



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

**OUR CONSUMER PLACE
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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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This month's newsletter is a bumper edition, for no particular reason except perhaps that it's later coming out than usual (due to the Easter Break), so there was more time for submissions to slip in! It is such a pleasure to share this edition with you – more so than usual even. Enjoy!



Kiera van Gelder reflects on what “the mental health consumer movement” is up to ...

Recently, Merinda Epstein interviewed Kiera van Gelder, the American author of the wonderful book “*The Buddha and the Borderline: My Recovery from Borderline Personality Disorder through Dialectical Behavior Therapy, Buddhism & Online Dating.*” The interview began with the set of questions we usually ask interviewees. But then the conversation went in a different direction – Kiera’s answer to the first question was so beautiful (and extended) that we’ve included it by itself, as a soapbox.

Merinda Epstein: How would you describe what consumers/ psych survivors/ madfolk are doing - changing systems and/or the world? And where does your own work fit into this?

Kiera van Gelder: I take a broad view of what can be termed the “consumer movement” and what is being done. On one level it consists of psychiatric “patients”, historically silenced and marginalized, taking an active role in our own treatment as well re-configuring traditional power structures. I love the maxim, “Nothing about us without us,” which I first heard from the Massachusetts-based peer advocacy organization M-POWER. Their work focuses on rights such as inclusion, peer support, self-determination, informed consent, even access to fresh air - things that we easily grant to medical patients but not to those identified as “mentally ill.” In this sense I consider the work to be a civil rights movement.

... the founders of Alcoholics Anonymous were “consumers” and when the medical and psychiatric fields couldn’t help them, they learned to help each other, with spectacular results.

Another level, and equally important, is that psych survivors are creating treatment and recovery practices that, in a historical perspective, will make the work of non-consumer’s look primitive. We have to remember, for instance, that the founders of Alcoholics Anonymous were “consumers” and when the medical and psychiatric fields couldn’t help them, they learned to help each other, with spectacular results. A more contemporary example of a service-user establishing a peer treatment is Mary Ellen Copeland’s Wellness Recovery Action Plan (WRAP). She is an American social worker who developed the WRAP after her own hospitalization and treatment impressed on her the need for an approach that was focused on wellness and relapse prevention rather than acute care and crisis management. This program is being taught consumer-to-consumer and receives national funding [in America].

Another impressive example of a psych survivor’s work is that of Dr. Marsha Linehan, who responded to the lack of effective treatment for her symptoms (borderline personality disorder) by creating a new therapy (Dialectical Behavior Therapy). Unlike Copeland and the AA founders, Linehan did not publicly self-identify with other patients while creating and implementing DBT, nor did she set up the practice in a traditional peer support format, which might lead people to think that DBT, while a valuable therapy, cannot be considered as consumer driven. I’d argue that it is, and that even while Dr. Linehan doesn’t identify with a

... psych survivors are creating treatment and recovery practices that, in a historical perspective, will make the work of non-consumer’s look primitive.

recovery movement herself, her personal experience of suffering from psychiatric symptoms allowed her to find solutions no one else could.

Another level of consumer work, and one that I consider myself to be most involved with, is creative expression of recovery through story, narrative and testimonial. Like the above, not everyone who

Art, self-expression and personal testimony break the silence clinical objectification and cultural shaming perpetuate on those with mental illness. If we lack voices, others will talk for us and about us.

does this work identifies as part of a “movement” nor frames it within an illness or recovery model, but this work is an essential component because. Art, self-expression and personal testimony break the silence clinical objectification and cultural shaming perpetuate on those with mental illness. If we lack voices, others will talk for us and about us. When we don’t tell our stories, we also fail to map out for ourselves and each other where we’ve been, where we are, and where we can go--all three processes critical to recovery and

healing. This is the premise of the twelve step approach. Before founders Bill W. and Doctor Bob formalized the AA community or established the now ubiquitous Twelve Steps, their work was narrative. They went from one hospital bed to another, telling their stories to other sufferers. It was simply one alcoholic sharing with another “experience, strength and hope.”

As a writer and as someone who spent a decade in twelve step communities, I had a strong belief in the value of shared stories, and it was a lot like Alice falling down the rabbit hole when I discovered that both within and outside of the consumer movement, I was not helping myself by sharing about my most debilitating diagnosis, borderline personality disorder. It was also almost impossible to get legitimate information about it, and there were no recovery stories. As soon as I understood this situation, I wanted to do something about it. It seemed natural I should return to my roots and begin to help others with BPD through sharing. But on a more practical level, this was not like going to a meeting. Given my emotional makeup and “borderline” vulnerabilities, public exposure always feels like being flayed. I tell people you have to be a masochist to out yourself as having BPD. How else can you survive the pain of exposure? It carries a negative judgement like no other illness does, applied to a people who are the least equipped to handle rejection, isolation and shame.

We often think of advocacy or survivor work in terms of systems changes, activism, liberation, inclusion and integration, and we assume that the work heals the shame and isolation, but that’s not always the case. If you say you’re a peer-specialist recovering from Schizophrenia, you’re a hero. If you say you’re a peer-specialist recovering from borderline personality disorder, your legitimacy is in question. I got a sense from publishing the Buddha and the Borderline that to claim to be in recovery or to have healed from this disorder is impossible in many people’s eyes, while those of us who grapple with the experience of recovery are trapped in silence and have

When I meet mental health professionals who’ve read my book or seen me speak, one of the most common responses is “you’re not like them.” But who is “them” if none of us have ever spoken outside of a therapy session?

no basis for forming the kinds of communities and support systems others have. This is not because we’re always sick, but because our recovery and our needs are not the same as other madfolk and we exist in a network of treatment and relationships that cannot understand these differences.

