



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

**OUR CONSUMER PLACE
NEWSLETTER DECEMBER 2011**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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****SPECIAL INSERT IN THIS NEWSLETTER: ****

This is not about catharsis! My time in HDU, by Merinda Epstein

In this edition, we have included a very special 8-page insert with the newsletter – Merinda's reflections upon her recent experience (mid 2011) of involuntary 'treatment' in the High Dependency Unit (HDU) at a public psychiatric facility in Melbourne. It is deeply disturbing reading and may be triggering for some readers. At the end, Merinda presents some compelling conclusions for change. We believe this is an incredibly important piece of work.

INTRODUCING ... Julie Dempsey's *From Outrage to Determination*

A review by Flick Grey.

From Outrage to Determination is a history in cartoon form, by Julie Dempsey. It spans more than two decades of women's experiences of feeling unsafe in mixed-sex psychiatric wards, and the Victorian Women and Mental Health Network's (VWMHN) campaign for gender-sensitive facilities in psychiatric wards. It was launched in November by fellow cartoonist, Merinda Epstein, at the VWMHN's Annual General Meeting.

Cartoons are often able to convey more complexity than words alone. Julie's style is deceptively simple – rereading this booklet I am struck by the complexity and density of ideas, experiences and reflections she conveys. It's also often shocking, juxtaposing vulnerability, violence, confusion and systemic cruelty. It brilliantly captures that the system itself is full of madness! It's also exciting to see the achievements and progress of the Victorian Women and Mental Health Network – an alliance of consumers and staff, dedicated to improving conditions for women. In an environment where it often seems like things don't change much (or as quickly and extensively as they should!), the VWMHN is a shiny beacon of successful work towards important and significant changes.

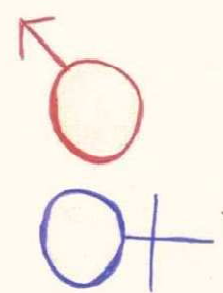
It's especially emotional reading Julie's work alongside Merinda's recent harrowing experiences in an acute psychiatric ward (these experiences are explored in the piece accompanying this newsletter), and juxtaposing James Kelso's passionate soapbox piece also in this newsletter (see p.12).

Outrage to Determination is available in full for download from the Our Consumer Place website (www.ourconsumerplace.com.au). Here are some extracts – the cover, an early page and a later page. Enjoy!



PSYCHIATRY ENTERS UNISEX ERA

1



1960's: SOCIETY MORE "PROGRESSIVE"

2

MIXED GENDER WARDS CREATED TO MIRROR COMMUNITY



3

EXTREME SITUATION RESULTS



WOMENS RIGHTS REGRESS IN SHARED WARDS

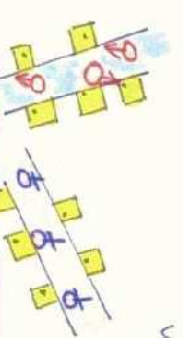


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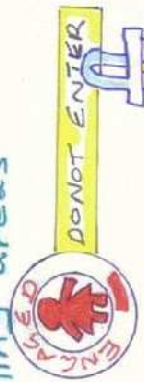
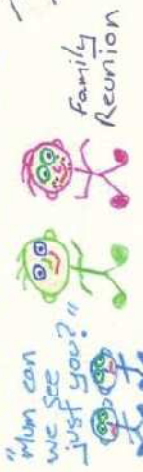
32 "NOWHERE TO BE SAFE" REPORT PUBLISHED IN THE RED

APRIL 2008

Womens' Ten Priorities for Improving Inpatient Safety:



- 1) Locate bedrooms in separate women's and men's corridors
- 2) Separate women's lounges, outdoor and family visiting areas



Lockable bedroom and bathroom doors

- 3) Dedicated women's and men's bathroom facilities in both low dependency and high dependency units
- 4) Introduce Patient Codes of Conduct which clarify unacceptable behaviour



"That Conduct is unacceptable. It is written."

- 5) "TIME OUT" Earlier intervention by staff to protect women and prevent escalating patient conflict



- 6) Better support by staff for women who experience harassment



- 7) Staff to be aware of patient's previous experiences of trauma



- 8) To be treated by female staff where possible, particularly at night

"It's O.K."

- 9) More opportunities for communication and therapeutic contact with staff

NEWS IN THE CONSUMER WORLD:

National Mental Health Commissioners Announced

The Mental Health Commissioners to Australia's first National Mental Health Commission have been announced. The Chair is Professor Allan Fels and the CEO is Ms Robyn Kruk (who will also be an ex-officio Commissioner). The eight Commissioners are: Mr Peter Bicknell; Ms Jackie Crowe (a carer consultant); Dr Pat Dudgeon; Professor Ian Hickie; Mr Rob Knowles; Ms Janet Meagher (a long-time consumer activist); Ms Samantha Mostyn; and Professor Ian Webster. Congratulations to Janet!

NSW Mental Health Commissioner to need lived experience

NSW have the right idea – a mental health commission where direct and personal lived experience of mental illness is a prerequisite for the job. As Ian Hickie noted: "If you really want to drive change in the mental health system you have got to use the experience of the people who actually use the system..."

