



**People diagnosed with  
'mental illness' doing  
things for ourselves**

**OUR CONSUMER PLACE  
NEWSLETTER MARCH 2010**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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## NEWS IN THE CONSUMER WORLD:

We acknowledge with sadness the passing of mad activist and psychiatric survivor **Judi Chamberlin**, who died on January 16, 2010. Sometimes known as the “mother” of the consumer/survivor movement, Judi's experience of involuntary psychiatric confinement in her early 20s led her to spend the rest of her life fiercely dedicated to change in mental health – from co-founding the Mental Patients Liberation Front in the 1970s, to active participation in the National Empowerment Centre, MindFreedom, NARPA (National Association for Rights Protection and Advocacy) and the growing Mad Pride movement. More recently she co-founded the Ruby Rogers Advocacy and Drop-In Center in Massachusetts (USA), a “self-help mental health alternative.” She is perhaps most famous for her 1978 book *'On Our Own: Patient Controlled Alternatives to the Mental Health System,'* which has been a manifesto for many of us. In her work as an activist, educator, writer, mentor and more, Judi Chamberlin has been a key figure in the development of consumer-run alternatives in mental health and in demanding that our voices be heard at every level. As she faced her own death, she wrote a blog “Life as a Hospice Patient” about her fight to die at home. She died, as she had wished, at her home in Massachusetts, surrounded by friends and family.

## INTERVIEW OF THE ISSUE – Mary O’Hagan.



For this edition, Merinda interviewed Mary O’Hagan, a leading international expert, and original thinker, in the field of mental health recovery-based services. Amongst her many achievements/contributions, Mary was the first chair of the World Network of Users and Survivors of Psychiatry (1991-95), an advisor to the United Nations and World Health Organization (1997- 2004) on disability issues as they relate to people with major mental distress and a mental health commissioner for New Zealand (2000-2007) – the highest government position held by an openly identified service user in any country ([www.maryohagan.com](http://www.maryohagan.com)).

**Merinda Epstein: Has the heyday of progress in consumer participation and initiatives come and gone?**

**Mary O’Hagan:** Twenty years ago, people were reasonably earnest in the pursuit of consumer participation, and it wasn’t just consumers but people who ran services. I guess that was given a bit more oomph by the whole recovery thing – that was a whole package that consumer participation was just a part of. It didn’t take long to realise that consumer participation, as a concept, wasn’t going to be strong enough. So we came up with the idea of consumer leadership. We have that in our policy documents in New Zealand, but it doesn’t translate, unfortunately, into anything very meaningful. I think at the moment in NZ anyway, and I get this sense from other parts of the world too, that the whole thing has gone into decline, the idea of people who use services having a powerbase and having an influence and leadership in what goes on has declined.

**(ME: Is that being driven by something internal or something external, do you think?)**

**MO’H:** I think there are all sorts of things going on. I think there is a bit of a conservative backlash. I think the recovery stuff has gone nowhere. I mean it couldn’t be implemented because actually it requires a fundamental change in the way things are done, and that’s just not happening. I mean you can’t really have recovery-based services until people change some fundamental views and practices, like about what is madness – madness as a full human experience – and how do we respond to people, as full human beings. These are fundamental issues that aren’t being looked at by services.

**ME: Is there a place for activism in mental health? What top three areas would you target?**

**MOH:** Yes, there is a place for it. There’s a place for people to be inside the system and a place for people to be outside, acting as an irritant. I think compulsory treatment should be one of the targets. I don’t think we’re going to get anywhere until we do something about compulsory treatment. I’ve read some shocking papers from Australia about it recently. And so I would say compulsory treatment. Also, the urgency of the development of a peer workforce. And the discrimination that is rampant within mental health services. Discrimination is rampant elsewhere

too, but particularly there (in mental health services) because everyone ignore it – it’s “too hard” – but really, the worst stuff goes on in mental health services themselves.