I think if you ask people who identify with the BPD symptoms and wrestle with whether or not they are “truly” borderline, you’ll find that that their experience is similar to that of lesbian/gay/bisexual / transgendered peoples. We exist secretly in a social network that has labeled us as “deviant” and “bad.” I can’t count how many times I’ve been handed a folded note after I give a talk that says “I have BPD too and I can’t tell anyone.” I’ve had private confessionals in bathrooms at conference breaks with clinicians. This isn’t paranoia. By claiming a public voice, we run the threat of being exiled, and if you have BPD, there is nothing more horrific than being hated or excluded. My nightmares are not about monsters chasing after me, but of standing in a group of the people I love most and watching as each person turns away. I wake up screaming from being rejected.

Some people have expressed disappointment that, at the end of my book, I am still struggling. They want some form of deliverance, a certainty to fix their hope onto ...

So there is a big difference between doing consumer work and doing BPD consumer work. As there are, I expect , major differences between the recovery needs of those with BPD and those without. Some people have expressed disappointment that, at the end of my book, I am still struggling. They want some form of deliverance, a certainty to fix their hope onto, and while I share the same desire, I’ve found that it’s as important to understand the inevitability of anguish as it is the possibility of happiness. The greatest gifts in my life come from

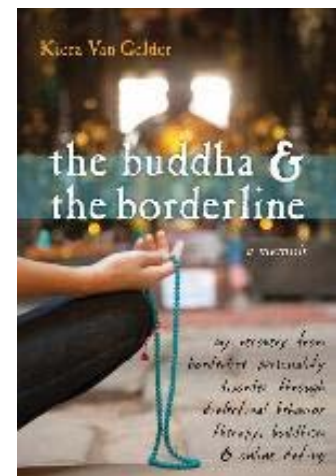
This is why I will always be grateful to illness. Through it I’ve learned how to transform pain into meaning and purpose and am learning a new kind of love.

people who compassionately witness my experience and then honestly share their own. It seems like such a simple thing, but it’s difficult and risky. Yet when that kind of connection happens, it’s like golden light pours from the sky. It’s not that though sharing our stories we become each other’s saviors at such moments, but that through total nakedness and acceptance, we are able to know ourselves as intrinsically ok. And this, I’d say, is the purpose of all the

work: by honoring ourselves and each other, suffering is not our deeper reality. It is there to teach us to be fully human and more compassionate. This is why I will always be grateful to illness. Through it I’ve learned how to transform pain into meaning and purpose and am learning a new kind of love.

The Buddha & The Borderline: My Recovery from Borderline Personality Disorder through Dialectical Behavior Therapy, Buddhism & Online Dating (2010) by Kiera Van Gelder, MFA

“This engaging memoir illuminates the experience of living with borderline personality disorder, a mental illness that is often misunderstood. The author shares her painful struggles with depression, drug addiction, self-harm and unstable relationships that ultimately lead to her diagnosis with borderline personality disorder. Through her pursuit of dialectical behavior therapy, Buddhist spirituality and adventures in online dating, she reclaims life and works towards recovery on her own terms.” (review from <http://www.buddhaandborderline.com/>)





SINGING THE B-B-BIPOLAR BLUES: A REQUIEM IN TWO PARTS

- By Ann Tullgren

Part 1: A chorus singing of fractured lives and lost possibilities

It has been called the most important issue facing psychiatry today. I'm not talking about compliance with treatment regimes or the pin-the-tail-on-the-donkey exercise that identifies where we are in our recovery journeys. The 'issue' is the extraordinarily high rates of morbidity (illness) and mortality (death) experienced by people with enduring mental illness.

We continue to die around 20 years sooner.

It has been known for many decades that we suffer far worse physical health than the general population. We continue to die around 20 years sooner. While this has been acknowledged by the psychiatric great and good, few inroads have been made into these shameful outcomes. Even in Scandinavian countries that have arguably the world's best and most equitably distributed health care, disease and death rates experienced by those with enduring mental illness have declined only by a very modest extent.

In a nutshell, compared to 'normals', we have higher rates of:

- diabetes and cardio-vascular illness
- HIV, Hep C and tuberculosis infections
- kidney disease
- poor oral health
- impaired lung functions
- asthma
- brittle bones
- middle ear infections
- obstructive sleep apnoea
- fibromyalgia and other disabilities associated with altered pain sensation
- chronic back and neck conditions

Additionally, women:

- are less likely to have regular pap smears and breast checks
- have limited access to contraception, and
- face increased risk of complications in pregnancy and birth.

Health practitioners and Big Pharma are quick to blame the individual for illness and early death. They point to smoking, lack of exercise and obesity underpinning 'lifestyle' diseases. This sleight of hand in attributing responsibility to the individual reduces complex health, economic and social problems to a kind of personal moral failure.

Why is this happening?

Health practitioners and Big Pharma are quick to blame the individual for illness and early death. They point to smoking, lack of exercise and obesity underpinning 'lifestyle' diseases. This sleight of hand in attributing responsibility to the individual reduces complex health, economic and social problems to a kind of personal moral failure. This strategy takes the spotlight off some critical facts. Health and illness are determined by a complex interplay of factors to do with the individual patient, the practitioner, the sticky and perverse nature of much illness that makes it imperfectly understood, and the systems within which we live and health care is delivered. Disease and disability are found on the very margins of society; we live in enclaves marked by social exclusion, poverty, housing insecurity, low rates of literacy, high rates of incarceration and a myriad of problems that mark our 'otherness'.

Relationship between mental and physical illness

How mental illness is linked with physical illness in a genetic or biochemical sense is little understood. It would appear some mental illnesses are intrinsically linked with particular diseases; however this nexus, while acknowledged statistically, is yet to be fully elucidated.

What is known clearly is that some medications used to treat the symptoms of mental illness, especially the atypical anti-psychotics, are associated with the metabolic syndrome that leads to diabetes and cardio-vascular illness. Part of the explanation here is that psych medications can cause the weight gain and sedation that make it harder to keep slim and active. But, it is also now

You know how the mantra goes – mental illness is treatable and if you are compliant you too can become an ambassador for beyondblue, climb Mt Kilimanjaro and go on Sixty Minutes.

acknowledged that they also cause elevated blood glucose and fats quite independently of weight gain.

Fat really is a pharmacological issue and a LapBand is not really the answer!

