People diagnosed with ‘mental illness’ doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER OCTOBER 2011

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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

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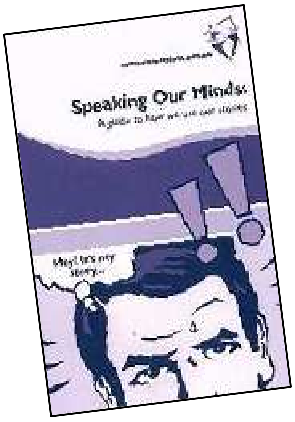
Editorial note: This month we have shaken things a bit up (as we like to do) – including an interview with a young and local emerging leader (instead of our usual interview with a well-established, overseas leader), and a profile of a survivor-organisation from one of our Pacific neighbours (in addition to our regular profile of a local consumer-developed initiative). If you feel like a laugh, check out Bernie McCormack's cartoon on page 7, or the back cover for advice on how to live and work with non-mad people (which can be challenging). Plus plenty of the regular features. Enjoy!

Speaking Our Minds: a guide to how we use our stories

– a new publication from Our Consumer Place



This 84-page booklet is all about mental health consumer's stories – how we use them, why we might not use them, and how we can best make use of our stories when we do share them. This isn't another book written by "mental health experts" telling us what's good for us; instead, it's all written from the perspective of those of us who have been there and have the stories to tell! And, it includes some *fabulous* new cartoons from Merinda Epstein.

The booklet will be available after October 17th 2011. It will be free to download from our website – www.ourconsumerplace.com.au. Consumers can request a single hard-copy be posted out to them. Otherwise, hard-copies will cost $10 each (which is below the cost of printing, postage and handling). It's being launched during Mental Health Week (details are still unconfirmed and beyond our control as we go to press, sorry!)

SAVE THE DATE: Our Consumer Place's 2011 Conference

Consumers As Educators, November 11th 2011, 9-5pm, FREE!

Join us for a one-day symposium on the topic of "Consumers as Educators". The day will be a veritable smorgasbord, bringing together historical depth, engaged thinking and contemporary examples of innovative and challenging educational practice. It will include:

- Historical context from key people involved in "the Deakin Workshops," which initiated the role of mental health consumers in clinical education in Australia,
- Plenty of insight, discussion and inspiring examples of what's going on today,
- A wide spectrum of contexts in which consumers are educating others,
- Discussion of where the opportunities and challenges might lie.

– *all led by consumers*!

Plus, there will be plenty of opportunities to network, brag, borrow and steal ideas, natter with likeminded people and debate contentious issues. And, amazingly, it's FREE!

Venue: Melbourne CBD, to be confirmed – check our website (www.ourconsumerplace.com.au), call: (03) 9320 6802 or email us (service@ourconsumerplace.com.au) closer to the date.

Speakers include:

Wanda Bennetts (Consumer Consultant and educator), Merinda Epstein (long-time consumer educator, Our Consumer Place), Helen Glover (Enlightened Consultants), Cath Roper (Consumer Academic, University of Melbourne), Ann Tullgren (University of Tasmania), Sandy Watson (independent consumer activist and educator), Professor Brenda Happell (CQUniversity), Kim Koop (VicServ), Associate Professor Meg Smith (President Mental Health Association NSW) + more!

SINGING THE B-B-BIPOLAR BLUES: *So, you weren't breastfed either?*

By Ann Tullgren

FEATURED ARTICLE

Ann Tullgren is a consumer from Hobart. She is co-author of the textbook 'Social Work Practice in Mental Health', by Robert Bland, Noel Renouf and Ann Tullgren, Allen and Unwin, 2009. She is an Honourary Associate of the School of Sociology and Social Work at the University of Tasmania and is passionate about developing the role of consumers as educators.

The concept of recovery is one that has popular currency in the mental health sector. However, the devil, as they say, is in the detail.

This is partly because there are many competing definitions that are attached to different parts of the sector (Bellack 2006:432). These definitions reflect the quarantining of ideas and practices about how to manage mental illness that underpin the various services available (or not) to consumers. One service may provide diagnosis and treatment and then refer on (or not) to a separate service for assistance with issues to do with poverty and exclusion (providing one exists). The scientific/health communities tend to consider recovery from the perspective of the definition of the disease, focusing on the reduction or elimination of symptoms, leaving consumers/survivors to get on with the rest of their lives, unencumbered by, or, with a manageable, residual burden of mental illness. Research definitions are usually about outcomes. Consumer definitions, however, centre on the lived experience and have a strong human rights focus, which emphasizes the importance of sociopolitical change.

