People diagnosed with 'mental illness' doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER OCTOBER 2010

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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"So, you've got a 'Mental Illness'? ... What now?"

The long awaited official launch of our first booklet:

October 10th 2010, 11-1 at BMW Edge Theatre (Federation Square, Melb)

Merinda Epstein will be speaking, and the booklet will be officially launched by the Federal Minister for Health, the Hon. Lisa Neville.

Want copies? This 100+ page resource is absolutely FREE! Written *entirely* by and for mental health consumers, it is an introduction both to the mental health system (including how things like diagnoses work and what the "medical model" is) and to consumer perspective. Please get in touch with us – (03) 9320 6839, service@ourconsumerplace.com.au, or order directly through our website: www.ourconsumerplace.com.au and follow the links to OCP resources.

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INTERVIEW OF THE ISSUE – Oryx Cohen (USA)

Oryx Cohen, M.P.A., is a leader in the international consumer/survivor/ex-patient (c/s/x) movement. Currently he is the Co-Director of the Western Massachusetts Recovery Learning Community. He has helped to spearhead an innovative peer-run approach focusing on recovery, healing, and community. Oryx is also the co-founder of Freedom Center, the Pioneer Valley's only independent peer-run support/activist organization. Freedom Center's purpose is to empower and support people with psychiatric labels while challenging oppressive mental health policies and practices.

*Oryx serves on several boards and committees internationally, nationally and regionally, including being a member of the International Network Toward Alternatives for Recovery (INTAR). Oryx volunteered for several years with MindFreedom International, directing its Oral History Project. This project involved collecting and documenting c/s/x stories of abuse, empowerment, and healing in the mental health system. Oryx is now featured in a book by Gail Hornstein called "*Agnes's Jacket: A Psychologist's Search for the Meanings of Madness*" where he and Will Hall are compared to the founders of Alcoholics Anonymous. Oryx is also adjunct faculty in the Westfield State College Psychology Department.*

Flick Grey: How would you describe what consumers/survivors/mad folk (or whatever language you use) are doing at the moment – a broad brush picture – in terms of changing the mental health system or the world?

Oryx Cohen: That's a big question [laughs]! I think that the biggest thing that we are doing right now is we're getting more active in terms of presenting an alternative view of extreme emotional states – trauma, madness, what have you. We're doing a better job of getting that out into the mainstream media. There are more and more people who are having these views, who are questioning the establishment, questioning the Big Pharma. There are more and more people all around the world who are thinking similarly, who are doing similar work and so it's just a matter of time until these ideas really catch on in the mainstream. It still hasn't happened yet. Yeah, I think the biggest thing that we are doing is trying to get these ideas out into the media and creating our own media. So that's my simple answer to a complex question!

Flick: What place does activism have in mental health? What top three areas would you target?

OC: I think that activism has a really important place in the movement, and I think that independent activist groups are really important because peer-run or survivor-run organisations that are funded by the government have a real danger of getting co-opted, and even if they are not co-opted they still cannot do the kind of activism that independent groups can do. And so, I think they are crucially important.

> *... peer-run or survivor-run organisations that are funded by the government have a real danger of getting co-opted, and even if they are not co-opted they still cannot do the kind of activism that independent groups can do.*

The top three areas: number one would be to protest the mainstream mental health system, for buying into the medical model that doesn't work – the "broken brain" theory. There's too much of a tendency to be co-opted into that. So, number two … [laughs] I'd like to see a moratorium on the term "mental illness." A campaign to strike that term, to stop using that term! Number three would be a protest of Big Pharma.

> *I'd like to see a moratorium on the term "mental illness." A campaign to strike that term, to stop using that term!*

Flick: Can you elaborate on that term "Big Pharma"? I mainly hear that term from activists in the US – we seem to use it less in Australia

OC: It's the big pharmaceutical companies, like Eli Lilly, Pfizer, the companies that make all the medications, psychiatric drugs. They are – at least in the US – extremely corrupt. In the United States, they are the most profitable industry, in terms of net profits. They have more lobbyists on Capitol Hill than we have members of the House of Representatives, they control the Federal Drug Administration, they fund all the research that is done on psychiatric drugs and other drugs. So, there's really no independent watch dog. The pharmaceutical companies have spun completely out of control. Now they have direct advertising on TV all the time, which is completely illegal in every country except the United States. It's very bad news. And the pharmaceutical industry has gotten in trouble for hiding documents that show that their anti-psychotics can cause early death, and all sorts of health problems. That was Eli Lilly with their drug Zyprexa, but there's another company … anyway, it's really bad! Does that answer your question?!

