People diagnosed with 'mental illness' doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER NOVEMBER 2011

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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NEWS IN THE CONSUMER WORLD:

In recent editions of our newsletter, we haven't included that much news from the consumer world, so we're doing our best to make up for that in this edition with a bumper news section!

New $4 Million National Mental Health Consumer Peak Body Announced

In June, the Hon. Mark Butler, federal Minister for Mental Health announced that up to $4 Million will be provided to establish a new national mental health consumer peak body. For the first 2 years the new body will be auspiced by the Consumers Health Forum, then transition to management in its own right. Congratulations to mental health consumers across Australia who have advocated long and hard for the establishment of this new national mental health consumer peak body.

$4 million going into making psychiatric inpatient units safer for women

The Victorian government has announced that $4million will go into capital projects that will increase the safety of women in psych units. These might include women's only corridors, women's only spaces, lockable doors, etc. Congratulations especially to the Victorian Women and Mental Health Network's tireless work campaigning on this critical issue.

Outrageous abuses in Victorian public mental health system exposed

For the past few months now, Victorian newspapers have been filled with reports of terrible events in public mental hospitals, including 36 people under psychiatric care in hospitals dying in 'unnatural, unexpected or violent circumstances' between 2008 and 2010. For example, see:

- www.theage.com.au/victoria/deaths-in-mental-health-facilities-unexpected-unnatural-and-violent-20110902-1jqdg.html#ixzz1cyeZgK2V.
- Or, here is a more recent report – about a sexual assault and a cover up: www.theage.com.au/victoria/mental-health-service-accused-of-rape-coverup-20111106-1n21n.html#ixzz1cycRnoSk.

In addition to the horrors that people in distress are going through, the government's response has been woefully inadequate – launching an official enquiry led by Dr. Ruth Vine, the Chief Psychiatrist (ie hardly an independent review!). Dr Vine's communication on the matter so far has been defensive of the status quo.

The Australian Human Rights and Australian Mental Health Human Rights and Law Reform Coalition has been at the forefront of exposing and protesting against these travesties. Check out their website: http://light1000candles.org/index.php/about-us-amhhrlrc. They are also on Facebook.

AUSTRALIA AND NEW ZEALAND
MENTAL HEALTH SERVICE

Achievement
Award
2011

Consumer Research and Evaluation Unit

Victorian Mental Illness Awareness Council

have been awarded the

Gold

Congratulations to the CREU

Congratulations to the Victorian Mental Illness Awareness Council's *Consumer Research and Evaluation Unit* which won an award at The Mental Health Services Conference in September. For more information, read the article about them on page 12.

Minister for Mental Health's Award short listing

Congratulations to Vrinda Edan and the team at the Consumer and Carer Relations Team at Southern Health for being shortlisted for the Minister for Mental Health's Award for enabling person & family-centred mental healthcare. We hope they win!!

Voices conference, 2012

Do you hear Voices? Do you care for or work with people who hear voices, see visions or have other unusual experiences? You are not alone. Hearing voices is a common human experience.

Do you want to learn more about creative and innovative ways to manage distressing voices? Or understand how different Indigenous cultures view these experiences? Or hear personal stories of transformation and recovery? Then you need to be at the Voices Vic 2012 Conference: "*Voices, Conversations and Transformations – Diverse Approaches to Recovery*".

The conference is being held at Storey Hall (RMIT University) in central Melbourne (easily accessible by public transport) on Thursday 23rd and Friday 24th February 2012. Bookings can be made online at **www.voicesvic.org.au** where there is also further information about our speakers, venue information and the conference flyer. It is worth noting that 3 of the 4 key note speakers, Ron Coleman, Eleanor Longden and Debra Lampshire, all have a lived experience of hearing voices. In different ways they have each managed to turn their lives around. We are also delighted to present Dr Lewis Mehl-Madrona, a Native American psychiatrist who specialises in working with Indigenous communities. Other themes will include narrative therapy, how to run a hearing voices group, voice dialoguing, carers' perspectives, music, laughter and MUCH more! So whether you're a consumer, a carer, a peer worker, a mental health professional or just someone who cares about how our society treats people with mental health issues – this is an event not to be missed!

Heavily discounted registration is available to people with a Centrelink Pension or Health Care Card, and an early bird discount applies to all registrations up until December 16th, so check out our website and book your place at this unique event today!

Need a good laugh?

If you haven't yet experienced Allie Brosh's wonderful cartoon blog *Hyperbole and a half*, now might be the time. Her most recent creation is about her experience of depression – but it's like nothing you've ever read before – refreshingly honest, quirky and profound in a way that cartoons do so well: http://hyperboleandahalf.blogspot.com/2011/10/adventures-in-depression.html

Doutta Galla video training

Penguin Artists in partnership in Doutta Galla Community Mental Health Services and Open Channel, a training organisation in film and television are running a video course for people with a lived experience of mental illness with a demonstrated interest in video.

Some places are still available. If you are interested call: Peter Lane, Co Convenor Penguin Artists, on mobile 0407 117 737.

Larissa's always-inspiring world of Art!

Congratulations to Larissa MacFarlane, a prodigious artist working in several different media. Her consistently high-quality art never ceases to amaze! One of her most recent creations is a 3-minute film called *The Point of the Handstand* and was runner up in a small film festival called "Mindscapes." It can be viewed on YouTube at: www.youtube.com/watch?v=Xjh-KSTm4IQ.

Stigma forum in Brisbane

At the beginning of Mental Health Week (Oct 10th- 14th), a forum was held in Brisbane to discuss anti-stigma campaigns. While there was a lamentable lack of consumer-perspective (or so we hear on the grapevine), an important contribution was made by Professor Patrick Corrigan from the Illinois Institute of Technology. He stresses the importance of interpersonal contact in changing attitudes – “Education’s the idea that if the public knows that mental illness is a brain disorder, a genetic disorder, they’ll stop stigmatising it, and most of the research shows that's not true,” he told AAP. “Contact, meeting people with mental illness tends to have the biggest impact.”