See: www.smh.com.au/national/health/mental-health-policy-to-be-run-by-those-who-have-fought-the-battle-20111123-1nv3v.html

Centre for Excellence in Peer Support update

Launched in June 2011, the Centre for Excellence in Peer Support is a great, expanding resource. Check them out: www.peersupportvic.org/

Consumers of Mental Health WA seeking an Executive Director

Consumers of Mental Health WA (Inc.) is seeking an exceptional person to work in partnership with the board to lead the association through the next exciting phase of its development. CoMHWA's founding Executive Director position has been advertised nationally and details can be accessed through this link: <http://www.seek.com.au/Job/executive-director/in/perth-perth/21292149>

The position will be open for applications for an extended period due to the Christmas and New Year holiday season with the selection process to be completed after the election of CoMHWA's new board on the 30th January 2012. Do you know someone suitable for this rewarding and challenging role? If so please encourage them to apply and please distribute this news widely to your networks!

New human rights obligations for agencies

On 25 November 2011, the Human Rights (Parliamentary Scrutiny) Bill 2010 was passed by the Senate and is now awaiting Royal Assent. It is anticipated the new Act will commence operation in early 2012. The Act will place new obligations on agencies to assess the compatibility of any legislation they are developing with certain international human rights instruments.

Victorian Human Rights and Mental Health Tribunal

The Australian Mental Health Human Rights and Law Reform Coalition have recently formed the Victorian Human Rights and Mental Health Tribunal. This will provide an opportunity for mental health consumers/survivors, families, carers and people employed in Victorian Mental Health/Community Services to make personal testimonies of their experiences of torture, cruel, inhuman and degrading treatment in the the Victorian Mental Health System and from Victoria Police. All testimonies will be filmed to be sent to the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Mr. Juan Mendez. A panel of eminent Australian Human Rights Advocates and Lawyers will witness all interviews and produce a report on their findings for the United Nations. See: www.australianmentalhealthhumanrightsandlawreformcoalition.com or look for the Australian Mental Health Human Rights and Law Reform Coalition on Facebook.

Consumer and Carer Consultant employment conditions review:

Some hospitals, who belong to the Victorian Hospital's Industrial Association seem to be looking at developing 'a structure for consumer consultants and carer consultants' for adding to their next 'Enterprise Bargaining Agreement.' Questions being asked include:

- How many Consumer Consultants and Carer Consultants you employ?
- What award / designation are they employed under?
- What is their role? (PD [Position description] is helpful)
- Who do they usually report to?
- What level of qualification do they have?
- Does your agency have arrangements for situations when Consumer consultants have periods of being unwell, or Carer Consultants needing to have time off to carers leave?

You might like to be aware that hospitals are asking these questions, and maybe see if your hospital is part of this process or needs any info from you to complete the submission by employers about a consistent structure for Consumer Consultants state-wide. (from VMIAC).



Flick's doodle during Inside Out's conference *More than Medication* in October

A B-B-BIPOLAR CHRISTMAS

By Ann Tullgren

Ann is what some call a “two-hats” – she has a background of both lived experience of being diagnosed with ‘mental illness’ and worked for many years as a social worker.

Are you sitting comfortably? I’m about to begin my Christmas tale, a story of ghosts past, stunted imagination and the getting of wisdom, hope and joy.

This is how TS Elliot begins his poem ‘The Coming of the Magi’:

A cold coming we had of it,
Just the worst time of the year
For a journey, and such a long journey:
The ways deep and the weather sharp,
The very dead of winter.

And so it was as Frank and I struggled to define our relationship. At one time he had been my client and I the dutiful social worker, trying to get him to a better place. Then, one Sunday morning at 7am, he rang me at home. Excited to have discovered my phone number at 2am, he had sat awake until the dawn, smoking and drinking thick coffee, the type that leaves stubborn stains in cups and rings on the furniture. For the next few months I tried hard to explain that social workers and their clients didn’t have friendships, but he couldn’t ‘get it’. I, of course, framed this as his limited insight and difficulty retaining new information. My next strategy was to limit contact times, hoping that his enthusiasm would wane. ‘I have to manage this’, I thought. I even wrote to the ethics panel of my professional body seeking advice. I have kept their written response; I think it is somewhere in the shed.

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and I the dutiful social worker,
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he rang me at home.*

In this particular year, for Frank, Christmas began in October when he rang to say he had decided to buy a Christmas tree and decorations. ‘Great’, I thought, ‘maybe I can use this enthusiasm to help improve his Activities of Daily Living’ (things like keeping the house clean and tidy).

‘I tell you what Frank, let me know when you’ve bought your tree and I’ll send you some money to buy decorations’. I was getting serious about the encouragement but felt uncomfortable that I was transgressing the worker/client border. I didn’t think the ethics committee would approve the exchange of money. This is probably why their letter of advice is somewhere in the shed.

Frank bought his tree, and the decorations and in the following March the tree was still up and he was still talking about it. Next step for me: encourage him to pack it away until next Christmas. I had a picture in my mind of Frank sitting at the table, with his cigarettes and ashtrays, the coffee cups and the usual horde of newspapers ... and the Christmas tree.

‘Frank, why don’t you pack up the tree until next Christmas? You must have so little room to spread out at the table, don’t you knock things over?’

‘Whadya mean? My tree isn’t on the table.’