Flick: What would you expect to be different if we lived in a community that embraced people with emotional difficulties or who experienced madness?

> *A lot of times when more sensitive people are freaking out, it's telling us something about the whole society, that something is wrong with the whole society.*

OC: Well we'd be a much better society because we wouldn't suppress those states, we could learn from what's going on! A lot of times when more sensitive people are freaking out, it's telling us something about the whole society, that something is wrong with the whole society. Like in terms of the environment, or what we're doing to each other, you know, wars, and in our families and in our communities. So, I think we would be a much healthier society if we were more enquiring and just accepted altered states and tried to learn from them, instead of trying to suppress them. I think we would be much better off.

Flick: If you were asked to give the government advice on how to spend $500 million on mental health, how would you spend the money? What if you only had $10,000 to spend?

OC: Actually my answer is about the same for them both. $500 million I would put into community – true community – mental health. Meaning, the idea of building community from the ground up, and that having to be led by people with lived experience. That doesn't necessarily have to be everyone who is involved in leadership, but it does have to be a critical component. There are people with lived experience leading these efforts. And what could it look like with $500 million? There could be peer-run respite, safe houses for people to go and detox from medication or get through a crisis. Community centres where people could go throughout the day with all sorts of things to do like yoga, acupuncture, support groups, exercise. And these community centres would be open to everyone, to members of the public, they would be integrated, and they would fight stigma that way. You know, you could open up bakeries, clubs … the sky's the limit with what we could do with $500 million!

> *$500 million I would put into community – true community – mental health. Meaning, the idea of building community from the ground up, and that having to be led by people with lived experience.*

As far as $10,000, well you could create a Freedom Centre for $10,000! The Freedom Centre doesn't have an money, but they have done a lot of great stuff for almost 10 years now.

Flick: Can you elaborate a bit on the Freedom Centre?

OC: Yeah, the Freedom Centre was started by people with lived experience who rejected the mainstream mental health system, and decided to start something of our own. I was a co-founder of the Freedom Centre, and we went from being a little group that met once a week to being a group that has 100s of people who are involved in the local area, and even more who have been involved in our website and on-line, you know at different conferences and whatnot. Locally, we have weekly support groups, weekly acupuncture for the community, yoga, a radio show that is syndicated nationally. We were featured on the Forbes magazine website and lots of people have healed through the freedom centre. And it doesn't cost that much money to create any of this.

Flick: What are some things that could happen in one day that would give you a really good night's sleep where you woke up feeling hopeful and ready to take on the world?

OC: Well, if one person makes a huge change in their life, well that's really inspiring. And we see that a lot! And if I woke up tomorrow and [laughs] the government decided to regulate pharmaceutical companies and had them stop lying to the public that would make me feel a lot better! Those are a couple of things I guess.

Flick: And now the final question, what's more important, the outcome or how you get there, and can you give an example?

OC: I think it's all about the process, how you get there. Because I think you can make positive changes in your own life, and positive changes in your community, and then that will have a ripple effect. But if you go about things the wrong way, then that's no good for anybody!

An example would be, you know, looking at leaders like Gandhi and Nelson Mandela – a peaceful, non-violent revolution is what we need!

> *… if one person makes a huge change in their life, well that's really inspiring. And we see that a lot!*

NEWS IN THE CONSUMER WORLD:

★★★★★★★★★★

Congratulations to Isabell Collins! (CEO of the Victorian Mental Illness Awareness Council) for her Award at the Mental Health Services (TheMHS) Conference:

For "EXCEPTIONAL CONTRIBUTION TO MENTAL HEALTH SERVICE IN AUSTRALIA OR NZ"

"Isabell Collins has made a significant contribution towards mental health reform as an active and effective voice for mental health consumers. She is well known in the mental health system at both national and state levels.

