



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

**OUR CONSUMER PLACE
NEWSLETTER JANUARY 2012**



Funded by:



Auspiced by:



ourconsumerplace.com.au

RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

Contents

Page News

3. **Soap Box:** *Psychiatric diagnoses: unexplanations.* By Jon Jureidini.
4. **Thumbs up/Thumbs down**
5. **Does your consumer group want more money?** Do you know about GiveNow?
5. **Callout for consumer perspective resources**
6. **Introducing ...** “Putting the community into Community Care Unit” A new consumer-led research report on Peer Support, offering a “Rich Knowledge Resource” – By Allan Pinches
9. **P.S. A necessary postscript to *This is not about catharsis! My time in HDU*** – by Merinda Epstein
10. **From the Archives:** Why is it so hard for consumers and staff to effect change in mental health services?
14. **News in the consumer world:** Film screenings, Protective Service Officers update, a job opportunity, RIP to John McCarthy, Occupy the APA, some controversy and the Mental Illness Research Fund.
17. **Because mental health matters ...** a cartoon by Merinda Epstein
18. **Introducing ... (an international Consumer/survivor Developed Initiative)** the Centre for the Human Rights of Users and Survivors of Psychiatry
19. **OCP update:** what we've been up to and what's in store.
20. **What are the Symptoms? ...** a (very cheeky) cartoon by Bernie McCormick



SOAP BOX

Psychiatric diagnoses: unexplanations

By Jon Jureidini

Jon Jureidini is a child psychiatrist at the Women's and Children's Hospital, Adelaide where he works with ill and disabled children and their families. He has also trained in philosophy, and is a Professor in the Disciplines of Psychiatry and Paediatrics at the University of Adelaide. He is spokesman for Healthy Skepticism, an organisation devoted to countering misleading drug promotion, and chair of Siblings Australia, an organisation which advocates for individuals with ill and disabled siblings, and of Australian-Palestinian Partnerships for Education and Health. His interests include quality use of medicines, immigration detention, suicide, medical education and child abuse. OCP approached Jon to write for us about his thinking on "unexplanations" after hearing him speak at InsideOut's conference on 'More than Medication.'

Sometimes receiving a psychiatric diagnosis can provide access to life-saving interventions. But more often psychiatric diagnoses are unexplanatory.

'Unexplanations' do not just fail to explain; they stand in the way of authentic understanding.

Labels like depression and personality disorder explain nothing; at best they describe. Depression as description can be benign: a doctor might say to a patient who meets criteria for depression, 'What you are going through – the hopelessness, loss of interest and energy and poor sleep – can be described as depression. This occurs quite commonly in our society, sometimes without an obvious explanation. It tends to last weeks rather than months, and you've had it for several weeks now, so it is likely that it will go away relatively soon. I am going to make some suggestions about some things you can do to speed up your recovery, and I will see you again in a couple of weeks so that we can review how you are going with it.'

'Unexplanations' do not just fail to explain; they stand in the way of authentic understanding.

But more often descriptions masquerade as explanations, and 'depression' is pressed into service as

unexplanation – 'you are feeling like this because you are depressed'. Unexplanation is dangerous. It locates problems within individuals and deflects attention from social context. It places us in systems where we are at risk of an escalation of potentially harmful 'treatments'. It distracts us from striving to make sense of our life circumstances, compromising our ability to exploit a crisis in our lives to make changes.

The psychiatric task is to provide a safe, validating environment in which patients can, with our help, come to an authentic account of where they are, how they got there, what needs to be accepted and what must be changed.

The psychiatric task is to provide a safe, validating environment in which patients can, with our help, come to an authentic account of where they are, how they got there, what needs to be accepted and what must be changed. When people come to psychiatry in pain, they often can't identify the source of that pain. The goal of the assessment should be to identify what is the story behind that presentation. Each person comes with a different story, but there are common themes – fear, loss or hunger (usually for relationships of some sort) – so that with help from the psychiatrist, the important story for that person, though not immediately apparent, can often be found. The aspiration is an authentic story, rich in emotional and interpersonal detail (rather than a glib and stereotyped script). This approach might prolong pain but it has the benefit of strengthening people in the face of subsequent difficulties and distress.

Of course the process isn't always straightforward. People hope that their medical consultation will resolve uncertainty, so that when we don't have answers there is pressure on us to find them. We

People hope that their medical consultation will resolve uncertainty, so that when we don't have answers there is pressure on us to find them.

doctors need to be much better at resisting that pressure and helping our patients to live with uncertainty rather than retreating to unexplanations. In medical jargon what is required is 'Watchful Waiting' – if there is no immediate danger we support our patients in living with the uncertainty and the expectation that issues will resolve or if not an explanation will emerge. Readers might be surprised that

there are few negative consequences from delaying understanding by a few weeks. We should work together to resist the false resolution of uncertainty by the introduction of unexplanations.

This paper is based on an address given to the Adelaide Festival of Ideas in October 2011.



THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** to rest.
2. **THUMBS DOWN:** to assumptions that the Christmas/holiday period is necessarily easy and joyful for all. This period can be especially difficult for those of us who are lonely or don't have enough money to buy the gifts we'd like to be able to offer, who are involuntarily detained, whose families are triggering or fractured or estranged for various reasons, or whose lives just don't seem to be following the path we hoped. You are not alone!
3. **THUMBS UP:** to following our own truth and doing what we need to do to get through.
4. **THUMBS DOWN:** to rhetoric about 'social participation' and the therapeutic value of being employed in the workforce getting used to kick us off the Disability Pension (and covering up the real point – saving the government money!). People debilitated by 'mental illness' who rely on income support get characterised as undeserving slackers. Yes, social participation is important, and yes, meaningful work can be life-enhancing, but there should be no shame in needing to use a social safety net.
5. **THUMBS UP:** to services that are open to real feedback. We understand that this can be deeply challenging, but we also know it's essential if services are to not cause harm (or to change when they have done so).
6. **THUMBS DOWN:** to workplaces that employ consumers for our lived experience but fail to support us in this – actively, thoughtfully, meaningfully supporting us and being changed by our presence (having a "good" attitude is not enough!!). Unfortunately, we here at OCP hear of this happening across the mental health field, and of good consumer workers leaving because of being so profoundly demoralised. "Allowing us" to work in "your" services is not good enough.
7. **THUMBS UP:** to all the extraordinary work, inspiration, change, creativity, thinking, wisdom, connections, healing and love that have emerged from the consumer movement.
8. **THUMBS DOWN:** to the loss of our history.
9. **THUMBS UP:** to those people working in mental health who don't really understand consumer perspective or consumer leadership, but who make space for us anyway.
10. **THUMBS DOWN:** to the colonisation of *our* ways of thinking and doing things. For example, "advance directives" becoming "advance statements," "recovery" becoming the fancy new name for rehabilitation, "the industry" deciding what peer work should entail ... Listen but don't co-opt!