‘So where is it?’ thinking that maybe it was on the sideboard.

'It's on the floor, of course'

There was a moment of feeling sick in the stomach, of my vision blurring and then clearing.

'Frank, how big is your tree?'

'Two metres.'

Gentle Readers: forgive my feeble imagination. I thought his tree was maybe half a metre high, a paltry thing, not the enormous, gaudy spectacle that it was, with flashing lights, tinsel and dangling twinkling ornaments.

So I, who write of hope, of the possibilities of ethical imagination, of not getting stuck in a deficit model of my own and others' shortcomings, had faltered at the first hurdle. All those conversations with Frank since that first Christmas, fed by my image of a tiny, stunted tree.

In case you're wondering: Frank packed up the tree. Each year, up it goes, with new ornaments. He's on the third lot of lights. Fifteen years later, we're good friends. I love his sense of humour. I enjoy the constancy of his friendship. We send each other birthday and Christmas presents. Each year I exchange cards with his family at Christmas.

Dear Reader: my gift to you this Christmas is one I couldn't give to Frank that first Christmas: let us put aside the cold comings of our disappointments, faltering hopes and fractured dreams. Let us hope in the wildest possible ways! Hope with extravagance – not just for the other, but also for the transformation of our clouded dreams for ourselves.

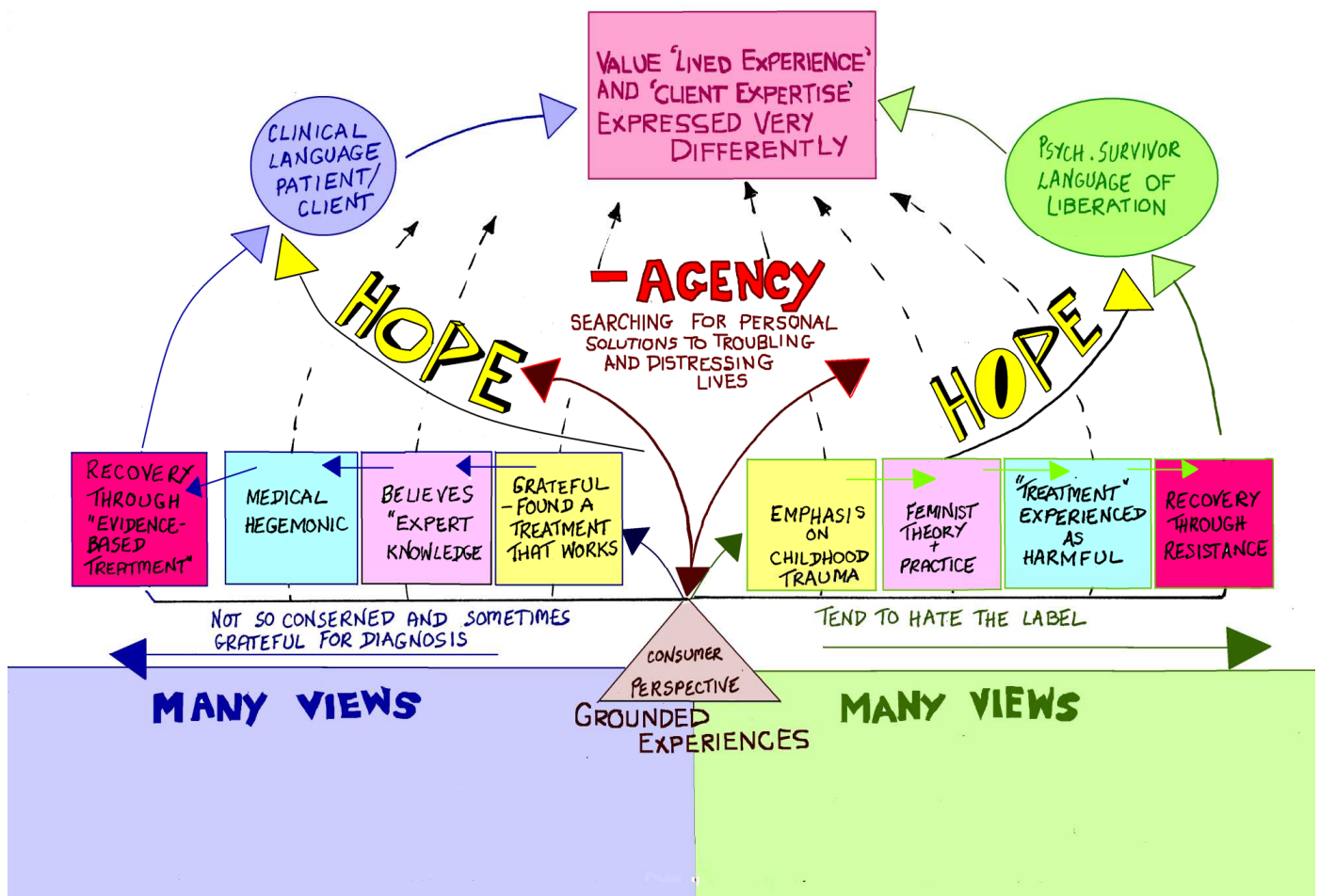


A cartoon from Bernie McCormack



CONSUMERS SPEAK AND WRITE ABOUT HOW THEY FIND HEALTH – THE BEGINNINGS OF A MODEL – by Merinda Epstein

After decades of talking with consumers, researching, thinking, thinking aloud, thinking with others, lecturing, networking and refining these ideas, Merinda has developed a tentative model for how consumers navigate different paths through our experiences, healing, hope, mental health treatments and identity. She presented this model at the Inaugural Borderline Personality Disorder Awareness Day, October 5th 2011. A full version of her talk is available on our website: www.ourconsumerplace.com.au/resources