> *To 'live well in the presence or absence of one's mental illness' has come to mean being complicit with treatments offered, practicing hopefulness, optimistically embracing possibilities for change, and cultivating a vigorous sense of personal agency (moving from passivity to activity) ...*

Essentially, because scientific definitions construe mental disorders as medical and treatable, they split our lived experience into clinical vs citizenship domains (*'We only do this, you have to go elsewhere for help with the other'*). Furthermore, embedded within the various recovery definitions are pervasive, and often obscured, ethical positions that impact on the ways we consumers/survivors are regarded and treated. I have problems about such views about recovery; recovery writ small and narrow – but always well footnoted.

The reality for so many of us is that our conditions are complex, pervasive and challenging (Bland and Tullgren 2011), and so the use of limited scientific/research definitions of recovery by practitioners and services provide them with a 'get out of jail free' card, absolving the bearer from accountability for poor results.

To 'live well in the presence or absence of one's mental illness' has come to mean being complicit with treatments offered, practicing hopefulness, optimistically embracing possibilities for change, and cultivating a vigorous sense of personal agency (moving from passivity to activity) – and other virtues that can be practiced in the privacy of one's own home, if you have one, and by individuals! In short, psychiatric diagnosis and treatment allows us to think clearly and sets the scene for us to take personal responsibility for our lives and to participate, economically and socially, in the life of our community.

This definition says that recovery is ours for the taking. It becomes both mythic quest and journey's end as the white knights of clinical service ride out of the sun, dazzling our eyes with the swish of their sabers; cutting edge treatments. The dark forces of depression and psychosis are banished, allowing us to claim our inheritance of full citizenship.

Andrew Robb, in his recent book 'Black Dog Daze: Public Life, Private Demons' (Melbourne University Press, 2011) (which is essentially about what a talented, responsible, inspiring and hard-working leader he is, capable of becoming Prime Minister) reflects the pervasiveness of this view:

> *In finally dealing with my own depression I hoped to demonstrate that, in many cases, if you confront it, persist until you find good professional advice that suits you and then show patience in finding the answer to your problem, the results can exceed your expectations. Usually you can stay in your job, taking on, if you wish, even more responsibility than you previously carried, and in most instances doing all this without telling the world. Tackling and managing your depressive condition can give even greater meaning to your life. (2011:173)*

In this construction, mental illness is seen as simple, medical and treatable, as long as consumers pull their finger out and take responsibility! This view of mental illness underpins many community stigma and and information campaigns, and is uncritically echoed by other mental health heroes and organizations such as *beyondblue*. Have a good look at the *beyondblue* website. Is mental illness being sanitised for popular consumption as simple, medical and treatable to the exclusion of a compassionate and thorough response to the many complex human rights failures that we live with? Specifically, have a look at their Publications page. It lists 50 journal articles by many psychiatric eminences from 2010-2011 that have been 'supported' by *beyondblue.* The topics for research and publication include explorations of cancer and psychological distress, medication overdose, mental illness in the emergency department, depression in aged care homes, the challenges of treating comorbid mental disorders and addictions and the usual topics of medication breakthroughs. There's even one on the 'effects of breastfeeding on child and adolescent mental health'.

... mental illness is seen as simple, medical and treatable, as long as consumers pull their finger out and take responsibility!

Don't mention 'The War' (poverty, marginality, homelessness), the terms 'lifestyle correlates' or 'quality of life' are nicer ways of considering the messy swill of life lived with the causes and consequences of complex, pervasive and challenging mental illness. Why are the complexities of the lived experience of so many of us silenced by such reductionist notions of a mental illness and recovery, and what is needed to sustain and support full citizenship?

Why does *beyondblue*, fail to 'support' research which comes to grip with the fact that mental illness does not exist in splendid biological isolation, and that clinical interventions need to be dovetailed with reducing social exclusion if robust outcomes are to be achieved? Where is the honouring of the complexities of our lived experience? Why is access to full citizenship always someone else's responsibility, a referral to a different agency that occurs after the pills work (or don't)? Or, is yet another writing competition for consumers a good enough response?

Why are the complexities of the lived experience of so many of us silenced by such reductionist notions of a mental illness and recovery ...?

The dominant discourses informing recovery are packed to the gunnels with implicit understandings about individualism, the triumph of science and the market economy. These ideologies, which are mainstream beliefs in America, also inform public policy and popular debate around mental illness in Australia. Recovery writ small, predicated on treatment compliance, and bravery, hopefulness and hard work, forms the basis of an insidious mental health prosperity gospel. Seek and ye shall find, work hard and the door will be open to you. Failure means you haven't tried hard enough, or believed fully enough, or seized sufficient opportunities that are there for the taking. Of course, failure could also mean you weren't breastfed for long enough! And what of the breastfeeding experiences of the White Knights? How do their breastfeeding experiences influence their values, their actions, their ability to partner with us?

