



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

**OUR CONSUMER PLACE
NEWSLETTER SEPTEMBER 2010**



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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

Contents

Page News

2. **News in the consumer world**
3. **Our Consumer Place Leadership forum:** *The* event of the year! Be there (October 14th in Melbourne) or spend the next year wondering what you missed out on!
4. **Soap Box:** *Paying for medical drugs we don't want* – by Merinda Epstein
6. **Feature Article:** *A Bill of Rights for people who self-harm* – by Deb Martinson
8. **Introducing ...(a consumer-run project)** *People Like You* – by Cameron Ralph
9. **Your responses!** Sometimes our newsletter generates a flurry of feedback – last month's soapbox did just that! Here are some of your responses.
11. **Thumbs up/Thumbs down** As always, some opinionated reflections/rants.
12. **Registration form** for the Our Consumer Place 2010 Leadership forum

NEWS IN THE CONSUMER WORLD:

Mental Health Act (Vic) Review update: You may be aware that the *Mental Health Act (Vic)* is under review at the moment. Lisa Neville (the Minister for Mental Health) has just announced that there will be “an exposure draft process” – this means they will release a draft of the new Act for more feedback, rather than just release it once it's finished. Her statement says that this is “the best way to ensure that the new Bill delivers on its key objective, which is to ensure we have consumer focused and carer inclusive legislation that works to ensure people's human rights and promote recovery.”

Congratulations Brook RED! (who we profiled in our April newsletter) – they have opened a second Peer (ie. Consumer) Operated Service in Genoa St in MacGregor, Brisbane. Given that there are so few peer-run centres in Australia, this is amazing that Brook RED is strong enough to be expanding to a second centre! QLD seems to be leading the way in Peer Operated Services!



STOP PRESS! *Consumers and leadership forum 2010.*

Date: Thursday October 14th 2010

Time: 10am-4pm

Location: Ross House, 247 Flinders Lane, Melbourne.

Cost: FREE!

Registration: We would greatly appreciate **registration by Friday Oct 1st** for catering purposes. Please fill out the registration form (on the back of this newsletter), then

- a. post it to us – Our Consumer Place 51 Stanley St, West Melbourne 3003
- b. scan it and email it to us – service@ourconsumerplace.com.au
- c. or fax it to us on 9326 6859

Please be in touch with us if you have any questions, comments or requests.

Why a forum on consumer leadership?

Leadership is so important if mental health consumers are to be effective in our work. We believe that it's incredibly important for consumers to be in leadership positions – as opinion-leaders, shaping mental health practice and policy, as mentors for other consumers, teaching all sorts of people about 'mental health,' and generally as people whose experience and insights are respected.

But leadership is a complicated issue when it comes to mental health consumers (actually, it's always complicated, but we'll focus on consumers). We certainly don't mean leadership in any simplistic sense (like "being the boss" or "knowing more than everyone else"), although this is how far too many people act when they are in leadership positions. This can be especially true if we have been disempowered – sometimes we overcompensate to get taken seriously. Also, we need to be so careful not to reinforce the idea that some of us are "high functioning" and should have more power than those who are described as "low functioning" or "inexperienced" or "lacking in insight" (or however such put-downs are framed). There are also huge barriers to many of us stepping up and becoming leaders – prejudice, learned helplessness and damaged self-esteem, inexperience on the part of services to trust and nurture us as leaders, lack of training, lack of opportunity, etc.

We think it's timely to discuss these issues together!

Speakers include (all consumers):

- Catherine Smith (former Leadership and Development Team Manager at Queensland Alliance)
- Merinda Epstein (High Profile Nutcase and winner of a Human Rights award in 2004 for her consumer work, see <http://www.takver.com/epstein>)
- Cath Roper (Australia's only consumer academic)
- Youth consumer leaders (unconfirmed)

If you are interested in some background reading, Vrinda Edan wrote a marvellous piece in a previous edition of our newsletter (August 2009), which is still available on our website (www.ourconsumerplace.com.au). She makes a compelling case for consumer leadership!

