



MDDA-RI Matters

Newsletter of MDDA-RI

(formerly the Manic-Depressive and Depressive Association of Rhode Island)

May 1, 2009

RI Consumers Attend Leadership Academy to refine leadership, advocacy skills

Mental health consumers associated with MDDA-RI and MHCA/OASIS attended a long weekend training in Leadership sponsored by the NAMI STAR Center and coordinated by that Center's Director, RI's own Jim McNulty.



Carefully selected individuals underwent intensive training in such matters as organizing and leading meetings, generating momentum around a cause, proper handling of challenging situations, and how to identify new leaders. The weekend culminated in joint planning exercises between the two groups.

The West Virginia Mental Health Leadership Academy, a longtime leader in the field of

training, sent two trainers to Rhode Island to conduct the three day training, which was held at the Radisson Hotel in Providence. Twelve volunteer trainees were successfully trained and graduated from the program, which has been in existence for over a decade and is described as and “Exemplary Model”, and is considered a “promising practice” in terms of evidence-based practice.

Graduates of the training described “feeling energized” and “renewed” about the advocacy work ahead, here in their home state of Rhode Island. Given the practical difficulties facing the publicly funded behavioral healthcare system, these advocates will need the energy and skills they learned and refined over the weekend.

The current principles underlying the training come from the President's New Freedom Commission Report on Behavioral Health, released in 2003. One of the primary outcomes called for by the Commission is a “consumer and family driven, recovery and resiliency-oriented system of care”. In training a new generation of leaders, MDDA-RI and MHCA/OASIS are seeing that at least part of the vision of the New Freedom Commission is kept alive.

For additional information, contact Jim McNulty 401-309-7575 or jim@mdda-ri.org.

Support Group Topics

Depression was a chronic theme during the past quarter. Group members seemed reassured to know that despite the fact that it is counterintuitive, it is ordinary for people to struggle more after the Holidays and as the days start to get longer. It does get better, and—for many people with manic-depression—the summers can get “too good.” Vigilance is, as usual, the watch word.

Sleep difficulties were another common problem. Sleep difficulties ranged from sleeping too much, not wanting to get up, not getting enough sleep, and not feeling like you need sleep. The Group offered many solutions like:

- Go to bed at the same time and get up at the same time every day
- Set up a reward or something to look forward to, to help make it easier to get up
- If you can't sleep, rest
- Take your night time medication in advance of when you desire to sleep
- Talk with your doctor about medication for sleep, or changing the time you take your medication
- Do something really boring until you get sleepy.

Stress was another big topic, in all of its forms. Many members expressed work-related stress and as many expressed experiencing stress from not working. Holiday stress, family and relationship stress, and economic stress were all discussed. Strategies included:

- Do less. Focus on one thing per day and take pride in getting one thing done
- Manage relationships: be clear about how much time and energy you have
- Try to enlist the support of your supervisor at work

- Volunteer or find other ways to fill time if not working
- Make sure you have at least one person you can talk with about the stress you are experiencing
- Keep your health care provider informed.



Upcoming Trainings

MDDA-RI Facilitator Training

There will be a training of support group facilitators on Saturday, May 30, 2009. This is a half day-long training for support group members who wish to become Facilitators. Facilitator-trainees spend time working with trained Facilitators before running groups on their own. The one day training covers basic facilitation skills and common problems and remedies experienced facilitating groups. There is a certificate presented to graduates who successfully complete the course. Training is offered at no charge. Call 401-309-7575 or email kathryn@mdda-ri.org if interested.

MDDA-RI Advocacy Training

Scheduled for Saturday, June 20, 2009 is a new training in advocacy for all persons who are interested and live with mental illness. Seating is limited and names will be taken on a first-come, first-served basis. This day long training orients participants to historical and current issues in mental health. Participants will learn how to use their stories successfully as an advocacy tool, in addition to special coaching on etiquette and opportunities. Training is offered at no charge. Call 401-309-7575 or email kathryn@mdda-ri.org for details.

MHCA/Oasis has a warm line for when you need someone to talk to in a non-crisis situation. Hours of operation are 4:30 p.m. to 9:30 p.m. Sunday through Thursday. The number is 401-529-7900.

Winter Rules

We had one cancellation due to snow this winter. A few people didn't get the word, so here's a review of the "Winter Rules":

At 4:00 p.m. on the day of the meeting, in the event of a snow cancellation, a message will be placed on the MDDA-RI phone at 401-309-7575.

The MDDA-RI website at www.mdda-ri.org will also be updated to reflect the cancellation.

So, in snowy weather please check before you set out for the meeting: we don't want you risking life and limb!

Support MDDA-RI!

If you'd like to make a donation to MDDA-RI to support our work in support, education and advocacy, please make checks payable to "MDDA-RI" and mail to PO Box 28, Pascoag, RI 02859. In addition to supporting our good works, your donation helps support our web site and phone access. Please come to an MDDA-RI meeting on Tuesday night at 7:00 p.m. at the Ray Conference Center on Butler Hospital Campus to see what we're all about.

If we're not on the second floor...

Look for the meeting on the first floor of the Ray Conference Center in Conference Room 1. When we have members with mobility issues, we meet on the first floor.

We're trying something new this month.