Meeting an average person with a mental illness was more important than hearing about a celebrity with the condition, he said. “A lot of famous people have come out, which is OK...but somebody you work with, or somebody you live next to, or go to church with, talking about their depression has a huge effect.” (Source: AAP)

What do we want? Bring on a Like Minds Like Mine-style approach – http://www.likeminds.org.nz – embarrassing as it is to admit, NZ’s approach to reducing discrimination and “stigma” is brilliant!

Don't let the Government ‘wind back’ the Vic Charter of Human Rights

The *Charter of Human Rights and Responsibilities Act 2006* (Vic) is currently under review by the Victorian Government. It is designed to protect the human rights of all Victorians, including mental health consumers, and has been operating effectively in Victoria for the past four years. It promotes fairer outcomes by encouraging the Government to consider human rights when it develops laws and policies, and ensuring that public authorities like public mental health services act consistently with consumers’ human rights.

The Victorian Government is considering winding back this critical human rights instrument. The Mental Health Legal Centre (MHLC) believes the Charter is an important tool for consumers and so winding back the Charter will have a negative impact on their rights. If you agree, please sign our CONSUMER PETITION calling on the Victorian Government not to 'wind back' the Charter:

- Go to the MHLC’s website: www.communitylaw.org.au/mhlc/cb_pages/the_legal_centre.php
- Download and print off MHLC's Fact sheet and petition;
- Sign the petition together with your name and Victorian street address (no PO Boxes) and post the original (no photocopies) to **Fiona Seymour, Mental Health Legal Centre, 9th floor 10-16 Queen St, Melbourne, 3000 by Monday 14 November 2011.**
- MHLC will present the petition to Parliament on behalf of Victorians who experience mental health issues.

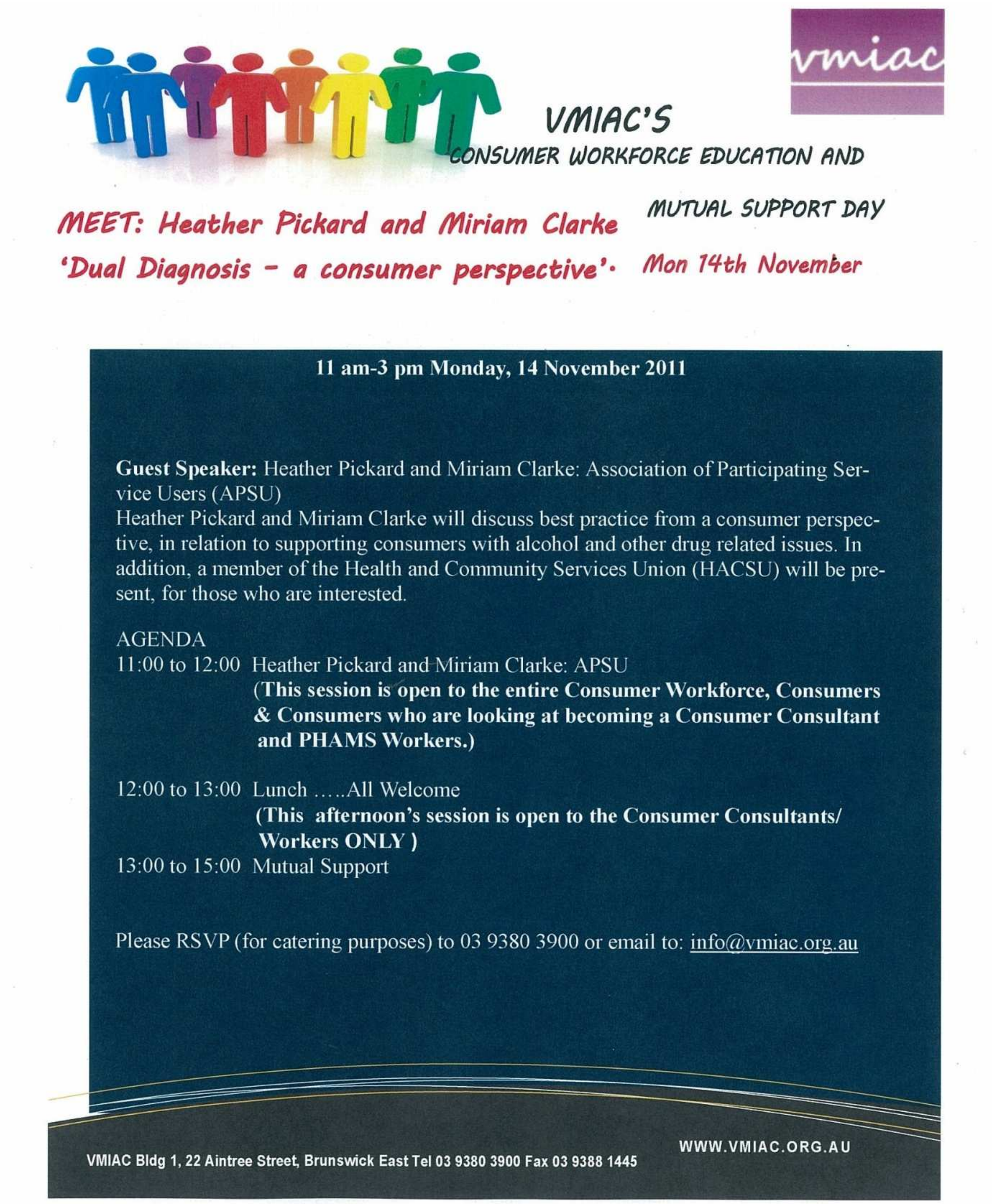
How else can you take action?

