

Voices for Change

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A Statewide Newsletter of the mental health community

Spring 2009



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What is a peer-run respite ?

by Andrew Leavitt

A respite house is a place where peers can go to manage stress and to find compassion and understanding from peer staff. Unlike a locked inpatient unit, respite houses have open doors where peers are free to come and go as they choose. There they can meet others with similar symptoms and experiences. And trained peer staff are capable of sharing their own stories or simply



The Peer Support Wellness Center in Decatur, GA

being caring listeners. Respite houses strive to provide warm and welcoming, *home-like* environments. This of course, contrasts greatly with the sterile and institutional setting of the locked inpa-

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Consumer overcomes internal stigma

By Gail Shamon

For as long as I can remember, I had a terrible, paralyzing fear that I was "crazy". I kept this fear locked deep inside me. I never saw the world as a safe,

hospitable place – I saw it as a place where awful things happened, and where no one was ever really safe. I think the place where I felt safest was school, and that probably kept me sane throughout my abusive childhood.

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Letters to the Editor

Transformation Center Mission

As peers in all stages of recovering our mental health wellness and freedom from addictions:

We promote the growth and voices of people with lived experience, individually, in communities and in organizations.

We facilitate these diverse voices to impact and transform policy and practice.



Transformation by Lyn Legere

Editor's Introduction

This is my first issue editing *Voices for Change*. I am learning a lot! I am interested in your feedback about articles or the whole issue. If you have access to a computer, please feel free to make comments about the newsletter or its contents on the Lived Experience of Massachusetts Forum, *lemforum.org*. There is a thread called "What do you want to see in a newsletter?" If you do have access to a computer, please feel free to email me susan.landy@verizon.net. Or call the Transformation Center at (617) 442-4111. Complete texts of articles will be available on our website. We are also always looking for writers to write about current events related to the mental health system in Massachusetts. We will also take recovery stories and publish them as they are appropriate and as we have space. We will soon have writers' guidelines that we will be able to send upon request.

We welcome volunteers to fold, staple and label the newsletter. This is an important job that is done in one afternoon (if there are

enough people) and we provide lunch.

I hope that you continue to enjoy *Voices for Change* and will comment on the forum, call or email if you have comments, suggestions or questions. We have no letters to the editor because this is my first issue. Thank you for your interest in *Voices for Change*.

RadioBoston Show on Budget Cuts

by Susan Landy

The radio show "RadioBoston", which airs on WBUR Fridays and Saturdays at 1pm, presented a show on the Massachusetts Department of Mental Health (DMH) budget cuts for 2009. These budget cuts have affected consumers of the mental health system in many ways. Through M-Power consumers are protesting the cuts and acting to restore the funding. The host of the RadioBoston, David Boeri, interviewed a series of guests, starting with DMH consumer Helen Cheltenham and M-Power Board President Ruthie Poole, and took calls from consumers. He also interviewed Marcia Fowler, Assistant Director of the Department of Men-

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Peer Run Respite

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tient hospital unit.

What are the benefits of peer run respites?

The benefits to peers are clear in surveys of people who have tried them. A survey of peers who have stayed at Peer Support and Wellness Center in Georgia, points to the priceless gain in self esteem through mutual support and release from stress. The respondents mostly had glowing praise of the respite and for those with complaints, they were minor usually and did not form consistent themes.

But the survey also reveals how much money can be saved through such an approach. 65% of respondents claim that the respite house in Georgia has either definitely or possibly prevented them from being hospitalized. Part of the appeal of the respite model is that it only costs the state about \$200 a night for someone to stay there. In contrast, inpatient psychiatric care in MA can cost \$800- \$1200 per day. In addition, peer respites save on ER visits and police and ambulance costs. Peers are also free to bring their own medication, as op-

posed to medicating practices of hospitals where what has already worked before is often overlooked. Ultimately, the gain is in peer self esteem and independence, something that is priceless but that also saves the state money in that less services in general are used subsequently.

What are some of the different models of peer run respite houses?

Some respite houses primarily provide a peaceful atmosphere, a soft place to land with trained staff



Andrew Leavitt

on hand to help peers develop coping mechanisms, or simply just to listen.. Others have many programs as well. For example, the respite in Georgia, the Peer Support and Wellness Center, provides both respite services and many activities and groups that can help peers on their roads to recovery, building self esteem. The Wellness Center in Georgia has all sorts of programs, from cooking to acting to sports to jewelry making. There are also more traditional groups, but that are all peer run. Peers also learn

skills that strive to prevent relapse and promote recovery such as in WRAP classes and Certified Peer Specialist trainings.