Recovery writ small, predicated on treatment compliance, and bravery, hopefulness and hard work, forms the basis of an insidious mental health prosperity gospel.

Although mental illness is ubiquitous (widespread) this does not mean that it is randomly distributed throughout society. It is to be found disproportionately on the margins, those grubby regions where poverty, homelessness, loneliness and exclusion mark day-to-day lives. This means that mental illness is almost less a disorder of health, to be treated by mental health services, than a disorder of citizenship.

A recovery focus *writ small* means that poor outcomes can always be attributed to poor compliance, the stickiness of the mental illness disease process, lack of commitment or a myriad of other explanations that focus on the malign other, who carries the stigmata of mental illness. This is the 'get out of jail free' card that I mentioned earlier, where the professional response to mental illness is split into the 'pointy hard end' (clinical services: diagnosis, biological treatments, psychological therapies) with the 'soft blunt end' (rehabilitation: housing, income, relationships) tacked on, almost as an after-thought.

Where is the grounded understanding that recovery depends not only on diagnosis and evidence based treatments such as medication and CBT, but also on having sufficient income to pay for co-payments when accessing treatment or paying for medications, to pay for food, housing and recreation?

Popular understandings of recovery writ small fail to acknowledge that politicians, policy wonks, academics, mental health professionals, families, friends and society generally also need to 'recover'.

Popular understandings of recovery writ small fail to acknowledge that politicians, policy wonks, academics, mental health professionals, families, friends and society generally also need to 'recover'. By this I mean to embrace and practice a deep belief in the worth and dignity of all people, which informs a willingness to reach into the national hip pocket to fund services that support, enable, encourage and empower people with mental health issues, including Centrelink, job placement agencies, child protection services, prisons and homelessness services.

> *True recovery is understood, by those of us with lived experience, as the ability to fully participate in all aspects of civil society as a global citizen. Global citizens are active agents in all aspects of civic life as defined by the rights, responsibilities, roles, and resources that society offers to its members through public institutions and informal associational life. Being global citizens, means we have a voice, both individually and collectively in the important matters of our community. - Daniel Fisher (2008).*

So, when I sing the Blues, and repeat the refrains "O Baby, baby …" or "Momma, don't you cry for me …" bear in mind that I'm really singing about that other piece of research I'm asking *beyondblue* to commission. One which seeks to explore the effect of breastfeeding on politicians' and mental health professionals' ethical beliefs, interpersonal skills and responsiveness to our needs and views! Maybe they weren't breastfed either!

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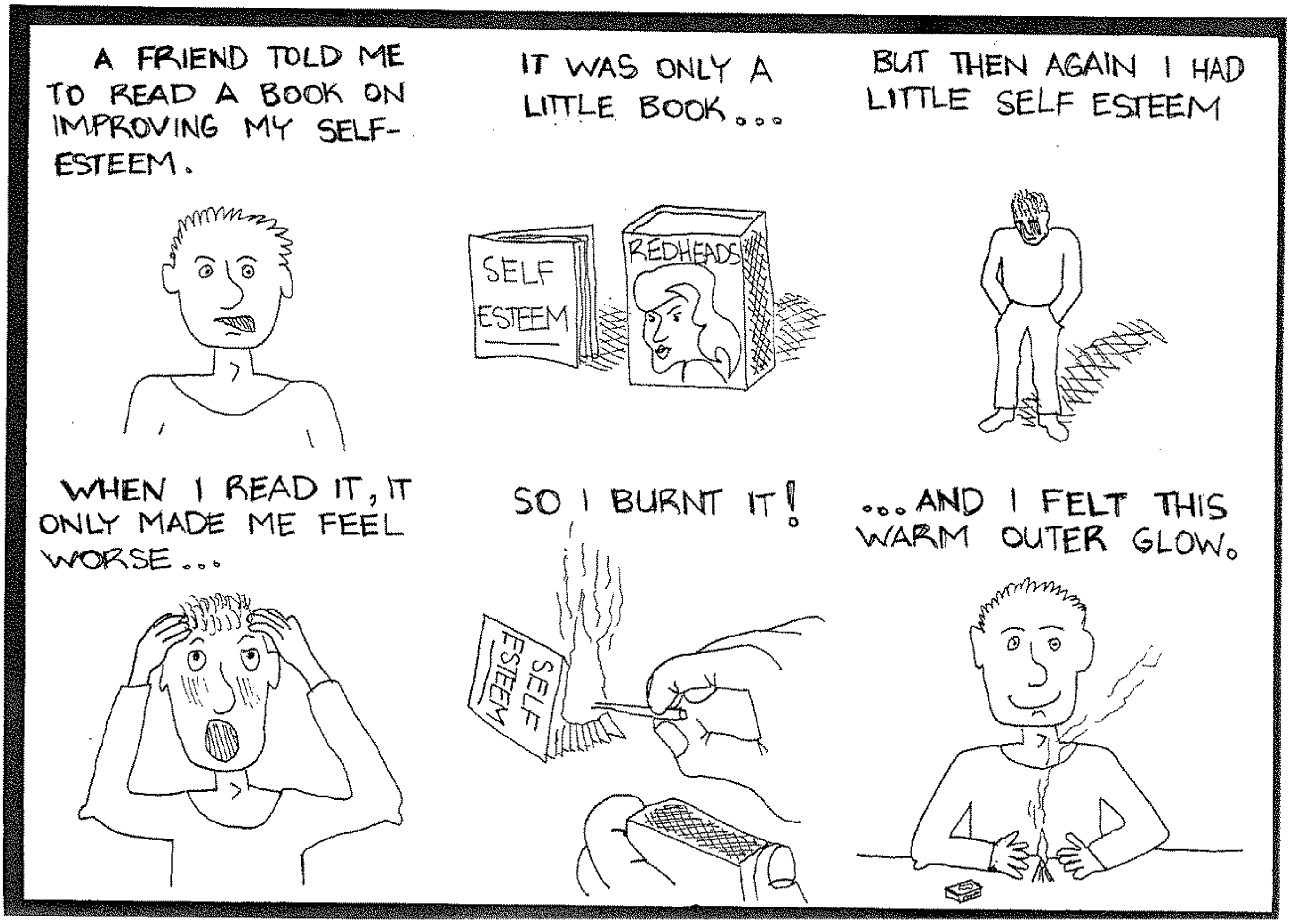