See you there with ideas, enthusiasm, frustrations, networks, dreams etc.



PAYING FOR MEDICAL DRUGS WE DON'T WANT – by Merinda Epstein

We don't want to pay for pills, potions and injections we didn't ask for and don't want. In Victoria in 2010 people using public mental health services can be forced to have 'treatment' – that often consists of nothing more than a ten minute appointment to receive an injection in the bum – and then be billed for the pharmaceuticals. In my opinion this is outrageous.

The justification given by some senior clinicians is that it would be untenable to have a dual system where those people using public services who are voluntary would pay and those who are involuntary not pay. This response draws a very fine distinction between fairness and a judgement of the worth of the consumer. Implicit in this argument is an assumption that those of us who do the right thing and take our medication without force should be rewarded and not disadvantaged because we have 'insight'. It completely misses the point that forced 'treatment' takes away our decision making opportunities. We can't say, 'NO'.

My argument would be that no one on a Disability Support Pension (DSP) using publicly provided mental health services should be paying for their medications.

Cost Shifting

Up until 2010 patients using public mental health services had their medications paid for by the State Government and dispensed free of charge by the clinic or hospital. Earlier this year the policy changed. If we are on pensions we now have to pay \$5.40 per script. Many of us will be on multiple medications. The political intention is to move the cost for medications from State (Victoria) run hospitals and clinics to federally funded Medicare. This is called cost shifting. Those of us using public services are the bunnies in the middle between State and Federal governments.

Medications and forced 'treatment'

This move away from free medications for public patients applies regardless of whether we have voluntary status or involuntary status under the Victorian Mental Health Act. We believe that this is wrong. Depot injections are commonly prescribed for people on Community Treatment Orders (CTO) which is forced 'treatment' in the community. Risperdal Consta, is a drug of choice at the present time for people with 'psychosis'. It is not only likely to empty our pockets, when we are already struggling on Disability Support Pensions, but it is also extremely painful when administered by injections, usually every two weeks. Surely this is a sizeable turn off for accepting this 'treatment', sometimes landing us back in hospital because we have broken the conditions of our CTO. Then we are lectured about 'compliance'!

Pamphlets and justification

Our Consumer Place has seen pamphlets from an Area Mental Health Service justifying this shift and we are astounded. The service makes itself out to be a benign benefactor which has no choice but to impose these costs on people who can't afford it because it is the 'right' thing to do (given the economic circumstances of the service) and that clients will all come around to this point of view when they've had time to think about it and talk about it with (implicitly 'neutral') 'case managers'!



Payment

In this pamphlet, the following options for people trying to pay this levy are:

- **Cope with the payment yourself by being a good budgeter:** implying that this is an important life skill so being forced to pay might qualify as therapeutic!?
- **Automatic withdrawal from Centrelink:** If Centrelink automatically withdraws the money from our pensions it might be a convenience but it might also mean that we'll soon forget that we were ever entitled to this money.
- **Families:** Another suggestion is to further trap us in the emotional as well as financial debt we owe to our families and friends. There is now evidence that indebtedness is extremely bad for one's mental health and for developing and renewing relationships.
- **Pharmacies:** Negotiating with the pharmacy is another suggestion. We believe that this has the potential to create even more people who know too much about us.

When we can't Pay

There is also a section on dealing with situations when we can't pay and again the road leads straight back to dependence: dependence on the 'case manager', doctor, families and 'carers'. This is all nuts when we consider just how much 'therapeutic energy' is put into increasing our success as independent humans in our own rights, making our own decisions and moving towards a new life. We estimate that the cost of the wasted therapeutic energy is probably greater than the financial benefits gained by the service from selling us medical drugs.

Where to from here?