**ME: What would you expect to be different if we lived in a community that embraced people who have mental health problems?**

**MO’H:** I think in a way we have a great opportunity. We live in much more pluralistic communities than we’ve ever done and we’ve got a great opportunity for this to happen now, more than ever. But what would it look like? Well people with mental health problems would have partners, they’d have children, they’d have decent housing, they would have the usual freedoms that everyone else enjoys, including the freedom to take treatment or not. And madness itself would be considered part of the cluster or continuum of human experience, that is not just an oddity, but something that we can all learn something from.

**ME: If you were asked to give the government advice on how to spend \$500 million for mental health, what would you spend the money on?**

**MO’H:** I would spend it on developing firstly the peer workforce, on creating alternatives to compulsory treatment and hospitals, and on initiatives that assist people to find jobs and houses and friends.

**ME: What about if you have \$10,000 to spend?**

**MO’H:** A holiday! I’d go on a holiday! ... \$10,000 of public money? I would probably hold a meeting and have a forum for opinion leaders, from all over the place. And get them together and try to get their commitments to take some action.

**ME: 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?**

**MO’H:** Some of the good things that could happen in one day and give me a good night’s sleep? Temazepam? ... I suppose I would get a good night’s sleep if I thought that people who are currently, you know, in the unfortunate position of having to use services, go into them and feel that they are helping them. If people felt that mental health services were assisting them in their recovery.

**ME: Which is more important to you, the outcome or how you get there? Can you give an example?**

**MO’H:** Well, I’m probably more of an outcome-oriented person, which is really a form of torture. If you’re just focused on how to get there, I think that’s easier on people. But I think they’re both important, because how you get there determines the outcome to a degree. But I am quite an outcome oriented person – I don’t want to think that I’ve been doing all these things for all these years for no outcome, or that other people have been doing all this work, I mean we all have. That would really depress me.

## INTRODUCING ...

### A Consumer Activist's Guide to Mental Health in Australia

Merinda Epstein's website: [www.takver.com/epstein/](http://www.takver.com/epstein/)

Welcome to my website. It is with some hesitation that I allowed Flick to persuade me to introduce my website to those of you who have not visited it. I agreed partly to publicly thank my friend and activist, John Englart who built the website for me and has maintained it without any payment for the last five years. John's activism is not in mental health but this doesn't matter. Issues for activists tend to be the same across many areas. I keep trying to find the time to add, subtract and work on the website but there never seems to be enough hours in the day! I guess this is the same for most of us.

Nonetheless, there are some parts of the website that may be of interest to people. Mostly people contact me wanting to use my cartoons. If you have not seen them they are worth a look, or that's what people tell me. They are my way of understanding the complexity of the 'Mental Health System' as simply as I can.



SO, WHICH OF THOSE COMPLAINTS DO YOU THINK STAFF WILL BE HAPPY FOR ME TO MAKE?