Points to note:

This schema was originally created for a chapter of a book on Complex Post Traumatic Stress Disorder (Borderline Personality Disorder –BPD). Hence, there is an emphasis on feminist theory and practice (for example). For a more general group of consumers the same theory applies but different words might work better. For example instead of feminist theory and practice we could use ‘politically informed theory and practice’ or theory and practice that respects the role of social power and powerlessness.

In reading many consumer accounts for this chapter it was obvious to me that both directions towards ‘recovery’ were talked about, celebrated and believed strongly in – in equal measure. This is absolutely not absolute! People pick and choose what they need from both sides of the schema – jumping back and forward. The schema is a useful theoretical tool.

There is no one way here. Some of us write and talk about finding health through (miraculously) obtaining good services/clinicians and others of us speak and write about finding health through totally resisting anything that seems to be related to mental health clinicians and both Psychiatric Disability Support Services and clinical services – indeed anything that relates at all to mainstream psychiatry.

The most important indicator of all is that people have agency; that is, they make their own decisions and take action based on those decisions (if they can).

PATHWAY ONE– road to greater happiness and healing through acceptance

1. Accept that ‘the problem’ lies in us;
2. Want to learn new practical skills;
3. Find very strong, clear boundaries essential. Grateful for them later;
4. Search for a therapeutic relationship that is predictable;
5. Concentrate on finding ways to make everyday life bearable;
6. Sometimes believe that the early trauma is too difficult to tackle;
7. Acceptance – of our lives (past and present) and of others in our lives. Accentuate the positive and find not holding on to blame feels good;
8. Acceptance of dominant therapy typologies - might be any one of the many run by mainstream clinicians, including ‘behavioural therapies’;
9. In searching for acceptance we often feel ashamed of who and what we are/were. Shame often drives service seeking;
10. Often searching for our lost self respect;
11. We often respond to therapy that holds ‘HOPE’ for us;
12. This path takes us towards finding acceptance of the things that happened a long time ago and we can’t change now.

PATHWAY TWO– road to greater happiness and healing through fighting back

1. Accepts that the problem lies squarely in society;
2. Respond to approaches to therapy which consider the political dimensions of distress;
3. Respond to therapies that appreciate that being angry is fair cop if you’ve been treated badly by society in the past;
4. Sometimes seek alternative treatment for the results of previous iatrogenic practice (illness induced by medical treatment);
5. Believe in therapists who believe us about childhood trauma and work primarily with this aspect of our distress;
6. We find health through not accepting - realising we are strong and can stand up for ourselves;
7. Strongly attracted to consumer-run alternatives to traditional services – responses that recognise the importance of power and the potential problems of any relationships where unequal power is an issue;
8. See ‘Borderline’ as a feminist issue and respond to feminist therapies;
9. Sometimes respond less well to ‘behavioural’ type therapies which often feel demeaning and disrespectful of the pain – both present and past;
10. See therapists as having to prove themselves;
11. Empowered by non-acceptance of the things society in general and some people in particular do to others and become politically active for our own health.



Are Mental Health Services Really That Bad? A Service User's Perspective

-By James Kelso

James Kelso works as a consumer consultant, but is writing in his personal capacity.

Traditionally, and particularly within the 'consumer' mental health sector in Victoria and elsewhere in Australia, the state and quality of treatment of people with mental illnesses generally has been regarded as rather sub-standard. These are some common complaints which I hear from people -

- Treatment is often forced (i.e. involuntary),
- People are given medications which both help and harm them, but sometimes against their will,
- People often don't really get 'better' in psych wards, but at best they are places to stabilise a person's mental health state before re-admission to the community,
- Seclusion, physical and mechanical restraint are sometimes used,
- Electro-Convulsive therapy (ECT) is still used,
- Treatment by the police is often seen as rough and unsatisfactory by many mental health consumers,
- It is traumatic to be handcuffed and bundled into the back of a paddy-wagon,
- The behaviour of other patients in most public psychiatric hospitals is often a reason why you're better off not being there.

Now all of this is very unsettling. I, too, have suffered many of the points which I have just recounted here. I have not enjoyed them, at the time or afterwards. I fully acknowledge that many of these conditions truly unsettle people for years to come. But it does not always have to be that way. We can get better, and move on with our lives.

One of the things that concerns me about the current debate in 'consumer' mental health is that I believe that many people's recollections of psychiatric hospitals are out of step, chronologically, with the average current conditions in many of our major public hospitals. Through my work, I have heard much about what conditions used to be like in some of the major institutions in Victoria, such as Laurindel Hospital and Royal Park. Some people had good recollections (especially about the healing properties of the large and well cared-for grounds), and many had bad recollections about the treatment of patients there. Others had mixed recollections about all sorts of things. Still others merely accepted the treatment which they received and continued with the bumble of life, neither praising nor blaming.

