit statistical analysis of the data.

Post-group interviews revealed that women had learned new ways of relating to their children, primarily through increased play and a better understanding of their children's needs. These effects seemed also to extend to women's behaviours with their children who did not attend the Theraplay sessions. Some women reported that they were able to acknowledge and express their own emotions more and to identify their children's feelings more accurately. Women who had previously experienced a lot of anger at their children reported using more nurturing behaviours and skills for de-escalating conflict. Some women also reported a reduction in stress, although most indicated that because their external circumstances had not changed (e.g., financial stress, illness) their stress levels were the same. In general women reported feeling closer to their children. The post-group *Parenting Stress Index* suggested that despite continuing high levels of stress in the women's lives, half of the group showed a change in stress directly related to parenting and to their children. The *Parent-Child Relationship Inventory* showed similar results.

Not all of the mothers noted changes in their children's behaviours as a result of

Theraplay, but those who did suggested that their children were calmer, more communicative, cooperative and happier. Prior to the group, the *Child Behaviour Checklist* showed that five of the children exhibited problem behaviours. There was not a consistent pattern of post-group improvement for these children. The responses were mixed: one child showed improvements in one area but not in another; three children showed consistently positive responses; in two cases the children's behaviour worsened. In the latter instance, for one child it was felt that factors external to Theraplay (i.e., very disturbing family events) had precipitated this. Explanations for worsening scores or mixed scores may be that mothers felt more able to talk about their children's problems following the Theraplay experience.

In general, women reported positive experiences with Theraplay, with all of them reporting that it enhanced their relationship with their child. The

quantitative measures suggest that eight out of nine mothers improved on at least one index. One mother-child dyad improved on six of seven scores, three mothers improved on five indices, two on four indices, and one mother on none.

There is thus some evidence to suggest that Theraplay is a useful tool for assisting mothers with mental illness in parenting their children. However, further investigation is needed though the use of larger sample sizes and control groups. One key factor impeding the ability of the group to attract more mothers appeared to be that practitioners in the community have a low awareness of the needs of mothers and their children, as evidenced by the lack of referrals from these practitioners. Most of the women in the group referred themselves after seeing the ads in their local newspaper.

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VIII

Discussion

Factors That Contributed to Success

The time-limited nature of these projects and the small sample sizes did not allow for statistical analyses or generalization of the results. However, the evaluations strongly demonstrate that the women who participated in the programs did benefit from their experiences. In some instances these benefits also appear to have been sustained over short periods of time (i.e., up to three months post-project). A number of different factors contributed to these successes.

Women-Centred Mental Health: Building Knowledge and Skills

Each project design differed in the degree to which the principles and methods of women-centred care were used. However, participants responded well to aspects of the project's programming that were women-centred. For example, women in the groups strongly validated the importance of women-only programming conducted using a women-centred framework that conceptualizes women's lives in a holistic way. That is, women reported better knowledge and understanding of their mental health problems and, in particular, increased knowledge about concerns (both medical and social) specific to women. This knowledge appeared, in some of the projects, to translate into better self-advocacy and self-care skills, as well as to better skills in dealing with important primary relationships with children and partners. There is some evidence to suggest that this knowledge and skill building reduced some women's dependence on the mental health system and improved their mental health status.

Individual and Community Capacity Building

The projects were either consumer/survivor conceived and led or had significant consumer involvement in the planning and

implementation stages. The respectful treatment of women as active participants in their own recovery process and, in some instances, in the research process itself appeared to build capacity for individual women in unique ways.

Women who led projects reported that they gained research, analytic and facilitation skills. This is specifically significant in the context of rural communities such as Williams Lake where geographic isolation often makes it difficult to develop the skills necessary to conduct research. The role of participatory action research (PAR) was key, especially in the Williams Lake example. PAR is a methodology that explicitly recognizes the interconnections between theory and practice and uses methods that actively involve the community that is being researched at every step of the research process. While contributing to theory building, the very process of PAR often results in positive changes for the communities that participate. This was borne out in the RESPECT project.

Participants in the projects also reported increased self-esteem and confidence that had a direct effect on their lives in a variety of ways. For example, in some instances women who were previously unemployable gained employment and, in other instances, women reported better relationships with their children.

In the case of the work done by the

West Coast/Fraser Valley Mental Health Teams, the involvement of women's supportive family and friends, as well as the engagement of other mental health professionals and community-based organizations throughout the development of the project, are clear examples of community capacity-building, where the project had an impact beyond the individual women for whom it was designed. In this instance, there was a genuine effort to help groups in the community build their knowledge about women with mental illness, developmental disabilities and abuse histories so that better services could be provided.

Collaborative Partnerships

Collaborative partnerships played an important role in each of the projects. These partnerships typically developed between a number of different organizations and academic researchers. Each of the projects was supported through the British Columbia Ministry of Health Services (formerly B.C. Ministry of Health), which took to heart the recommendations from the report that they had helped to fund, *Hearing Voices: Mental Health Care for Women*: specifically, that women with chronic and persistent mental health problems might benefit from programs designed to address the unique needs of women (Morrow & Chappell, 1999). The Ministry provided funding to the British Columbia Centre of Excellence to support, manage and evaluate the four

demonstration projects. The British Columbia Centre of Excellence for Women's Health in turn developed a relationship with each of the projects and supported the leadership of consumers. Each project established relationships with academics, community-based organizations and other mental health professionals to develop and implement their projects. These collaborations allowed for the exchange of information and yielded programs that were informed by a variety of different vantage points.

Ongoing Challenges

The projects experienced challenges related, in part, to their time-limited "demonstration" nature, but also to other kinds of constraints detailed in the next section.

