



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

**OUR CONSUMER PLACE
NEWSLETTER AUGUST 2010**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

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SOME NEWS IN THE CONSUMER WORLD:

The Mental Health Legal Centre has updated and released their booklet (in collaboration with the Victorian Legal Association) on Patient's rights. Check it out and help spread the word!

http://www.communitylaw.org.au/mentalhealth/cb_pages/patient_rights_booklet.php

We extend our congratulations to survivor and psychosocial disability activist, David Webb, whose book *Thinking About Suicide: Contemplating and Comprehending the Urge to Die* (2010, published by PCCS books, and based on his PhD research) has recently been published. Finally, a book that delves into what suicide means from the perspective of someone who has attempted suicide. For more information, check: <http://thinkingaboutsucide.org/> It's available through:

www.psychotherapy.com.au/



INTRODUCING (a Consumer Directed Initiative) ... *the Culturally and Linguistically Diverse Consumer Reference Group (CALD CRG)*

– by Maria Dimopoulos

In this edition, Maria Dimopoulos introduces the Culturally and Linguistically Diverse Consumer Reference Group (CALD CRG). Maria is a current member of Spectrum of Cultures, the North West Area Mental Health Services Consumer Advisory Group (NWAMHS CAG) and the Inner West Area Mental Health Services Consumer Advisory Group (IWAMHS CAG).

The culturally and linguistically diverse consumer reference group (CALD CRG) is made up of six supportive and dedicated consumers, with a background of multicultural heritage who get together to discuss issues that affect Consumers from a multicultural background.

The group is in partnership with the Victorian Transcultural Psychiatry Unit (VTPU), Advocacy Disability Ethnicity Community (ADEC), Victorian Mental Illness Awareness Council (VMIAC) and Multicultural Mental Health Australia (MMHA).

CALD CRG works together with these groups on the following important areas:

- Training and development for consumers, which involves activities such as meetings events and public speaking. CALD CRG members present relevant information to other consumers attending. We propose that by supporting other consumers in this way more CALD voices can be heard in mental health support services.
- Joining together consumer participation into existing organisations and using methods for more CALD consumers which can integrate with other mental health services within Victoria, in areas such as staff education, selection and community education.
- Encourage participation models of CALD consumers to other mental health services, so that we can promote more diversity in mental health services than what is currently available to consumers.

“We propose that by supporting other consumers in this way more CALD [culturally and linguistically diverse] voices can be heard in mental health support services.”

Contact details:

CALD Consumer Reference Group
Level 2 Bolte Wing
14 Nicholson Street
Fitzroy, Victoria 3065
(03) 9288 3335

Email:

cald.consumer.reference.group@gmail.com

CALD CRG contacts:

Evan Bichara (mob. 0411054 882)
Maria Dimopoulos (mob. 0438 087 941)



No revolution in youth mental health without young people leading it!

-By Flick Grey

I'm deeply glad that I never received "early intervention" despite being a deeply troubled, suicidal teenager. I do worry for many of the young people these days getting "caught" and "helped." Now, before you shoot off that irate email reply, defending the progress made in youth mental health, or recounting horror emergency rooms stories that "demonstrate how important early intervention must be," I want to be clear: too many people I care about have had either decent or horrific experiences in the mental health system for me to be entirely black-and-white about any of this stuff. BUT, I think we need to be much more thoughtful about what reforms in mental health might look like, who is leading them, and whose voices are being marginalized. I do know for myself that I am glad to the very core of my being that I survived this period of my life ("youth" being typically under 25) on my own terms. From what I've seen and heard about what "early intervention" means, it's certainly not being led by young people themselves, and that matters.

I am writing this rant specifically because someone alerted me to the fact that the *First International Youth Mental Health Conference* (held in Melbourne, July 2010) included NO youth consumers (actually no consumers) as keynote speakers on the program and made very little mention of youth consumer voices in their promotional materials. Convened by none other than our Australian of the Year, Patrick McGorry, it was promoted as having many professors this and

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professors that speaking, but not youth, consumers, nor youth consumers. That is, there was no sense that "youth consumers" might be experts on this issue. Once my attention had been pointed in this direction, I realised that amongst all the talk of early intervention and a youth-focus in mental health, the leadership of young mental health consumers is conspicuously absent.