Cartoon by Bernie McCormack, reproduced with permission.

SOAP BOX

PLANNING FOR BPD AWARENESS DAY

By Merinda Epstein, Our Consumer Place.

Wednesday 5th of October has been set aside as a Borderline Personality Disorder Awareness Day, which will hopefully honour the experiences of those of us who have been diagnosed with Borderline Personality Disorder (BPD). The organising group included Flick Grey and myself from Our Consumer Place, along with Isobel Collins from the Victorian Mental Illness Awareness Council (VMIAC), Julie Anderson from MIND, clinicians from Spectrum, Julian Leith from the Victorian Mental Health Carers Network and Janne McMahon from the Private Mental Health Consumer and Carer Network. The impetus behind the day came from a visit many months ago from Spectrum staff to the Carers Network. Consumers were then approached to help organise the event.

There is no doubt that organising this day has been interesting. There were several significant challenges as we brought together the consumer, carer and clinical discourses – each of which holds different authority and different priorities. To add to this, getting to the point of shared objectives for the day tested us. The area of BPD is fraught and despite the original conceptualisation of the day as a way to broadcast an ultimately positive message there have been conceptual, practical and political problems that have troubled both Flick and I through this process.

The Awareness Day is supposed to address stigma against BPD as well as debunk the surrounding myths, like that we are untreatable troublemakers who don't have a 'serious mental illness'. The idea was to help stir up a groundswell of people prepared to fight for more services. We have had to tread carefully through the discourse that governs these assumptions:

> *We argued that we need the day to hold the real tensions that exist between the different groups in the room and this means people may feel at times quite uncomfortable; this is good.*

We struggle with the word "stigma", which just doesn't work for us in this context. We also don't want a day that is all about 'everyone pretending to be nice to each other' when we know this camouflages the reality. We wanted a space safe enough to be able to discuss, for example, that:

- the worst oppression for people diagnosed with BPD comes from services;
- some of the most damaging books written about Borderline are designed for the carer market; and
- some of us with a diagnosis of BPD drive ourselves and others to distraction!

We argued that we need the day to hold the real tensions that exist between the different groups in the room and this means people may feel at times quite uncomfortable; this is good. We wanted a place where we could challenge the label. I like to suggest Complex Post Traumatic Stress Disorder, a diagnosis which goes to the heart of the white Elephant that would otherwise remain unspoken on the day – childhood trauma, defined carefully to include a large variety of felt-trauma experiences.

We asked for an acknowledgement of differences in amount of power different discourses held and which, challengingly, is mostly unfelt by the nice people engaged within the dominant discourses. In all discussions, we tried to change people's thinking away from clinicians-as-real-experts and consumers and carers as mere "perspectives". This was important.