Isabell is an outstanding and determined advocate for the protection of the human rights of mental health consumers. It is not unusual for Ms Collins to be seen working with clients and their families long after normal office hours and on weekends. No one in need is turned away. She has been providing support and assistance to countless people living with a mental illness, inspiring people with hope.

Isabell participates in more than 20 mental health committees at all levels. She is a member of the National Mental Health Standing Committee, Chairperson of the National Mental Health Consumer and Carer Forum and member of the Victorian Mental Health Ministerial Advisory Committee.

Isabell has a strong passion for her work and she is still indefatigable.

This award is in recognition of her dedication well beyond the "call of duty", of passionate advocacy for human rights, of commitment at all levels of service planning, and for simply being there when needed. It represents our deep respect for an exceptional contribution, the results of which will flow on to enhance the mental wellbeing of all."

★★★★★★★★★★

Isabell is also a finalist in the 2010 Victorian Public Healthcare Awards, in the category "Outstanding achievement by an individual in mental healthcare." Winners to be announced on October 6th.

Peer workforce national training breakthrough Community Services & Health Industry Skills Council

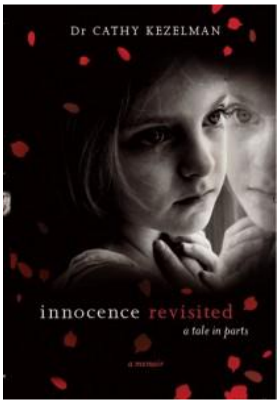
There is some good news for those of you working in peer roles within the mental health sector. A new qualification is currently being developed specifically for the peer workforce (consumers and carers). This qualification will be recognised nationally and will cover the skills and knowledge you need to work in your job roles. It is hoped this initiative will enhance the workforce by setting groundwork for improving training and support and working towards consistency in job roles.

You will have an opportunity to have your say about the draft 1 material when online and face to face consultation takes place in November.

For more information, visit the Community Services & Health Industry Skills Council website under the current projects page www.cshisc.com.au

-submitted by Rebecca Tidey | Project Coordinator (CSHISC)

NEWS IN THE CONSUMER WORLD (continued)



One of the gems that we discovered at TheMHS was Dr Cathy Kezelman, someone who wears "two hats" – she's both medically trained and a consumer. She's written a book about her experiences of childhood abuse – called "*Innocence Revisited: a tale in parts*", which Merinda describes as "un-put-down-able." Cathy is a passionate advocate for survivors of childhood abuse, and has a website devoted to her work: http://cathykezelman.com. Her book was released earlier this year, and attracted significant media attention (there are links on her website). We're hoping Cathy will contribute to this newsletter in the foreseeable future.

Congrats also to **Key We Way**, a Peer Delivered 'Recovery House' in New Zealand, for taking the TheMHS prize in the "Consumer Provided Services" category. We won't say more about them here, because they have promised to write about themselves for us in the future!

But wait, there's more – Congratulations to **Voices Vic** who are a finalist in the 2010 Public Healthcare Awards, in the category "Responding to mental health & drug & alcohol service needs award."

OZ MAD is back online! "OZMad is an e-list fighting for the human rights of People with Psychosocial Disabilities in Australia and Internationally. We demand the full implementation of the Convention on the Rights of Persons with Disabilities which no longer permits forced medication or hospitalization and requires Governments to end substituted decision making and Guardianship. The Convention requires Governments to provide support to all People with Disabilities make their own decisions in all aspects in their lives and particular when exercising our legal rights. This group will challenge the old institutional methods of substituted decision making and forced treatment. Users, Survivors and friends are welcome to join this elist to challenge the old status quo." Either send an email to: OZMad-subscribe@yahoogroups.com OR go to: http://groups.yahoo.com/group/OZMad/

Gems from TheMHS (these two words apparently DO NOT rhyme!):*

"You're only given a small spark of madness. Don't Lose it"

"Do not disturb. Disturbed already"

"If it's not voluntary, it's not treatment"

"They told me I was an agent of change. But they didn't tell me that this system resists change." – Douglas Holmes

"If as individuals and as communities, we all learn to accept and share our vulnerability as human beings, we will begin to tackle stigma in all its forms." – Cathy Kezelman

Consumers: "A community that says we don't like that knowledge, we're going to create our own and we want to use it to bring about social change."