I am being a bit harsh – the voices of young people *were* involved in this conference and that *is* progress. Young people's voices, however, were largely contained within a stream called "Youth participation." But this stream was concurrent with others, rather than being absolutely at the centre, and understood as central expertise that has to shape everything! Also, when the organisers of this conference answered their own question "Who should attend?" there is NO mention of young people or consumers (it says "Anyone working at the intersection of youth health and mental health"), and at a whopping registration cost of \$770, I suspect young consumers weren't the target audience. There *was* a subsidised registration for "students/consumers/carers," but who knows how many of these places were taken up by students who are neither consumers nor carers? This also points to another pet peeve of mine – the assumption that consumers and carers are more akin to students (i.e. in a position to be taught) rather than us having important lessons to teach the professionals! And, to be clear, I don't think this particular conference is more culpable than most – this is just so frustrating to witness again and again. And, in case you're asking the obvious question – did I go to this conference? – No, I don't put myself in such environments anymore – unless consumers are explicitly in leadership roles, I am wary. My standards are higher these days.

OK, I'll be honest, it's bigger than this – I'm miffed that the consumer movement has been relatively ignored by Pat McGorry and those in his wake this year (e.g. Get Up! have been similarly silent about consumer voices).

Also, I have to admit that – despite my youthful appearance – I'm officially not "youth" any more, so I don't speak from that position. I was 26 (*just* too old for "youth services") by the time the mental health system finally caught up with me. By that time, they didn't have much to offer me (which was simultaneously a blessing and a crushing disappointment, but that's a different story). I speak as someone who believes passionately in the motto of the disability movement: **"NOTHING ABOUT US WITHOUT US."** How many decades have consumers been fighting for our voices to be heard?? And, as a bonus, I am also willing to admit that here at Our Consumer Place, we are probably a bit light on in terms of youth voices (maybe you can help us remedy that!?). But we couldn't even imagine organising a conference on youth mental health with NO youth consumer keynotes. How can this kind of thing still be happening???

Maybe it's easier to disregard youth consumers because they have the double whammy of being "too young to know what's good for them" AND "too crazy (and lacking in insight) to know what's good

ANYONE MISSING FROM THIS PICTURE?



© Simon Kneebone & Yoland Wadsworth,
From Y. Wadsworth (2010) *Building in Research and Evaluation: Human inquiry for living systems*, Action Research Press,
Melbourne and Allen & Unwin, Sydney Ch 4. Reprinted with permission.

for them” ... Just to be clear – young consumers can and *must* be the leaders in this area. There shouldn’t be discussions about youth mental health that aren’t *fundamentally shaped by the lived experiences of young people*. This is so obvious my brain hurts.

There shouldn’t be discussions about youth mental health that aren’t fundamentally shaped by the lived experiences of young people. This is so obvious my brain hurts.

Maybe I’m wrong, maybe I’m way off the mark, maybe young people who are experiencing mental distress, or madness, or are hearing voices, or are proud nutters are integral to shaping the approaches in youth mental health. Maybe ... but I don’t just mean integral to making the services “youth friendly” or “integral” because they have their own committee which makes some minor decisions, but doesn’t actually have any real control, or they have a few tokenistic seats on the real decision-making bodies (but are totally outnumbered by the “real experts”) ...

Anyway, there *are* youth voices out there – some of them were speaking at this conference. I’ve also been fortunate enough to hear a few. Zines* seem to be one way some awesome young people are getting their ideas out, on their own terms, sharing their experiences and thoughts with the world. Also, one of my all-time favourite books (although, I confess, I have many) is “*Hello Cruel World: 101 Alternatives to Suicide for teens, freaks and other outlaws.*” (2006) It’s written by Kate Bornstein who is an awesome freaky radical thinker (she’d probably run a mile from the word “consumer”!), writing from her lived experience as someone who has been through many periods of deep despair and has an intimate relationship with suicide. But, afraid to say it, Kate Bornstein is not exactly a young ‘un anymore either – she is, however, funny, irreverent and actually in touch with young people.