- Share this information with other mental health consumers who may be interested. You can gather as many or as few signatures as you like & send the petition sheet(s) back to MHLC;
- Contact your local MP or the Minister for Mental Health, Mary Wooldridge MP and urge them not to 'wind back' the Charter.

Further information about the Charter and the Revies: go to the MHLC’s website, or contact Catherine Leslie at the MHLC tel: (03) 9629 4422.

VMIAC's Consumer workforce Education and Mutual Support Days

Are you a consumer worker? If you aren't yet connected in with the Consumer Workforce Education and Mutual Support Days at the Victorian Mental Illness Awareness Council, then you might want to check out this next event and get more involved.



vmiac

VMIAC'S
CONSUMER WORKFORCE EDUCATION AND
MUTUAL SUPPORT DAY
Mon 14th November

MEET: Heather Pickard and Miriam Clarke
'Dual Diagnosis – a consumer perspective'.

11 am-3 pm Monday, 14 November 2011

Guest Speaker: Heather Pickard and Miriam Clarke: Association of Participating Service Users (APSU)
Heather Pickard and Miriam Clarke will discuss best practice from a consumer perspective, in relation to supporting consumers with alcohol and other drug related issues. In addition, a member of the Health and Community Services Union (HACSU) will be present, for those who are interested.

AGENDA
11:00 to 12:00 Heather Pickard and Miriam Clarke: APSU
(This session is open to the entire Consumer Workforce, Consumers & Consumers who are looking at becoming a Consumer Consultant and PHAMS Workers.)

12:00 to 13:00 Lunch …..All Welcome
(This afternoon's session is open to the Consumer Consultants/ Workers ONLY)
13:00 to 15:00 Mutual Support

Please RSVP (for catering purposes) to 03 9380 3900 or email to: info@vmiac.org.au

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WWW.VMIAC.ORG.AU

Singing the B-B-Bipolar Blues: Toothless Tigers

In this edition, the inimitable ***Ann Tullgren*** *untangles the complex links between poor dental health and mental illness. Ann is a regular contributor to Our Consumer Place's newsletter.*

They say we don't smile much: we're too mad/bad/sad. We distance ourselves from others, secluded by our in-the-corner lives. Or perhaps others want to distance themselves from us.

Have you noticed that the dominant model for explaining 'our problems' focuses on 'our mental illness'? In thinking of a way to describe this, I've adopted the metaphor of the solar system. In this representation the planets/constellations of our experiences – including exclusion, poverty, suffering, homelessness, loneliness – all revolve around this disordered centre, the black hole of our existence: mental illness. No matter what the problem/ experience, refer back to the centre for the explanation and solution. Problems are usually seen to exist because of the sticky dominance of the condition, or our non-compliance with treatment, or our lack of motivation.

> *Have you noticed that the dominant model for explaining 'our problems' focuses on 'our mental illness'?*

The orbiting planets of despair and otherness remain bound to the centre, which is described as mentally ill (the centre that explains all). Such totalising discourses become the dominant story about our existence. According to the logic, fix the disorder and the other things take care of themselves. Follow the treatment and get on with recovery.

In a similar way, the discourses surrounding recovery theory – by focusing on the individual, their mental illness, and their journeys of healing and transformation – obscure the necessity for structural reforms and the recovery of systems and of society, for the exercise of the full rights associated with citizenship.

I want to critique the dominant model by looking at the intersection of oral health and enduring mental health concerns. So, getting back to our solemn faces, the dominant discourse is about us being mad/bad/sad. But, perhaps there's another explanation; we don't smile much because as the muscles twitch and the lips part and the corners turn upwards into a smile what is revealed is teeth which are decayed or broken or missing, red and swollen gums, and bad breath.

What exactly is the problem and where are the solutions? Is mental illness the core problem, or is it how we exercise (or can't exercise) our human rights? How does oral health sit in relation to mental health? How is it positioned with respect to our rights as citizens? The answers lie in a very complex set of relations.

First, some context about oral health and enduring mental illness. Did you know that:

- The dental health of those of us with enduring mental illness is impaired?
- Oral disease is also linked to low socio-economic status? Most people with enduring mental health problems are poor and this poverty is pervasive and longstanding.
- We have worse oral health than our neighbours who come from a similar socio-economic backgrounds, but who do not have mental health concerns? We have more missing teeth, in fact we're 3 times more likely than them to have lost all our teeth?

While we know that diseased teeth and gums cause a lot of pain and suffering, what many don't appreciate is that oral disease, besides being closely linked to mental illness and to poverty, is also implicated in some major physical health problems. In turn, those physical illnesses impact on oral health and mental illness.

Some more evidence:

- Poor oral health can cause life-threatening systemic diseases such as coronary heart disease, stroke and respiratory disease. The bugs in our mouths can travel to other parts of the body via blood vessels, or are inhaled into sinuses and lungs; they can cause infection and clots.
- People with enduring mental illness have high rates of physical ill health, including diabetes, cardio-vascular disease, chronic lung disease and cancer. Much of this is undiagnosed and untreated.
- People with schizophrenia die 15-20 years younger than the general population. I suspect that this figure also extends to those of us with other enduring mental health conditions.
- While the cardiac health of general population has improved, this is not true for people with ongoing mental health concerns. Compared to 'normals', we have not benefited from community-wide heart health campaigns or the chronic disease management programs run by GPs and other health professionals. Indeed we have been left far behind.

Explaining our poor oral health

The reasons for our impaired oral health are many. Most of us cannot afford dental care. Our diets may be poor. The medications we take may make our mouths dry (saliva helps fight the bugs that cause oral disease). It can be difficult for us to get into the habits of flossing and brushing (when our worlds are imploding caring for teeth and gums can seem like an avoidable distraction). When we are distressed or unwell, our immune systems are compromised and we are more susceptible to abscesses and mouth infections. Our high rates of homelessness may mean that we lose our teeth cleaning gear or we don't have access to bathrooms and the privacy necessary to floss and brush. And of course smoking is also associated with poor oral hygiene.

