

On Our Way: Recovery News

Vancouver Acute & Community Mental Health Services

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*Hope & Goal-Directed & Self-Determination
Awareness & Potentiality & Meaning & Purpose*

Peer Run Groups at the Kitsilano-Fairview Team

By Susan Trapp



From the editor:

Our Continuing Exploration

Welcome to the seventh edition of “*On Our Way: Recovery News*”. Previous issues have featured cover stories regarding initiatives at South and Northeast Mental Health Teams. This issue continues the exploration of what is happening at the teams with a look at Peer Run Groups at the Kitsilano-Fairview Team.

We also explore the theme of people living with mental illness making a difference with an article on the emergence of survivor groups in BC, an article on peer support, and also some brief information on the peer run website “*Spotlight on Mental Health*”.

As well, this issue includes information on the new and soon to be widely used Client Self-Appraisal of Needs and Interests (CSA) too, and an update on the work of the Recovery Advisory Committee.

As always, we’ve included the “*Perspectives Pages*”, this time featuring an article by Sandra MacKay, a poem submitted from Tokyo by Izumi Nagasawa, and a moving article on thoughts on recovery from family member, Pat Parker.

Happy reading!

Over the past few years, the mental health system in Vancouver has been making a shift towards a more recovery-oriented system. Although there have been many recovery-oriented programs and groups prior to this the growing emphasis is to make all clinical practices congruent with recovery. Peer run programs are an important aspect of a recovery-oriented system.

At the Kitsilano-Fairview Mental Health Team, the Healthy Steps Support Group is a great example of a successful peer run and driven recovery-oriented program. I have been a facilitator for this group since June, 2005. Prior to this, an Occupational Therapist (OT) at the team ran the group for one year. He slowly passed the group over to me and a co-facilitator. The group originally met at the Self-Help Resource Centre, which at the time, was located in the same building. The Self-Help Resource Centre, now called Peer-net BC, relocated a few years ago, so we no longer had easy access to their space. We now run the group at the team again because it is the most

convenient location for the group members. The purpose of our peer run group is to promote healthy living and improve the quality of life of our clients at our team. Currently I am the only facilitator. I meet with the OT who photocopies the researched material and provides money for healthy snacks. During the first hour of the group we read information gleaned off the internet about diet and exercise and how to stay healthy. Then each person reviews their past week and set goals for the coming week. This is followed by a walk and a healthy snack. We do accept new members although we have a core group that attends regularly. Members say that they enjoy the focus being on healthy lifestyle versus it being on weight loss.

We all have different problems that may be related to lifestyle choices and the medications we are on. These include diabetes, cholesterol, and weight gain. There are some people for whom diet and exercise is not the whole answer. Social support and information can go a long way in helping people manage their health problems. Sometimes peer run programs are a better fit for people. When one member is having a hard time with a personal health challenge the group supports them. In the past we also did the 10 km Sun Run on a few occasions. Our focus is very organic and led by what the members want.

From running this group, I have developed confidence in my ability to facilitate and lead others. To learn more about facilitation I took the Grassroots Facilitation course which was a good fit for me. This course was also helpful for me with another group I run, the Tardive Dyskinesia Support Group. Over the years of running Healthy Steps I have also learned how to network better and make those people connections which are crucial to running a support group. Furthermore, having and developing my computer skills

has opened up a whole world of resources and information from the internet.

At the Kitsilano-Fairview Team, I have also had the honour of being a consumer representative on the Consumer Advisory Committee for the past 8 years. On this Committee we often have guests who speak about their recovery journey. The Committee shows empowering and educational videos and gives the clients a forum to express their views. During our last session we had Jude Swanson lead a session where he shared some stories of his recovery journey. We had 25 people in the room and each person shared about their journey and what recovery meant for them.

Some other peer run highlights include a bowling group that meets once a week. It has been client run for the past 5 years now. There are 5 peer support workers at the team who support clients one-to-one with their goals. We have also hosted 3 WRAP groups at the team which are also consumer run groups. These groups focus on empowering clients to develop their own wellness plans. In the past we have had a peer run acting workshop. In 2005-2006, two consumers ran a Kitsilano-Fairview Team Newsletter, a seasonal publication that allowed clients at the team to publish their poems and stories.