Does your consumer group want more money?

Do you know about GiveNow?

Our Consumer Place gets many requests for money for consumer groups. We suspect people misunderstand what a “resource centre” is and they think – or hope – that it means we provide money. While we can’t provide consumer groups with money, we understand that there is a need for *better information* about how to get money for consumer-perspective projects. And so we’re working on developing more resources on this topic. There’s already quite a bit of information about sourcing money for consumer-developed initiatives on our website (www.ourconsumerplace.com.au – click on “for consumer groups”), but we want MORE!

So we looked to Our Community. Our Consumer Place is auspiced* by Our Community, an organisation that exists to support community groups to become stronger and smarter. One of the ways Our Community does this is by providing information, including on the topic of sourcing money for community groups. Our Community runs an online donations website called “GiveNow.”

What is GiveNow? GiveNow is a website that lists community groups seeking money; it makes it really easy for people who want to donate money to donate to these groups. GiveNow is a really simple (and free) way facilitate online donations.

Why would I use GiveNow? Because your group or project does something worthwhile, needs money to do this and believes that there are people out there who would financially support you (if only they knew how).

Is it really that easy? Yes and no. You can’t just register “Jo B’s personal retirement fund” on GiveNow – you need to be able to prove that you’re a community group. And you still need to get the word out there about who you are and why people should give you money (ie. GiveNow doesn’t do publicity for you). But it is a very easy and convenient way to accept and solicit donations. (And there are lots of mental health charities listed on GiveNow, and not that many of them are consumer-developed!)

For more about GiveNow, see our helpsheet on the topic (written specifically for consumer groups): <http://www.ourconsumerplace.com.au/consumer/helpsheet?id=5123> or www.givenow.com.au.

**We’re not always entirely sure what “auspiced” means either, but it’s a form of collaboration and includes us working in the same office space as the rest of Our Community*

Callout for consumer perspective resources

We know there are LOTS of consumer perspective resources out there that are useful, brilliant, witty, insightful, critical, etc, but that go “under the radar.” We are updating and expanding our clearinghouse (www.ourconsumerplace.com.au/clearinghouse) because we want to make consumer perspective resources (ie. those that respect, value and draw on people’s lived experience of ‘mental illness’) as accessible as possible. *We are seeking your help.*

If you know of any materials that could be added to our clearinghouse (including your own contributions!) – talks, radio shows, Youtube clips, books, journal articles, cartoons, snippets, etc – please let us know. If you are able to send us the resource (e.g. as a PDF, jpeg or weblink) – preferably in a form that can go straight onto the web – that would be most appreciated. But even a title would be most helpful. Thanks so much!

A new consumer-led research report on Peer Support offers a “Rich Knowledge Resource.” – By Allan Pinches

A new in-depth report from the consumer-led Northern CCU Peer Support Research and Development Project: “Putting the *community* into Community Care Unit” has its first release in this issue of the Our Consumer Place newsletter.

Consumer Consultant Allan Pinches was the Principal Researcher for the 16-month project, which was funded by a Department of Health Victoria Mental Health and Drugs Research Fellowship Grant. The main purpose of the project was to research and develop ways to build a possible Peer Support program and culture into the Northern Community Care Unit (CCU), a 20-resident adult psychiatric rehab service in Preston.

The project, as shown in various ways in the final report, resulted in a clear consensus among CCU consumer participants and expert project consumer co-facilitators, that a Peer Support Program and the employment of a Peer Support Worker (or workers) was likely to be beneficial to consumers. This trend was confirmed by the favourable results of the formal Evaluation forms after the three Peer Education Sessions of the trialling stage.

While discussions took place about ways that a peer support program could be developed at the Northern CCU, the highly participatory project workshops generated a rich knowledge resource, in which consumers identified a myriad of ways that peer support could “make a difference” – whereby friendship and mutual support could help fulfil a range of needs, hopes, states of health and wellbeing, participation in the community, empowerment, and progress towards personal recovery. Residents/ consumers could be encouraged to share coping strategies, lessons/ insights from life, information about opportunities in the community and actively supporting each other in exploring options.

A range of possible structures and processes emerged from consumer discussions towards a multi-faceted Peer Support Program at Northern CCU, including the employment of a Peer Support Worker (or workers.) This was partly based on a review of notable examples of the increasing

... peer support often has a natural tendency to spring up among consumers in service settings, and ... adding consumer leadership, structures and resources could greatly amplify the benefits of such interactions.

number of articles about peer support as a form of paid service provision within mental health services, including some key consumer “grey literature” materials. Supplementing was some networking with local consumer movement knowledge holders.

The research project recognised the importance of ensuring that any Peer Support Worker (or workers) should actively engage with the resident/ consumers on site, and encourage them to share their experiences,

lessons from life, insights, problem solving, the values of friendship and mutual support, and sharing knowledge and strategies about pathways towards personal recovery. Collaboration between PSWs, consumers and program staff is seen as important.

Part of the rationale for the project was a widespread consumer movement belief that peer support often has a natural tendency to spring up among consumers in service settings, and that adding consumer leadership, structures and resources could greatly amplify the benefits of such interactions.

Another major part of the rationale was the apparent “gap” that while PDRSSs (Psychiatric Disability Rehabilitation and Support Services) receive some government funding to provide peer support programs and peer workers, clinical services do not, at this stage receive funding for peer support. Recent policy statements suggest this may change in the medium term.

One message that comes through strongly in the Northern CCU project is that there is an abundance of ways that peer support could be beneficial to consumers and so many ways that it can increase the effective reach, degree of meaningfulness and diversity of responses that could be offered to consumers of mental health services. Peer support addresses a different and more personalised domain of the consumer’s life, compared to standard mental health treatment and care, but both service types can co-exist.