"You always transform beautiful things into shit in psychology" – Alan Topor

"But to live outside the law, you must be honest" – Bob Dylan, quoted by Alan Topor

*"Two psychologists meet each other and one asks the other 'What time is it?' the other replies 'What time do **you** think it is?'" – Alan Topor*

*apologies for the lack of attributions, let us know if you want us to amend this!

FEATURED ARTICLE

WHY MENTAL HEALTH DISCRIMINATION COSTS US ALL

By Jeff Cheverton, CEO of the Queensland Alliance for Mental Health, the peak body for the community mental health sector and a Board Member of the Mental Health Council of Australia. Visit: www.qldalliance.org.au

Half of all Australians will experience a mental health disorder at some point in our lives. Why is it that an experience so common, is so rarely spoken about?

Governments in the UK, USA, Canada and New Zealand have all invested in anti-stigma mental health campaigns to reduce the costs to society of mental illness. A reduction in discriminatory attitudes towards mental illness means people are more likely to talk about their own stresses and mental health needs, and to seek treatment and support early, resulting in a significant economic benefit. It speeds peoples' recovery. It reduces: their call on expensive hospital services; payment of disability or unemployment pensions; costs to family and friends; and productivity loss through days off work and/or loss of trained employees.

With the support of a Churchill Fellowship, I was able to visit countries that have successfully changed public attitudes towards mental illness and mental health. The longest-running campaigns are New Zealand's 'Like Minds Like Mine' campaign (www.likeminds.org.nz) and Scotland's 'See Me' campaign (www.seemescotland.org.uk). Similar campaigns operate in Canada the United States and England, where *Time to Change* (www.time-to-change.org.uk) is an £18M investment challenging mental health discrimination.

A national survey identified 32% of Scots believed people with mental illness were dangerous. After only four years of the *See Me* campaign this reduced to 17% of the population. National surveys in New Zealand showed only 69% of Kiwis would accept someone with mental illness as a workmate. This increased to 83% after the campaign.

The fear of mental illness stops people from even admitting to themselves that they need help. Research shows that in countries where anti-stigma campaigns have run for several years, people are more likely to seek help early. This speeds their recovery and reduces their call on public health services.

Significant progress has been made in Australia – thanks to organisations like beyondblue – in raising awareness of depression. In the June 2010 budget the Queensland Government announced Australia's first anti-stigma campaign in mental health, with an investment over four years of $8.5M. This is a visionary initiative that will open doors for people with mental illness in the community.

It is now time for a national campaign that talks about schizophrenia, bipolar disorder and other mental illnesses.

INTRODUCING ... THE BALLARAT HEALTH SERVICES – PSYCHIATRIC SERVICES (BHS – PS) CONSUMER ADVISORY COMMITTEE

Ballarat Health Services – Psychiatric Services has had a Consumer Advisory Committee from 2000 until 2003 and then again from 2007 until now. Since the beginning of the work of the consumer consultancy, it has been recognised that there is need for a broader voice than just that of the consumer consultant. The CAC has had some significant small wins for consumers in the organisation prior to the last twelve months. Such successes include:

- Better entries in the phone book so that those in crisis could more easily find access to the service.
- A sign in seclusion rooms telling people of their rights and responsibilities.
- Better parking for consumers and families at the adult acute unit.

A review of the committee and its roles and responsibilities was undertaken in July 2009. Results showed that members didn’t all have the same understanding of the committee’s role and their role as individual members. The survey showed that communication between the committee and the service could be improved.

The review highlighted areas that could be improved and the following changes that have been made:

- The terms of reference for the committee now state that all decisions that will have a “major, direct impact on consumers” need to come to the committee.
- There is a guest speaker program where new initiatives of the service come to the committee for consultation and review.
- All policies and protocols that would profit from a consumer review come to the committee.
- We have started an education and training program for the committee and others on the consumer participation program. This should mean that members’ skill levels improve and so the committee is more effective.
- There is now an induction and orientation program for consumer advisory committee members. This means that the members better understand their role in the organisation and so can better play their roles.
- We have designed a brochure for any consumer to fill in to register as part of the consumer participation program, which feeds into the committee.
- The committee is now open to all consumers of the service to attend.
- Meetings are now held monthly.
- Consumer newsletter “Livewire” has been redesigned and re-launched.
- Recruitment to the CAC to ensure an influx of new group of members has begun.
- We have also planned an annual planning day on a weekend, so that members can shape where we go in the next year.
- The self audit will now be redone each year, so that we can make sure we are continuing to grow and improve.