Research Requirements: Partnership Models

Although, as indicated above, partnership models were one of the key strengths of each of the projects, certain challenges arose from these models, especially for the consumer-led, peer support projects. In particular, the

demands and expectations of academic researchers could not always be met due to lack of resources. In Williams Lake, the British Columbia Centre of Excellence for Women's Health had hoped that two groups (one women-only and one co-ed) could be run simultaneously in the community so that the co-ed group could function as a control group. In this way the evaluator would have been able to compare the experiences of women in a co-ed group with those of women in a women-only group. However, as reported by the project leaders of RESPECT, this demand placed a lot of stress on the participating organizations which found it difficult to recruit enough people for two groups with their limited resources. This example points to a broader issue that is always at play in any academic/community research partnerships. Often the resources (in terms of money and research knowledge) are held primarily by the academic researchers, who then hold their partners to research standards that prove difficult to meet. In part, what is also at issue here is what kinds of research are considered legitimate by the broader research community. Given the limitations outlined at the beginning of this report with respect to traditional evaluation for women-centred programs,

In the design of the evaluation, one of the challenges was the lack of specific evaluation tools and measures for women-centred programs to draw from. In many ways these projects were breaking new ground.

it becomes clear that these standards may be inappropriate for understanding the usefulness of programs that are designed for women.

In the design of the evaluation, one of the challenges was the lack of specific evaluation tools and measures for women-centred programs to draw from. In many ways these projects were breaking new ground.

Resource Limitations

The resource limitations of individual organizations and of isolated rural communities was another issue that was raised. Some participating organizations did not feel they had the resources to meet the demands of the projects (as described above). Some organizations felt that the work they were doing could have been better supported by the mental health community. This is particularly critical for women after they leave a program and may seek ongoing support from other organizations in their communities. This was exacerbated by the fact that most communities do not have women-centred programs; that is, no other organizations or professionals were available who had specific knowledge about women with serious mental illness.

Another way in which resource limitations presented a challenge was that these projects had a very specific and limited time frame, which meant that there was no funding commitment to

take the projects beyond a demonstration stage.

The Role of Mental Illness

In all of the projects, mental illness played a role in how the groups played out. In a concrete sense, illness meant that project timelines had to be adjusted in the consumer-led projects and, in some instances, it meant the loss of group leaders. Emotionally, women often had to “process” the mental illness of another group member or, in some cases, a group leader. Women’s mental illnesses are rarely accommodated in the management of projects of this nature, which often operate within larger bureaucracies with other demands. This made it more difficult for the consumer project leaders to ask for time or assistance when they needed it. In the RESPECT project one of the hosting organizations (Women’s Contact Society) was handling the administration of the project and therefore took on the role of negotiating with the managers of the project (e.g., the British Columbia Centre of Excellence for Women’s Health). This model was useful because it meant that consumers who were ill did not have to deal directly with the managers of the project. In the case of the Whole Woman Project – which did not have a partnership with a non-consumer organization – illness and/or other difficulties in carrying out the project were sometimes covered up for fear of funding repercussions. As building consumer capacity is one of the

primary goals of women-centred programs in mental health, specific models for managing mental illness and project disruptions must be built into the research design. In the RESPECT project, the support group development was put on hold until all members could participate equally. In the Whole Woman Project, physical illness was an issue for one of the group leaders who decided to give up her role in the project altogether.

Leadership Issues

Throughout the Whole Woman Project difficulty was experienced with respect to maintaining consistent leadership. This was partly due to conflicts between individuals, but might also suggest the need for stronger supports to assist consumer leaders in fulfilling their roles. Once this project shifted to a shared model of coordination, these problems appeared to diminish, suggesting that support was a necessary component to leadership. Further direction may also have been needed from the British Columbia Centre of Excellence with respect, for example, to assisting the project coordinators in making decisions. The question is what kind of partnership role should research institutes and other kinds of institutions play with respect to facilitating consumer-led projects? At what point would assistance be seen as helpful and at what point, controlling?

Diversity

Several of the projects had difficulty recruiting a diversity of participants, especially in terms of race and ethnicity. The RESPECT project in Williams Lake did have participation from Aboriginal women, but was unable to get substantial involvement from the Aboriginal community in their area. The one Aboriginal group that initially became involved was unable to continue because of the time commitment. In the Whole Woman Project, 30% of the group participants described themselves as not of Caucasian/European descent, but some participants who were French or Acadian defined themselves as part of this 30%. In both of the projects, women from non-European ethn racial groups did not participate, which suggests that more outreach is needed to these communities and more research to understand whether peer support models are useful to a variety of consumer communities.

IX

Conclusion

The benefits reported by the women participating in all of the programs make a strong case for the development of further programming based on women-centred mental health care principles. Overall, women responded well to aspects of each program that respected their contributions and knowledge about their illness and conceptualized their illness as part of a larger social context. And women consumer leadership ensured that the projects were designed in a way that took women's needs and concerns into account. It was demonstrated that consumer leadership not only builds capacity in important ways for the individuals and communities involved, but also helps to ensure that the programming will be relevant to potential participants.

Demonstration models, because of their time-limited nature, can set up false expectations in communities where services are already lacking. They serve an important function, however, to try out and evaluate innovative programs, provided they are accompanied by follow-up in the communities where they are instituted. Policy makers and leaders in mental health can play an important role in supporting communities by reflecting the findings about women-centred mental health care at all levels of policy-making and planning – federal, territorial, provincial and regional.

Finally, the paucity of literature that examines innovative treatment approaches for women with serious and persistent mental health problems strongly suggests the need for more attention to this area. Program development that is consistently evaluated will assist in building the evidence base about the kind of support and treatments that will be most useful to women with serious mental illness.

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