In the six specially themed project workshops and the three Peer Education Sessions of the trialling stage, participants discussed in creative workshop sessions with the Principal Researcher and a number of eminent consumer co-facilitators, many possible elements of a dedicated multi-faceted Peer Support Program for the Northern CCU. The participants became increasingly enthusiastic, creative and conversant with the possibilities of peer support.

The project maintained a clear and conscientious dedication to its consumer-collaborative Participatory Action Research (PAR) methodology, with every effort to maximise consumer participation and the wisdom and insights that can flow from consumer perspective discussions.

The project maintained a clear and conscientious dedication to its consumer-collaborative Participatory Action Research (PAR) methodology, with every effort to maximise consumer participation and the wisdom and insights that can flow from consumer perspective discussions. In many ways, the PAR methodology was worthy of being highlighted as a project outcome in itself, because of the inclusive quality of consumer discussion, good feelings, and the articulation it promoted.

The project report was showcased in the Northern AMHS/NCCU Accreditation Presentations to the Australian Council on Healthcare Standards in late November, and

was well received. Articles will be written up for journal articles and conference presentations as part of the funding agreement. It is hoped that an on the ground peer support program will grow out of this project at Northern CCU and maybe beyond.

The research project was carried out under the auspices of the Northern CCU, which is part of the Northern AMHS. The Northern AMHS Clinical Director Assoc. Prof. Suresh Sundram and Darebin Community Mental Health Service Manager, Ms Christine Hodge were Supervisor/ Co-Researchers for the Project. The project went through the extensive ethics approval processes with the Mental Health Research and Ethics Committee (Melbourne Health). An Executive Steering Committee also supported the project and an eminent group of Consumer Co-facilitators assisted in scoping and running the workshop sessions. A total of nine Northern CCU resident/ consumers participated, to varying degrees.

The research report contains a number of easily navigated sections, drawn from creative discussions with Northern CCU consumers, with the potential to be built upon in a myriad of ways. This includes:

- Recommendations about a range of initiatives towards a multi-faceted Peer Support Program and culture at Northern CCU, and with possible wider application across other services. This has yet to be actioned.

- A model for a Peer Support Program, under four sub-headings: (1) Peer education and support groups; (2) Foundational consumer participation activities; (3) Systemic advocacy, relationship building and shared learning with staff; (4) Consumers to support each other exploring options and getting more involved with the community.
- A Literature Review covered many recent developments and key debates in mental health peer support, based on growing numbers of articles, conference presentations, mental health service models, and consumer “grey literature”. This was intended to help provide a baseline for developing a model.
- Augmented information came from networking with local consumer experts, and key peer support related organisations and individual “knowledge holders” were consulted to help create a base for thinking about the possible shape of peer support models at the Northern CCU.
- Edited highlights of the six Creative workshop discussions among consumers and the three trialling stage Peer Education Sessions – provide a wealth of consumer perspective thinking about needs identification, peer support as part problem solving and creative building of life options. These sections are filled with interesting and compelling quotes and form a valuable knowledge resource within the already valuable report.
- Some special subjects were: Defining peer support and the peer support happening informally; leadership and possible role and duties of peer workers; peer support and the search for personal recovery; peer support and building bridges back into the wider community; and meaningful activity, education and employment...and much more.

For a copy of the full report, go to: www.ourcommunity.com.au/files/OCP/NCCU_Peer_Support.doc.

TWO WORKSHOPS ON USING STORY

Following the runaway success of our 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 Epstein is an experienced storyteller and member of the Australian Guild of Storytellers

The first workshop (10th February 2012) 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 2012) 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!

Each workshop will be 3-4 hours long , in the afternoon. 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.

P.S. A necessary post script to *This is not about catharsis! My time in HDU** – by Merinda Epstein

I need to write a post script. I knew this as ‘Catharsis’ hit the press. I was uncomfortable and there was something niggling at me from the beginning but I wasn’t sure what it was. I knew that what I had experienced in the High Dependency Unit was awful but there was something that almost seemed more urgent. What was it? ***I had been taken seriously.*** Despite everything, that was a belief and blessing even though it hadn’t always turned into attentive behaviour by staff. Bad things happened, absolutely, but at least I had the opportunity to name them. A funny kind of respect came from the legitimacy accorded my experiences. There was never any doubt that I was worthy of ‘care’ or that I deserved staff’s time and watchfulness and was not blamed when I hurt myself. As my psychiatrist commented after I was belatedly released, “well at least there were no problems with fraudulence this time”. She was right. I have a terror of being seen as purposefully disordered, ‘attention seeking’, and ‘manipulative’, fraudulent and inherently unworthy as a person. This horrible stay did not leave me feeling unworthy and untrustworthy, despite the experiences I endured.

I have two diagnoses, Complex Post Traumatic Stress Disorder (CPTSD) and Bipolar Affective Disorder. I am careful where and to whom I mention the former. Experiences of flashbacks, distraction, self harm, dissociative voices and shame are my perpetual companions. They lead to staff symptomatology:

judgment, reaction and counter reaction, need to allocate blame, forgetfulness to be attentive, feeling personally attacked, needing to punish, decisions to ignore me, and trivialisation of anything that looks like distress. These I did not experience with my late admission despite everything that went wrong.

This is why I felt so uncomfortable. The landscape of the HDU was drenched in ugliness and the violence was palpable but I was not made to feel responsible for it or for the part my experiences played in it. There was an assumption of innocence despite everything. It was describable in a way people inside and outside the institution were able to hear. It could be captured in a picture of *‘things that should not happen’*. My other world of psychiatric distress is often impossibly hard to name, let alone share to gain solidarity, compassion and credibility. Being treated like you are nothing, because you have the wrong diagnosis, hurting yourself and having the sterile bandage kit thrown in your face, being told your bed is better occupied by someone with real problems, being ignored and dismissed as nothing, are real experiences for many. “There’s nothing wrong with you” they claim and blame stays within rather than be displaced (healthily) on to the institutions that help create it.

So, this is why I needed a post script. I felt uncomfortable about finding legitimacy in experiences that short circuited the complexity of my story. I never ever want to go through those HDU experiences again. They really were horrible. But I also want to acknowledge this darker side that can’t be told as easily.