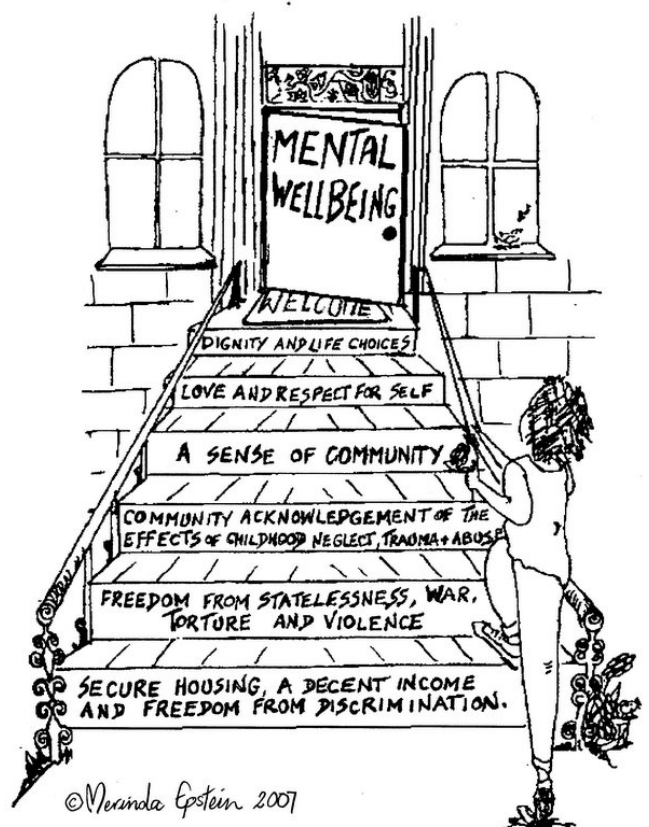
©MERINDA EPSTEIN





My policy is that all consumers can use any cartoon they like for nothing – they are ours to share with consumer integrity and spirit. However, the best thing to do is to contact me at the above site so I can send you an email version that is at a resolution that can be reproduced well. However, for organisations and bureaucracies there is a charge that helps me to make the cartoons available to consumers for nothing. This can be negotiated by contacting me through the website.

There are also some papers that I have written. I guess I am most well known for the work that I have done over twenty years on ‘personality disorders’, particularly so-called ‘Borderline Personality Disorder’. There’s also writing on consumer politics and policy issues, as well as 20 years of reflecting on consumer issues. There are articles, conference papers, some stuff about my own story and my Australian Human Rights Award, which was a highlight for me in 2004.



-Merinda Epstein



*In this edition, we hear from **Piers Gooding**, an ally and Melbourne-based researcher/ writer/ activist working toward mental health human rights and choice. He has been involved in consumer and family-led research and evaluation in Victorian MH services and is presently labouring a Masters of Philosophy in Law at Monash University, focusing on supported decision-making, disability and human rights. He has a large-ish collection of teapots.*

## **An ally's travels through America**

I'd have to say it was the most unusual Halloween of my life. I was dressed in a ninja suit and dancing in the Hilton Hotel in Omaha, Nebraska - in the dead centre of Middle America - with over 600 consumer/ survivors. I was at *Alternatives '09*, the largest consumer-led conference in the USA, and possibly the world.

This was one exciting moment among many during a four-month trip of volunteering and connecting with inspirational mental health human rights activists across America. I met consumers, survivors, peer support workers or ‘recovery experts’, families, psychotherapists, psychiatrists, nurses, as well as legal experts, activists and community organisers.

It's hard to condense my experiences so I've settled on three gems which I'd like to share here. The first was a large-scale consumer-led conference, the second was the emerging connections between the environmental and 'mad' movements, and the third was intentional peer support. I'd also like to briefly share my thoughts on being an ally to consumers in this movement for mental health human rights and choice.

Firstly, and it sounds quite harsh, but *Alternatives '09* is far superior to Australia's version (TheMHS), which, in my experience, is a token, single day event tacked onto the 'real' business of a conference of Australian and New Zealand clinicians and policy-makers. (TheMHS is also sponsored by pharmaceutical companies, which is rather problematic). *Alternatives'09* was run by and for survivor/ consumers, using some helpful federal funding. Consumers were particularly leading the charge in the areas of recovery expertise (or peer support), peer-run crisis respite centres, and trauma-informed support.

The second interesting thing I noticed was an emerging connection between the environmental and 'mad' movement. It's hard to describe because it's only emerging but I'll do my best to explain. On a pragmatic level, the climate crisis is mobilising many people into social change activity, opening them to other marginalised issues like mental health/ disability rights that they might not have come into contact with otherwise. At the therapy and support level, there is an emerging field called 'eco-psychology' which is drawing connections between psychosocial wellbeing and having a positive relationship with nature (for example, through community gardens, eating wholefoods, or therapeutic bush retreats). Where eco-psychology can help in acute crisis is less clear. There is also scope for consumers to bring their recovery and wellbeing expertise to environmental activists (and all activists), many who are reporting burnout but who consciously avoid mainstream mental health services.