I also want to raise the thorny issue that often the mental illness itself gets in the way of becoming healthier. There is a tendency to sanitise the difficulties of life lived with enduring mental illness. You know how the mantra goes – mental

illness is treatable and if you are compliant you too can become an ambassador for beyondblue, climb Mt Kilimanjaro and go on Sixty Minutes. However, as I get older I have become aware of the development of cognitive deficits that seem to be associated with the illness. I'm less resilient. My executive skills (planning, organization, maintaining focus, problem solving etc) aren't as good as they were. I'm more prickly and angular around people. I also experience more 'days out of role' (a technical term meaning 'stuffed if I can get going this morning').

This isn't helped by the fact that compared to 'normals', we are less likely to spontaneously report symptoms of ill health. It takes time for us to form a relationship of trust and respect with our health care providers so that we feel safe to confide in them. Often we fear being seen as a hypochondriac or embarrassed. Sometimes enduring mental illness just overwhelms our awareness that things may not be right for us physically.

Access to health care

The other cause of our elevated rates of illness and death is less palatable for the health industry and policy wonks to admit and address: we have poor access to health care and when we do it often fails to meet our needs. Some examples:

- Many of us have no regular GP. While wealthy suburbs have an over abundance of GPs/health professionals, poorer suburbs, and rural and remote regions have a scandalous undersupply. Overwhelmingly, we live on the physical margins of society.
- We have special needs when it comes to health care. For example, we may need longer and more frequent appointments. We often experience a complex interplay of symptoms and illnesses. We may experience some symptoms of illness differently to 'normals'.
- The fee for service model used in Australian health care means that short appointments are the norm. It doesn't pay for GPs to have too many patients on their books with complex problems. Blame for this should not lie with

It doesn't pay for GPs to have too many patients on their books with complex problems.

individual practitioners; they should not have to shoulder the cost of meeting the needs of those of us with complex health problems.

- Health care is expensive. Most of the health practitioners I consult do not bulk bill and this means that I am out of pocket for about half the fee. Many of them appear not to bulk bill for anyone, even those on Centrelink and Veteran's pensions. I spend a significant part of my fortnightly budget on prescriptions. Were it not for my husband, who is employed, I would struggle with this. What is your experience?

Disease and access to appropriate health care are issues of citizenship. Our blighted lives are in large part caused and maintained by structural oppression and discrimination.

The Education of Health Professionals

Sometimes our 'otherness' and the label of mental illness are a barrier to health professionals taking time to build a relationship of trust and respect with us. Sometimes I think the experience of living with mental illness is more akin to having one of the Four Horsemen of the Apocalypse walking before us in society, ringing a bell and intoning 'Unclean, unclean'.

Additionally, there's a phenomenon called 'diagnostic overshadowing' that may occur when health professionals mistakenly think that symptoms of physical illness are part of the mental disorder. Common parlance calls this not seeing the wood for the trees! Research also shows that psychiatrists also often neglect to pick up on our physical health problems. And if they do, liaison between mental health professionals and GPs and specialist doctors about our treatment and care continues to be difficult to achieve. To put it in everyday-speak: why can't everyone sing from the same song sheet?

Some results of diagnostic overshadowing and the operation of good old power and stigmatizing beliefs and practices include these additional facts:

- Although we have hugely increased rates of diabetes and cardio-vascular illness compared to 'normals', we are less likely to be diagnosed and treated.
- If we are diagnosed with such chronic diseases, Medicare-funded disease management plans (eg. for diabetes, heart disease, lung disease etc) are less likely to be offered to those of us with mental health problems. How many people with enduring mental illness do you know have either a mental health care plan or a chronic disease plan which pays for use of psychologists or social workers, podiatrists, diabetes educators and various other health practitioners?
- How many people do you know who have a mental illness and a chronic disease management plan and associated poor oral health who also are referred to a dentist for free treatment funded under a special Medicare-funded programme?
- We are less likely to be investigated and treated with cardiac catheterization (to determine if our arteries are blocked, to have them unblocked or a stent put in to keep the arteries open).
- If we develop cancer we are treated far less aggressively compared to normals.

Back to the recurring chorus in this Requiem: Why is this so?

Stigma by self and others

My last appointment with my psychiatrist was different. I handed him a list of the medications I take, saying to him that because I'd been researching the physical illnesses associated with enduring mental illness, I thought that it's time for me to 'fess up about what tablets I take.

‘Why do you need to ‘fess up’ he asked. ‘Because I am so ashamed of the amount of medication I take and that I can’t manage some of the illnesses better.’

While he made soothing comments about not needing to be embarrassed, I wondered why he’s never asked me much about my ‘other’ illnesses and treatments; we’ve always focused on managing the bipolar. The research says that this is the norm. But I also realized that I have been self-stigmatising. Many of us carry a sense of responsibility and attendant shame that is more appropriately placed on the shoulders of Big Pharma, governments and health services.

Underpinning many health and support services are subtle forms of organizational stigma and discrimination. Many of the diseases we experience are also known as lifestyle diseases. In a nutshell, the lifestyle chorus goes ‘Live well, life long’ and if you don’t it is your fault. In the magazines sent out by Diabetes Australia to its members there is a long running debate in the letters to the editor (opinions expressed in letters are not necessarily those of the management). The letters go goes something like this: Diabetes Type 1 (insulin dependent, often starts in childhood) is a REAL disease. Sufferers did not cause it by eating too much, exercising too little and generally leading slothful and indulgent lives. Those with Type 2 diabetes caused their own illness because of poor lifestyle choices. Type 1s are portrayed as blameless and more deserving of care. Type 2s suck up money and energy and organisational focus that they don’t deserve.

The question of responsibility divides the deserving from the non-deserving sick.

This heated conversation occurs around a simplistic binary – ‘Type 1 is good, Type 2 is bad’. It is emblematic of the situation in which many of us with enduring mental illness find ourselves as we grow older and sicker. In reality, our excess morbidity and mortality rates are only partly explained by hazardous health behaviours.

Many of the diseases we experience are also known as lifestyle diseases. In a nutshell, the lifestyle chorus goes ‘Live well, life long’ and if you don’t it is your fault.