One of the issues central to my thinking was that in 2013 when the next Diagnostic and Statistical Manual (DSM-V) – one of the most important classification systems in psychiatry – comes out, BPD will be re-assigned from Axis II to Axis I. This means it will be classified as a 'real' mental illness. Then, following this logic, BPD might be designated a 'Serious Mental Illness.' Then, people with this diagnosis would be able to access services much more easily – no doubt a good thing. But I have had trouble with whole logic of this for the following reasons:

> *Being told your 'personality' is 'disordered'... feels in every way radically different from a 'real' (biological) mental illness that you can understand as being separate from yourself ...*

1. Being told your 'personality' is 'disordered' (or 'pathetic', 'needs repairing', 'needs replacing', 'doesn't work'), feels in every way radically different from a 'real' (biological) mental illness that you can understand as being separate from yourself, like Churchill's 'Black Dog'. Being told your essential self is deficient is, for many of us, totally destructive regardless of what bows and ribbons are tied around it;
2. We know that 'serious mental illness' is relative and so the term automatically implies that something else is not serious. So there's unease about if the DSM-V slips BPD into the "serious" category, which groups are going to be left out and which of our friends and colleagues are going to be left in the space people with 'Borderline' presently occupy.
3. Such logic doesn't ask questions about the experiences of all these potential new services. Services for people diagnosed with mental illness have a bad track record. It seemed to us totally not OK to argue for more and more services without a sound, consumer informed, critique of what could be created which was respectful, would honour our exquisite sensitivity and was not based on more shaming. For us, an Awareness Day that just plugged for more money to create more of the same would be a disaster waiting to happen.
4. We are also aware of the 'behavioural' components buried in the classification of 'serious'. Regardless of where BPD stands in the DSM-V, if triage into services continues to involve proving we are a danger to ourselves or others then the services will continue to 'train us' to hurt ourselves or threaten violence. There's an imperative not to be silent on this one. This is a tension that we don't want grey-washed out of the day. The whole issues of self harm and Accident and Emergency Departments was potentially another white elephant.
5. Finally we carried a misgiving about increasing people's awareness of BPD before any new services have been created. Our questions were ethical ones.

> *... if triage into services continues to involve proving we are a danger to ourselves or others then the services will continue to 'train us' to hurt ourselves or threaten violence.*

There is no doubt that other people in the planning group had questions and reservations. There was politeness and a real sense that people wanted us to be happy with the organisations and respect for us, as Yoland Wadsworth would say, representing the Critical Reference Group. People were really respectful and we were grateful for this. It makes communication a lot easier. Nonetheless it was an interesting process because, no matter how polite people were, we had to be loud to be heard because assumptions matched the relative power of the different discourses. If we hadn't stood firm and resolute, less than ideal processes would have marred the potential of the day.

INTERVIEW OF THE ISSUE – Catherine Reidy

In this edition, Flick interviewed Catherine Reidy about her work on Pridentity – an inclusive sexuality teaching resource developed by queer young people, and arguably an example of the kind of "early intervention" work we so desperately need for better mental health in our communities.

Catherine Reidy, 22, describes herself as 'queer, fat, eclectic and epileptic' and identifies as an activist for social change in the areas of sexuality, gender and health. Currently completing a Social Work degree at RMIT, she has been working on inclusive sexuality education programs since high school. Ultimately she'd like to achieve 'community development nirvana' and make such programs redundant, and to live in a world where all individuals are valued and respected for who they are. Sadly, she doesn't see herself being out of work anytime soon.

Flick Grey: How would you describe what you are doing? How does your work relate to mental health consumer work more generally?

Catherine Reidy: With Pridentity we have developed a series of workshops that address homophobia, transphobia and sexuality more broadly, in schools. That's been running since 2009, but the main focus in the last six months has been the transforming of these workshops into a teaching resource. It's aimed at schools, but is also being used by community centres, youth workers and a whole bunch of other facilitators and practitioners, including young people themselves. I guess that's where the link is to consumer participation, this is a resource that has been developed by young people, who initially delivered it, and it's aimed at young people, stepping up and doing some work in their own communities, if that is what they feel safe and comfortable doing.

I started doing this work because of the high level of homophobia I experienced as an 'out' lesbian during secondary school- verbal abuse, rumour spreading, cyber-based stuff- experiences that inspired me to try and make things better for the next generation of queer students. As it stands, queer young people in Australia have a far higher risk of suicide attempts, 'completed' suicides and self harm than the general population, a correlation that (not surprisingly) rises in line with the amount of homophobia/ transphobia that they are subjected to.

FG: What you pick out as some real gems from your work – things that inspire you and that perhaps mental health more generally could learn from?