On a more general level it is likely that the underlying ideas causing man-made environmental chaos may also inform the terrible responses our society has to emotional disturbance and seemingly bizarre behaviour. This is a bit vague and I won't go into it further because it's something I'm not too sure about. But given climate crisis is raising very fundamental questions about how we live as a society (as consumer politics does) I hope people remain open to connections between these two important areas of social change.

One group known for a relationship with land that is complex and often remarkably sustainable are many Indigenous peoples. I was interested to see modern indigenous healing strategies and concepts for emotional crisis being used across America. I met a woman whose mother was Cherokee and her father was African-American. When she started hearing voices in her teenage years, her mother gently asked, "What are the voices saying?" and encouraged her to carefully listen in the tradition of her people. Her father panicked, "Aw, Hell no!!!" he cried, and took her straight to hospital! It was a true culture collision! But it goes to show there are different ways of understanding experiences typically understood as mental illness. Another interesting conversation happening among minority groups is centred on the disabling effect of 'historical trauma.'

The final thing I'd like to relate is 'Intentional Peer Support', an empowering support strategy I'm delighted to have first discovered at Our Consumer Place and am glad to see spreading to the consumer/ peer/ recovery experts of Australia. I'll leave it to OCP to cover this but I'd recommend

anyone who values self-determination in mental health to pay close attention. I also think it holds tremendous potential for *families and friends* to be more supportive toward consumer empowerment and recovery (and to create support strategies for themselves). This brings me to my last point.

While travelling, a lot of people asked me why I was volunteering on my holiday. They asked, Are you a “survivor” or “consumer”? I am neither but if asked I’d probably answer that my involvement started with my family being damaged by awful and discriminatory experiences in mental health services. But that was just the beginning. There are many reasons why this issue is important and fascinating to me. And besides, who wants to be reduced to a single defining label (say ‘family survivor’) if they can help it? I am plenty of other things – a historian, a Masters student, an amateur boxer even. But surely here, the most important thing is my intention to contribute to change. And though I’m not a consumer or a psych survivor I feel deeply part of this movement and I’m grateful for it.

I would never speak for consumers but I can speak as somebody working for non-discrimination and more alternatives to mainstream psychiatry in our MH services. And I really believe our issue, if it’s possible for me to call it that, is starting to filter into the mainstream. So maybe now, more than ever, consumers/ survivors and their allies can reach out to one another and collaborate in this global movement for mental health human rights and choice.



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## Consumers on (other people’s) committees

Are we wasting our time sitting on other people’s committees? In the early years after the First National Mental Health Strategy [released in 1992] there were some gains. Many clinicians and bureaucrats had never experienced consumers as anything other than “their patients”. They had a lot to learn.

It is almost impossible to influence committee decisions when there is only one of ‘us’ and many of ‘them’. Right from the beginning we insisted that there should never be less than two consumers around the table – and preferably a ‘critical mass’ –or, the same number of consumers as there were clinicians. When we started to protest about our lack of progress towards ‘real’ participation, costs were cited - a spurious response given the amount of money injected by the strategy into mental health at that time. However, we knew we were easily replaceable if we jumped ship in frustration. There were so many consumers and consumer groups fuming and wanting to be heard.

Over the life of the first strategy clinicians, bureaucrats and others lost decision-making authority not just to consumers but also to carers and the new priorities of the strategy. They didn’t like it. Not surprisingly they started to claw it back in various ways. Decisions started to be made in the corridors rather than the meeting rooms or decisions were delegated to subcommittees that had no



consumers on them. A myriad of other groups were demanding a seat at the table and as each new group was added our voice was diluted.