How have peer run respite houses been funded?

Funding for these programs have come from a combination of federal block grants and general state funds. There is no reimbursement by Medicaid. There would not need to be anyway because the services are free to the visitor. Staff salaries and training are paid through Peer Support Agencies (PSAs), which in Massachusetts' case could be the Transformation Center.

Radio Show

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tal Health (DMH), as well as a researcher, a state representative and a public interest lawyer.

Boeri opened the show with a discussion with DMH consumer Helen Cheltenham and M-Power Board President Ruthie Poole. (M-Power is a statewide mental health consumer advocacy organization that works on legislation and other issues that affect consumers.) Ms. Cheltenham talked about how much help her case manager had been to her, coordinating her medical care and giving her rides to medical ap-

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Recovery Stories / Creative

Internal Stigma

(Continued from page 1)

For years, I would mentally touch on the thought, "Where is my fear coming from?" I didn't know. Just thinking about the fear terrified me, and back to hiding it I went. I would get a break in its intensity, and then it would return. It seemed to be cyclical, like my symptoms for so many years after I was diagnosed with a dissociative disorder.

Drugs were the only way I could live. When I found heroin, I thought I had discovered "the secret to life." For me, it was because it medicated the fear. Then I found methadone, a legal alternative that also kept the fear and the memories hidden. But after a while, that didn't work, and I became a decade's long valium addict, in addition to the other drugs I still took.

After the secret of the abuse itself came up, I still had four years while I watched myself get worse and worse. I was cut off from everyone except my therapist, who did not know how to help me and came up with

stranger and stranger (and all re-traumatizing) ideas on how to help me. I felt like I was in a trap. I lived alone, and had almost no friends. I was clean, but getting sicker and sicker. I still worked and went to school. Eventually, I had two very serious suicide attempts. The second one almost killed me. I spent 8 days being kept barely alive on life support.

I had a life-changing experience in the hospital. I know I was close to dying, and I did not want to! When I finally left, I knew I had to do anything to save my own life. I could not live alone. I moved into DMH housing for 18 months, for which I'll always be grateful. I spent 15 months in MMHC (Mass Mental Health Center) DBT partial hospital treatment, learning skills to handle my symptoms. That's another thing I'll always be grateful for. Through DBT, I learned to act opposite to my emotions, especially depression and helplessness. I learned many ways of distracting myself when I wanted to curl up in the foetal position. And, possibly most helpful, I learned to distinguish between my emotions, instead of having a "big ball of yech," as my doctor called

it.

And then I ventured back into the world again. I was full of shame and self-loathing. I felt less than everyone, like I was a defective human being. I got my own apartment, and went to the B.U. Center for Psych Rehab's

Training for the Future program. Somehow, in the positive, recovery-oriented atmosphere at the BU Center, I began to lose that self-hatred and shame. From there, I applied for a job at the place where I most wanted to work. Maybe it was the name, M-Power at the time



Gail Shamon

(now it's the Transformation Center), but I knew there was something there that I needed. And I got it – acceptance, positive energy and great compassion for all people with mental illness. Working in an environment surrounded by people who, like me, struggle with illness and wellness and trauma and life in general has been an incredibly enriching, empowering experience. It hasn't always been easy, but

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Sadhu

By Naomiruth Pinson

When

having read the signs
along the street

a handprint here, a wing there
an arrow pointing past where

you came

with your
beloved face

that the Sun has witnessed
that the Moon sang down
that the Stars encircled in their dusky dance

You

Just My Dime's Worth

“As you know, hope is one of the most essential components for recovery. So, when I think of a goal of VFC, a “hope messenger” jumps to mind. I think it’s vital that voices from all across the recovery (and not so recovery) spectrum have a place within VFC, but that we should highlight stories that communicate hope in every issue and that it should be on the front page so the person that just sees a front page will be hit by the hope piece.”

- Lyn Legere, Director of Education

Internalized Stigma

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it’s always been rewarding.