> *That breaking of silence, that shattering of stigma that happens when you share experiences, allow people to talk and ask questions- that keeps me going, for sure.*

CR: Delivering these workshops in schools can be nerve-wracking: how will young people react? Will I be abused? Do they even care? But what shines through, time and time again, is the bravery and sheer *gratitude* from young people. They say things like, 'We've never ever had a chance to talk about sexual diversity in this way before, and we're so glad it's finally being discussed'. That breaking of silence, that shattering of stigma that happens when you share experiences, allow people to talk and ask questions- that keeps me going, for sure. I hope one day we'll move it beyond gratitude, that sexual diversity will be integrated into mainstream curriculum- I look at Pridentity, both the workshops and now the Resource Kit, and it makes me proud to think It has contributed to that social and educational shift. I guess the lesson for mental health policy and programs is that they have to be willing to take that leap, to push boundaries, and be proactive about leading change in the community.

FG: What would you expect to be different if we lived in a community that embraced diversity – people with mental health problems, and queer youth – rather than just tolerating our presence?

CR: I think we would see things like a lowered suicide-attempt rate. We'd see more resources directed towards community health initiatives, rather than acute care. We'd see a lot more diverse representations in media, in arts, in curriculum. And I guess that's part of the aim of Pridentity, to put what has been virtually non-existent firmly into the mainstream curriculum. I think there's so much work that needs to be done in that area!

And similarly, madness and mental health are things that need to be integrated, rather than "touched on," or like you said, "tolerated." We need to get past "awareness days" and into mainstream, everyday teaching, learning and discussion. When I think about times when my attitude has shifted or my view on a particular topic has been changed, it's been when I've had the chance to talk to real people, hear about their experiences, ask them questions. And I think that's where we need to lead the broader community- past the negative perceptions, past the stereotypes and into the reality.

When I think about times when my attitude has shifted or my view on a particular topic has been changed, it's been when I've had the chance to talk to real people, hear about their experiences, ask them questions.

FG: What's the relationship between activism and the work that you do? And what top 3 areas would you target?

CR: I see work like Pridentity – education programs, training, resources – as activism. And I started doing activism as a protective factor for my own mental health. I knew that if I didn't become vocal, if I didn't speak out about these issues that I probably would not survive the amount of homophobia and discrimination that was levelled at me, that is thrown at so many queer young people. I think that's a pretty common thread throughout the queer community- for all our diversity, what we have in common is being harassed or discriminated against, and that collective experience naturally lends itself to activism.

... I started doing activism as a protective factor for my own mental health.

Of course, homophobia and discrimination can (and does) contribute to mental ill-health, and with that in mind, I'd push for more funding for community mental health; different models of mental health care than what we've currently got – more diversity, more options. And more varied representation in the curriculum, rather than just seeing mental health as a 'problem' or shortcoming of the individual. The way that difference and diversity are represented in the curriculum is quite limited. I'd like to see that expanded, see more attention paid to the structural and social factors that contribute to people's wellbeing.

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

CR: If I had $500 million that would be pretty exciting! I would look at mental health across the life-span, and look at the differences that are often ignored in mental health programs and policy, such as gender and sexuality. I think there's a lot of pressure to do early intervention because that's where certain powerful people are pushing at the moment. I don't dispute early intervention being important, but I find it problematic that such a homogenous, 'one-size-fits-all' model is being offered to try and address the concerns of such a hugely diverse population and I question it being the only thing that we spend money on. I'd be interested to put money into other initiatives and research, led by consumers themselves (radical notion, I know!) that address different concerns at different stages of the life-span.

> *I'd be interested to put money into other initiatives and research, led by consumers themselves (radical notion, I know!) ...*

And, you know, maybe we do need more acute care beds, but we also need to fill that gap between what we've currently got in community mental health and what we've got in acute care. There's a big, giant hole in the middle there that needs a lot of attention. We don't get a lot of attention because we haven't got the funding, we haven't got the programs, we haven't got the good will really, or the momentum. And I guess that amount of money would go a fair way to addressing that.

If I had $10,000, and I was purely advocating for my areas of interest, it would be around teacher training in inclusive sexuality education. I don't think that teachers realise how much influence they have, both by what they do and what they *don't* do. By allowing homophobia, by not questioning it, they are sending as powerful a message as when they do overtly homophobic things themselves. By ignoring and allowing, you're not off the hook and I think that message could be better expressed to teachers.

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

CR: Gosh! I think it would be a good day when we had people talking, rather than policy that seems to come out of not much consultation. A day when all sections of society were talking to each other, that would be a good start! A day when consumer's voices were just as valued as "experts" or doctors or psychs or whatever. A day when it was safe for people to live in their identities, rather than hide them and thereby causing a great deal more distress than is necessary. Particularly for young people who are queer, a lot of the distress comes about from not being able to live in their true identity. And that would be a good day for me, when young people could live as they are, and not fear for their lives, fear for their mental health, fear for their safety. That would make it easier to sleep!