These changes already seem to have had some effect. The reforms we come up with seem more routine rather than sporadic. And the committee members seem happy with the extra level of responsibility given to them by the reforms. And skilled enough to deal with them, because of the education and training provided. This process has assisted in developing a culture where consumers’ views are valued and, where appropriate, acted on by the service.

- By Mark Lacey, Consumer Consultant, Ballarat Health Services- Psychiatric Services.

Let me tell you about a girl ...- by Katie

Let me tell you about a girl. She was a normal girl. She liked books and words and going out with friends. Life was pleasant.

One day, after nothing in particular, the girl realised that she didn't feel like going out with her friends, and she didn't feel like reading her books. She felt the enjoyment she had found in these things was gone *(anhedonia)*. This continued for a time. In this time, the girl found that she was having difficulty sleeping, often lying awake for hours on end *(insomnia)*, with troubling thoughts stuck in her head.

One day, the girl went into a book shop, to see if she could find a book to read that would distract her mind and make her feel cheerful again. She had not been out of the house for a while and found the open space of the book shop and the people within it terrifying *(agoraphobia)*. She started to have difficulty breathing *(hyperventilation)* and stumbled in to an aisle where there were no people. She rested her head against the book shelf and waited until the feeling of terror *(anxiety)* passed. When she had recovered her breath she looked up and realised she had stumbled in to the self help aisle. This made the girl laugh, but then she could not stop laughing *(hysteria)*. She laughed so much it made it hard to breath.

The girl went to see a doctor. The doctor asked her some questions. He asked if she felt angry or agitated for no reason *(dysphoria)*, if she felt particularly tired *(somnolence)* or if she thought about death *(suicidation).*

He prescribed some medication to make her feel better *(serotonin and noradrenalin reuptake inhibitors)* and some to help her sleep *(nonbenzodiazepine hypnotics)*.

Things seemed to be getting better for the girl (convalescence). Some days she felt quite alright (euthymia).

But some days she would feel like a bubble about to burst. She would get an overwhelming feeling of well-being *(euphoria)*, she'd flit about and fidget *(psychomotor agitation)* and had no time to rest. If anyone asked, she would tell them how well she was feeling *(hyperthymia)*.

Soon the people around her began to realise that the girl was not as well as she claimed to be feeling *(relapse)*. She would swing wildly *(oscillate)* between feeling life was a joyous wonder and a crushing burden.

A few months of taking the medication *(serotonin and noradrenalin reuptake inhibitors)* made the wild mood swings worsen *(exacerbated)*. She would some days be capable of extraordinary feats *(hypomania)*, requiring little sleep *(hypersomnia)* only to find that the next day *(rapid cycling)* she felt physically weak *(asthenia)* and wanted to sleep all day *(hypersomnia)*.

This went on for some years *(chronic)*. She went to see her doctor again *(review)*, he gave her more medication *(tricyclics antidepressants)*. For a few weeks she felt better *(placebo)* but the few weeks passed and she went back *(relapse)* to the unpredictable *(volatile)* pattern of thoughts *(cognition)* and moods.

In public, she felt she couldn't breathe *(dyspnoea)*, she'd stumble *(ataxia)* through crowds, her heart beating *(palpitations)* wildly, embarrassed *(erythema)*, copying the way people spoke *(echolalia)* and acted *(echotaxia)* so she could feel normal, all the time, trying to breathe *(attempting respiratory function)*, trying to *(attempting)* breathe *(respiratory function)*.

She saw her doctor *(medical practitioner)* again *(review)* in hope he could tell her *(diagnose)* why she felt so shit *(coprolalia)*. She thought *(cognition)* that she was being punished *(psychosis)*, that she was going to die *(delusions)* and that other people were trying to hurt her *(paranoia)*.