Our limited access to health care that works for us needs to be acknowledged as yet another form of structural oppression that we face. The cynical disregard for our lost and faltering lives demonstrates just how much those of us with mental illness are valued less than others in our society. This is in clear violation of the ‘right to health’ in international covenants to which Australia is signatory.

Part 2: In which we rise up!

In Singing the B-B-Bipolar Blues I’m fond of including in my repertoire some of the great Anglican hymns. A line from one of them sums up how I would like to end this essay and my Requiem for our blighted lives: ‘Rise up and follow me!’

We need to get more organized. By this I mean informing ourselves about issues such as those raised in this essay. Critical reflection within our consumer community comes next, as does challenging stigma and discrimination wherever they are found. We need to drive our own research agendas, based on our lived experiences and our priorities. While it is encouraging that consumers are involved in delivering professional education, there’s also an imperative to put our health care needs firmly on the agendas of the organizations to which we belong or which claim to represent us, so that policies and practices that be developed that will mean that we live longer and healthier lives.

Fractured lives can be mended. Lost possibilities can be found.

INTRODUCING ... *Autonomy in Jeopardy*, a journal article exploring the tensions between mental health laws and participatory health.

– by Cath Roper and Vrinda Edan

Cath Roper is the consumer academic at the Centre for Psychiatric Nursing (CPN), at the University of Melbourne. In terms of research, education and knowledge development, the consumer academic program at the CPN focuses on two distinct but related domains: consumer perspective education and training in the preparation and professional development of the clinical workforce, and supporting consumer autonomy in legislated contexts. Vrinda Edan is the Director of Consumer and Carer Relations, Mental Health, Alcohol and other drugs Program at Southern Health, Victoria.

Autonomy in Jeopardy: Contrasting Participatory Health Models with Patient Decision Making Under Mental Health Law

Recently, Cath Roper and Vrinda Edan had an article published in the *Journal of Participatory Medicine* that uses Victorian mental health law (MHL) as a case study through which to tease out some of the thorny aspects of supporting consumer decision-making under Victorian mental health legislation. The paper adopted an ethical lens to explore these tensions.

Respect for autonomy is fundamental to participatory health models where treatment decisions are made through a partnership based on mutually acknowledged expertise between consumer and provider.

We argue the overlay of participatory frameworks onto mental health policy and law serve to mask significant ethical issues at stake for people who are governed by MHL, because this population are not free to make autonomous health care decisions in a voluntary context.

For consumers subject to mental health law (MHL) in Victoria, autonomy can be overridden on grounds of incapacity to make treatment decisions. In such cases, providers become substitute decision makers and

consumers may be treated without their consent, presenting a challenge for participatory practices. Providers may be placed in ethically challenging positions, attempting to establish partnerships and encourage participation on the one hand, yet working with a mandated treatment plan that the consumer may not have agreed to, on the other.

In the case of people subject to MHL, autonomy is the ethical principle most at stake and it should be accorded intrinsic and independent value. We argue that providers need to clearly understand their roles as substitute decision makers and learn to be transparent about and accountable for the statutory powers conferred on them. Any departure from respecting consumer decision-making needs to be considered an aberration rather than a norm. The goal of service use would need to shift to voluntariness. Service quality standards and professional guidelines would need to reflect directives aimed at taking responsibility for creating environments supportive of consumer decision-making and voluntariness.

In an age where national and state mental health policy directs services towards a recovery orientation, tensions between paternalism and consumer autonomy need to be made overt.

New practices are also needed to promote consumer self-determination and affirm autonomous decision-making. 'Conversation models' are one way to encourage participation, rendering clinical thinking transparent to the consumer and then tailoring information to the individual. The model requires clinical skills such as sharing one's thought processes, encouraging the consumer to ask

The paper concludes by arguing that the first step must be to recognize loss of consumer autonomy under MHL as an ethical problem worthy of attention.

questions and finding out how much the person wants to participate. Flowing from this, practice needs to be always directed toward facilitation of autonomous decision-making, and provision of opportunities for consent. We further suggest such practices could form the substance of therapeutic alliance.

The paper concludes by arguing that the first step must be to recognize loss of consumer autonomy under MHL as an ethical problem worthy of attention. Only then can the impact this may have on consumers and providers alike be appreciated and faced and ethically grounded practices affirming autonomy, consent, and voluntariness be developed. In an age where national and state mental health policy directs services towards a recovery orientation, tensions between paternalism and consumer autonomy need to be made overt.

To read the full article, go to: <http://www.iopm.org/evidence/case-studies/2011/09/12/autonomy-in-jeopardy-contrasting-participatory-health-models-with-patient-decision-making-under-mental-health-law/>



Calling all consumer groups, projects and organisations!

Would you like information about your initiative shared on the Our Consumer Place website?

The Our Consumer Place Directory is being redesigned to be a resource that specifically shares information about projects, groups and organizations with genuine consumer leadership. We hope it will be a place to share what's going on for us, what brilliant things we are doing, and what challenges we're facing.

If you would like your project /organization /group to be listed in this directory, please go to: <http://www.ourconsumerplace.com.au/article?id=5263>. If you have any questions, please contact us at: service@ourconsumerplace.com.au.

NB: If your organisation involves consumers only as recipients of therapeutic services, Our Consumer Place's Directory will no longer be the appropriate place for a listing. There are many other directories for such services – we are focused specifically on fostering consumer leadership and consumer perspective.