> *... it would be a good day ... when it was safe for people to live in their identities, rather than hide them and thereby causing a great deal more distress than is necessary.*

The Pridentity Resource Kit was launched in August this year and is available to download free at www.whin.org.au.

RESEARCH OF INTEREST: Experiences of Stopping Antipsychotics Study

-By Carmela Salomon, PhD candidate, University of Melbourne

This PhD project looks at the important and under-researched topic of stopping antipsychotic medication. The researchers would like to find out more about people's past experiences of trying to stop antipsychotics including:

- What information people are given about stopping antipsychotics and how accurate/useful they have found this information to be?
- What, if any, physical, social, psychological and spiritual changes people have experienced when stopping antipsychotics?
- What strategies and services people find helpful or harmful when trying to stop?
- Any other thoughts about how practice can be improved in this area.

> *The researchers would like to find out more about people's past experiences of trying to stop antipsychotics ...*

For those of you who missed previous information about this study on the Our Consumer Place website, it's not too late to participate. You can still follow this link to find out more about the study or to give your feedback by completing the confidential survey: www.ourconsumerplace.com.au/consumer/article?id=4900

Thank you to all those people who have already completed the survey… We have only received 40 responses to date but we hope that as more people hear about the study these numbers will grow! People who have indicated that they may also be interested in being involved in the second phase of the study (in-depth interviews) will be contacted by the research team in the next 2 months, to organise a time for this to occur.

We have learned a lot from the feedback and experiences people have shared with us so far. While it's early days yet, and we are still wanting to collect more information about this topic, we can already see that this is an area of practice that can be improved, both in terms of how information sharing occurs and what supports are offered during the coming off process.

People have told us about experiences that vary greatly. Some people have talked about finding the experience frightening and isolating and feeling like they did not had adequate support from mental health professionals during the process. Others have described the process as liberating and exciting. Many people have described it as a mixture of both. Regardless of whether people have ended up deciding to stay on antipsychotics or to remain off them, most have highlighted the value of being listened to respectfully in any discussion about treatment, and feeling in control of the decisions that are made.

> *Regardless of whether people have ended up deciding to stay on antipsychotics or to remain off them, most have highlighted the value of being listened to respectfully in any discussion about treatment, and feeling in control of the decisions that are made.*

We will be sure to send updates to Our Consumer Place as findings become available.

Are you interested in the mental health workforce?

The Victorian government has recently put out a discussion paper – *Meeting Victoria's Funded Specialist Mental Health Workforce Needs: A consultation paper to inform the development of the Victorian mental health workforce strategy (2012-15)*, September 2011; Response period closes: **COB Monday 24 October** 2011 and should be sent to: mhworkforce@health.vic.gov.au. We will make the relevant documents available on the OCP website (after October 10th), so that more consumers can contribute.

This document is relevant to consumers for many reasons, including because *our mental health* is the focus of the entire mental health system (!!), but also because it specifically includes "consumer and carer consultants, consumer and carer peer-support workers" (p.5) Some relevant parts include:

- "**Increased consumer and carer employment** in clinical and community support settings" (p.8);
- **"Consumer and carer participation:** Mental health services should engage in ongoing consultation with consumers and carers regarding the planning, delivery, development, monitoring and evaluation of services and service should ensure that support and training are available to consumers and carers, in order that they can perform these roles." (p.12)
- **"Trauma informed:** Mental health services should be provided in a way that recognises and responds to the role that trauma can play in the lives of people accessing mental health services, and also the connection between trauma and mental illness, alcohol and other drug use and dual diagnosis." (p.12)
- "Consumer and carer workers are employed in various roles across the workforce, and recently the roles of consumers ... in the paid workforce has increased steadily however, ***limited data is available on this workforce***. It is timely to review these roles with a view to more strongly aligning them with consumer needs and new directions in service delivery, to provide clarity about how Victoria can better draw and utilise the potential consumer ... workforce and to ensure ***a career pathway and adequate remuneration*** as part of the specialised mental health workforce. Increasing support for the consumer ... workforce may include ***clearer role delineation and position descriptions, access to mentoring, supervision and support***. In particular, greater differentiation of systems advocacy roles (such as consumer ... consultants) and direct service roles (consumer ... peer-support roles) will provide improved role clarity." (p.15)
- **"**Strategy 3b: Fostering more positive views of mental health through ***positive exposure to mental health consumers*** and to discipline specific role models" (p.16)
- **"**Strategy 5a: Undertake a strategic review of the role and function of existing paid consumer, carer and support worker roles as an integrated part of specialist mental health service delivery; Objective 5: ***Strengthen the design and delivery of paid consumer leadership***, carer leadership and peer support worker roles in mental health. Strategy 5b: ***Develop carer, consumer and support role definitions with a view to clearly specifying the accountabilities, required competencies, training requirements and support mechanisms for these roles***." (p.17)
- "Professional barriers and organisational climate can impede effective multidisciplinary team work. Deeply embedded views on professional roles and responsibilities constrain team work and act as a major barrier to effective consumer ... involvement in treatment and care." (p.20)
- "The role of consumers and carers in the identification and assessment of the required competencies for the mental health workforce should be explored, consistent with the principles of recovery oriented practice." (p.24)