Two months following my near-successful suicide attempt, I began to practice Nichiren Buddhism, which involves chanting twice a day and many activities with other Buddhists. My recovery has more to do with my Buddhist practice than with anything else. Through practicing and studying, I have changed inside very deeply. In fact, I did an “experience” where I shared with my fellow Buddhists at a meeting how chanting had helped me to stay out of the hospital. I was feeling very vulnerable, as most of my fellow Buddhists are not consumers, although many are. But talking about my experience was the last time I have ever felt shame about having a diagnosis.

I no longer fear everything and everyone; in fact, there are very few people I do fear. I used to be pathologically afraid of everyone. No more. Once I understood where my fear came from, after several years, I stopped blaming myself.

I am still dealing with the fear my childhood experiences left behind. Now it is fear of myself, fear of the memories, and fear of the “junk in my head”. That’s my new name for it. Some days it does seem like a never-ending story, but I don’t believe that. Someday, I will completely overcome the fear and the junk in my head will finally have lost its power to hurt me.

“Hope is crucial to our recovery, for our despair disables us more than our disease ever could.”

- Esso Leete, consumer leader

Community News

Eliminating Restraint/ Seclusion:

Transformation Center Initiative Focuses on In- volving Peers and Changing Culture

By Nicki Glasser, Policy
Coordinator, The Transfor-
mation Center

The Problem: Unfettered Use of Restraint and Seclusion

Few people would argue that the experience of restraints and seclusion is one of the worst and most damaging things to experience while in an emergency room or hospital. Historically some staff and hospitals have felt like it was OK to use them as punishment or to coerce or control people. These days DMH regulations require that DMH or licensed facilities use them only if there “serious risk of imminent physical danger to self or others”, but changing staff assumptions, behavior and culture to support this policy does not happen easily after years of unfettered use.

For example, I used to be restrained as a matter of course when I *voluntarily* went to an emergency room desperate to be admitted to a hospital. The last thing I wanted to do was turn around and go home. Yet I was still routinely tied down – one wrist to the gurney – regardless of my docility and want for help. I became used to such treatment and accepted it as a matter of course; they untied me to use the bathroom most of the time so it seemed fair: I

was used to be treated as less than fully human. Other times my experience of restraints and seclusion was much more traumatic, so traumatic in fact that I won’t risk triggering people here by telling these stories. Suffice to say these incidents continue to haunt me; after years and years of psychotherapy I still feel I have not healed from what others did to me so unnecessarily when I was already in such a vulnerable and powerless state.

The Solution: Partnering with Peer Advocates to Change Cul- ture

So it was with much excitement and some fear that I learned that DMH accepted our proposal and wanted to partner with us on the important work of eliminating the use of restraints and seclusion. I was really scared for a long time to be meeting with people who oversaw units where restraints and seclusion were being used fairly often. At the beginning it took me months to just get the nerve up to call, say, a statewide DMH Director of something or a Chief Operating Officer at a hospital. But in time as I grew more accustomed to taking a deep breath and putting one foot in front of another the work became easier – not easy but easier.

Our main mission in working with DMH state hospitals has been to open communication and understanding between peer advocates

and state hospital administrators and staff; for example, working to create linkages between the regional Recovery Learning Community members and state hospitals. We also did a lot to support an increased statewide peer voice on restraint and seclusion elimination. While much progress has been made there is still much further to go.

One of the most exciting activities we accomplished was coordinating and participating in a dialogue facilitated by the Public Conversation Project. Fourteen members of the statewide DMH Restraint/Seclusion Advisory Committee were involved - 7 peer advocates and 7 DMH staff. The dialogues were at times a deeply personal exploration of restraint and seclusion issues, why people were involved, and what they thought were the ongoing challenges. Although this was a one-time pilot dialogue most participants felt that it was a valuable experience and that the lessons learned will continue to benefit our work together. It was felt that this dialogue model would be a useful tool to help the state facilities across the state to continue to work on restraint and seclusion elimination and culture change. You can reach more about the dialogue on our web page at

<http://www.transformation-center.org/advocacy/policy/restraint/dialogue.html>

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Another exciting activity was hosting the first ever statewide Peer Summit on Restraint/Seclusion Elimination. On June 5-6, 2008, 30 people with lived experience of a mental health condition, many of whom have personally experienced restraint or seclusion, concluded that the mental health system can enact many changes that will ensure no one is harmed by these practices again. Moreover, they stated it is not enough to simply refrain from harm; the system must transform itself so that people are helped – consistently and always. The summit participants concluded that transformation and culture change embraces people with mental health conditions as the experts and that the first and most important step to implementation is to partner with people with lived experience at all levels of the system; this includes hiring people in recovery as administrators, consultants, policy experts, advocates, trainers, clinicians, direct care staff, and in specialized Peer roles. The group drafted 11 position statements which can be found on the Transformation Center's web site – click on Advocacy and you will see all the restraint/seclusion information, or go to [http://www.transformation-](http://www.transformation-center.org/advocacy/policy/restraint/position.html)

[center.org/advocacy/policy/restraint/position.html](http://www.transformation-center.org/advocacy/policy/restraint/position.html) .