One of the things that concerns me about the current debate in 'consumer' mental health is that I believe that many people's recollections of psychiatric hospitals are out of step, chronologically, with the average current conditions in many of our major public hospitals.

However I am concerned that some still working in consumer mental health (and I emphasise some, but not all) are using their recollections to inform current debate in a way which someone, who has experienced public mental health services from the mid 1990s and beyond, just did not see. It was not that bad.

As I have said earlier, there are many things about public mental health services which are not perfect, and it would be great if they could be. Unfortunately, due to the nature of extreme mental illness and human behaviour in its midst, that is not always possible, from both staff and patients. I think the best response to that is to understand it, but not to criticise something, which by its very nature, is very difficult to operate well.

*What have I got to complain about?
When I was unwell, I was cared for.
When I couldn't afford it, I was
catered for.*

There are other things which I remember about my experiences of public mental health services which were good. I had hospitalisation when I needed it. I was given a free public psychiatrist, for which the ongoing treatment continued for seven years. I was given a Case Manager, someone to talk to, confide in, and make progress on my

issues. When I was discharged from the service, I was referred to further counselling options, at no cost, and gained a private psychiatrist, at no cost, whom I see to the present day. When the Medicare rebated psychology reforms came through, I was able to access a skilled psychologist for a fairly reasonable rate.

What have I got to complain about? When I was unwell, I was cared for. When I couldn't afford it, I was catered for. My friends, family and relations nurtured me back to recovery. I also put in a substantial amount of work into my recovery myself, which continues.

Hospital wasn't all bad, either. Meals were provided for free. They were okay, and there was choice. We could play games, do educational activities, I loved practising art, I played table tennis and basketball. We did psychological group therapy. We went on walks. We had leave. We could be visited by our family and friends, which was great solace at an extremely low, and often suicidal time of life. My church minister visited me - in fact, I am told my whole church youth group all came in, about 10 people, and visited me when I was drugged up, in High Dependency, drooling and in another world.

I met new friends in hospital, some of whom became close, and who were able to provide crucial peer support both during and after my hospital stays. We looked after one another, like nobody else could know how.

I met new friends in hospital, some of whom became close, and who were able to provide crucial peer support both during and after my hospital stays. We looked after one another, like nobody else could know how.

We need support like this, at times like this. I acknowledge that there is much that is imperfect about public mental health services, some of which can be improved, and some of which should be.

But I disagree that it was all bad, or (importantly) that it is helpful to hold on to the belief that it was all bad, forever, and to increase and amplify this feeling. For me, it was not, there is a lot to be thankful for, and for anyone who helped me then or continues to help me now, all I can offer is my most profound gratitude.

The opinions expressed in this article are those of the author. [Ed: this disclaimer was written by James, not OCP]



Participation in Other People's Committees drives me crazy!!

By Flick Grey

In this collaborative committee we had an opportunity to discuss the kinds of topics which at present rarely happen. You know when a committee gets into a very rare discussion about fundamental values, philosophy, purpose, and 'what we're all here for'... and everyone says, "Gee we never have this kind of discussion, this is really good, why don't we do this more often?" And then the chairperson calls the meeting back by saying, " Well I'm afraid we have to get back to the real business of the meeting – the staff's leave provisions, the auditor's report, the productivity savings the funder wants, and the quarterly statistics."

– from The Essential U&I¹

I have come to find the phrase "Other People's Committees" useful. It may not sound particularly fancy – the phrase is intentionally simple, to cut through the crap that is so rife in bureaucratese. But despite its apparent simplicity, this concept is rich in consumers' experiential, embodied knowledge, and is supported by some fantastic consumer-driven Participatory Action Research.

We ought to be setting our collective sights much higher than "participation" in Other People's Committees. I would go so far as to argue that consumers should be leading the mental health system – at the moment, it's "Other People's Mental Health System" – but for now, I'll talk about committees. These ideas are not new,² but I'm elaborating on them because there's a tangle of issues – including "representation," "valuing" consumer perspective, and "appropriate issues for this committee to discuss." I find it useful and sanity-inducing to tease these issues out. It's also the end of the year, so it's time to review my personal policy of "One OPC³ per year" – I made a decision a few years ago to sit on

*At the moment, it's truly
"Other People's Mental
Health System"*

only one Other People's Committee each year. I choose to spend the bulk of my time and energy on projects where I feel I have a real capacity to shape the process and outcomes. Too much energy spent on Other People's Committees drives me crazy (sometimes literally)!

What is an Other People's Committee?

Other People's Committees are those committees where consumers are "participating," but we know we don't really have power. Despite the (usually!) good intentions of other committee members, we experience tokenism, disrespect, and dismissive or otherwise demeaning behaviours. These can be extremely subtle. We might even convince ourselves for a while that things aren't so bad, "it's just because we weren't very articulate about that particular (important) point", or "people are really very nice to us, even though they don't seem to understand what is important to us," or "perhaps we don't fully understand the purpose or process of this committee" ... the excuses are endless, but sometimes the actual reason is that this is really "Other People's Committee."