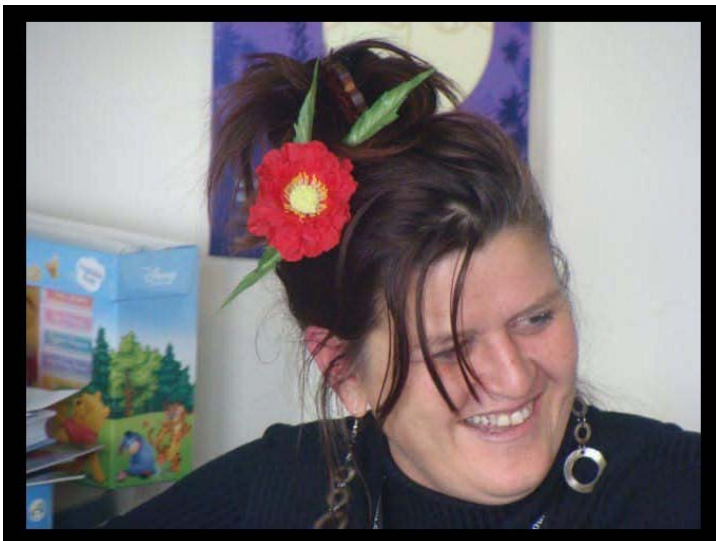
INTERVIEW OF THE ISSUE – Mary Campbell

Consumer Consultant, Te Korowai Whariki, Regional Forensic Rehabilitation and ID Mental Health Services, NZ

Merinda Epstein met up with Mary Campbell at the Mental Health Services (TheMHS) summer forum on Self Harm.

Mary Campbell's brief biography:

I am the stroppiest out of my siblings. I try to argue points but never win. Sometimes that's the nature of being born last. I wish I had been born first but that's another story. When I was 8 yrs old I was given my ancestral name *Maringikura*. People mostly call me Mary or Maringi.



My parents suffered from mental illness. My father experienced untreated post traumatic stress from losing both his parents when he was young. My mother clinical depression and post natal depression. I was very close to my parents; I still am, even though they have gone. I am a mother of 3 sons whom I adore - each one for different reasons. I am a singer, I write my own songs. I am a published poet. One of my goals is to travel to Peru to research our Tongareva ancestors who were taken from Tongareva in 1862, (in the Northern Cooks) to Peru.

I work as a Consumer Consultant using my own life experiences to connect with others. I believe in the power of creativity and how it significantly impacts on recovery.

Merinda Epstein: How would you describe what consumers/psych survivors/mad folk are doing – changing systems and/or the world? And where does your own work fit into this?

Mary Campbell: My colleague is a social change agent. If she is afraid of anything she doesn't show it. She shoots from the hips and pretty much knows that there are going to be ramifications but she does it anyway. She speaks for those who are unable to speak for themselves. We work on the land where she was incarcerated from fifteen years of age and so, you know, it must be hard for her: all the memories that she carries. It doesn't stop her from challenging those in power, she just says, "Oh Hell! I've got to do this no matter how much it hurts or is difficult."

I make a difference in my own way. I am aware of my own fragility, my own energy. I am very important to me.

My Mum had also been incarcerated here.

I have a different approach. I run poetry workshops with young people. I am involved in the VIP Violence Intervention Programme training which is soon to be rolled out right across our service. I have put together scenarios/ poetry/ visual displays for this VIP training programme.

ME: Do you come from a consumer perspective yourself?

MC: Yes. Yes. I first got unwell when I was 14yrs old. I was smoking a lot of pot and eventually ended up very depressed very unwell. My parents took me to Carrington Hospital in Auckland to see a psychiatrist Dr Fraser McDonald. He was kind to me and put me on medication that really helped. It was years later that I learnt from a family friend that my parents were worried about me committing suicide.

I had post natal depression with my first child. I was very, very unwell. I took myself into hospital and I stayed there for a long time, didn't ever want to leave. I stayed a ridiculous five months. Every morning at six o'clock I would go to the children's ward and pick up my son and take him back at 7.30 every night.

ME: Did this inform your practice now?

MC: It does when I see women that are 'postnatal' very depressed, my heart goes out to them. It is a very painful and scary illness both depression and postnatal depression. I think through my illness it has made me more open to others, more approachable, more understanding and more compassionate.

ME: Does the job you do require you to have used Maori/ Pacific Islander services or be Pacific Islander specifically? Tell me a little about the job that you do?

MC: I have never used a Pacific service when I was unwell. I am not sure if there were such services back then.

I do think being Pacific is a bonus, it can help open doors to many possibilities especially in the Pacific consumer world and hey I have my place in the sun, I can fit in both sides of the camp. There are many Pacific people who live with a mental illness. People know I have Polynesian blood, they also know I'm very proud of that. I have many close Pacific consumers that support me and I them. I am forming a Pacific Woman's Advisory Group.

We are the experts when it comes to our mental wellbeing.

ME: What would you pick as some real gems in this area, things that inspire you, nurture you, or that you think are brilliant?

MC: I am trying to think what you mean by 'gems' then I thought of the youth I work alongside. I run a poetry workshop every week for an hour and what amazes me is that these young people participate. They are not disruptive but very respectful. I start off by reading poetry, all different styles of poetry, and once in a while I do a bit of performance type stuff and they don't object or complain. They stay in the room 99% of the time. Some of their writing is good; some of the writing is very, very good. In fact, I am going to publish a second book of poetry, this time a poetry book written by *Rangatahi* (youth.) The first book was poetry written by mental health consumers all over New Zealand. That was a highlight. This will be another highlight for me.

ME: Do you see this as therapy or poetry? What's the difference?

MC: Well I think it's therapeutic but it's also entertainment. The reason why I chose poetry is that I come from a family of poets. Both my father and my mother were well known New Zealand poets so I have a love for their works and others and I wanted to introduce different styles of writing to young

people and so I look for my favourites to share, Maori, Pacific, African, Aboriginal, English and so on. I bring them all into our world.

I think that happens because I am not 'a therapist'. I just go in there and say, "OK I've got some fun things we are going to do today and we'll have a lot of different exercises too, and it just happens."

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

MC: What would I expect to be different? What is the difference between tolerating and embracing? One day I was speaking to one of the mothers and I told her a little bit about myself, about how I get

I'd be putting large amounts of money in setting up creative places for artists, actors, poets. I would set up a gym and have health experts giving motivational tips on physical health and wellbeing. The list is endless. These places would all be consumer run.

depressed and I remember after that she was a bit distant with me and I remember thinking, that I shouldn't have said anything. I thought, what if she tells the other Mums and then I thought, hey I am the role model here. I need to hold my head up high. I still think that communities aren't anywhere near embracing and accepting those who suffer from a mental illness. If we don't talk about it openly how can we educate others on this topic? One out of five in this country has a mental illness. That is a lot of people.