If you share a concern about this issue please do something! Some suggestions are:

1. Write a **'letter to the editor'** to your local paper, particularly if the mental health service you use is in the catchment area of the paper. Think about whether you want your name published. As long as you give your name most papers will publish: name and address supplied to protect your privacy. However, the letter is much more powerful if you are prepared to use your name.
2. Start a local campaign in your own service. You can get some help to do this from Our Consumer Place. It might involve organising a rally or a public meeting. It would be great if you could get clinicians involved – we know some clinicians are furious about this issue. However they will have conflicting demands if the service is their employer.
3. Write a complaint to the Mental Health Branch or, Ruth Vine, the Victorian Chief Psychiatrist.
4. Contact one or all of the following:
 - The Australian Human Rights Commission: <http://www.hreoc.gov.au/>
 - The Victorian Equal Opportunities and Human Rights Commission: <http://www.equalopportunitycommission.vic.gov.au/home.asp>
 - The Mental Health Legal Centre: http://www.communitylaw.org.au/clc_mentalhealth/cb_pages/the_legal_centre.php
 - Health Issues Centre: <http://www.healthissuescentre.org.au/>
 - The Victorian Mental Illness Awareness Council: <http://www.vmiac.com.au/>
 - The Health Complaints Commissioner: <http://www.healthcomplaints.tas.gov.au/>





BILL OF RIGHTS FOR PEOPLE WHO SELF-HARM

-by Deb Martinson

Deb Martinson is an American psychologist with an interest in self-harming practices. As far as we know, she's not a mental health consumer – this is not how she positions herself in relation to these issues – but she is a wonderful ally: her work deeply respects the lived experience of people who self-harm. Amongst other roles, she is the Chair Administrator of the American Self Harm Information Clearing House (ASHIC). This article is reprinted with permission.

Preamble

An estimated one percent of Americans use physical self-harm as a way of coping with stress; the rate of self-injury in other industrial nations is probably similar. Still, self-injury remains a taboo subject, a behavior that is considered freakish or outlandish and is highly stigmatized by medical professionals and the lay public alike. Self-harm, also called self-injury, self-inflicted violence, or self-mutilation, can be defined as self-inflicted physical harm severe enough to cause tissue damage or leave visible marks that do not fade within a few hours. Acts done for purposes of suicide or for ritual, sexual, or ornamentation purposes are not considered self-injury. This document refers to what is commonly known as moderate or superficial self-injury, particularly repetitive SI; these guidelines do not hold for cases of major self-mutilation (i.e., castration, eye enucleation, or amputation).

Because of the stigma and lack of readily available information about self-harm, people who resort to this method of coping often receive treatment from physicians (particularly in emergency rooms) and mental-health professionals that can actually make their lives worse instead of better. Based on hundreds of negative experiences reported by people who self-harm, the following Bill of Rights is an attempt to provide information to medical and mental-health personnel. The goal of this project is to enable them to more clearly understand the emotions that underlie self-injury and to respond to self-injurious behavior in a way that protects the patient as well as the practitioner.

The Bill of Rights for Those who Self-Harm

1. The right to caring, humane medical treatment.

Self-injurers should receive the same level and quality of care that a person presenting with an identical but accidental injury would receive. Procedures should be done as gently as they would be for others. If stitches are required, local anesthesia should be used. Treatment of accidental injury and self-inflicted injury should be identical.

2. The right to participate fully in decisions about emergency psychiatric treatment (so long as no one's life is in immediate danger).

When a person presents at the emergency room with a self-inflicted injury, his or her opinion about the need for a psychological assessment should be considered. If the person is not in obvious distress and is not suicidal, he or she should not be subjected to an arduous psych evaluation. Doctors should be trained to assess suicidality/homicidality and should realize that although referral for outpatient follow-up may be advisable, hospitalization for self-injurious behavior alone is rarely warranted.