At the same time more powerful groups in the sector were learning how to 'manage' us. The more obvious it became that there was now rhetoric but no substance to the claims of consumer participation, even consumer partnership, the more tempting it was for us to demand to be noticed in less conventional ways and the more we were dismissed. We did have a choice. We could continue to battle on and take no notice of the way our voice was being misheard and used to divide us or we could split into a myriad of different fragments pulling in different directions and lose our unity – all thoughts of a critical mass now pointless – or we could withdraw, and put our energy into things that actually lead to change.

Managing us is done cleverly. It is often not in the interests of the powerful people in mental health to have a united, loud and reflexive consumer voice. Managing us also requires manipulation so things like confidentiality clauses get inserted in the conditions of committees or our language is appropriated. For example, we started to use the word 'recovery' to denote a different way of describing our journeys towards something new. Soon services also started to use the term 'recovery' rather than 'rehabilitation' but in the process it lost most of its meaning for us. The issues that were most important to us started appearing in the 'other agenda items' section of meetings when everyone is too tired to care. Euphemisms cleverly maintain a charade that we have power in the sector.

## CONSUMERS ON COMMITTEES



So I've stopped playing these games. There are so many more local, more activist, more subversive ways that our collective energy can be used: concentrating on imperative issues like forced 'treatment', advocacy, writing from a consumer perspective, educating clinicians, consumer research using consumer compatible research methods, supporting each other instead of canning one another, developing the movement, writing our history, supporting small groups, organising politically, and orchestrating a Mental Health Week coup!



## THUMBS UP/THUMBS DOWN

1. **Thumbs up** to the consumer who was able to find the confidence to politely tell another consumer that they couldn't process more talking about mental health on weekends.
2. **Thumbs up** to peer support training that starts from the assumption that people will and must allow discomfort to sit in the room and not try to rescue people.
3. **Thumbs up** to the clinician who actually read a consumer's Advance Directive and asked insightful questions for clarification before signing it.
4. **Thumbs up** for the Occupational Therapist who, when asked to run a program on budgeting for people on the Disability Support Pension, taught people how to roll their own cigarettes.
5. **Thumbs down** for the new policy on no smoking in inpatient settings, forcing people in distress to suddenly stop smoking.
6. **Thumbs up** for St Vincent's hospital putting out a card warning people on certain medications (Clozapine, Olanzapine and Haloperidol) that stopping smoking could be problematic.
7. **Thumbs down** to the fact that St Vincent's advice and this new policy on smoking have come out at approximately the same time!!
8. **Thumbs down** to the person who was noticed in St Kilda Rd taking photos of someone who was extremely distressed.
9. **Thumbs down** to all the community education programs which teach people about 'mental illness' using only the medical model of distress, leading to further labelling.
10. **Thumbs down** to glossy pamphlets produced by pharmaceutical companies which add another layer of guilt for people diagnosed with 'mental illness,' preaching about weight control and at the same time taking no responsibility for the fact that their products so often cause weight gain!

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

You may have noticed (maybe you haven't!) that we have been rather quiet lately. Our Consumer Place has been through a difficult period. Cath and Jon both left Our Consumer Place late in 2009 to focus on their other work (they had each been working at OCP one day a week). Their work here has been enormously valuable and inspiring, helping to establish a vision of what a consumer resource centre could be and lay sturdy foundations. We hope they'll stay connected!

Merinda found carrying the workload on her own shoulders during this period to be overwhelming, and chose to prioritise producing and organising written materials. By the end of 2009, over 200 pamphlets had been written by nearly 20 consumers on everything from doctor shopping to Penguin Artists. Networking continues around these contributions.

In early 2010, Flick Grey came on board, working 2 days a week at Our Consumer Place. Together with a third consumer editor, Merinda and Flick have brought a selection of these 200 pamphlets together into the first of what we expect to be at least 10 booklets. The first is provisionally titled – 'So you've got a "mental illness"? What now?' It responds to demand for information from a consumer perspective. It brings together an array of topics including diagnosis, medication, the mental health system, discrimination, rights, recovery, transformation, creativity, spirituality, consumer groups, the consumer/survivor movement and consumer literature. The intention is both to introduce consumer perspective to people who may be relatively new to this way of looking at 'mental health' and also to share a diversity of consumer knowledge and thinking in these areas.