For me, this knowledge starts in my body. It may take a few meetings for the feeling to become loud enough that I listen. Maybe I raise a point that is critically important from a consumer perspective, and

¹ Wadsworth, Y. (2001) The Essential U&I – a one volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services, Vic Health.

² As Chris Hansen – a wonderful consumer/survivor leader originally from New Zealand, now based in the US – has long said "We might have gained a seat at this table, but actually we want to damn well own this table!" An interview with Chris is included in our upcoming publication *Deep Insight: Leaders in the international consumer/survivor movement share their thinking*, available early 2012.

³ Please excuse the acronym – I find it amusing to reclaim elements of silly bureaucratic language!

notice that it's not recorded in the minutes. Or it's discussed in a way that makes it obvious that it is seen as annoying or trivial to other people on the committee. Or the psychiatrist on the committee (I don't mean to criticise psychiatrists gratuitously here, it usually *is* psychiatrists who do this) intervenes with "sage words" – just a few, but enough to close the issue and silence the consumers. Or it is declared that "this is not something this committee is here to discuss" – it's beyond the Terms of Reference, or is "really" the business of another committee, or wasn't on the agenda ... or whatever. But ultimately, our participation and contribution are deemed "inappropriate" – "appropriateness" trumps "importance" when it comes to consumer priorities in the context of Other People's Committees. And of course, someone else decides what is or is not "appropriate." Maybe that's the test of whether a committee is really Other People's – who decides what is or is not appropriate?

But aren't the issues the same for everyone on the committee? No, there is historical, structural disrespect for consumer perspective. *The system has been set up by other people and then we have been allowed/included/invited to participate.* We begin on the back foot. It was never *really* ours!

Why do consumers participate in Other People's Committees?

Consumers have various experiences – many like to participate in Other People's Committees and value having a voice. Also, the line between Other People's Committees and collaborative committees is blurry. Usually there's a mixture of people in the room – some deeply listening, some trying, some just passing time, some with their own agendas. I participate in these committees sparingly because: (a) I feel disrespected – usually subtly – and I don't believe I (or consumers more generally) deserve this disrespect, and (b) after 20 years of "consumer participation", the problems in our mental health system are still so dire that I honestly wonder how *effective* our participation is. Some days I wonder why spend a sunny day inside, sitting at a table following an agenda, when REAL CHANGE is urgently needed...

Maybe that's the test of whether a committee is really Other People's – who decides what is or is not appropriate?

There are other reasons I've gotten involved in such committees.

Sometimes it's flattery ("ooh, they want *me*?"). Or it seems like "too important an opportunity to waste." Or I feel so grateful to be listened to. Or I think "Gosh, *someone* really ought to be on this committee ... I'll be there as a go-between." Sometimes, it's misplaced optimism. Other times, it's appropriate optimism. Sometimes I'm not sure.

"Are you representative"??

There's a whole bag of tricks that get pulled out to undermine our credibility. One of the most persistent is questioning whether we are "really representative." This notion needs to be squarely debunked– it's both impossible in practice and inappropriate as an aspiration. The idea that consumers involved in committees can "represent" anyone has been debunked at length⁴ and anyone serious about consumer involvement ought to have given these issues some sustained thought. Anyway, if we were expected to "represent" others, then we would need to be resourced to be able to engage with our constituency. But why is "representative" the aspiration anyway? What does that say about the potential for consumers (individually and collectively) to accumulate expertise, experience, leadership qualities, political savvy, etc? We should not be claiming to "represent" consumers either, unless we are actively engaging a constituency. We are providing consumer perspective. These are complex issues, but are too often really just used to undermine consumers on Other People's Committees.

⁴ See for example, Happell, B and Roper C, (2006), The myth of representation: The case for consumer leadership, *Australian e-Journal for the Advancement of Mental Health (AeJAMH)*, 5 (3), 1-8.

Do people actually value consumer perspective? What would that look like in practice?

For my 2c worth, I honestly don't think that many committees *really* understand what consumer perspective could bring. They have pre-conceived or limited ideas of our value, or of how different the world would be if our experiences, thoughts and lives were taken seriously. *Really seriously.*

There's a great deal of fabulous, consumer-perspective Participatory Action Research that explores generative, *honest* ways of harnessing consumer insights, taking into account structural power issues (for example, the U&I mentioned earlier). What I've learnt from this research, is that for real consumer "participation" to be possible, Other People's Committees need to be supplemented by: (i) **Consumer Only sites**: we need space and time to develop our thinking together, and (ii) **Collaborative committees / Deep Dialogues**: where we can all have real conversations together, not dictated by agendas, strict time-frames and a "meeting" mentality, where no one wants to open up uncomfortable issues!

Instead of (or, perhaps, as well as) participating in Other People's Committees, we need to create more spaces where we can talk about the challenging issues that most need to be talked about!

DO YOU WANT TO JOIN A NEW NATIONAL WORKING PARTY?

An open email message from Indigo Daya

Hello everyone,

I have sent this email to individuals and organisations who have already expressed interest in the Smoking Mad campaign, or who I think may be interested.

As most of you would be aware, I have been challenging smokefree policies in psychiatric wards in Victoria for the past 18 months, including taking legal action against my local hospital, promoting the issues in media stories (TV, press & radio), and publishing a popular blog (<http://smokingmad.blogspot.com/>) on the issues.