Because of the large increase in number of members this Spring, we'll be trying something new. The MDDA-RI meeting will start promptly at 7:00 p.m. We will divide the group into two on nights that we have a particularly large number of participants. Both groups will be run by trained Facilitators, and both groups will use the same guidelines and procedures with which you are familiar. By dividing the Group roughly in half, members will have more sharing time and more issues will be processed.



My MDDA-RI Story

By Mike Sicard



Devastation. Newly divorced and back living with my parents. My Father's cancer now spreading through him and knowing he was going to die. Myself newly diagnosed with metabolic syndrome and dealing with my own depression. Life didn't seem like it could get any worse. Then my Uncle Sted died followed by my father and then my Aunt Dolly. I got so depressed I couldn't keep up with the things I needed to do at work. I lost my job and I had to be hospitalized. Life felt like it was all over for me. I couldn't handle everything that was happening. After being released from the hospital I started in the Butler day program. After a week there I was informed my insurance wouldn't pay for any more time there so I was started at the day program at the Providence Center.

Through all this I had only a few constants in my life. My family, my friends and the MDDA of Rhode Island. Had it not been for these three things I don't know if I would be here today. Because of the support I got from all of the people at group and the help I had at home I made it through this trying time. Just as I was really getting my feet back under me my Mom passed away. It was three years later, but it

had taken that long for the trauma to diminish and this threatened to undo all that I had accomplished. My doctor got me into his office that day and started an aggressive treatment of medication. My brother and his family kept me busy and as productive as possible. My friends from the MDDA rallied around me and helped to keep me sane.

Without the help and support of my friends at the MDDA, I don't know if I would have made it through these trying times. Being with a group of people who understood the myriad of emotions that were coruscating through me at this time and being complicated and amplified by my mood disorder brought me some peace and ability to cope.

Because of the encouragement and hope that the group was able to instill in me I was able to get through going on disability and having to move into subsidized housing with my dignity intact. The group process helped to get me through all the varied transitions that my life had to go through to get me to where I was headed. With all the bumps in the road and pain of the trip I managed to survive and thrive. I went back to work part time as an advocate for the Alive Program at NRI Community Services. I got to travel all over the country to conventions and on information gathering trips. I became a board member at NAMI-RI and went from a general board member to secretary of the board and finally to board Vice President. I am currently co-Vice President of the MDDA. The MDDA-RI has been a supportive force throughout my journey of recovery with my illness. It is because of many people from the group who I will not name here for confidentiality purposes that have kept me on the road to recovery and constantly looking for improvement to my

life. I owe the people and the group all that I have and all that I am.



What Recovery Means To Me

By Kathryn McNulty

Long ago, I was a case manager in one of our Community Mental Health Centers. I was well acquainted with mental illnesses and had the same low expectations for “chronicity” and “maintenance” that all my colleagues held. I thought inside that box for years, until acquiring my own diagnosis and needing something more. I didn’t know it had a name, but I knew what it was when I first attended an MDDA-RI meeting.

I have a theory. Let’s call it the “theory of diminishing expectations.” It goes something like this: you work with a provider for a while and attain a certain level of stability—not recovery—and that level is duly noted in your record and becomes your “baseline”: the level at which you are expected to function. Then, you are transferred to another provider and don’t quite meet that level. The new, lower, level is recorded as your baseline and you go on to the next provider. The next provider expects a lower level, and unless you exceed expectations, your level will appear to be declining. Basically, the system—with its high turnover rate and non-recovery orientation—traps people in a system of diminishing expectations. People

don’t recover because no one expects them to.

Contrast that with MDDA-RI, where recovery is emphasized along with practical steps and know-how from peers. Certainly, MDDA-RI is no substitute for the formal treatment system, but it sure is complementary. Instead of “maintenance” and “chronicity”. MDDA-RI members expect change. Recovery is not the return to some previous way of being (although many new people come in hoping for that exact experience), it is the moving forward having consolidated the new experiences and new information contained in the experience of mental illness. It is living life fully *with* the life-changing experience that is mental illness. It is finding a new niche, discovering new strengths and abilities, applying a new measuring stick to progress and setbacks, making new adjustments in oneself and among others, and “finding one’s feet” in very fluid occurrences.

How do we get there?

I have another theory. “Support is to recovery as carbon is to life.” We get to recovery by being with others who are making the same journey, who have the same questions and uncertainties and the same need for reassurance that we are not alone. We get to recovery by asking “is this normal?” and hearing from others that the “abnormal” is, in fact, ordinary when you live with mental illness and that **that** is okay. We get to recovery when there are examples in the room of people who are just a little farther down the road than we are, just a little more hopeful than we are, just a little more settled than we are. We get to recovery with others. But we do the work of recovering ourselves. Having a group makes it easier and less lonely.

I am not fond of the word “recovery”. It implies too much that something was broken and is now fixed and I don’t think of any of us as broken people. I think we are extraordinary people living extraordinary lives which require extraordinary effort at times, bearing extraordinary rewards. Alternatives to “recovery” are words like “transformation”, “renaissance”, “recuperation”, “revitalization”, and “rehabilitation”. None of them quite capture the experience of the attitudinal and lifestyle shifts which take place when someone lives well with mental illness. And that is, after all, the goal for all.