All in all, the message that is portrayed by peer run groups is that consumers of mental health services can improve their quality of life and participate in providing recovery-oriented services. ■

Spotlight on Mental Health



Go to the peer run Spotlight on Mental Health website for mental health news and resources.

spotlightonmentalhealth.com

Look under resources and then newsletters to find *On Our Way Recovery News* ■

The Emergence of Survivor Groups in B.C.: A Historical Perspective

Authors: Rosalyn Choi, MSN, BSN, RN, Vancouver Coastal Health, and Dr. Geertje Boschma, PhD, RN, UBC School of Nursing.

Rosalyn Choi works as a staff nurse and as a community health nurse. She has recently written a major essay on the historical trends of mental health care within British Columbia.

Dr. Geertje Boschma, PhD, RN, is an Associate Professor at the School of Nursing of the University of British Columbia. She teaches in the undergraduate and graduate programs. Her research focuses on the history of nursing and mental health care.

We examined the history of survivor groups in BC as part of a larger project on the history of deinstitutionalization, which in BC began in the late 1950s. In BC, Riverview Hospital was the most important provincial institution. Patient numbers peaked at 4,630 in the 1950s, whereafter the hospital continued to downsize (1). An important response to this change was increased patient and family activism, often born out of necessity, if not desperation, because few resources were available in the community when a large number of ex-patients had to find accommodation and support outside of the hospital. We believe it is important for all people involved with mental health care to understand the important shift brought about by active ex-patient, client, survivor, and consumer involvement - terms we will use interchangeably in the remainder of this article.

When consumers began to organize themselves, the notion of “being a patient” gave way to new identities that signified how people with mental illness took on an

active and often critical role in the organization of support and resources. A movement of consumers, survivors, and ex-patients (c/s/x) became a critical voice and established a range of new resources (2). Despite the new opportunities brought about by community care, availability of resources was often insufficient to accommodate all people in need of support. Increased homelessness, increased family stress, stigma, and continued discrimination became more apparent. In 1971, one critical response came from a group of ex-patients in Vancouver, who formed the Mental Patients Association (MPA) (3). This organization was led by Lanny Beckman, a client at the Burnaby Psychiatric Day Program, who felt that there were noticeable gaps in service, particularly a lack of emergency psychiatric coverage on weekends and holidays. While in a day program, Lanny noticed three clients had committed suicide, all on weekends. In reaction, Lanny understood the need for patients to organize themselves. He began exchanging phone numbers with other consumers. Among themselves, they generated a phone list so they could find “more real support from their information network” (3, p.1). From then on they began to establish support services and housing, forming a cooperative member-led organization in which consumers had a central role, and, supported by grants and governmental funding, also found employment.

The critique that arose over the mental health care system must be understood in the context of psychiatry also being a history of power. Foucault described the history of psychiatry as a ‘genealogy of power’ (4, p. 41). The power of psychiatry is, for example, reflected in its diagnostic power; medical diagnoses are determined by medical professionals, whose power in turn, is backed by a governmental and legal regulation. Individuals experiencing medical

treatment may not always agree with the appropriateness of the services or with its beneficial intent. Moreover, amongst service providers, insights vary as to what is deemed appropriate treatment. The anti-psychiatry movement arose over such differences, with opposing views over many aspects of mental health care, including the notion of mental illness itself. Notions of “consumer” and “survivor” highlight a focus on rights of mental health patients as citizens (4).

Consumers established their own power. MPA leaders Lanny Beckman and Barry Coull, for example, were influenced by the Radical Therapy Movement in North America (3), stemming from a “viewpoint which approaches emotional problems by determining sources of oppression, exploitation and repression in our society” (3, p. 4). MPA members formed self and mutual help groups, sharing their personal experiences. The MPA recognized the need for mental health consumers to obtain a voice. In addition, many consumers also needed to learn basic skills of day-to-day living, which were not usually learned in mental hospitals. The organization identified these skills as ‘participatory democracy’ (3). One of the main goals was to “assist and promote welfare of mental patients and former mental patients” (Vancouver Mental Patients’ Association Society, 1983, p. 1), and create housing, vocational, and recreational resources. The MPA still exists today, but has changed the meaning of its acronym. It now stands for Motivation, Power and Achievement (MPA, 2009).