Thus, our poor oral health is explained by a very complex web of facts and relationships. It doesn't exist purely because of mental illness

But there is something more. Many of us take new generation antipsychotic drugs and it is now well recognized that some of them are associated with a metabolic syndrome that leads us to develop diabetes, stroke and heart disease due to the effects of the medication on blood fats and sugar levels. This effect is separate from the weight gain so many of us also experience when we take these medications, weight gain that also leads to abnormalities with blood sugar and blood fats. Diabetes can make us more susceptible to infections, including those in our mouths.

Thus, our poor oral health is explained by a very complex web of facts and relationships. It doesn't exist purely because of mental illness; it is also because of the many socio-economic causes and consequences of lives blighted by exclusion and structural indifference. Big Pharma is implicated. The neat metaphor of the planetary solar system, although charming in its simplicity and imagery, cannot sustain either the explanations or possible solutions about the oral and physical health problems of consumers and survivors.

So, rather than thinking that the heart of the problem (no pun intended) is our mental illness, and that if this problem is managed/treated, the revolving planets of physical ill health, poor oral health, homelessness, poverty, etc will sort themselves out. We need to address the impediments to the just exercise of our human rights, our rights as citizens to be able to access dental care, health care and other social and economic resources in proportion to our need.

Medicare funding for dental care

(www.health.gov.au/internet/main/publishing.nsf/Content/Dental+Care+Services)

Are you aware that people with chronic diseases and complex care needs (that’s many of us), on referral from a GP, can access up to $4,250 in Medicare benefits for dental services over two consecutive calendar years?

> *It is being argued by the psychiatric great and good that our poor physical health is the most serious problem facing psychiatry today.*

I wonder how many of you know about or have been able to access this funding? I suspect the figures are quite low. Similarly, how many of you have chronic disease management plans with your GP, enabling you to access the services of podiatrists, dieticians, diabetes educators and other allied health services?

There are several possible explanations for this low take-up rate. Many of us don’t have a regular GP (or can’t afford one). Additionally, the primary focus on mental illness by many GPs and mental health service providers means that chronic illnesses such as oral disease, diabetes and vascular disease are under-diagnosed and under-treated (there’s good research to support this contention).

There’s an additional problem that concerns how various services and professionals work alongside us, and with each other, to diagnose and manage poor oral health, diabetes, heart disease, etc. Basically, they’re not too good at it. Many struggle to keep up to date about non-mental health programs and initiatives that might benefit their clients. But surely this is what holistic and personalized care is all about.

Where to from here?

It is being argued by the psychiatric great and good that our poor physical health is *the most serious problem facing psychiatry today.* Oral health is an important marker of our general health and well-being. Can I stop here and reframe the statement ‘this is the most serious problem facing psychiatry today? ***It is actually we consumers/ survivors who face this problem … we face it every day and have been doing so for a long time.*** It is time for action!

There’s been quite a bit in the media recently about Medicare-funded dental benefits. This is because the scheme has gone way over budget - there is no means testing, or careful targeting to ensure that the most needy can access this initiative. Legislation to close the scheme failed to get through parliament before the last federal election, and the government is reluctant to try this again. However, Federal Minister for Health Nicola Roxon is looking at how the scheme can be better targeted and a committee that reports to her, The Dental Advisory Group, is looking at how dental care of Australians can be improved.

A coalition of interested parties could effectively lobby government to ensure our better access to appropriate dental care. Dental care could make an enormous difference to our longevity, our health and well-being. But achieving real change could be stymied by the usual focus on the mental illness as the root cause of all ills. Reconstructing the dominant paradigm so that our human rights as citizens are placed centre-stage is critical. To use the metaphor of the solar system, placing citizenship at the heart of the issues that confront us, may well be able to help us achieve better outcomes.

So, when we toothless tigers sing the B-B-Bipolar Blues, it isn’t us who should feel ashamed about yet another marker of our difference and exclusion. Reduced life expectancy, pain, exclusion….GRRROWL…. sing high, sing low!

FEATURE ARTICLE: The Inaugural Australian Mental Health Commission

- Commentary by Merinda Epstein, Our Consumer Place.

Our Consumer Place would like to congratulate Allan Fels on his appointment as chair of Australia's first National Mental Health Commission.

Consumers have been some of the loudest lobbyists for the creation of an Australian Mental Health Commission as an overseeing body for mental health services in this country, a watchdog of service delivery and policy agency. One of the reasons for our enthusiasm has been our experience watching our comrades in New Zealand, especially during the early years of their commission. It was very obvious to us that much of the success of NZ's Commission was that one of the three inaugural commissioners was a consumer, Mary O'Hagan. Not only was Mary O'Hagan a passionate consumer, she was also talented, confident, able to mix it with anyone who came into her sights, a natural leader and a good bureaucrat. Her appointment was, we believe, the significant component which enabled New Zealand services (and consumer run services and programs) to become world leaders.

> *... one of the three inaugural commissioners was a consumer, Mary O'Hagan. ... Her appointment was, we believe, the significant component which enabled New Zealand services (and consumer run services and programs) to become world leaders.*

There are two important angles to approach this discussion from - one is a reflection and the other a challenge.

The reflection:

In 1993, under the first National Mental Health Strategy, consumers entered the national stage for the first time. Brian Howe, an excellent health Minister in the Keating Government, invested interest and money into forming the National Community Advisory Group in Mental Health (NCAG) made up entirely of consumers and carers. I sat on NCAG. The first chair was Trish Goddard, a consumer, a bit of a famous one. Later Leonie Manns, a consumer from Sydney, chaired NCAG.