3. The right to body privacy.

Visual examinations to determine the extent and frequency of self-inflicted injury should be performed only when absolutely necessary and done in a way that maintains the patient's dignity. Many who SI have been



abused; the humiliation of a strip-search is likely to increase the amount and intensity of future self-injury while making the person subject to the searches look for better ways to hide the marks.

4. *The right to have the feelings behind the SI validated.*

Self-injury doesn't occur in a vacuum. The person who self-injures usually does so in response to distressing feelings, and those feelings should be recognized and validated. Although the care provider might not understand why a particular situation is extremely upsetting, she or he can at least understand that it **is** distressing and respect the self-injurer's right to be upset about it.

5. *The right to disclose to whom they choose only what they choose.*

No care provider should disclose to others that injuries are self-inflicted without obtaining the permission of the person involved. Exceptions can be made in the case of team-based hospital treatment or other medical care providers when the information that the injuries were self-inflicted is essential knowledge for proper medical care. Patients should be notified when others are told about their SI and as always, gossiping about any patient is unprofessional.

6. *The right to choose what coping mechanisms they will use.*

No person should be forced to choose between self-injury and treatment. Outpatient therapists should never demand that clients sign a no-harm contract; instead, client and provider should develop a plan for dealing with self-injurious impulses and acts during the treatment. No client should feel they must lie about SI or be kicked out of outpatient therapy. Exceptions to this may be made in hospital or ER treatment, when a contract may be required by hospital legal policies.

7. *The right to have care providers who do not allow their feelings about SI to distort the therapy.*

Those who work with clients who self-injure should keep their own fear, revulsion, anger, and anxiety out of the therapeutic setting. This is crucial for basic medical care of self-inflicted wounds but holds for therapists as well. A person who is struggling with self-injury has enough baggage without taking on the prejudices and biases of their care providers.

8. *The right to have the role SI has played as a coping mechanism validated.*

No one should be shamed, admonished, or chastised for having self-injured. Self-injury works as a coping mechanism, sometimes for people who have no other way to cope. They may use SI as a last-ditch effort to avoid suicide. The self-injurer should be taught to honor the positive things that self-injury has done for him/her as well as to recognize that the negatives of SI far outweigh those positives and that it is possible to learn methods of coping that aren't as destructive and life-interfering.

9. *The right not to be automatically considered a dangerous person simply because of self-inflicted injury.*

No one should be put in restraints or locked in a treatment room in an emergency room solely because his or her injuries are self-inflicted. No one should ever be involuntarily committed simply because of SI; physicians should make the decision to commit based on the presence of psychosis, suicidality, or homicidality.

10. *The right to have self-injury regarded as an attempt to communicate, not manipulate.*

Most people who hurt themselves are trying to express things they can say in no other way. Although sometimes these attempts to communicate seem manipulative, treating them as manipulation only makes the situation worse. Providers should respect the communicative function of SI and assume it is not manipulative behavior until there is clear evidence to the contrary.



INTRODUCING ... *People Like You*

In this edition, Cameron Ralph introduces us to a consumer-run project specifically for young people, based west of Melbourne.

The People Like You – Foundation for young people affected by mental illness (People Like You) is a not-for-profit foundation that provides support, guidance and training to young people affected by mental illness. People Like You provides novel therapeutic activities such as wilderness therapy and horticulture, that allow young people to grow, rediscover their sense of self-worth and self-confidence whilst working toward recovery.

People Like You was founded by Cameron Ralph who was diagnosed with schizophrenia at 24. After 5 years of treatment Cameron took control of his life and his illness, and now, has been living medication and treatment free for over 3 years. The experience of living with and recovering from schizophrenia showed Cameron that the mental health sector was not catering to the needs of young people, hence, he launched People Like You.