My other world of psychiatric distress is often impossibly hard to name, let alone share to gain solidarity, compassion and credibility.

*This was a supplement to the December OCP Newsletter: it is available on the OCP website:
<http://www.ourcommunity.com.au/files/OCP/ThisIsNotAboutCatharsis.pdf>

FROM THE ARCHIVES: Why is it so hard for consumers and staff to effect change in mental health services?

In the process of updating our clearinghouse, we are unearthing some real gems of consumer perspective literature. We believe these are well worth sharing in bite-sized chunks to whet your appetite for more!

Between 1989 and 1996, the Victorian Mental Illness Awareness Council conducted dialogic research between consumers and staff working in a large public acute psychiatric system. Merinda Epstein was employed as the research officer and many other consumers were employed as casual researchers and consultants. Yoland Wadsworth was employed as a research consultant to the project. The research that emerged was groundbreaking, deep, insightful and incredibly useful, but unfortunately not as widely read as it really ought to be! It also laid the foundations for consumer consultant roles.

So, we are profiling a short, very accessible piece – Yoland Wadsworth's *Dialogue across distance – Between users and staff of acute adult psychiatric hospital services*, a paper to the Ethnographic and Qualitative Research Methods conference – Reclaiming Voice, University of Southern California, 1997. This is a fabulous read for anyone interested in exploring the challenges for real change in mental health service. This is a small excerpt, but the full article is available in the clearinghouse on our website – <http://www.ourcommunity.com.au/files/OCP/DialogueAcrossDistance.pdf>.

Why it is so hard for consumers to effect change in mental health services?

1.	It's too stressful, too confrontational.
2.	I want to make a good impression – otherwise who knows when I will get out?
3.	They're too busy – I don't want to be a bother.
4.	They know what they're doing – they're the professionals.
5.	I don't want to upset them – it's hard enough for them as it is.
6.	They could take it personally and I don't want to hurt their feelings.
7.	I might have to come back here and I don't want them to see me as a trouble maker.
8.	I don't want to upset them – some of them are really good.
9.	I don't want to upset them – some of them are my friends.
10.	I don't want to upset them – some of them I am afraid of.
11.	I don't want to upset them – they're really doing a good job under the circumstances.
12.	I don't want to feel worse.
13.	They're the ones who need looking after.
14.	Maybe I'm wrong.
15.	Maybe I only saw it as negative because I am depressed.
16.	If I say what really happened they will say it is my illness.
17.	If I get really upset they'll put me back in the lock up.
18.	I'm not sure that I have the right.
19.	I don't want to upset them – some of them I am afraid of.
20.	I don't want to upset them – they're really doing a good job under the circumstances.
21.	I don't want to feel worse.
22.	They're the ones who need looking after.
23.	Maybe I'm wrong.
24.	Maybe I only saw it as negative because I am depressed.
25.	If I say what really happened they will say it is my illness.

26.	If I get really upset they'll put me back in the lock up.
27.	I'm not sure that I have the right.
28.	I must have done something to deserve it.
29.	Things are not that bad.
30.	They have all the power – I can't buck it.
31.	Personally, I'm not political.
32.	They can't hear it anyway – they are so stressed out themselves they're more stressed out than I am.
33.	It's not really them, they're just doing their job under a whole lot of stresses – its 'Their' fault ... government, politicians, the hospital, the drug companies, psychiatrists / nurses, the managers, carers, the lawyers, the medical establishment...
34.	They're doing the best they can.
35.	I couldn't do their job.
36.	Some consumers don't deserve to be listened to.
37.	I didn't deserve it – but I'll just keep quiet.
38.	I don't want more blood taken / ECT given / time in seclusion / disapproval / disrespect.
39.	It can't have happened – it's a hospital, how could they have done that in a <i>hospital</i> ?
40.	It was alright last time – maybe it was just my bad luck.
41.	Nothing ever changes.
42.	Nothing happened last time I wrote a complaint.
43.	I prefer to 'shut up and ship out'.
44.	It was just that one person, the others have been really good to me.
45.	I don't want to be here/ I want to leave/I don't want to come back.
46.	Why should I have to try and improve the service? I'm meant to be the patient. I'll be out of here soon.
47.	Last time I tried they explained why it is impossible.
48.	Last time I tried they wrote it in my file.
49.	I'm just in a bad mood/paranoid/anxious.
50.	It's all too hard and too big to change.
51.	Even if they wanted to do something they would have to contend with their peers.
52.	It's not so bad.
53.	I just need to concentrate on getting better.
54.	I want to get on with my own life.

List of Excuses by staff against effecting change in mental health services

(A) "We'd like to but we can manage without it because ..."

1.	We already pretty much know what to do.
2.	We already know what to do but are prevented from doing it by... lack of time or by 'Them' – funders, politicians, government, cutbacks, the hospital, the network, managers, carers, the influx of agency nurses, the pharmaceutical companies, the threat of litigation, ... etc.
3.	We don't really need to be told how to do our jobs.
4.	Managers and the department tell us what to do quite enough as it is – we don't need patients doing it too.
5.	Reforms are already in place, we have already worked out what to do and are getting it

	underway.
6.	If we are meant to be professionals then we already know what to do.
7.	We already observe, monitor and pretty well guess pretty accurately what consumers think and need.
8.	Things seem to work well enough without it.
9.	We did all that in the 70s.
10.	Nothing really matters except for waiting for the drugs to work.
11.	To be honest, things work more efficiently without it.
12.	There's no time for talking here, they'll get that in the community.
13.	Consumer participation is just another management fad imposed on us.
14.	We're not actually hearing about any problems, our patients don't seem to complain.
15.	We did ask but no one had much of a problem.
16.	There can't be any real problems, they'd tell us if there were.
17.	They tell us their problems all the time, we don't need to hear more.
18.	I'm sure we would hear if there was something really big like a rape or an assault.
19.	Patients are too ill/too confused/too paranoid to give accurate/valuable feedback.

(B) "We'd like to but we can't because ..."