Consumer organization continued to grow as a participatory and critical response to a changing mental health context. Soon the Lower Mainland saw a variety of consumer and social activist driven organizations, which now form the backbone of the community mental health service system. Various organizations formed drop-in centers, clubhouses and supportive housing, including Coast Mental

Health Foundation, Kettle Friendship Society and Mental Health Housing (5). Other important organizations in BC from the 1950s onwards were the BC Division of the Canadian Mental Health Association, which became an important advocate for changes for legislation and mental health policy, and the BC Schizophrenia Society, formed in the 1980s by families and friends of people living with schizophrenia. Finally, we mention the Vancouver/Richmond Mental Health Network Society founded in 1993 by consumer Garry Long (6), later renamed West Coast Network Society. This client-run group provides advocacy, counseling and crisis management for individuals with mental illness. Increased activism resulted in consumer representation on mental health committees, boards and councils at various levels of the government over the last few decades. The history of the consumer movement highlights the importance of critique, collaboration, participation, and continuous renegotiation of the terms on which mental health care is build.

References

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5. Killam, J. (1999). “Advocacy” and the mental health consumer/survivor: *In pursuit of quality of life for all British Columbians with a mental illness*. Vancouver, BC: ARA Mental Health Action Research & Advocacy Association of Greater Vancouver.
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Discovering Needs & Interests: A New Tool

By Renea Mohammed

“We’re trying to find the voice of the client in what we are doing. It’s about self-determination and shared responsibility.”

-Member of the CSA Steering Committee

“Client identified needs have been shown to differ from those identified by health care providers and identifying and addressing client-identified needs can improve the quality of care and quality of life.”

- Lane (2011) The Self-Appraisal of Needs at Vancouver Coastal Mental Health Services (p. 1).

Vancouver Community Mental Health Services (VCMHS) has a new tool called “Client Self-Appraisal of Needs and Interests” (CSA). Starting in September 2011, all clients who have new referrals will be offered the opportunity to complete a CSA. By 2013 it will be offered to all clients. The purpose of the tool is to facilitate conversation that will lead to effective client-centered mental health services. One of the tool’s developers notes: “Our focus has predominately been medical. We wanted a more holistic tool that touched on other domains.”

It is hoped that the tool will help service providers to engage with clients in a range of areas that include but go beyond the medical. The tool is also intended to showcase the client’s strengths and achievements that can then be used as resources for recovery. The hope is that as the case manager and client work on it together a better understanding of the needs of the client will come about, and a stronger relationship will develop between the two.

The tool consists of a form divided into four sections:

(1) A quick look at basic needs, such as documentation, banking, medical and money. Clients indicate if they have, want or wish to comment on everything from Bus Pass and BC ID to GP, Dentist and Trust.

(2) A longer look at various categories where the client may point out a need. Here, the client indicates: “Is there a need?”, “Are you interested?” and “Comments, Assets and Strengths”. Items include Housing, Physical Health, Mental Health, Medication, Activities, Education, Leisure, Work, Relationships, Spirituality, Cultural Perspective, Cognition, Communication and Legal – to name only a few. Each item contains a description of what it entails. There is also opportunity for the client to identify areas of need and interest not listed.

(3) A place to prioritize up to three needs in particular after going over the categories in the second section.

(4) An area for pointing out strengths and achievements, as well as for making plans towards recovery.

The tool may be done in conjunction with the client care plan which is updated annually, and will help to focus sessions with the case manager. In keeping with the principle of self-determination client use of the CSA tool is always voluntary.