Moreover, soon, using the Forum accessed through our web site, visitors will be able to share their thoughts about restraint and seclusion, stories and vote on the position statements – so be sure to check it out as we want to hear from you about this issue! We want to hear about your experiences and thoughts! Please keep an eye out for this forum.

Over the past 3 ½ years many people have contributed to this work. I have had the privilege of coordinating the activities working in partnership with Transformation Center team members Marina Colonas and Kerrie Fallon. In addition, peer advocates from all over the state have participated and contributed in so many ways I would need to fill up this entire newsletter to cover it adequately.

All our activities over the past few years were paid for by DMH using funds from a federal state-incentive grant to reduce restraints and seclusion. Although the grant is over we will continue to be involved in the process, including participating in the statewide Restraint/Seclusion Committee, which is now a subcommittee of the state Mental Health Planning Council. In March committee members decided our mis-

sion will expand to trauma informed care though we will continue to prioritize restraint and seclusion elimination. We also agreed that involving the private DMH-licensed hospitals in our work is worthy and important.

Healing from Bi-polar Illness

By Nancy Courage

I was lost in my misery
Trapped by my history
God saw me through the gate
No, I said, you're not late
He's just now setting you free

I survived this past Christmas in the intensive care section of a prominent psychiatric ward in Boston, coming out of a week-long blackout prior to dealing with my history of rape.

Thanks to massive doses of Zyprexa, I returned to a conscious state and came to in a room on a locked ward. The amounts of medications I had been given rendered my left hand numb, my feet were swollen like balloons and my gums were bleeding profusely.

That evening, the nurse came to give me my night meds. She stated that if I didn't take the prescribed increased doses, I wouldn't have any meds at all, including my anti-

Bi-polar Illness

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psychotic, Abilify. I didn't panic, however. I thought, What would it be like in this psych ward if I couldn't think clearly?

There was a telephone in my room. I dialed 911 and told this police officer about my situation. Ten minutes later I had my regular medication. The hospital staff shut off the phone in my room for days – until Christmas. I'm not sorry I made that call.

I'm grateful to the hospital for helping me get my mind back. Since my discharge I have addressed my Bi-polar condition head on through: Dialectical Behavioral Therapy (DBT), individual and group counseling, by keeping on schedule with my medications, getting plenty of sleep and eating regular meals. It has been a good year so far on the whole and I hope I'll never be hospitalized again.

“The task is not to become normal. The task is to take up your journey of recovery and to become who you are called to be.”

Survivor of Clergy Abuse

by Randy Orso

In August, 2008, I attended “Leaping Upon the Mountains: A Men's Recovery Weekend” for male survivors of sexual abuse. The retreat was held at Kirkridge Conference and Retreat Center which has a proud tradition of prayer and protest within the Christian tradition and is located in Bangor, PA on a wooded ridge in the Pocono Mountains.

Mike Lew M. Ed. and Thom Harrigan L.I.C.S.W. of The Next Step Counseling in Brookline, MA led the retreat. Next Step Counseling has a very informative website <http://www.nextstepcounseling.org>. Mike Lew is also a noted author of *Victims No Longer: the Classic Guide for Men Recovering from Sexual Child Abuse*, and *Leaping upon the Mountains: Men Proclaiming Victory over Sexual Child Abuse*. Thom leads groups for male survivors and works extensively with sur-

vivors of clergy abuse.

The retreat embraces the new dynamics of recovery that have happened in recent past years, such as no longer being forced to suffer alone and the collaborative efforts of survivors and professionals to develop and recognize resources and support systems that benefit the recovery process. This was the 18th annual weekend workshop at Kirkridge for non-offending adult male survivors of sexual child abuse and other boyhood trauma, the goal of which was “to



Randy Orso

offer a recovery experience in a safe, powerful environment of shared healing.” The reality of the possibility of recovery from such trauma was evident as each person shared his feelings, stories, struggles and successes.