1.	We just haven't got the time.
2.	This is not a very good time at present – perhaps in another year or two.
3.	We haven't got anywhere near enough staff.
4.	There are a lot of competing demands.
5.	All we've got time for is processing people in and out.
6.	Eight hour shifts don't give you enough time to speak to patients as well as everything else – review meetings, admissions, discharges, transfers, reports, arranging for patients to see everyone – doctors, consultants, the social worker, procedures, tests, it just goes on and on...
7.	Other things always seem to be more important, urgent, pressing.
8.	We have to go really slowly with introducing this idea.
9.	We've had a lot of changes and need to let them settle first.
10.	There doesn't seem to be any point because there really aren't any solutions.
11.	It'll just be a Catch 22 – and it will raise patients' expectations.
12.	I'm not sure we have management support.
13.	They're only going to want the impossible anyway.
14.	We can't give them what they want.
15.	I don't like it either but I can't challenge it on my own.
16.	I would like to ask consumers but the other staff would talk about me behind my back / think I was breaking ranks.
17.	This is new, staff don't really understand it yet.
18.	They might find it a bit threatening.
19.	It'll only make staff defensive.
20.	We can't force consumers to give their feedback if they don't want to.
21.	Staff aren't ready to hear it.
22.	We have to maintain a secure environment.
23.	We haven't found consumers who are available / representative enough / keep attending meetings.

(C) "It'd be alright if it was constructive, but criticism really is unwarranted because ..."

1.	We are doing the best we can.
2.	We have to do 'certain things' to people.
3.	There are no other choices that anyone has been able to identify.
4.	It's what is expected by the job – by managers, by the institution, by my profession, by my job description, society at large.
5.	We do a good job really.
6.	We've tried everything else.
7.	This is the way it has to be – and when consumers become more well / get insight they usually accept it too.
8.	There have to be rules and procedures.
9.	Of course they'll be critical – it's an acute ward.
10.	They magnify things because of their illness.
11.	If we made it any nicer they wouldn't want to leave.
12.	Who made that criticism?
13.	They're not here long – we turn them around as fast as we can now.
14.	I'm just doing my job.
15.	We have to keep control, you can't be too soft – especially in a crisis.
16.	This is an acute ward – there are always crises.

(D) "We'd like it but we just don't want criticism. ..."

1.	Morale is low enough here as it is
2.	You think I like all aspects of my job? – get off my back per-lease
3.	You think I think this is good nursing?
4.	It would only stir things up.
5.	I like to focus on the positive.
6.	It might clash with things we already believe / are committed to / from which we gain respect in team meetings / from which we gain status as professionals / have to say and do to be listened to.
7.	I already feel bad enough as it is – I don't want to feel even worse.
8.	I don't deserve it, I've always stuck my neck out for consumers.
9.	I have a hard time too.
10.	I suspect consumers wouldn't want us if they had the choice.
11.	Consumers give us a hard time – I'm not allowed to talk about that.
12.	I get abused but I don't complain – it's part of being a professional, it's up to me to hold together / get it right / not wimp.
13.	Actually I'd prefer thanks rather than criticism.
14.	We never get much appreciation.
15.	No one else wants to do this.
16.	We're the ones who have stayed in the public sector – the private send us their 'too hards'.
17.	I couldn't bear to think they never forgot some of the things that get said and done to them.
18.	I'm getting out of acute as soon as I can.
19.	You should criticise – 'Them' ... funders, government, politicians, the hospital, the network, managers, carers, lawyers ... etc.
20.	It's too hard and too big to change.
21.	I just need to survive.

News in the consumer world

Film screening

Doutta Galla, Penguin Artists and Open Channel invite you and a friend to the screening and launch of the Creative Pathways to Engagement Project (CPE) on Tuesday 24th January 7pm at Cinema Nova, 380 Lygon st Carlton. Please RSVP by January 17th to zoe.horsfall@doutta.org.au



Doutta Galla, Penguin Artists and Open Channel invite you to the launch and screening of
MEDICATION TIME and **Media and Mental Illness**

Join us on Tuesday 24th January at 7.00pm
at Cinema Nova, 380 Lygon Street Carlton, cinema 4 - refreshments afterwards

Creative Pathways to Engagement Project has created two short films made by people some of whom have an experience of mental illness.

MEDICATION TIME Horror Comedy (7 minutes)

Media and Mental Illness Documentary (10 minutes)

Please RSVP by 17 January to zoe.horsfall@doutta.org.au or 0418 580 051



Protective Service Officers (PSO) update

Protective Service Officers (PSOs) are currently being recruited and trained within Victoria Police, to "protect and serve" people on metropolitan trains in Melbourne, as well as to "apprehend" people who "appear to be mentally ill." Alarmingly, these PSOs will be able to use force (and will be armed with guns, batons and capsicum spray), but receive significantly less training than regular police (only 12 weeks).

Our Consumer Place, along with a number of consumer, legal and community organisations have been expressing our concerns, including vigorously campaigning against these powers when they were first proposed. We argue that the conflation of making trains "feel safer" and policing mental illness is unhelpful, stigmatising and very likely to lead to the escalation of distress (or worse) of people who are simply using public transport. Of course, certain groups are even more likely to be targeted – young people, Indigenous people and people whose physical appearance may be perceived as "unusual" (e.g. heavily affected by psychotropic medications).

In December, we were invited (with representatives from other concerned groups, including legal advocates for young people, Indigenous people and homeless people) to meet with several members of the Victorian Police to be briefed on and then discuss some PSO implementation issues. Unfortunately, there seemed to be minimal interest in incorporating into the training real skills in responding to people in distress, or in de-escalating confronting situations. For more information, see: www.communitylaw.org.au/mhlc/cb_pages/crime.php

Job opportunity: Project Worker Centre of Excellence Peer Support

The overarching aim of the project is to develop a centralized professional centre of excellence for peer support, which provides specialist knowledge and input for community mental health organizations, small NGO's and individual community members who are seeking to implement peer support programs for people with a mental illness and their families.

This is a collaborative project between ARAFEMI and a consortium of mutual support self help organisations including: Eating Disorders Foundation Victoria, Compassionate Friends, Post and Ante Natal Depression Association, Anxiety Recovery Centre Victoria, Action on Disability in Ethnic Communities and Grow.

Position Summary:

This project role is responsible for the day-to-day operations of a new Centre for Excellence in Peer Support. The worker will provide a first point of call for information, advice, linkage and support on peer-mentor models to the non-profit mental health sector. This position will also build service quality and sector capacity to deliver peer based mental health support.