The CSA was developed by a steering committee comprised of service providers with a variety of backgrounds, two mental health service users and a health researcher. It was inspired by work done in Ontario. There, the Ministry of Health had designed and successfully implemented a needs assessment tool called the Ontario Common Assessment of Need (OCAN) which was designed to “...capture the consumer’s perspective on their needs and goals, to

stimulate conversation between consumers and case managers, and to increase continuity and standardization of care across all mental health services,” (Lane (2011), p. 1). The success of the tool in Ontario spurred interest in Vancouver Coastal Mental Health Services in developing a similar tool geared toward best capturing the needs of their clients and geared toward melding with current service structures. The result was the CSA.

The CSA was piloted across mental health teams by participating case managers with a total of 37 clients returning questionnaires regarding their experience with the tool. All participating case managers and clients were invited to focus groups. A detailed discussion of the pilot and focus groups with results can be found in *The Self-Appraisal of Needs at Vancouver Coastal Mental Health Services: Evaluation and Feasibility* by Suzanne Lane. Please e-mail renea.mohammed@vch.ca if you would like a copy. The results were favorable and suggestions for changing the tool were minor. “Clients felt that this tool did empower them towards recovery and strengthen their voice in their care... [and] case managers felt that this tool improved the quality of care provided,” (Lane (2011) p. 22).

One service provider reported using the tool with a client she had known for ten years. “We thought we knew each other,” she said. “But when we used the tool, the client identified something important to him that neither of us had previously realized was important.”

Another service provider used the tool with a brand new client. He reported that the goal she prioritized through use of the tool was something that he and her doctor wouldn’t have identified. It was related to getting back in touch with her cultural heritage. The service provider noted that this is something that would have been missed. The tool made a difference.

A service user on the steering committee who completed one of the first drafts of the tool reported that it helped him identify things in his life he was happy with and things he wanted to work on. It increased his self-awareness. And, he says, “this makes the client active, not passive.” Others note that this is a tool to get at questions that may never have been asked at all. If mental health services are about making a difference for people - supporting them in moving forward in areas that are important to them - this tool seems a valuable resource.

Reference

Lane, S. (2011). *The Self-Appraisal of Needs at Vancouver Coastal Mental Health Services: Evaluation and Feasibility*. (SPHA 590 Project, Master in Health Administration, University of British Columbia). ■

Words of Wisdom



“Recovery is a journey of self-reflection and discovery.”

- VCMHS Core Competency Series
Workshop Participant

“A person can live a hopeful and fulfilling life separate from their condition and in the presence of symptoms.”

- VCMHS Core Competency Series
Workshop Participant ■

Recovery Advisory Committee Update



The purpose of the Vancouver Community Mental Health Services (VCMHS) Recovery Advisory Committee is to support the work of implementing recovery philosophy in the organization. Its goals are to:

- 1) Provide support to parts of the service as they implement the recovery philosophy.
- 2) Increase interprofessional stakeholder participation, coordination and organizational investment in recovery.
- 3) Increase consumer and family access to recovery-oriented services through support for best practices.
- 4) Ensure culturally appropriate recovery-oriented services.
- 5) Create relationships and partnerships with recovery experts, programs and services from inside and outside VCMHS.
- 6) Work with families (ie. Family Advisory Committee), consumers (ie. Consumer Advisory Committee and Special Advisory Committee) and staff regarding integrating recovery philosophy.

Currently the committee is examining the Australian Mental Health Outcomes and Classification Network's *Sharing Information to Improve Outcomes: Review of Recovery Measures*. This is an extensive document that includes a number of recovery measures and instruments. The VCMHS Recovery Advisory Committee is reviewing the report to see if there are tools

that could be adopted for VCMHS services. The committee is also looking at the University of Adelaide Library's website which includes a list of recovery rating scales as well as a large number of links to different Australian and overseas recovery related resources,

As well, the committee has been exploring issues such as client transition from services and the possibility of continued linkage afterward.

The committee has also been hearing presentations on recovery related topics such as findings from the Client Directed Outcome Informed (CDOI) Pilot, the VCMHS Recovery Dialogues and the Client Self-Appraisal (CSA) Tool. The CDOI was featured in the April/May 2009 issue of *On Our Way Recovery News*. It received mixed reviews via its pilot and will not be implemented. The Recovery Dialogues will be continuing. The Client Self-Appraisal Tool received positive reviews after its pilot and is the subject of another article in this newsletter: see "Discovering Needs and Interests: A New Tool".