Towards its end, NCAG was chaired by John McGrath, who later became the first chair of the new Mental Health Council of Australia (MHCA) in 1997. Before the formation of the MHCA, I remember the consumer members of NCAG imploring the then Health Minister, Michael Wooldridge, to rethink his decision to replace NCAG with the Mental Health Council. He assured us that the voices of consumers and carers would remain as strong as they were under NCAG. We knew this was not possible because there simply were not enough national consumer organisations to compete with what we knew would be a flood of non-consumer bodies keen to become members of this new organisation. We were right. With every new non-consumer organisation the consumer voice was diluted and this has kept happening at a rapid pace ever since. Long gone are the days when consumers had direct entré to the Minister by decree.

> *We had a hard time. No one was used to consumers sitting on influential boards and committees and many resented us having direct access to the Minister.*

What has happened since that time has been the growth of a gaping differential at the very highest level between the authority of consumers and the authority of carers. Although NCAG worked feverishly on the constitution of the new body to make sure a consumer would always sit on the Executive, the paucity of national consumer organisations has stilted this opportunity for authority. Although the Mental Health Council has it Consumer and Carer Forum http://www.nmhccf.org.au/ and its National Register of Mental Health Consumers and Carers http://www.mhca.org.au/the-national-register-of-mental-health-consumers-and-carers, these are relatively minor forces compared with the role of the Executive and, especially, the Chair. And although the new consumer network, auspiced by the Consumers' Health Forum, is in formation, there is one truly significant problem. This major problem is that every chair of the Mental Health Council of Australia since its inception in 1997 has been a male parent of an adult child with psychotic illness: 1997 – 2002 John McGrath; 2003 – 2005 Keith Wilson and 2006 – present Rob Knowls. Co-incidentally, or maybe not, they are also all ex-politicians.

This is the Challenge

Allan Fels has just been appointed chair of the newly formed Australian Mental Health Commission. In the fashion of the many chairs of the Mental Health Council who come before him, Allan Fels is the father of an adult child with psychotic illness. Nothing has changed. The same silences will be perpetuated and the same biases inculcated into the new commission unless pressure is applied and applied quickly to make sure the other commissioners are appointed with wisdom.

If we go back to the highly successful New Zealand model, we have a picture of three commissioners with one a highly respected consumer. This is the model that we have been lobbying for. It seems obvious then that for the consumer voice to be heard in an appropriate way, *when there are 9 commissioners to be appointed then 3 of them should be strong, highly respected, high calibre consumers from within the consumer movement.* Without this we fear that what the Government will be creating is yet another organisation biased in all the same ways, forcing the least powerful voice to either become compliant or shrill in order to be heard.

> *In the fashion of the many chairs of the Mental Health Council who come before him, Allan Fels is the father of an adult child with psychotic illness.*

We want this Commission to work. Australia needs a watchdog Commission even if (unlike New Zealand) it is severely complicated by the fact we have a Federation of States and there will be many jurisdictions where the Commission may be powerless.

We want this Commission to work in Australia even if (unlike New Zealand) we have a powerful, publicly funded, private sector over which the Commission might find contested jurisdictions.

We don't want the Commission hijacked by Big Pharma, big NGO (non-government organisation) lobby groups, big names in psychiatry like Hickie, Mendoza and McGorry or dominated by carer or psychosis-specific concerns, or depression-specific concerns.

What we want more than anything else is to learn from the structure of the New Zealand Mental Health Commission, including their Maori inclusiveness and the embedding of consumer leadership. We want a properly thought through Commission with the right mix of Commissioners – one that will truly make a difference.

INTRODUCING … *The Consumer Research and Evaluation Unit of the Victorian Mental Illness Awareness Council*

In this edition, Lei Ning writes about VMIAC's award-winning Consumer Research and Evaluation Unit. We congratulate the team for their recent award and hope they inspire the expansion of more consumer-developed research!

The Consumer Research and Evaluation Unit of the Victorian Mental Illness Awareness Council received the Gold Achievement Award presented by the Federal Minister of Mental Health, the Hon. Mark Butler, at The Mental Health Services Conference held in Adelaide in September of 2011.

The CREU represents a unique consumer created and led research team. The CREU has a team of skilled personnel with experience in research and evaluation techniques with their greatest strength being derived from their lived experience. The CREU advocates for consumer research as an emerging field where research is initiated, designed, controlled, and conducted by consumers whereby new methodologies and approaches are developed from a consumer perspective. Rights based, grass roots consumer philosophy underlies CREU activities and seeks to add a different and complementary approach to research in the mental health sector. The CREU was established in 2006 with the commencement of a collaborative project – MH ECO (Mental Health Experience Co-design). MH ECO has become a national flagship initiative in mental health service quality improvement (http://mheco.org.au).

MH ECO is based on the recommendations of the Review of the 2003—2004 Victorian surveys of consumer and carer experience of public mental health services. The Initiative moved away from rating the satisfaction of consumers and carers to eliciting their experiences. The satisfaction rating had minimal impact on service quality improvement, whereas consumer and carer experience of mental health services provides concrete evidence that can be readily translated into meaningful service quality improvement activities. One of the main characteristics of the Initiative is that it represents an effective model of high level consumer and carer participation with the primary researchers themselves having the lived experience as consumers and carers. While gathering experiences of consumers and carers is the first step, using this information to improve mental health services is the fundamental focus of the Initiative.
MH ECO applies the most recent theory and practice of Experience-Based Design in health service quality improvement. The core of this approach involves engaging consumers, carers and service providers to actively work together to co-design the services with a strong commitment to change and improvement.

The CREU represents consumer views and perspectives at many national and state mental health committees and has undertaken a number of national and state-wide research projects which have contributed to the Victoria and national mental health system reform and improvement.

> *The CREU advocates for consumer research as an emerging field where research is initiated, designed, controlled, and conducted by consumers whereby new methodologies and approaches are developed from a consumer perspective.*

Contact Person: Mr Lei Ning, Building 1 / 22 Aintree Street, Brunswick East 3057; Phone: 03 9380 3900, Email: lei.ning@vmiac.org.au

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

Here at Our Consumer Place, we have been chugging along quietly, business as usual. Or rather, busy-ness as usual! There is always more to do than we could possibly fit in.