I am in the process of reaching a settlement with my local hospital (I am bound by confidentiality from saying any more about this until all paperwork is signed), and am very excited to see the WA parliament may be lifting the bans in their state (thanks to the hard work of the Council of Official Visitors). A campaign is also underway in NSW called The Right to Choose Alliance (<http://www.righttochoosealliance.com.au/>) which is also very strong. I have also been contacted by similar campaigners from the UK, USA and Denmark.

My experiences to date have led me to believe we have a good chance of overturning these policies, but only if more of us work together. Public sympathies were much more positive from my media campaign than I expected - and there is plenty of scope for more media coverage (I am working on another story now). The WA experience shows us that political support is possible. From my legal action I have also come to understand more effective ways of framing future legal action where needed.

NOW, what I believe we need is a national working party. The current campaigns are too fragmented, and too many consumers (and often staff as well) are still experiencing great distress because of these policies. We need to pool our passion, ideas and resources. ...

Please let me know if you would like to join, or to find out more. Please also feel free to forward this email to others who may be interested. I

look forward to hearing from you all.

Kind regards, Indigo Daya

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." - Margaret Mead

The Smoking Mad public statement has been made available on the Our Consumer Place website (www.ourconsumerplace.com.au), and you may also be interested in reading Indigo's brilliant analysis of this issue, printed in our June/July 2011 newsletter (p.12), also available on our website.

SMOKING MAD



Smoking Bans in psychiatric wards are a human rights abuse.

The Smoking Mad National Working Party - will you join & help make a difference?

I have devoted many of my nights and weekends over the past 18 months to promote the Smoking Mad cause and bring about changes to smokefree policies in psychiatric wards. I am not the only consumer who has experienced the enormous distress caused by these bans, and I am committed to do what I can to restore people's rights and dignity.

To find out more about the campaign, read the attached statement, or visit my blog at: www.smokingmad.blogspot.com

It's time to work together

The time has come for more of us to work together to get smoking bans in psych wards lifted. My recent legal and media activities have taught me a lot, but mostly that I can't change the system on my own. I have lots of ideas – but I want more of you to join me.

What would a national working party do?

There's lots of action happening around Australia – but it's not coordinated yet. I hope to form a Smoking Mad National Working Party. This group will coordinate the Smoking Mad campaign across Australia. It would:

- Include people who are passionate about the issue;
- Include a majority of consumers, but other interested parties too (eg, family, advocates, legal experts, mental health workers);
- Include representatives from each state/territory;
- Develop and implement strategies for legal action, public action and PR, as well as political action and dialogue. This will help raise support for the campaign and increase pressure for change;
- Collect & publish people's experiences and stories of the bans through coordinated research and public meetings.

Basically, this would be group of passionate people working out how we can bring about change – then getting on with doing it.

Can you help?

If you're passionate about this issue, and sick of seeing consumers stripped of their rights and dignities, then

please consider joining this working party. We can bring about change if we work together.

What's the time commitment?

Until we have agreed roles and responsibilities, and some agreed strategies, I suggest we initially meet on a fortnightly basis to keep up momentum, and then shift to monthly meetings supported by an online discussion group once we are up and running.

For those who are interested, there would also be work outside the meetings. It will be up to you to decide what best matches your skills, talents and interests.

When and where?

The Victorian Mental Illness Awareness Council (VMIAC) has kindly offered their premises for meetings (they are in Brunswick, Victoria). Because this is a national group, we would have telephone conferences set up for each meeting, so anyone outside of Melbourne can phone in.

So how do I join?

If you want to join or find out more, please email me at: smokingmad@yahoo.com.au

Thanks for taking the time to read this – I hope to hear from you!

Kind regards

*Indigo Daya
Smoking Mad*

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

BREAKOUT ROOM 2



Consumers as Educators Conference

Our one-day conference on “Consumers as Educators” was well attended and received overwhelmingly glowing feedback. A conference pack with readings is available on the Our Consumer Place website:

www.ourconsumerplace.com.au/trainingevents. More resources (and in a much more accessible format) will be loaded onto the Our Consumer Place website over the coming weeks. A great deal emerged from the conference and we cannot possibly do it all justice here but we believe that some ongoing collaborations are emerging, so watch this space!

One challenge that emerged was how to create space for people who are very experienced consumer educators as well as consumers who are new to this, to all feel valued, challenged and nourished. Our experience has been that there has been scant space for experienced consumers to come together, but we also need to hold fast to the awareness that we *all* have potential to contribute and lead. There were also some

generative tensions between people who see this work as a viable career, and others who resist professionalization of this work.

The Politics of Madness: Consumer Leaders Speak

Also, our sessions in collaboration with the Melbourne Free University – “The Politics of Madness: Consumer Leaders Speak” – were valuable opportunities for a broader audience to engage with some of the brilliant thinking of local consumer leaders. The three sessions were on: an ‘Introduction to Intentional Peer Support’; ‘Madness in the Academy’; and ‘What we want from the mental health system.’ We thank Cath Roper and Indigo Daya for their involvement in these sessions.