The project worker will provide support via a statewide clearing house and resource centre utilizing web based technologies, dedicated help and information line and enhanced coaching, training and mentorship to support service mapping, quality and sustainability, project development and volunteer management.

More information is available here: http://www.jobseeker.org.au/employment/results.chtml?filename_num=396811. Closing Date 31st January 2012. (Source: Nicola Paton, CEPS)

We Will Carry on Your Mad Pride, John McCarthy! - by David W. Oaks

John, you've gone and done it now, my friend. Now you've gone and done it.

You, the champion of the normality of madness, you are now exploring what is perhaps most normal about all of who are alive: We die.

John was a poet, a friend, a psychiatric survivor, an activist, and - as he called himself - a sales person for the idea of Mad Pride. He felt that all we humans had madness, that madness was normal, and that we ought to be proud.

The movement for deep change in the mental health system has often had a problem reaching out to the public. John found a solution: Celebration. Creativity. Music. Festivity. Costumes. Family-friendly free events. Sometimes his events would reach thousands.

John, one way to remember you is to carry on, and to let others know about your work. Whether or not people knew you, they can celebrate what you have done. I hope those who knew and loved you will share their memories. My thoughts and prayers to John's family. John is survived by his wife Liz, his children David and Jill, and grandchildren.

~~~~~

John McCarthy & Mad Pride Ireland Remembered

MadPride FineCut1: <http://www.youtube.com/watch?v=RfRXOOyMjxI>

For more links and photos of John go to: <http://www.mindfreedom.org/campaign/madpride/john-mccarthy-rip>

(Source: MindFreedom International News - 10 January 2012)

## **Occupy the American Psychiatric Association -- BOYCOTT NORMAL!**

A Call for Peaceful Resistance in 2012 to Mental Health Industry Human Rights Violations, by David W. Oaks, Executive Director, MindFreedom International (MFI).

Thursday, 22 December 2011 is a very special day for MindFreedom International, marking the 25th anniversary of the incorporation day for the project that became MFI's independent, united, nonprofit coalition for a peaceful revolution in the mental health system!

The MFI community has taught me a lot about combining the power of mutual support with activism, thank you everyone! Today, MFI affirms our community's call for peaceful, nonviolent direct action in the face of a tidal wave of human rights violations our people experience every day:

- The over-drugging.
- The poverty.
- The electroshock.
- The psychiatric coercion.
- The restraints.
- The discriminatory labeling.
- The segregation.
- The enforced hopelessness.
- The lack of real alternatives.

***MFI has an answer: Support one another. Unite. And engage in independent activism, NOW!***

MFI calls for speaking out ... for resisting... and for withdrawing cooperation with the psychiatric industry. For too long we have been witnesses to this oppression... It is time for united, global nonviolent protest, direct action and resistance.

### **"Boycott Normal!"**

Today, MFI announces a new web address about 2012 Boycott Normal actions:

<http://www.boycottnormal.org>. Already you may download an announcement about protests on 5 May 2012, or go directly here: <http://www.mindfreedom.org/campaign/boycott-normal/occupy-apa>

Everyone can participate in this 5 May protest action, from now until 5/5, wherever you are. Toronto is already planning a solidarity protest! But individuals can also creatively participate through leafleting, YouTube, Facebook, blogs, etc. Martin Luther King once called this "creative maladjustment," and said he was proud to be psychologically maladjusted in that way. So are we! Join us!

Everyone who is can is especially encouraged to join me and many others in Philadelphia on 5/5. This home of American liberty is where the American Psychiatric Association is expected to give their blessing to the newest version of their devastating label bible (the infamously flawed DSM-5).

We're encouraging everyone to 'occupy the mental health industry!' wherever people live, even if you can't get to Philly! (*Source: MindFreedom news alert, December 2011*)