The lived experience is paramount in everything that we do at People Like You and we are entirely recovery focused. We exist to provide innovative, appropriate and specific services for young people affected by mental illness in a positive learning environment. We believe that mental illness is treatable, it is curable and research clearly shows that when a person gets the right treatment, early, their outcomes improve significantly. The stigma attached to mental illness is still too prevalent and prevents many people from seeking the help they need.

Our main project, the fresh projects, is located on a 30-acre property on the outskirts of Melbourne. The property consists of an orchard, an organic market garden, free-range chickens and 30 acres of pure potential. From the property we have ongoing projects that run every Saturday as well shorter and more specific programs.

People Like You recovery training is very popular with mental health professionals and those living with a mental illness. Cameron is a PhD candidate at the University of Melbourne where his research focuses on stress physiology. The recovery sessions combine his personal experience of living with and recovering from schizophrenia, with his academic knowledge of mental illness, to deliver an insightful seminar. The sessions give participants a clear understanding of recovery and many skills that can facilitate the recovery journey.

People Like You also run mental health seminars for high school students where Cameron and various other people with lived experience of mental illness go into high schools to talk about mental illness with the aim of giving mental illness a face, a name and a personality. These sessions aim to reduce stigma and break down the stereotypes associated with mental illness.

People Like You invites everyone to join us at the fresh projects on Saturdays. For more information please visit – www.peoplelikeyou.org.au or email: Cameron@peoplelikeyou.org.au or see the People Like You Facebook group.





YOUR RESPONSES TO OUR PREVIOUS EDITION!

We get quite a bit of feedback here at OCP – ranging from glowing praise to mixed feelings to vehement disagreement! We are grateful for your feedback and recognise that challenging, respectful engagement is crucial to effective social change! We also encourage more contributions from YOU – we write a lot but want to include a diversity of voices from the consumer community. We consumers are such a mixed bag and we want to honour that! We hope that rather than “dividing our movement” (as is sometimes lamented), our passionate dialogues – often about difficult, complex issues in which we are deeply emotionally invested – will open up new spaces of exploration and relationship. ... Anyway, that’s a rambling way to introduce some of your responses to the most recent newsletter (all are responses to Flick Grey’s Soapbox in the last edition).

First up, we’re stoked that VicServ (the peak body for the PDRS sector in Victoria) are reprinting in full the soapbox in their upcoming edition of *New Paradigm*. Here are some emails we have received (reprinted with permission!)

“That was an especially excellent OCP newsletter. An excellent article on the lack of youth involvement in McGorry’s campaign. ...” -Piers Gooding (Masters candidate in Mental health law, Monash University, who describes himself as being “at the tail end of youth”)

“Just wanted to say how much I LOVED your soapbox piece. Great stuff!” - Heather (Youth Worker)

“Once again, thank you both so much - Loved it loved it loved it. I don’t realise how much I look forward to the next OCP newsletter until it appears in my email - then I jump straight to opening it up for a great read...I’m always so excited when the new edition comes out.

Flick - I could exactly hear your voice when I read your rave - such a wonderful gust of fresh air.”

-Cath Roper (Consumer Academic, University of Melbourne)

Response to Flick Grey’s ‘No revolution in youth mental health without young people leading it!’

-By Mairead Cardamone-Breen

I am writing in response to the article ‘No revolution in youth mental health without young people leading it!’ by Flick Grey, published in your August newsletter. Firstly, I 100% agree with Flick on the importance of consumer participation in youth mental health services. However, as a consumer who attended the First International Youth Mental Health Conference last month, I could not disagree more regarding consumer presence at this conference. I am glad to be a member of a youth advisory group for the mental health service which I was involved with as a teenager. I can happily report that not only are our opinions listened to at this service, but we are also regularly sought out to offer advice and consult with the “real experts”. Our group was contacted by conference conveners of the First International Youth Mental Health Conference, invited to attend (free of charge, I might add), and Headspace went out of their way to assist us in all possible ways to prepare for and be actively involved in the conference.