My central concern is that under the banner of “helping” people, we all too often stray into “managing them” or just plain controlling them. I’m sure I’m not alone in finding the expression “early intervention” creepy – and I don’t think it’s just a superficial wording thing – who wants “intervention” in their own lives? I want support, love, dreams, growth, etc. Anyway, bring on youth consumer voices! Why aren’t they more prominent? Why aren’t they leading this revolution?

** For those of you not up with young hipsters, zines are self-produced, photocopied little booklets, distributed via word-of-mouth, the internet or zine distros.*

Do you passionately disagree? Or have you got your own rant inside?

We love discussion and debate on any issues that matter to consumers! Consumer perspectives will always be prioritised, but we welcome contributions from allies too – those who understand the importance of lived experience and speak with us, not for us. Email us at: service@ourconsumerplace.com.au. We are always looking for more contributors to the newsletter!

INTERVIEW OF THE ISSUE – Ron Coleman

Ron Coleman is a Mental Health Trainer and Consultant specialising in Recovery and Psychosis. Following his role as national co-ordinator of the 'Hearing Voices Network' he used his experiences of recovery to design Workbooks and Training packages, to enable voice hearers to gain ascendancy over the negative aspects of the voice hearing experience.

Ron's own route to recovery after spending 13 years in and out of the psychiatric system has given him many insights into the numerous difficult issues facing today's mental health services. He is now back in his homeland of Scotland after 20 years of self imposed exile!

Ron is the author of 'Recovery - An Alien Concept?' and co-authored 'Working With Voices' and 'Working To Recovery'. Ron has published several books including the above and also 'Politics of the Madhouse'.

[Photo and text from <http://workingtorecovery.co.uk>]



Flick Grey: How would you describe what consumers are doing – changing systems and/or the world? Do you think our political heyday has come and gone?

Ron Coleman: That's a really difficult one because I think there are different levels at which we are changing things. The consumer movement will always have some impact. It is a broad movement, in terms of driving things. A good example is that the ideas around "empowerment" came from the consumer movement, the ideas around "partnership" came from the consumer movement, and now a lot of the ideas about "recovery" have come from the consumer movement.

I think what happens, though, is that after a while that's all colonised by traditional and academic thinking, in a way that almost makes it totally acceptable to a broader medical model. But that's never stopped the consumer movement and consumer individuals having an impact on the system. So now you begin to see consumers talk about "thriving" or "wellbeing," pushing beyond "recovery," pushing against that boundary. So clearly, any space, any discourse, has to be felt and the people that feel it at the beginning are the consumers, with academics and professionals coming along later on.

... without the consumer movement, an interesting question to ask would be: where would we be now?

So, we're always pushing the agenda – we're not in total control of the agenda, but we tend to push and expand the boundaries of the agenda. So, yeah, without the consumer movement, an interesting question to ask would be: where would we be now? If we didn't have any activists, I think we might just all be stuck in some kind of medical bubble, without any other discourse – for example, about the role of trauma.

And it's not all just consumers on their own, there are some great allies – John Reed from New Zealand, Michael White from Australia (in terms of his narrative work), Marius Romme in Europe, and a whole host of others who are allies, who are professionals. They are more in thinking with the consumer than with their own professions.

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

RC: In terms of mental health, I think activism is absolutely essential. The areas we need to really target are the use of compulsion, where people are detained or forcibly treated - that whole area of compulsion is an area I think we need to target. We need to target the relationship between the pharmaceutical industry and the medics, and also the need to grow peer support workers, who can take the lead within recovery-oriented services.

FG: What would you expect to be different if we lived in a community that embraced people who have mental health problems or experienced madness?