STOP PRESS Consumers as Educators forum

If you have not yet registered for this one-day forum THIS FRIDAY, it's not too late!
DETAILS: Friday November 11th, 9am-5pm at Karstens, Level 12, 123 Queen St, Melbourne.
COST: Sliding scale, from $145 for non-consumers with funding, to free for unwaged consumers.
HOW CAN I REGISTER? To register, either download a registration form from our website (www.ourconsumerplace.com.au/trainingevents) or call us on (03) 9320 6802 OR (03) 9320 6839.
We prefer people to pre-register, but if you haven't had the chance to register, please come anyway!

Melbourne Free University events

Our Consumer Place has teamed with the Melbourne Free University to present a series in Oct/Nov on "The politics of Madness: Listening to lived experience." See page 20 for full details.

Publications

Our newest booklet "Speaking Our Minds: A guide to how we use our stories" is moving like hotcakes (whatever a "hotcake" is!). A hard-copy can be posted to consumers in Victoria for free (sorry interstate consumers, our funding is for Victoria). Anyone can download it for free from our website: www.ourconsumerplace.com.au/resources. Hard copies can also be purchased for $10 each (also through the website). Merinda will be hosting workshops on the topic of storytelling from early 2012 (see below). We also have several other publications coming out soon, so stay posted!

TWO WORKSHOPS ON USING STORY

CONVENOR: Merinda Epstein

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

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

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

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

Thursday 9th February; and **Tuesday 14th February 2012.**

There will be opportunities to participate in **collective storytelling**, to listen to **different techniques**, to **practice your own stories**, to **perform** in a safe environment and to utilise experiences quite outside mental health to bring home messages for clinicians and the community.

The workshops are relevant both to **people who want to gain confidence in** telling their own story living with 'mental illness' and for people who want to use story as a technique but who want to stay well away from their own personal experiences of 'illness' and services.

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.

Borderline Personality Disorder Conference:

One of our main priorities for October was to provide consumer leadership for the inaugural Borderline Personality Disorder (BPD) Awareness Day (Oct 5th). Merinda has decades of experience and expertise from working at local, national and international levels, providing consumer perspective on this complex and controversial diagnosis (we both prefer "Complex Post-Traumatic Stress Disorder" but that's another story ...). And Flick's PhD is on such "Awareness-raising" activities (she calls this "benevolent othering") and she is especially interested in BPD as one of the most challenging diagnoses to ideas about what "stigma" means, and what we might need to change practices and attitudes.

Flick's talk on the day is in this newsletter (p.15), and the power point presentation for Merinda's keynote is on our website (www.ourconsumerplace.com.au/resources) We believe that this is one of the most neglected diagnostic groups – not that we generally like to engage in comparing or in using diagnoses as our basis for engagement, but when there is such silence, vitriol and neglect, we thought it worth our while to provide some consumer leadership!

We are intending to bring together consumer leaders to discuss the situation for people with a BPD label, possibly drawing on the model pioneered by Hearing Voices. If you are interested, please contact us at: service@ourconsumerplace.com.au.

Other OCP activities:

We've been consulting with many consumer-run projects, consumer groups and consumer workers. This work is guided by both need and demand, with priority always given to initiatives where consumers are completely in control from conception through all stages. Our job is to strengthen consumer-developed initiatives, so get in touch if you would like support!

Flick attended the WONDERFUL "More than Medications: Critical conversations about medication, mental health and recovery" conference in Canberra, organised by *inside out* – hopefully there will be a report back from this in the next edition of the newsletter.

And finally, our website has been expanding lately, so if you haven't been on it for a while, check it out. There are new cartoons from Merinda, recent presentations by OCP staff, and new resources in the Clearinghouse. It is such a pleasure to be able to share these with our community.

HOW CAN WE TALK ABOUT THIS?

This is Flick Grey's talk which opened the inaugural Borderline Personality Disorder Awareness Day, October 5th, 2011. It has been printed due to numerous requests that it be made available. Flick and Merinda were both involved in conceptualising and organising the BPD Awareness Day and Merinda was a keynote speaker. Both these talks are available on our website: www.ourconsumerplace.com.au/resources. Flick's brief was to lay foundations for conversations on the day – recognising the different positions in the room and encouraging honest engagement with difficult issues.

Hi, my name is Flick Grey. My role here today is to open up our thinking and enable deeper conversation around this challenging and controversial diagnosis. If we are to truly "raise community understanding," we have some difficult dialogues ahead.

To do this, I'm going to start with some of my own lived experience. I was labelled with Borderline Personality Disorder in 2005. Now, I'm not going to tell you a story about how back then, I was suffering immensely and behaving in inexplicable and challenging ways, but then I got properly diagnosed, linked into appropriate treatment, co-operated (of course, because co-operation is *so* important) and am now in recovery, living a better life, and grateful for the interventions I received.

> *If we are to truly "raise community understanding," we have some difficult dialogues ahead.*

That would be too comfortable a story and it's not my truth. In fact, it's light years from my lived experience. My truth is far messier and painful – for everyone involved. My truth sings of constant emotional pain and shame and blame and suffering and inarticulable traumas, invalidation and neglect and judgement and confusion. And wading in deep shame, wading through shame. And grappling, constant grappling.

I'm also not going to indulge any voyeuristic tendencies, by displaying just how "severe and disabling" my experiences have been, how "sick" I was, or how "serious" my Borderline experiences were (or are?), how traumatic my childhood was (or wasn't?), how "real" my suicide attempts were, or how "shocking" my self-harm. Just trust me, I can be extremely messy ... and extremely competent, often both simultaneously. This is part of the paradox of Borderline, and it does make it challenging to get our heads around.

But I'm not here as a harbinger of doom and despair. At least not today. That comes and goes.