If I felt mental illness was embraced I think I would not be nearly so protective of myself. I am quite protective of me. That's what happens you know. My mother always said: "Don't throw your pearls before swine". I have always listened to her advice and so, it would be absolutely amazing if people did embrace people but it's still not happening.

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

MC: Education is a great weapon to use. I would implement education around health which would include mental health physical health, spiritual health, family / tribal health. I would implement something about mental health into primary schools, secondary schools and university. This would include educating people about the hazards of drugs and alcohol which fits into physical mental spiritual health. Holistic education is essential. Caring for our spiritual, physical, mental health is crucial.

ME: 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?

MC: Well, you know, I was very impressed when I was shown around a place in Sydney. There was this place that I went to where people were playing chess and people making coffee and chatting with each other, working on their art in the art space, people giving financial advice and so on all in the same building. These were consumers getting on with it. There was also a consumer theatre group practicing there.

ME: What about if you just had \$10,000 to spend?

MC: We have a lot of trouble with people *Kiaora* (that's our consumer name) – a lot of problem with people putting on a lot of weight because of Clozapine and stuff. And what they're doing of course is that doctors are focusing a lot on the mental health but while that's going on their physical health is falling apart – literally falling apart which makes you feel depressed anyway. I would spend money getting support workers in and getting alongside people who had gained a lot of weight or who had weight problems and helping them because of the whole thing around diabetes and stuff. This is another issue that is major. I would get peer support to keep people going. One thing that we know is that being physical actually helps your mood, makes you feel better, improves how you're feeling. Being active is important so I would spend that money on things like that.

ME: 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?

MC: Hopefulness would be doing something about the unnecessary suffering of man, man's inhumanity to man. Somewhere where greed, contaminated oceans and rivers, stolen land, starvation, deprivation, the suffering of children of women and of young men in battle would cease. Hopefulness is seeing people heal, recover, becoming emancipated, seeing people shine. We are meant to shine. That is the heart of who I am and what I believe in – *Te Atua* (God), my family, my ancestors ... *taku henua* (my land, where I stand), the people whom you meet every day that become your teachers, your friends, colleagues, mentors, soul mates.

I'd like to go to Peru because my people from the Northern Togaverans (Cook Islands) were kidnapped by Peruvian slavers in 1862 and our population was just about wiped out. I'd like to go over there and see if I can find any of our people. That is the heart of who I am – my culture, my ancestors, my children of course, everything around family and stuff like that.

SEE THAT GIRL... Dedicated to Merinda Epstein by Mary Campbell

See that girl
with the pretty yellow hair
she got pretty as eyes
cute as smile
she got cuts up her arms
and the media want a piece of her
the doctors want a piece of her
I just wanna talk to her
She's really really sweet
She's got a lovely as figure
pert breasts and all
and everyone loves her
the doctors really love her
the crowd really love her
I kinda love her

she's got deep as cuts
right up her arms
and everyone pretends
they pretend
that they can't see them
I can see them
you can see them
everyone can see them
hell she's so damn pretty
no one gives a toss
that she carves up her arms
that they look so horrific
because she's so damn pretty
see that girl,
with the pretty yellow hair
as pretty as a button!

INTRODUCING ... Portraits in Blue – a Narrative Research project into the social construction of depression

In this edition, we introduce a new project called Portraits in Blue. This project is examining narratives of depression in a highly innovative way, and is meaningfully embedding consumer leadership while drawing on the expertise of non-consumers. Sophisticated research indeed!

The purpose of Portraits in Blue is to explore the social construction of current perspectives and assumptions about depression, by collecting narratives about:

- the stories people with depression tell themselves and others to explain their illness and why;
- the stories people assign to others with depression, and what factors cause people to define different stories to different people;
- major influences in coming to these perspectives.

The project hopes to change the conversations about depression, and influence policy directions. We are also intending to hold workshops with consumers and service providers, and address how the negative stories

The project hopes to change the conversations about depression, and influence policy directions.

/archetypes might be dismantled and positively enhanced. Our experience with the narrative research approach is that it provides insights and unexpected connections as the basis for determining appropriate action. Publication is, of course, also an option. However, as this is an emergent process, the precise publications and focus would emerge.

The project is being led by Michael Lockwood, who is coming from his lived experience of clinical depression, and Viv Read with technical support from Chris Fletcher. The reference group for the project includes a critical mass of consumers, a psychiatrist, an action learning consultant, a consultant with expertise in community mental health, the director of research at the Department of Community Services and a lawyer. The group have been actively networking with people with appropriate expertise, but the project is not aligned with any existing research, consumer or advocacy group. This is a deliberate decision to determine whether new insights might emerge using the narrative research methodology. All those currently involved are providing their time and expertise pro bono.

The ethics and governance of the project are consumer led. Flick Grey (from Our Consumer Place) is co-ordinating a consumer-led ethics process. The project team have found that existing ethics approval processes have been obstructive and have not really addressed ethics considerations that would be important from a consumer perspective. Anyone interested in contributing to this process is encouraged to contact Flick: flickg@ourconsumerplace.com.au.

One of the particularly interesting elements of this research is the use of Sensemaker™ which is a narrative capture and analysis tool, developed by Cognitive Edge, Pty Ltd. Using the principles of complexity science, the development was supported by the US and Singapore governments. It has been used in a variety of projects and settings, including PhD research. Making sense of the data collected is done in two ways: the identification of patterns, trends and other statistical analysis provided by the software, and engaging people in working with the narratives to identify themes and issues as a basis for advice and action. Both processes are designed to enable moving from insight and understanding to action.

At the moment, the project is in its developmental stages, with a view to piloting the project later in the year. For more information, see: <http://portraitsinblue.com/>.