## **Mental Health Foundation of Victoria: questions about fundraising**

When is a mental health organisation technically a charity? What's a legitimate fundraiser? The Mental Health Foundation of Victoria has been in the news lately – Consumer Affairs Victoria is investigating the fundraising activities of the organisation. While they charged up to \$16,000 for a table at their gala Crown Casino fundraising event, financial records from 2010 do not list a single cent going to charitable activities. (*Source: Herald Sun, December 23rd, 2011*)

## The Mental Illness Research Fund (MIRF)

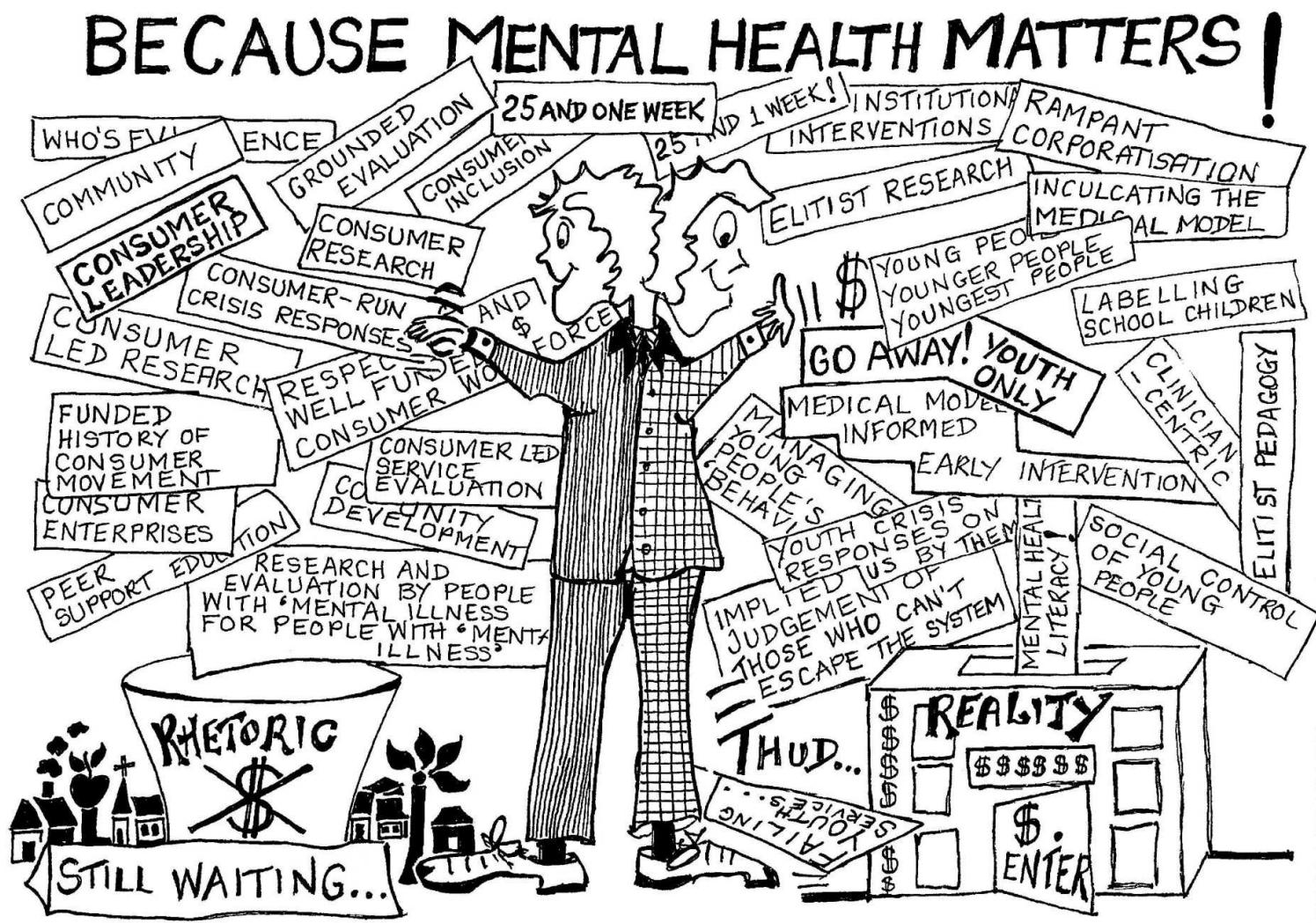
The Mental Illness Research Fund (MIRF) was established in 2010 by the Victorian state government, to provide funding for a small number of "significant research projects," each running up to 4 years.

*"The Fund will promote the development of new knowledge that will improve the evidence-based treatment and care of people with mental illness in Victoria. It will leverage the knowledge of Victoria's research and treatment delivery sectors, and translate this knowledge into practice to improve treatment and recovery outcomes for people with mental illness."*

*"Research projects are expected to also demonstrate consumer and family/carer involvement, ensuring that their perspectives are included in the planning, development and conduct of the research projects."*

The MIRF Funding Application Guidelines and Proforma document can be downloaded from:

<http://health.vic.gov.au/mentalhealth/reformstrategy/mi-research-fund.htm>. Applications must be emailed to Neurosciences Victoria at [info@neurosciencesvic.com.au](mailto:info@neurosciencesvic.com.au) by 5pm, 13 April, 2012.



## **INTRODUCING ... the Centre for the Human Rights of Users and Survivors of Psychiatry (CHRUSP)**

*We first heard about CHRUSP from Tina Minkowitz, a human rights lawyer and survivor of psychiatric abuse. Tina is a leader in the international consumer-survivor movement, an international representative for the World Network Of Users and Survivors of Psychiatry and played a key role in the drafting of the UN Convention on the Rights of Persons with Disabilities. She has visited Australia to share her work (we interviewed her for our newsletter in April 2010).*

### **CHRUSP Year-End Update and Appeal**

Dear Friends and Supporters,

CHRUSP would like to thank you all for your support both moral and financial since our beginnings in 2009. At the end of this letter is information on how to donate to CHRUSP – please remember us in your year-end giving.

Here are some of the highlights of our activity in 2011.

CHRUSP began a campaign to Repeal Mental Health Laws, working with activists in the United States and Canada. The campaign is an independent entity that is working to establish its own public presence. CHRUSP will inform its friends and supporters who may want to become involved.

CHRUSP continues to support the work of the World Network of Users and Survivors of Psychiatry, a democratic membership organization representing our community at the global level. CHRUSP assisted with several UN submissions, including a response to a questionnaire on violence against women with disabilities.

That questionnaire explicitly asked about forced psychiatric interventions and incarceration as violent practices – a milestone achievement in itself, that responds to our earlier advocacy: CHRUSP contributed its analysis of this issue to a paper by the International Network of Women With Disabilities (INWWD) in 2010.

CHRUSP also continues to provide analysis and commentary to user/survivor organizations and allies regarding the CRPD and other human rights obligations. This year, we contributed to work in Norway, India, Uganda, Ghana, Peru, Colombia, Ireland and Australia, among others. CHRUSP also provided expertise to the Ibero-American Network of Experts on the CRPD, which develops proposals for law reform dealing with legal capacity.

CHRUSP issued a major statement on CRPD Article 14, discussing the obligation of countries to repeal mental health laws to comply with human rights law. The statement has been translated into Japanese and a Spanish translation is being finalized. It received many endorsements from user/survivor organizations and allies, and was published in the Journal of Critical Psychology, Counseling and Psychotherapy, special issue on Human Rights. A human rights expert at the UN has responded favorably saying he will find it helpful in his work.