We will continue to have regular updates on the Recovery Advisory Committee in this newsletter. Watch for them to see what the committee is up to. ■

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Vancouver Acute & Community Mental Health Services

Credits

Renea Mohammed, Editor

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PERSPECTIVES PAGES

My Schizophrenic Life

by Sandra Yuen MacKay

I developed a serious mental illness at the age of fourteen. *My Schizophrenic Life: The Road to Recovery from Mental Illness* is a memoir about my struggle and journey to wellness. It describes my hallucinations and delusions, and how I navigated through high school, college and university, despite reoccurring symptoms. I recognize the support of my family, including an understanding husband. I wrote the book to inspire others, offer hope, and share knowledge about my personal experience with schizoaffective disorder. The message is: recovery is possible. I may never be cured, but I can still have a happy, full life and reach my potential.

I give talks on recovery to students and families. Also, I publish articles in *The Bulletin*, a mental health magazine published by the West Coast Mental Health Network. I wanted to explore and reflect more deeply and thus my book was born. I wrote the first draft in 2008. I signed with Bridgeross Communications, my publisher, in March 2010 and the book was released in September the same year.

I had a book launch in October 2010, which was attended by 75 people. The bookseller sold out of books! I did a reading and also signed many copies. The positive response was wonderful.

Vancouver Film School students chose me and family members to be in a six-minute documentary called "Psychopia" on mental illness and my recovery. My art and writing are included in the film.

The memoir is available at Odin Books, Amazon and chapters.indigo.ca online. For more info, to listen to radio interviews or read reviews, please visit: <http://symackay.blogspot.com>. ■

Making a Difference through Peer Support

Vancouver Community Mental Health Services has a formal Peer Support Program. People who live with mental illness receive training and then provide one-to-one support to others, helping them to attain goals, link with community resources and acquire new skills. Clients or peers have the opportunity to meet and receive personalized support from someone who "walks the walk" of recovery themselves.

We wanted to take a moment to share two stories of making a difference submitted by Peer Support Workers (PSWs):

"My Client proudly explained his aunt was now the third person who believed in him and his strengths. I congratulated him and asked who the first two people were. He explained that he, himself was the second person who believed in him. He then said "Do you know who was the first person who believed in me?" I admitted I didn't know. He said "YOU! You believed in me before I did. You were always sharing what you thought were strengths and talents I had. You kept doing it until I started believing in me too!" – Jude Swanson

Another of our PSWs notes:

"One lady stands out to me. She was on a locked ward in a senior's home. I was only allowed to take her for walks. We started with a small walk around the ward and worked our way up to going for walks around the park. I noticed she never tried to run away and wasn't a danger to herself or anyone else. I advocated, saying she didn't need to be on a locked ward. They assessed her again and it turns out she wasn't as demented as believed. They decided she had been misdiagnosed. Now she lives in her own apartment, writes poetry and tutors at a school." ■

Recovery: A Family Perspective

By Pat Parker

The family perspective: it is an emotional perspective. You can't get around it. We try hard to be rational, logical and intelligent in our approach to dealing with doctors, case managers, occupational therapists and others but the truth is, that for the family, it is all about the emotions.

It was my worst fear. That someone I loved would have schizophrenia. To me it was a terrifying disease, one without cure or treatment, something to be endured for a lifetime – a lifetime taken away. I only knew what I saw in media and the experience of having met two people with this disease and it scared me deeply. The first months of dealing with my son's illness were therefore full of fear, grief, dread - an entire litany of powerful negative emotions. Most devastating of all however was a vision of a long lifetime of struggle and incapacity that my son would face.

My husband and I began the process of learning about the disease, the treatments, the health care system and services. We took classes, read books, studied the internet, and went to support groups. We did whatever we could do to get knowledge because with knowledge, we had a glimmer of control regained, a base to work from. As our son began his healing journey a new word was quietly and almost incidentally introduced to our vocabulary - recovery. I don't recall now when or who first planted this idea in our hearts and minds: that there would be, could be, recovery. A small light began to glow and hope arrived.