The doctor *(general practitioner)* sent *(referred)* her to another doctor *(psychiatrist)* who gave *(prescribed)* her more *(increased dosage)* medication. Some *(selective serotonin reuptake inhibitors)* to help *(assist)* her *(patient)* up *(antidepressants),* some *(benzodiazepines)* to help *(assist)* her *(patient)* down *(sedatives),* some *(azapirones)* to stop *(cease)* her *(patient)* panicking *(anxiolytics),* some *(sodium volproate)* to keep *(maintain)* her *(patient)* even *(mood stabilisers)* and some *(risperidone)* to keep *(maintain)* her *(patient)* safe *(antipsychotics).* She *(patient)* didn't *(negative)* feel happy *(hyperthymic)* or sad *(dysthymic)* anymore, she *(patient)* didn't *(negative)* feel anything *(hypoesthesia).* She *(patient)* wasn't *(negative)* part *(function)* of anything *(depersonalisation).* She *(patient)* didn't *(negative)* know *(cognize)* what *(conjunction)* she *(patient)* looked like *(body dysmorphic disorder).* She *(patient)* felt *(proprioception)* she *(patient)* was being *(hallucinations)* erased *(eradicated).* And she had lost all her words.

OUR CONSUMER PLACE UPDATE: WHAT HAVE WE BEEN UP TO?

TheMHS conference: Merinda and Flick attended the Mental health Services Conference in Sydney (Sept 14th -17th), relishing the opportunity to chat with other consumers, hear what others are getting up to and present our own work too. We ran a workshop introducing Intentional Peer Support, which stimulated lively discussion. Merinda also gave a talk called "The Power of Language: Co-opting the Consumer Imagination." Flick was going to present on the topic "Can the consumer speak?" but actually, in that context, this consumer felt she couldn't speak ... but that's a-WHOLE-nother story. Oh, and Merinda was chuffed to hear Leonnie Manns (a keynote speaker) refer to Merinda's keynote (from 1996!) as something like "the most memorable keynote in the history of TheMHS." Except that Merinda had slept in and missed that accolade ... We intend to put the paper on our website soon.

Keeping busy: This month has kept us busy, preparing for our Leadership conference on October 14th (see our website for details: www.ourconsumerplace.com.au), the launch of our booklet "So you've got a Mental Illness"? ... What now?," a gradual overhaul of our website (let us know if you see any howlers!) and work towards our next booklets. Given that between us we work just over the equivalent of one full time person, we're remarkably productive (at the moment ...)

Merinda and Flick are going to be TV stars!! Well, OK, we will be on a very brief slot on the "No Limits" Disability Show on channel 31. It will be aired some time in December. It was enormously fun even just getting our stage makeup done!

On the radio ... Merinda was interviewed about Our Consumer Place on "The Boldness" on 3CR radio on Wednesday 29th Sept.

In the classroom. Merinda and Flick have both been entrusted to shape and mould influential young minds ... mwah ha ha! Over the last month, we've been teaching social work students in various subjects and unis. Topics have included: consumer perspective, recovery and "diversity" as it applies to mental health.

THUMBS UP/THUMBS DOWN

Thumbs up to everyone at Our Community who helped us publish our first booklet: "So you've got a 'mental illness'? ... What next?"– to Kathy, Lisa, Den and Amy in particular.

Thumbs up to all the 'carers' who take the time to come to consumer gigs and just sit, listen and learn.

Thumbs up to clinicians who are humble.

Thumbs up to Alan Topor, a keynote speaker at TheMHS who was encouraging clinicians to connect with us on a human level, to break the rules as needed and to trust their intuition in doing so. Was such a refreshing presentation!

Thumbs up to people connected with the Psychiatric Disability Support Sector who understand the concept of power and understand that they don't "empower" us.

Thumbs up to everyone who contributes in their own way and in their own time to the growth and nurturance of a consumer movement in Australia.

Thumbs up to our 'blat humour' (black and batty) which helps us keep fighting, against the odds.

Thumbs Up to the bureaucrat who spoke to us in bureaucratic language and then burst out laughing recognising how silly that language is.

Thumbs up to our pets who nurture us, lead us into new friendships at the park, bring us together with those with whom we would otherwise have nothing in common, love us and never judge us.

Thumbs up to all the consumers who had lunch, dinner, coffee, wine, fresh air and a laugh with us at TheMHS. It was so wonderful to share ideas, critiques and desert with you!

Merinda's response to Tina Minkowitz's interview (Newsletter April 2010) Blat humour?