Our Consumer Place website

If you haven’t visited our website lately, you might like to take a look – there’s a raft of new materials up there – cartoons from Merinda (including these fabulous “breakout room” signs Merinda created for the *Consumers as Educators* conference), and recent talks given by OCP staff, including both Merinda and Flick’s presentations at the Inaugural Borderline

BREAKOUT ROOM 3



Personality Disorder Awareness Day, and Flick's talk to the Mental Illness Fellowship on 'Becoming More Consumer-Focussed'. The clearinghouse is also always expanding, with wonderful new resources to explore. If you know of resources that *should be* in our clearinghouse, please do let us know! (service@ourconsumerplace.com.au).

TWO WORKSHOPS ON USING STORY

CONVENOR: Merinda Epstein

Following the runaway success of our second booklet, *Speaking Our Minds: A guide to how we use our stories*, Our Consumer Place will be running two storytelling workshops in February 2012.

Merinda is an experienced storyteller and member of the Australian Guild of Storytellers

So, get out your diaries now and make sure you mark off one or other of the days in your diary and keep it aside to join Merinda for a rollicking good time playing with the techniques of using story.

These workshops will be three-four hours long and will be in the afternoon of:

Friday 10th February (beginners); and Friday 17th February (advanced) 2012

The first workshop (10th February) will be a 'beginners' workshop concentrating on telling our own stories publicly. It is a four hour interactive workshop with plenty of time to practice. There will be lots on public speaking, looking after yourself, predicting which bits of your story are 'safe' for you to tell. Everyone is welcome. It's fine if you've never told your story before. As a consumer only space it will be safe and, hopefully, fun.

The second workshop (17th February) will be an advanced workshop on using story. It will be about using story techniques to teach clinicians and the community. It will introduce interactive storytelling, group work, stories and the media, writing story (as it applies to storytelling), using multiple stories, perceiving the world through storyteller eyes, using stories written by other authors, mixing and matching story and more formal teaching ... It will not be what is usually dished up by non-consumer experts on public speaking!

The venue is not yet firmed up but if you would like a place on either of the days (numbers will be limited to twenty each workshop) you can email Merinda on: merindae@ourconsumerplace.com.au to reserve a place.

The event is free and a booklet will be available for each participant.

Where have the overseas interviews gone?

If you are an observant reader of the OCP newsletter, you may have noticed that in recent editions, we have not been including interviews with prominent overseas leaders in the consumer/survivor movement. This is because we have been focused on putting together a booklet of interviews conducted so far. The collection is called *Deep Insight: Leaders in the International Consumer/Survivor Movement* and will be available on the OCP website and in hardcopy early in 2012. So keep an eye out!

There are many more booklets in the pipeline too. Merinda in particular has been extremely busy writing over the past few months, finishing a booklet called *Psychobabble: The Little Red Book of Psychiatric Jargon*, which demystifies and critiques some of the language used in the psych system.

TheMHS 2012 Summer Forum, 23-24 Feb

Merinda has been invited to be a keynote speaker at the Mental Health Services Summer Forum, on the topic of "Confronting Self-Harm: from understanding to responding." This forum will be held at UTS in Sydney.

Congrats!

Flick's paper "Positive thinking about consumers" has been accepted for publication in The Mental Health Services 2011 Book of Proceedings. In fact, it will be included in the 'Recommended Reading' section. The paper is available on the Our Consumer Place website:

www.ourconsumerplace.com.au/resources



THUMBS UP/THUMBS DOWN

Because it's the festive season (and the traffic alone is enough to make anyone grumpy), we've decided to include only Thumbs UP in this edition.

1. **THUMBS UP:** to the amazing array of consumer educators who came together for the recent OCP conference. What a magnificent critical mass of brilliant thinkers and educators!
2. **THUMBS UP:** to the incredible depth of thinking, research, writing and drawing that emerges from our lived experience, combined with fierce intellect, courage, determination and skill. It is deeply humbling to bear witness to the collective talents of the consumer community.
3. **THUMBS UP** to collegiality in general when consumers are there for each other whether it be for emotional or intellectual support or just a strategic hug.
4. **THUMBS UP** to the many friends, parents, families, clinicians and staff who are our radical comrades.
5. **THUMBS UP:** to approaches to mental health care and support that validate, recognise and address the origins of our "symptoms" in traumatic, neglectful and invalidating experiences.
6. **THUMBS UP:** to all the consumers who understand our political battle as bringing us together in shared experiences with other marginalised groups.
7. **THUMBS UP:** to those who allow us care for them. Reciprocity in care empowers all.
8. **THUMBS UP** to those of us who 'don't really understand' a project, a tool, a picture, an artefact, a booklet, a musical contribution or an academic article produced by another consumer/s but make it our duty to trust it does make sense to others and find out more about it.
9. **THUMBS UP:** to spaces of healing and transformation.
10. **THUMBS UP:** to knowing when it's time to rest, to withdraw or to recharge. Life can sometimes be hard, living with a 'mental illness' can be tiring, and living with a 'mental illness' and trying to change things for people with 'mental illness' can be exceedingly draining. Hope you have time to rest and recharge over the holidays.

And finally, a little letter we just loved and wanted to share with you all.

Dear Santa,

I don't want much for Christmas, I just want the person reading this to be happy. Friends are the fruit cake of life – some nutty, some soaked in alcohol, some sweet but mix them together and they're my friends. Send this to all your fruit cakes.

Merry Christmas!