A second booklet is moving along very smartly and we are thinking about the third. As many of the pieces have already been written our task is easier but it is still a major editing role when there are many authors, and the booklet still needs to be held together both stylistically and in terms of content. We have also concentrated on the ethics of editing for a consumer publication - we are writing about this too. Tentatively at this stage it looks like the second booklet will be targeted towards people who are involved in changing the world from a consumer perspective. The aim of this second booklet is to bring together and share some of the wisdom consumers have developed in our work, activism and efforts to change the world.

Merinda and Flick went to Brisbane at the end of February for 'train the trainer' Intentional Peer Support (IPS) with Shery Mead and Chris Hansen. Shery and Chris had been in Melbourne in early 2009 and shared IPS with many consumers then, with the support of Our Consumer Place. This second training was so that we can now facilitate the training ourselves! We hope to be able to share more of this wonderful approach to peer support in the future – stay tuned!

Finally, we are continually connecting/networking ... whatever you want to call it. Let us know how we can support what consumers are doing, and feed back any insights and lessons learnt to share with other consumers. We hope to make this newsletter more regular now that we're settling into the new year. We'd love to know your thinking, insights, feedback, news, etc. Stay in touch!

## 10 WAYS OUR CONSUMER PLACE CAN SUPPORT YOU

(AND YOU CAN SUPPORT US!)

1. **Membership:** To join Our Consumer Place, go to our website – [www.ourconsumerplace.com.au](http://www.ourconsumerplace.com.au). It's free and we won't send you any spam! Membership is open to *anyone* interested in what consumers are doing and thinking. Members receive our regular newsletter and advance notice for events. Also, you need to be a member to participate in the 'message board' section of our website. Maintaining a membership is important to funding bodies, so sign up your friends, family and pets – this helps us stay alive.
2. **Newsletter:** Our newsletter is a way to connect, inform and inspire consumers and consumer groups. We aim to share a range of consumer ideas and practices and to reflect on what consumers are doing and thinking. We send our newsletters to members (semi)regularly and they are also available on our website.
3. **We can visit you:** We can visit your consumer group to discuss what we do and how we can help strengthen what you do. Over time, we are getting a stronger sense of what consumer groups are needing – individually and systemically. We are working to link groups to resources and producing resources where nothing yet exists.
4. **Website:** Have you checked out our website? It contains a wealth of written materials, drawing on the expertise of many consumers as well as Our Community. There is extensive information about building robust consumer groups (or "Consumer Directed Initiatives").
5. **Rants:** Do you have a rant inside that you'd like to share with others? Let us know and we can discuss contributing to our newsletter. We *love* debate on issues consumers care about.
6. **Message board:** Alternatively, you might have an idea you want to discuss with other consumers – post a message on the 'message board' on our website and see what other consumers have to say.
7. **Publicising groups:** Are you a consumer group? Would you like to be publicised through our website? Send us your details and we'll include you in our directory. If your group has something to say or is doing something particularly interesting, contact us about being profiled in our newsletter.
8. **Interested in training?** Heard about Intentional Peer Support and want to know more? We are keen to roll out training around Intentional Peer Support (as developed by Shery Mead in the US). We're open to suggestions for any training consumers would like to see.
9. **Interested in reading up?** Our website has a "clearinghouse" (ie. a collection of resources – websites, books, reports, radio programs, etc) written by or recommended by consumers. Check it out, and let us know if there's more we could add – it's growing!
10. **Got ideas?** If there's something we're not doing that you think consumer groups need, let us know! We can't do everything, but we also can't think of everything ourselves, so we always appreciate input.