RC: I dream of the day when I can walk down the street and talk to my voices and no one would take a blind bit of notice. People would just find that totally acceptable, you know. And they wouldn't feel alarmed by it or threatened by it, they would understand I was in a dialogue. I would see that as one of the most amazing things that would show, if you like, a healthy society, in terms of mental wellbeing.

FG: If you were asked to give the government advice on how to spend \$500 million for mental health, what would you spend the money on? What about if you have \$10,000 to spend?

RC: If I could control this amount of money and I could advise the government on what to do, I would say "don't spend it on hospitals and beds, or doctors!" I would argue that we should spend it on much more clear structures, recovery units, crisis houses, peer workers, and a whole host of things that would normalise the experience.

If I could control this amount of money and I could advise the government on what to do, I would say "don't spend it on hospitals and beds, or doctors!"

If I had \$10,000, I'd probably spend it on one of the self-help networks, like the hearing voices network. Because they could impact with \$10,000 in a way that I don't think any of our "normal" organisations could. Now I wouldn't just leave that with the Hearing Voices network, I would also look at other self-help groups – if there were any of the self-help movements who could use \$10,000 effectively, I'd give it to them.

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

RC: I guess one thing that does that for me at the moment is when I've been doing training and, you know, one fellow would come up to me and say "I've got it!" and they have their own light bulb moment where they actually get what we're talking about in terms of recovery or working with

voices. You go away feeling confident that that person's going to make the changes needed in their practice to become a brilliant worker.

And with consumers, when a consumer comes up and says – and I've had this happen with people I work with – "Look, I don't need you anymore, I know what I've got to do now and I'm going to do it. Thank you very much, but goodbye!" That gives me a real buzz. I think those are the great moments in your life!

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

For me, it's often outcome.

I remember I was working with this guy who was hearing voices and we couldn't find any rationale for these voices. And when we asked him why he heard voices he said he was telepathic. And of course, in mental health services, telepathy is seen as maladaptive, delusional framework which we shouldn't encourage.

But the way I work, you can't do that – you can't just turn around and say "well that's just maladaptive and delusional." So I started reading up on telepathy – and I thought it was a load of rubbish – but I read a book called "*Psychic Self-Defence*" which was recommended and this was meant to help with working with this guy. And, as it happened, it didn't make sense to me. But I gave it to the guy and he said it was brilliant. I asked him, "What does that mean?" and he said "Well, it tells me how to deal with this." And I said "How do you deal with it?" He said to me "I need to build a psychic wall around myself." I said "OK ... How are you going to do that?" He said "With my third eye."

And I thought, Oh my god, I'm in trouble here, you know, I have to go to this review meeting and his psychiatrist is going to say to me "Well, Ron, what are you doing with him?" And I'm going to have to say "Well ... we're building psychic walls with his third eye" And I thought I'm going to be in trouble. But we did it and it worked for him! So, he was able to walk down the road and the voices would bounce off this wall he had created, the psychic wall.

I do find myself often having to break rules in order to achieve "good outcomes."

I went to the review meeting, and the doctor said to me, "Well, what are you doing with him?" And I said "Well, doc, we are exploring different forms of thought-blocking, using visualisation." And I used that as an explanation. What I did was translate the language! I thought the outcome totally justified breaching this idea that we shouldn't enter into a person's belief system – which is one of the common fallacies in mental health. I do find myself often having to break rules in order to achieve "good outcomes."

Afterword: Ron Coleman says he is "making probably my last trip down for the foreseeable future next feb – april [2011] if you think of anyone that may want some workshops or anything could you put them in touch." We her at Our Consumer Place are thinking about what we could organise, but if you would like to engage Ron's services, email him at: ron@roncolemanvoices.co.uk