> *I can say that almost everything I read about Borderline after I got the diagnosis was horrific to read.*

I can say that almost everything I read about Borderline after I got the diagnosis was horrific to read. I read everything from textbooks to pop-psychology, current journal articles to "anti-stigma" materials from all the mental health charities.

It wasn't until I came across the work of Merinda Epstein that I found non-shaming explanations of my distress, explanations that didn't objectify me, deeply invalidate me, blame me and shame me. And later I read Kiera van Gelder's wonderful book "The Buddha and the Borderline." Soul food for me.

Borderline is what I call “someone else’s diagnosis.” It’s not MINE; it’s an account of my experiences from someone else’s perspective. It colonises my experience but actually says more about *your* experiences than mine. Gunderson has called it “collective counter-transference.”

Borderline is what I call “someone else’s diagnosis.” It’s not MINE; it’s an account of my experiences from someone else’s perspective.

Has the BPD diagnosis been helpful to me? Yes and no. It has certainly politicised me!

As an *observation* of patterns of my behaviour, it was a revelation.

As an *explanation* of my pain and shame, it hasn’t been that useful: developmental trauma, neglect and invalidation are better explanations for me.

As a *tool* to guide service provision and supports, it has been worse than unhelpful. It has been used to blame me, exclude me, neglect me, and shame me. In other words, it has been re-traumatising.

But, my experiences with borderline have opened up new and profound spaces. Borders are always uncomfortable and productive spaces. Why else do we talk so fervently in this country of “border protection” as if a handful of desperate people at the borders could possibly threaten our national security. I suggest to you that Borderline – like all borders – is rich and intriguing, and that it shines a light on much broader tensions in our mental health system, in our own emotional lives and in our communities. There’s a beauty in that complexity that I want to hold. I refuse to simplify the paradoxical truths I hold in my body so that other people can feel comfortable and hopeful.

So, today, I want to speak of discomfort, and its value. If you go away with nothing else from today, I hope you reconnect with and value your own discomfort and what it is telling you. If you come away from today feeling relaxed and comfortably hopeful, then I’m afraid you’re not listening deeply enough, or thinking critically enough. *And you will be part of the problem.* You would probably have stopped listening to that little voice in your own body that whispers that all is not well. I ask you to try to listen to and honour that voice inside you.

And don’t misunderstand my tears. I value this exquisite sensitivity of mine. It’s a gift of Borderline.

If I hear one more “expert by training” publicly declare that we have all the answers in mental health, we just need bucket loads more money, I think I will cry. Honestly. And don’t misunderstand my tears. I value this exquisite sensitivity of mine. It’s a gift of Borderline.

I yearn for spaces where we can hold the totality of our lived experiences, in all their various shapes and sensations. I’m sharing my truth with you, and I hope you will share yours. And that’s what I hope for us all today, that we can honour our true, lived experiences, in as much complexity as we can hold.

All too often when the topic is Borderline Personality Disorder, our defences come up. The main one that I witness is silence, a deafening cultural silence.

Another is blaming someone else. “I don’t know what to do in this situation, so it must be his fault” or “it must be her fault.” ***We all do this.***

So, for example, we may be a service provider at our wit's end, trying to support someone who repeatedly self-harms. Our tool kit feels inadequate. And so we blame them and call them "manipulative," "attention seeking," "splitting," "not serious" or "engaged in a power struggle."

Or we may be a partner or a parent struggling with someone whose behaviour is at times challenging, maybe even abusive, and we don't know where our own boundaries lie, or should lie. Or maybe we feel guilty that we genuinely don't know how to really support this person we love. So we learn to blame them. Maybe, we read pop-psychology books like "Stop walking on Eggshells" or "I hate you, don't leave me" which blame those of us with this label and refuse to see these problems as relational and profoundly complex, deeply human and meaningful.

> *... when we seek attention in our shame and distress, we may be insulted and humiliated over here, locked up and traumatised over there or turned away, ignored or neglected. And we too learn to blame others.*

Or we may be someone who has been diagnosed with this disorder, struggling to receive support in our healing journey: when we seek attention in our shame and distress, we may be insulted and humiliated over here, locked up and traumatised over there or turned away, ignored or neglected. And we too learn to blame others.

We feel a need to defend ourselves from the painful bits and so we use our various defence mechanisms. Today, I ask that we try to sit with discomforts instead.

To the mental health workers here, I ask that you stay open to hearing how the language and conceptual tools you use to understand us may be experienced as shaming. That even when you work hard, in good faith and with thoughtfulness, you may be unwittingly doing harm. Despite the value of your learning, you may have much to unlearn too. Please accept such feedback as a gift, even if it's sometimes wrapped in shit.

To the families in the room, please be open to hearing about our experiences of trauma, abuse, neglect and less than nurturing childhoods. Having our experiences invalidated can be the most harmful experience. But I know it can be hard to hear. And, again, it's often wrapped in shit.

To the consumers in the room, people with lived experience of being labelled as "Borderline," please try to stay open to hearing uncomfortable facts-as-experienced-by-others, that sometimes we do react in ways that are difficult to be around, that our sensitivities can be challenging to hold, and that we too can drive those around us a bit mad.

Today may well be challenging, indeed if it isn't, I don't think we'd be doing our job properly. There are people you can seek support or debriefing from, should you need that. If you want support, please approach the Spectrum table and they can discuss the options with you. There are professionals, consumers and carers who have put their hands up for this role.

> *Just for today, I ask that we all keep listening to those little voices inside, honouring our lived experience, and holding the complexity that is Borderline and resist the temptation to settle for less than our deepest truth.*

Just for today, I ask that we all keep listening to those little voices inside, honouring our lived experience, and holding the complexity that is Borderline and resist the temptation to settle for less than our deepest truth.

One of the most healing paths I have explored is spoken word poetry, for this medium is expansive enough to hold my multiple truths. Here's one I prepared earlier.