NEWS IN THE CONSUMER WORLD:

Employment Opportunities:

New Consumer Consultant position at Forensicare (who provide specialist mental health and associated services to mentally ill offenders). The position is fixed term (12-months), and 16 hours per fortnight (one day per week, on a Monday). For more information, contact Lisa Wright, Chief Social Worker, Tel: 03 9495 9249, or see <http://forensicare.mhr.com.au/jobdetail.asp?jobid=2679>.

Peer Leadership Initiative, Doutta Galla Community Health

There are currently two peer worker positions available at Doutta Galla Community Health. Both positions are within the "Peer Leadership Initiative" within the Social Inclusion Program at Doutta Galla Community Health, one part time and one casual. Both are to facilitate a group program called Flourish. Below are links to the positions as advertised:

<http://www.ethicaljobs.com.au/Members/dgchs/peer-worker-2013-social-inclusion/?searchtermurl>

<http://www.ethicaljobs.com.au/Members/dgchs/peer-worker-2013-social-inclusion-1/?searchtermurl>

For more information, see www.peersupportvic.org/employment.

Life in a public mental ward - enough to drive you insane

An article published in March in the Sydney Morning Herald exposed some of the horrors many people experience in public mental hospitals. "... Allegedly designed to protect me, to help and heal me, it has done nothing but traumatise and brutalise me, destroy my career and steal great chunks of my life. ..."

Read more: <http://www.smh.com.au/opinion/politics/life-in-a-public-mental-ward--enough-to-drive-you-insane-20120314-1v3ng.html#ixzz1s9zjfw00>

The Victorian Mental Health Consumer Workforce Conference 2012

CONSUMER WORKFORCE CONFERENCE CONSUMER WORKFORCE CONFERENCE

Raising the Standard

VMAC 2012

Conference theme: The consumer workforce provides leadership in moving towards a truly consumer-centred mental health system by using the unique and diverse expertise of lived experience to represent consumer views and perspectives, to advocate for systemic change, to improve quality of service, to provide peer support, and to implement rights-based, recovery and wellbeing-oriented practice.

Conference Dates: Monday, 28th – Tuesday, 29th May 2012

Conference Venue: Treacy Conference Centre, 126 The Avenue, Parkville Vic 3052

Keynote Speakers: Janet Meagher (distinguished mental health consumer activist and advocate and currently the Divisional Manager- Inclusion, for Psychiatric Rehabilitation Australia) and Anne Beales is a Brighton-based campaigner. Anne has been awarded an MBE (Member of the British Empire) for services to mental health.

For more information: (03) 9380 3900 | conference@vmiac.org.au

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

Storytelling workshops on the road

Merinda is working with Wanda Bennetts to take our storytelling workshops on the road. There are two workshops – beginners and advanced – that work with consumers on how we tell our stories (and not necessarily own “own illness story”), as well as where and why. These workshops were run earlier this year in Melbourne and there has been demand for them elsewhere as well.

Paper copies of our newsletters

We endeavour as much as possible to make our materials available to people who don't have access to the internet or a printer (or whose computers are just *really* old). We have now set up a better system for mailing out paper copies to those who need this. Please let us know if you need a paper copy posted out to you (we can only do this for consumers).

The National Expert Advisory Committee on Borderline Personality Disorder

Merinda has spent a lot of time trying to bring a consumer perspective to the deliberations of the National Expert Advisory Committee on Borderline Personality Disorder. This has been demanding, at times, frustrating work. However, the recommendations that will soon go to the relevant Minister, The Hon. Mark Butler, are good so its fingers very tightly crossed from here.

Check out Paws for Purrfect Therapy

Merinda has been supporting a group of consumers setting up a wonderful service to look after the pets of people diagnosed with ‘mental illness’ who are removed from their homes for whatever reason. The tentative first steps of the ‘Paws for Purrfect Therapy’ project have taken place with the support of Lort Smith Animal Hospital.

Intentional Peer Support training update

In late March-early April, Flick was fortunate to be included in a round of Intentional Peer Support (IPS) training with Shery Mead and Chris Hansen, which was organised for peer workers in Queensland. Flick attended training on co-supervision and facilitation. As many of you know, we here at OCP are keen to facilitate Intentional Peer Support training in Victoria (and elsewhere), but we have had many hurdles to navigate! The main issues involve fidelity, ethics and resources. We want to ensure that what we offer is genuinely Intentional Peer Support, and not some motley blend of IPS + random other stuff that doesn't really fit (which, unfortunately, has been the story of some “IPS” training internationally). We also wanted to make sure that we run the training in ways that are ethical – remunerating Shery Mead appropriately for her intellectual property while making the course available to people who cannot afford to pay a great deal of money, or who may have other barriers to participating, and making sure it's sustainable for us (the training is very intense and we are aware of our own limits). Finally, it's been a challenge to balance fitting IPS training into our already rather busy workload – it is quite a tricky juggling act to do all the things we'd like to do, that the consumer community would like us to do and what our funders would like us to do! But, we are much closer to having clarity about where IPS fits into the mix. Stay tuned, as they say, and drop us a line if you are interested in Intentional Peer Support training (if you don't know what it is, check the description and links on our website: www.ourconsumerplace.com.au/trainingevents).

Consumer Operated Services (COS) in Queensland

While Flick was in the sunshine state, she also visited several consumer operated services that were operating using an Intentional Peer Support model. We hope to share some of these wonderful

initiatives in upcoming newsletters. Queensland has been doing brilliant work in recent years in expanding consumer operated services (COS), which have their own (significant) funding stream. We here in Victoria have much to learn from our northern neighbours (and they used to say we were “miles ahead”, how embarrassing that the balance has tipped!).

Are you “out” as having a mental illness?