THUMBS UP/THUMBS DOWN

1. **Thumbs up** to the residents in a Community Care Unit (CCU) who had the tenacity, persistence and gall to take an important complaint through process after process up to the Health Complaints Commissioner.
2. **Thumbs up** for all the dogs who tirelessly support, encourage, forgive, and protect us, especially in times of terror and despair.
3. **Thumbs up** to the clinicians who recognise they have 'Compassion Fatigue' and do something about it before it does something to us.
4. **Thumbs up** to the psychologists who do pro bono work with the Asylum Seekers Resource Centre and other areas where the need is great.
5. **Thumbs up** to those who stand up against the medical lack of imagination that renders us ill rather than different, interesting, determined, leaders in a new way of seeing the world.
6. **Thumbs down** to the first "International Youth Mental Health Conference" being organised without youth leadership! Consumer voices should be integral to any such talkfest!
7. **Thumbs down** to managers of services who just don't understand the necessity of having consumers routinely evaluating their service. Don't they care if they are doing a good job?
8. **Thumbs down** to the non-government organisations in the PDSS sector which simply assume they are miles ahead of the clinical sector in relation to consumer leadership without bothering to test this hypothesis.
9. **Thumbs down** to the colonisation of the term "recovery." How come whenever we get a good idea, it gets stolen by professionals to mean the same old thing: submission to their ideas of what a "good life" should look like?
10. **Thumbs down** to the Mother (of one of us) who has got the opinion that our newsletter has got too many 'gots' in it!!

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

What HAVE we been up to? ... Some months, it feels VERY busy and this has definitely been one of those months! These are some of the things we've been up to. This might also give you a sense of how you might want to be involved with Our Consumer Place or how we could work with you.

Training in Mildura (Consumers volunteering): Merinda and Flick went on a road trip to Mildura to train paid workers and consumers at the Murray Mallee Community Mental Health Service. There had been some interest from consumers wanting to volunteer at the service, and we were asked to come up and train the consumers. We felt strongly that the staff would also need to think through some of the issues that come up when service-users become workers (albeit unpaid) at the service. So, we ran a day of training with the paid staff and a day of training with the consumers. The material was very similar on both days and included some consumer perspective 101, an introduction to Intentional Peer Support, working through some of the issues that the participants could foresee and plenty of lively discussion!

Save the date! Our Consumers and Leadership conference is in the planning stages – put October 14th in your diary and come to Melbourne and listen and talk about consumers as leaders! More information soon ...

First Consumer Think Tank! A motley crew met at Errol's cafe on a cold, rainy Friday evening (whose idea was that timing?! ... oh, yeah, mine!) and chatted for about two and half hours. We solved all the world's problems! Keep your eyes peeled for more ... and do suggest a better time if this doesn't work for you but you're keen to be involved.

Peer Support in a Community Care Unit (CCU): Alan Pinches has received funding to establish a peer support program at a CCU. Merinda is participating in this project in an advisory role.

Borderline Personality Disorder in the media: We have been contacted to see if any of our members might be interested in being part of a group discussing consumer input into representations of Borderline Personality Disorder in the media. At the moment, there are very consumers willing to contribute to this discussion publicly, and we support the idea of getting a group together to discuss the various issues. Please do contact us if you are interested.

Keynote at Psych Nursing Conference: Flick gave a keynote presentation at the 11th Victorian Collaborative Psychiatric Nursing Conference on *Whose recovery? "Promoting recovery" through listening differently*. This was an exciting opportunity to present a consumer perspective on recovery and to stress the importance of consumer control of the recovery process, and how nurses *listening* can support that process.

Consumer Reference Group at MIND: Merinda is both on the Board at MIND and the liaison between the Board and the Consumer Reference Group. I (Flick) am not entirely sure what the means exactly, but know it involves lots of meetings!

In the classroom: Merinda has been teaching in the Social Work course at La Trobe University, and Merinda and Flick are both teaching in the Social Work Course at Victoria University. We're also both involved in helping to develop a Consumer Perspective Academic program in the Centre for Psychiatric Nursing at the University of Melbourne (under Cath Roper's direction).

Consumer Experiences of the Psychiatric Disability Support Sector :Our writing tasks continue ... Thanks for continuing to communicate your experiences in the Psych Disability Support Sector – keep sending these in (see our last edition or call/email for info).