Strange and beautiful things grow

Strange and beautiful things grow where there has been a pond of tears
I water them with a watering can.

Strange and beautiful things grow where there has been a heaping
of shit and blood and sweat and tears.
With constant churning, deep inhalation and the passing of time,
abjection nourishes new growth.
Some clumps don't soften, remain hard.
Strange, beauty, growing.

Strangely, beautiful things blossom where there has been a withering
an apparent paralysis and closing down,
breaking down,
life withdrawal.
In darkness, spirit stirs.

And
where there has been gnawing, sharpness of blades,
blood and guts spilling out, boundaries breached ...
strange and unruly beauty grows.

Strange and beautiful things even grow
in harsh, arid desolation,
in fetid decay,
in neglected wastelands,
in the crevices of desecration.

Strangely familiar beauty grows
where there has been a convocation of erudite sophistication
and life's yearnings.

For it is in quietness that we grow
and in stirring
in neglect,
in joy-pain,
in tenderness,
when whole limbs are hacked off,
we grow.

Strange and beautiful things grow.

THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** to Heidi Everett whose beautiful singing made the official Launch of Mental Health Week in Victoria bearable (it was otherwise terribly bureaucratic).
2. **THUMBS UP:** to Cath Roper and Vrinda Edan's *wonderful* recently published journal article about the ethical dilemma of patient involvement in health care decisions when people are under the Mental Health Act – "Autonomy in Jeopardy: Contrasting Participatory Health Models with Patient Decision Making Under Mental Health Law" *Journal of Participatory Medicine* 2011 Sept 12 3:e41. How wonderful it is when consumer thinking gets recognition (and can be cited)!
3. **THUMBS DOWN:** to the constitution of the Mental Health Council of Australia (MHCA) which obliges all member organisations to be national bodies. By their very nature, consumer organisations/groups tend to be smaller scale, grass roots, smaller budget entities and we are effectively excluded from membership by the very nature of who we are.
4. **THUMBS UP**: to Mind's upcoming new newsletter ("Write Mind"), produced entirely by consumers, which includes some great contributions and an interview with the gorgeous and talented Heidi Everett. Congrats especially to Sally Fisher for her editorial role. (We've had a sneak peek).
5. **THUMBS DOWN:** to Jeff Kennett's outrageous and vilifying comments that straight marriages are the best environment for raising children. Thumbs down also to Beyond Blue for failing to censure him for these comments. Homophobia has such clear links to mental distress!
6. **THUMBS UP:** to the NSW Education Centre Against Violence who run training on "Implementing sexual safety in mental health inpatient units" alongside training in domestic violence counselling, violence against women in refugee communities and Aboriginal Specialist Trauma Counselling. All too often, the broader community assume that inpatient units are havens of safety, which – appallingly – they are not.
7. **THUMBS DOWN:** to The Inaugural Forum for Suicide Prevention Policy in Australia 2011 for having NO visible presence of consumers or suicide survivors (people who have attempted suicide and survived – for example, Victoria's own Dr David Webb who wrote the world's first PhD on suicide by a suicide survivor). And just to make sure we couldn't be there in any critical mass, participation in the (full) conference cost nearly $2000 with NO subsidised places for consumers. How can these crucial conversations be had about us without us??
8. **THUMBS DOWN:** to the lack of presence of consumer perspectives at the "Mental Health Stigma Summit" held recently in Brisbane. Without being fully grounded in consumer perspectives on what stigma actually is, *in deep thinking about what "the problems" actually are*, "anti-stigma" campaigns will keep labelling and medicalizing our experiences. They also tend to presume that the point of such work is to increase "help seeking" behaviour – specifically "expert," medically-oriented, help. We think this is deeply simplistic and in many ways counter-productive.
9. **THUMBS DOWN:** to elitist Research and Ethics Committees made up of people who have no background in, no understanding of and no recognition of their ignorance around consumer-informed, small-scale research ethics and methods.
10. **THUMBS UP:** to Yoland Wadsworth who during the famous Understanding & Involvement (U&I) consumer evaluation of acute psychiatric hospital practice created a Project Ethics Committee which had the following members: a patient of a psychiatrist, a client of a lawyer, 2 very important lay consumers, and a parishioner of a Priest.

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THE POLITICS OF MADNESS:
Listening to lived experience

This series will discuss mental distress/madness from the perspective of people with lived experience. The voices of other experts have been dominating community understanding of "mental health"– this is a chance to engage differently.

SESSION 1:
Introduction to Intentional Peer Support (IPS)

DATE AND TIME: Saturday 29 October, 10.30am-12.30pm

VENUE: The Railway Neighbourhood House, 20 Solly Ave, Nth Carlton.

How do you support someone going through intense emotional distress or acting in ways that you find confusing, distressing or mad? This introduction to IPS is trauma-informed, non-coercive, honest, transformative and practical.

FACILITATORS: Flick Grey and Merinda Epstein, Our Consumer Place

SESSION 2:
Madness in the Academy

DATE AND TIME: Wednesday 16 November, 6.30-8pm

VENUE: Red Wheelbarrow Bookshop, 105 Lygon St Brunswick East

This session will explore how universities are taking up, or not, the impressive intellectual work of people with lived experience of madness.

SPEAKERS: Cath Roper (mad academic, Melbourne Uni), Merinda Epstein (Our Consumer Place), and Flick Grey (Our Consumer Place)

SESSION 3:
What do we want from the mental health system?

DATE AND TIME: Tuesday 29 November, 6.30-8pm

VENUE: Dexter bar/cafe, 123 Queens Pde, Clifton Hill

This session will explore what people who have used the mental health system think and want. The mental health system is grounded in coercion and paternalism, but these three leaders are at the forefront of the winds of change.

SPEAKERS: Merinda Epstein (Our Consumer Place), Indigo Daya (Voices Vic and Smoking Mad) and Heidi Everett (Psych Ward Support)

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