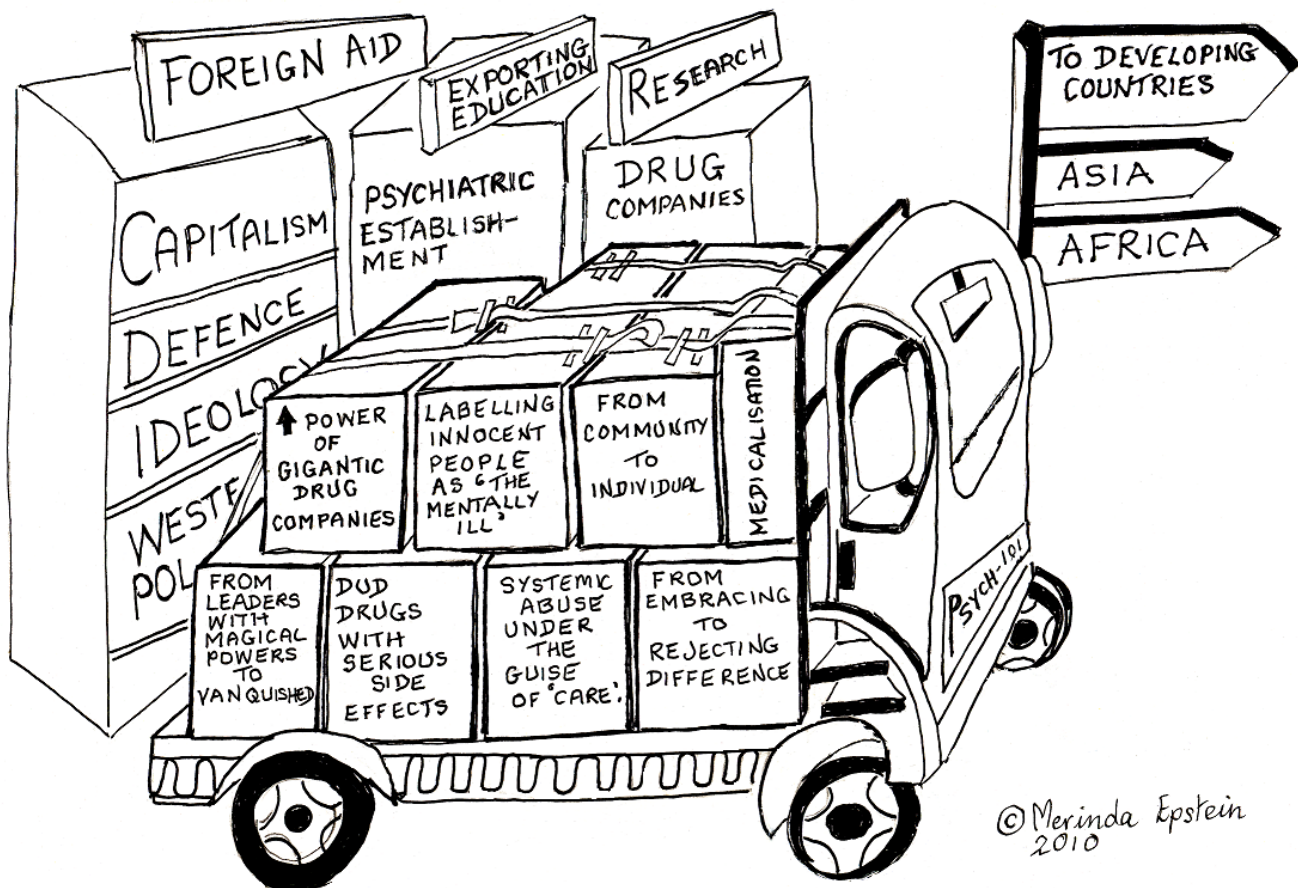
Merinda has started a small project looking at the choices people make about whether they are ‘out’ (as a ‘mental illness’ identity goes - in the way we use that language of ‘out’ in the Gay, Lesbian, Bisexual, Transgender and Transsexual community). We are interested to know when people are ‘out’ and when they are not ‘out’ and what drives decisions to be ‘out’ or not and whether they are ‘out’ about certain aspects of their personal experiences and not about others. This project is in its beginnings and Merinda has been working with Gill Halliday.

Updating the “directory” section of our website

As part of updating our website, we are doing a complete overhaul of the “directory” section. At the moment, anyone can register their organisation, project or group (including service providers) and we haven’t really felt this reflects our orientation properly. So, we’re completely redoing this section, focusing on consumer led projects. For more information, see page 11 of this newsletter.

Upcoming OCP publications

Merinda and Flick have both been squirreled away at various points recently, writing materials for our upcoming booklets ... we hope to be able to share more soon!





THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** to those consumers who can match it in the hurly burly of the politics of state and national committee sitting.
2. **THUMBS DOWN:** to the consumers who sit on state and national committees who forget they are there because they are consumers, who are co-opted.
3. **THUMBS DOWN:** for the demarcation between 'carers' and consumers when we know that the vast majority of consumers are also 'carers' and many 'carers' are undeclared consumers.
4. **THUMBS DOWN:** for the demarcation between consumers and 'carers' when people insist that they are the same interest. This is a fabrication. Our "lived experiences" are different!
5. **THUMBS UP:** to consumers who can 'get things done', recognise this as a talent and be pleased and driven but who are *also* sensitive and responsive to peers who provide reflection and introspection. Both are necessary.
6. **THUMBS UP:** for the consumers, clinicians and 'carers' who truly understand the disciplines of sociology, cultural studies, women's studies, indigenous studies and anthropology. To all the people who recognise the importance of: different discourses, power, social class, gender, culture, ethnicity and labelling theory.
7. **THUMBS DOWN:** to consumers who bow and scrape to those in power so they can feel important and powerful themselves.
8. **THUMBS UP:** to consumers who know how to play power chess at a national and state level and can use a variety of strategies, including bowing and scraping when necessary, but never lose sight of their roots – consumers of mental health services.
9. **THUMBS UP:** to a non-consumer working as a research consultant with a group of mental health consumers who almost immediately put up two large pieces of butcher's paper on the wall asking us to document when she 'got it wrong' from a consumer perspective.
10. **THUMBS UP:** to this EXQUISITE floral art installation to commemorate an old psych hospital closing down. Honestly, this is breathtaking and well worth a look!



<http://www.thisiscolossal.com/2012/03/bloom-28000-potted-flowers-installed-at-the-massachusetts-mental-health-center/>