To join Our Consumer Place, go to our website – www.ourconsumerplace.com.au. It's free and we won't send you any junk! Membership is open to *anyone* interested in what consumers are doing and thinking. Members receive our regular newsletter and advance notice for events. Also, you need to be a member to participate in the 'message board' section of our website. Maintaining a membership is important to funding bodies, so sign up your friends, family and pets – this helps us stay alive.

Also, if you would like us to send you paper copies of this newsletter, please let us know – we know this suits some people better.

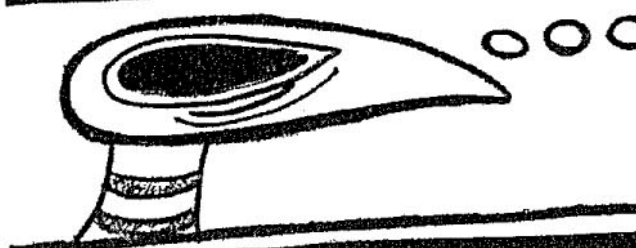
Our contact details are: ph.(03) 9320 6802 or (03) 9320 6839; email: service@ourconsumerplace.com.au or 51 Stanley St, West Melbourne.

Contemplation

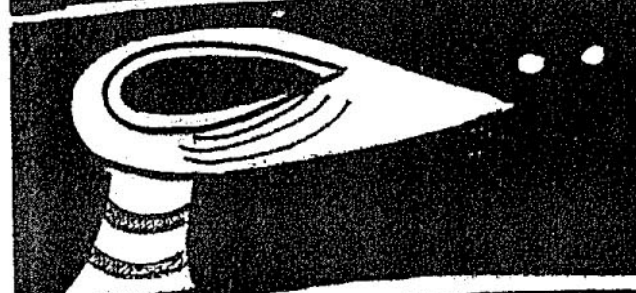
by Sue E Armstrong



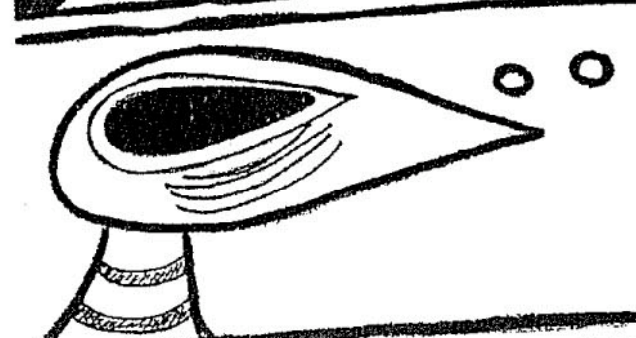
It's hard being a woman in this sexist society



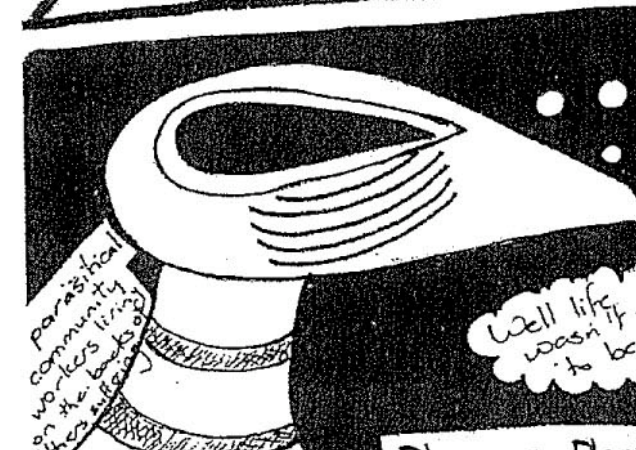
It's very hard being an intelligent woman in this society



It is extremely hard being an intelligent woman with a psychiatric disability in this society



It's impossible being an intelligent woman with a psychiatric disability with radical politics in this society



It's more than impossible being a talented, creative innovative intelligent woman with a psy. disability with radical politics in a society full of small minded, petty, jealous, careecrist opportunist boros!!!

Well life wasn't meant to be easy

parasitical
community
wonders living
on the backs of
others suffering

NON-TALENT PERFORMERS
RULE OK

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