All four of us who attended gave either a personal reflection, sat on a panel discussion, co-chaired, or a combination of all of these roles, for streams including education and vocation, suicide prevention and early intervention. We also had a poster about our group on display. Throughout the conference we were made to feel incredibly welcome by all, and after each presentation were overwhelmed by the responses we received. Numerous audience members came to thank us for our valuable inputs and commented that hearing our stories had made the stream for them. Similarly, we could not have received a warmer welcome from the Headspace conference conveners, who supported us in every way possible over the 2 days, with



our own 'chill out' volunteer room, arrangements for transportation, and someone always around to check up that we were OK and having a good time. In fact, I only just received another Thank-You card in the mail! I am also glad to report, having actually attended the whole conference, that every stream I went to had a youth consumer involved in some way, and I'm sure that this was actually the case for more streams than not. In fact, I think the only presentations I saw without a consumer participant were the 'Youth Participation' streams, and this is because all of the presenters were actually youth participants at various services! I would also like to point out, on the comment that there was no youth leadership at the conference, that if you open the program you will see that the profile of the two Youth Co-Conveners appears in prime position second only to the welcome of Patrick McGorry himself. These two played an integral role in the conference, their presence was certainly felt, and it was recognised that the conference would not have been what it was without them.

The First International Youth Mental Health Conference has without a doubt been one of the highlights of my year so far. It was incredibly uplifting to see consumer voices being heard, and such a wonderful opportunity to speak to consumers from other services and share ideas on how we can all be involved in improving the mental health service for the next generation. I would like to extend a huge thank you to Headspace for inviting us to be involved, and it is a pity that you didn't attend Flick - I'm sure you would have been made most welcome!

Mairead Cardamone-Breen, Youth Advisory Group member, Austin CAMHS.

Dear Flick,

I am writing to you regarding your comments about youth participation at the International Youth Mental Health Conference in Melbourne (29-30 July).

At the International Youth Mental Health conference I was one of the youth participants speaking. I am 20 and a past and present consumer of youth mental health services. I am also an advisory member on the Austin Child and Adolescent services youth Advisory group. I felt that my youth participator team mates and I helped bring the youth voice to the conference bringing insights into my struggles and the struggles of those youth around me who have challenges with their mental health.

We (the youth participators) were called upon to give a personal reflection on the topic being discussed at the sessions. Some of us sat on the panels and others of us co-chair the sessions. When there were breaks people attending the conference took the liberty of asking us (youth participants) questions about our past and opinions of things. I was asked by members in the audience questions such as what was the turning point to my recovery, and what would you like to see changed in the mental health sector.

I was really pleased to be given such a chance to express myself in front of so many people. I felt that others that I was once like could be heard. The young people who at the moments that are going through a really tough time. I was wrapped with the amount of youth participation at the conference. The time in the volunteer room was my favourite because we were able to bounce ideas off each other. I think that the young people struggling with mental health issues were represented by the youth fantastically. I was thoroughly inspired by my fellow youth participators. Thanks also to the people that helped us, organising us and keeping us on track. Your efforts made it possible for all us young people to say our bits and help out.

Sincerely,
Elleni Lysikatos

Registration for Our Consumer Place 2010

Consumer Leadership Forum

10am - 4pm, Thursday October 14th 2010, Ross House – 247 Flinders Lane, Melbourne. FREE!

Please complete your details

Name

Org and job title (if applic)

Address

Email

Phone

Specify any specific needs (wheelchair access, dietary requirements, etc)

Any particular topics you would like to see covered?

Are you a member of Our Consumer Place? Y N

Would you like to become a member (it's free and you will receive our monthly newsletter) Y N

Registration

We would greatly appreciate **registration by Friday Oct 1st** for catering purposes. Please return your completed registration form:

- By post to Our Consumer Place 51 Stanley St, West Melbourne 3003
- OR by email to – service@ourconsumerplace.com.au
- OR by fax to – (03) 9326 6859