The Mental Health Commission's first report introduced me to the idea of recovery as a foundational philosophy or principle that would influence and determine policy and treatment. As I involve myself in various advocacy efforts and with working

to ensure that families are included and considered in the complex processes that comprise treatment, my understanding of the idea of recovery is evolving but so are some unsettling questions. How long will this process of recovery take? What exactly are we talking about when we say recovery? What can we expect to happen? How can we prepare ourselves for in the future? How do we best participate in the process? How do we sustain ourselves as a family while our son recovers? How do we as a family recover? What are we recovering?

So what are we meaning by recovery? Is it recovery in the sense of the "recovering alcoholic" - someone who was ill and will forever be in the process of getting better, ever threatened by the possibility of a return of the problem? Is it recovery like when we have the flu - sick as can be for a while and then we get better and we are just like we were before? Or is it recovery as it is for someone who has lost a limb -- deeply traumatized, healed of the wound but forever changed and debilitated. Is recovery a return to the previous path? Can we get back on the road and continue the journey after a significant detour?

Nothing is clear cut or linear when dealing with brain health issues. The brain is a complex organ, everyone is unique and special. The answers to my questions have not necessarily been proffered by the health professionals who are treating my son. I slowly gather more insight into the idea of recovery from meeting inspiring individuals who have regained their lives and their health. I am learning by working with the health professionals who are striving to establish a "culture of recovery". But I also meet parents who support, guide and fight for their children's health and have done so for many years - facing continuing challenges. As a family member it often does feel like a battle. You must be ever vigilant for your child/loved one who is vulnerable, sometimes very unwell and not

thinking logically. My vision of what to expect for my son and our family is cloudy. We stand guard.

As I continue to learn about the idea of recovery, we live the process. There are so many factors that can affect the process/progress: choices our loved ones make such as adherence to medication and lifestyle choices; choices doctors and other care givers make; choices family members make in relationship and support; scientific advances in neuroscience and treatments; philosophy and politics - all enter into the process in different ways. And then there is the course of the disease - do we even really know what that is? For families living with the unanswered questions and the lack of clear prognosis and, in some cases diagnosis, it can be difficult. It's a bit like catching the greased pig just when you think you've got things figured out, the understanding escapes; it slips away and you are left with more questions. You live with ambiguity. Expect the unexpected.

I have learned that recovery is not a linear process, not the gradual uphill climb that brings us eventually to the top of the hill. It can be a wild roller coaster ride of emotions that parallels the health of my child. When he is well and we are progressing, hope burns brightly ahead. I dare to let myself believe. Then comes the sickening drop that feels as if the earth is not there when he goes into a valley and my heart goes with him. I grieve again and I am angry again and I am frustrated again. There is nothing to do but start over, reassess, intervene, seek help from where ever we can find it and begin the climb again. I can only hope that each successive hill is a little less steep and that each valley is a little less deep and one day the journey will be smooth.

There are no simple and deeply satisfying answers to most of the questions. If there are then I have not yet heard them. Perhaps I haven't asked the right person, or the "right"

questions. Granted, my family is only at the beginning of this process. It seems that the recovery will be the journey. We as a family are on a path that we did not anticipate or expect and we continue to encounter new twists and turns and hills and valleys in the road. I don't know if there will be a day when we all feel that we have arrived at the end of the journey, arrived at a place where we all feel safe, well, happy and healed. Arrived at a day when my son lives his life with fierce independence, profound confidence and exuberant joy.

What is the family perspective of recovery? I can only describe recovery from my perspective within a family. Recovery is belief, a process, a journey, a ride, at times a battle. It is forging ahead in spite of obstacles, expectations and confusion. It is taking each day as it comes. It is walking a path that is sometimes shrouded in doubt and fear. It is being drawn forward by hope through the fog, down into the valley, up and over the hill traveling on toward wellness. ■

Road to Grace

By Izumi Nagasawa

We should trace

The ocean current with this ship like small tray

Because you face

And show us a clear and hopeful way

We will chase

Along the road whatever they say

When the time comes that you may ■