I purchased Mike Lew's books and was particularly glad to have a chance to have the new expanded edition of *Victims No Longer: Second Edition*. Mike was gracious to sign the copies for me, which was very meaningful to me. Mike has been very supportive. My ef-

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forts to have the Archdiocese of Boston pay for treatment like weekends like this for survivors of clergy-sex abuse were continued by my lawyer at the time, Laurence Hardoon Esq. of Brody, Hardoon, Perkins and Kesten, along with his able secretary, Nicole Romano. Upon my return they drafted a letter appealing that treatment be made available through the Office of Pastoral Outreach and Support, of the Archdiocese of Boston, in their efforts to pay for treatment for victims of clergy-sex abuse. The Archdiocese has replied to this most recent request with an emphatic no, even though Amy Strickland, Delegate for Investigation for the Archdiocese assured me of the reasonable nature of my request when I reported the abuse to her and asked her to fund the retreat as part of my treatment. My most generous parents, both disabled and living quite humble lives, paid for my attendance at the retreat. I was certain to include in my prayers at a small chapel at Columcille, which is patterned after the Celtic Christian center of Iona, a special intention that more victims be able to attend retreats like these through the help of spiritual communities that learn to see

their full responsibility for the scope of abuse perpetrated against children in their care.

The statute of limitations on sexual abuse expires often before perpetrators can be apprehended and I join leaders like Cheryl Jacques a lawyer and gay rights activist, Eileen McNamara a Globe Columnist, David Clohessy leader of Survivors Network of those Abused by Priests (SNAP), and others on calling on the Massachusetts Legislature to eliminate the statute of limitations on sexual assault. I continue to stay in touch with the attendees of the retreat weekend by email and phone and they have helped me through the disappointing times I have had seeking justice and recovery. Leaping Upon the Mountains is not merely a retreat weekend but a community of support and a network of coping, courage and recovery for survivors of abuse.

* The author, Randy P. Orso, is a former Board of Director Member of M-POWER and the Transformation Center, a former NAMI-MASS volunteer and a former Peer Educator with Vinfen's Peer Educator's Project. He also was formerly employed by South Bay Mental Health in Plymouth, MA as an group discussion leader for their Day Treatment Program. He is a victim of

clergy-sex abuse that occurred when he was only 7, serving as an altar boy at Our Lady of Assumption Parish in Green Harbor, Massachusetts. He has moved to Pennsylvania and continues to advocate strongly for good mental health treatment for victims of clergy-sex abuse.

Radio Boston

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pointments.

DMH assistant director Marcia Fowler said that the cuts had been very sudden and that was what accounted for the gap in services. She added that when the DMH thought about which programs to cut, they wanted to save the programs for clients "with the most acuity." This writer assumes that means "with the most need of services" as judged by the DMH. Ms. Fowler also said that the DMH wanted to avoid cutting housing programs.

Representative Kay Kahn, the chair of the joint committee of Children, Families and Disabilities, says that she wants to keep community services in place and she wants to "work with DMH to promote supporting the needs of consumers." Boire also talked with consumers from Center Club (a clubhouse in Boston near North Station), and Work, Inc. of Quincy. Attorney

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Voices for CHANGE

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Nothing about us without us!

Radio Boston

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Bob Fleischer of the Center for Public Representation said he thought there would be more use of emergency rooms, and use of hotels for shelter for the homeless after the cuts, and this would be expensive to the state.

If such publicity of DMH budget cuts raises community awareness, it may have a positive influence on DMH policy in the future. You can listen to a transcript of the show at the website radioboston.org.

Metro Boston Recovery Learning Community Warm Line

By Rachel Hays

The Metro Boston Recovery Learning Community's Warm Line opened in the middle of January and answers calls Mondays, Thursdays, and Saturdays from 4 pm to 8 pm at the nationally-accessible toll-free number

1-877-733-7563 (which can be remembered as 1-877-PEER-LNE). The Warm Line, like the Metro Boston Recovery Learning Community (MBRLC) itself, is staffed entirely by people who are ourselves in recovery from psychiatric conditions and who have been trained to attentively and empathically listen, offering compassion and validation as we assist callers in connecting with their own internal resources, strengths, and direction. For more information, go to the website www.metrobostonrlc.org.