In 2012, CHRUSP is planning some organizational changes for development and expansion of our work. Among these will be an email list for Friends of CHRUSP, which will allow us all to stay in touch more regularly. Watch for an update in early January, and thanks for your much appreciated support.

In solidarity, Tina Minkowitz, Daniel Hazen, Lauren Tenney

\* \* Donations to CHRUSP can be made via a link on the CHRUSP website [www.chrusp.org](http://www.chrusp.org) \* \*

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

Hooray, it is finally quiet here at OCP. Flick took time off over Christmas/New Years, but Merinda was busy writing a chapter and other pieces for the textbook *Mental Health in Australia* (3<sup>rd</sup> edition). Our main priorities at the moment are writing and strategic planning.

### ***Upcoming written resources***

On the writing front, there are many new materials coming out in the foreseeable future, including Merinda's wonderfully incisive *Psychobabble* – a demystification and exploration of psychiatric jargon, and *Deep Insight* – a collection of interviews with international consumer/survivor leaders. These are both “in the works” as they say (ie. out of our hands and in production). After that ... well, you'll just have to wait and see, but let's just say Merinda and Flick have both been busily writing.

### ***Strategic planning***

In terms of strategic planning, we are acutely aware that there are always far more things that we *could* do (and that need to be done) than we have the time and resources to do justice to. It is a challenge for us to balance writing resources, providing individualised support for consumer developed initiatives, giving talks from a consumer perspective to mental health organisations, preparing and delivering training, expanding our website resources, participating in consultations and responding to the many challenges thrown our way (and there's also this little newsletter that we put together...). We also have to balance meeting the needs and expectations of experienced consumers and consumers who are new to the consumer movement, consumers who are desperate for information about getting support from (and protecting themselves in) the system as it currently operates, consumers who are desperate to overthrow the current system and consumers who work in the current system ... And of course, we work with all sorts of other people who engage with consumers – we believe this makes the environment more conducive to the flourishing of consumer perspective and consumer leadership. Add in juggling the priorities of us as individuals and those of our funding body ... Needless to say strategic planning is necessary to keep us sane(ish)!

### ***Keynote on self-harm***

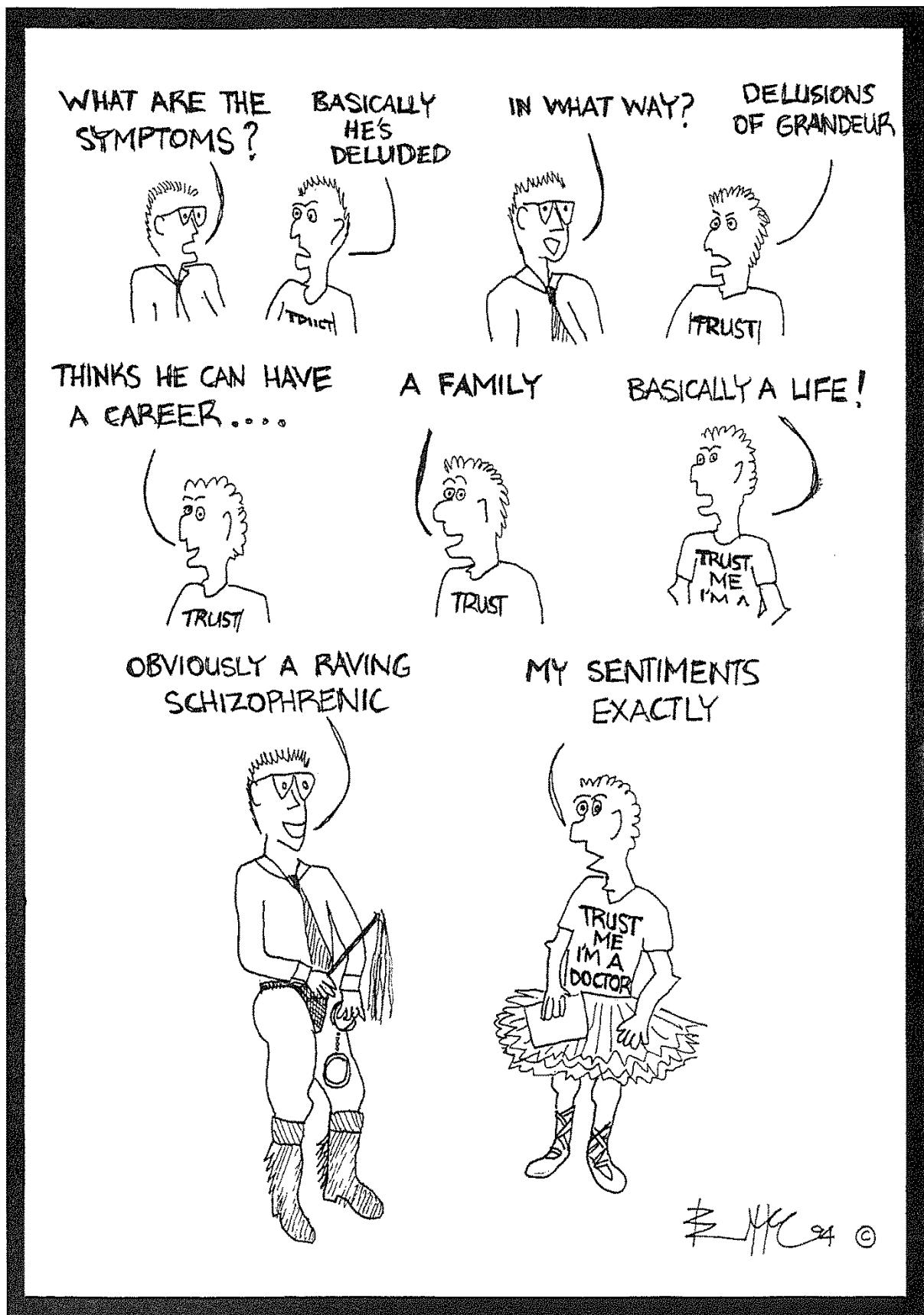
Merinda has been invited to give a keynote at The Mental Health Services Summer Forum, on Self Harm. Merinda's talk is called “Shame, trauma and self-harm: When self-harm is a sane response to an insane world.” It will be on Thursday 23<sup>rd</sup> Feb, in Sydney. The exact time is unclear, but she is speaking straight after Patrick McGorry. For more information, to go [www.themhs.org/summer-forum/2012-summer-forum-](http://www.themhs.org/summer-forum/2012-summer-forum-)

### ***Website expansion***

Our Consumer Place's website is also expanding and changing. We are endeavouring to make more materials accessible through the website – we realise that this is the main way many people access our resources. Too many consumer perspective resources end up being stored in memories only, or in dusty library basements or in piles on personal bookshelves and we believe sharing this knowledge and insight will sustain, inspire and nourish us all.

### ***BPD Expert Reference Group***

Following our participation in the Inaugural Borderline Personality Disorder Awareness Day in 2011, we have decided there is a dire need for consumers who have been labelled with BPD to come together as a critical reference group and build our collective wisdom, knowledge, critique and priorities. If you would like to join us, please let us know ([service@ourconsumerplace.com.au](mailto:service@ourconsumerplace.com.au)). We will endeavour to make participation options for wherever people are at.



-A very cheeky cartoon by Bernie McCormick