Introducing ... Psychiatric Survivors Association (PSA), FIJI

This month's featured organisation comes from one of our Pacific neighbours! This article was written collaboratively by the president of the Fiji Psychiatric Survivors Association, Ana Nanovo, and Viv Topp, an Australian lawyer (who was formerly employed at the Mental Health Legal Centre in Melbourne), who recently visited Fiji to work with PSA.

This is Ana Nanovo President of the Psychiatric Survivors Association (PSA) speaking at a village meeting in Vanua Levu a Northern Island of Fiji. Ana is a designer/seamstress, mother of 9, a highly respected friend and mentor to her extended family and many young people and a tenacious advocate. Prior to joining the PSA Ana had 2 admissions to St Giles in Suva a large psychiatric hospital, and only mental health service in Fiji. Ana tells her story and promotes the PSA and human rights throughout Fiji travelling often with the Fiji Disabled Persons Association.

The Psychiatric Survivors Association was formed in 2004 by a small group of people previously diagnosed with a mental illness. It is led by and exists for people with mental illness throughout the islands of Fiji. PSA decided to call themselves 'psychiatric survivors', as they seek to survive the experience of mental illness, the interventions and discrimination, and to enjoy life and well being.

Since PSA started it has focused on recruiting members, developing member skills, accessing funding and creating links with other mental health organisations. It is run by a group of hard working devoted volunteers all of whom have the experience of mental illness as survivors or family members. Despite complete lack of support and funding from the Government of Fiji the PSA has survived on meagre piecemeal donations from local business and overseas donors. The support from international organisations has increased in 2011 and PSA are hopeful for more funding.

> *PSA decided to call themselves 'psychiatric survivors', as they seek to survive the experience of mental illness, the interventions and discrimination, and to enjoy life and well being.*

PSA has managed to maintain all core and important key functions and more – with the hard work, passion and commitment of a team of volunteers they open the office every day, organise and conduct monthly meetings and visited PSA members in the community, at St Giles and in the prisons.

With a grant from AusAID through the Pacific Disability Fund PSA are conducting visits to psychiatric survivors around Suva and throughout Fiji. The funding has also enabled the organisation of a series of workshops on various topics – commencing with the strategic plan, vision and to design future activities. Workshops planned for the remainder of the year will focus on the Disability Convention, the new Mental Health Decree and mental health awareness raising.

PSA has more than 170 members and is keen to contact many of them over the next 12 months to provide them with information and support. This is not easy as many members live isolated, impoverished lives and it is difficult to keep contact when they have transient accommodation, no family support and no telephone contact. As PSA moves through Suva and in the villages they are meeting new survivors who are keen to join. The PSA has much to do to ensure that their issues are raised and their voices heard.

It is a crucial time for psychiatric survivors in Fiji – since 2010 when the government has signed the Convention on the Rights of People with Disability there is a focus on equality, inclusion and non-discrimination. Members must be informed of these rights and ways to assert them. It is our role to assist survivors, to advocate for PSA members and promote these rights.

In addition the Ministry of Health introduced a new Mental Health Decree, which commenced in July 2011. This decree gives people new rights and protections. It aims to challenge the way that medical services have been provided moving towards patient centred service provision and the establishment of centres for stress management at general hospitals and throughout Fiji.

PSA has formed good links with other civil society groups and aim to develop partnerships particularly with women's groups, prison groups, peace and justice organisations, human rights bodies and Fiji legal aid.

PSA has formed good links with other civil society groups and aim to develop partnerships particularly with women's groups, prison groups, peace and justice organisations, human rights bodies and Fiji legal aid. PSA plans to form strategic alliances with other significant organisations to promote mental health and wellbeing throughout the islands of Fiji.

PSA members are great story-tellers and speak warmly, openly and with humour. They are pleased to share their stories to educate peers, the civil society and stakeholders to assist them to understand and accept people with mental illness - psychiatric survivors.

PSA President Ana Nanovo has represented the organisation at conferences of the Pacific Disability Forum in 2010 in Nadi and this year April 2011 in New Zealand. New Zealand also invited Ana Nanovo to participate in the Pacific Women's Forum and raise issues for women with mental health issues and psychiatric survivors.

"The campfire" is coming to you! – a callout from Heidi Everett

After the fantastic Campfire night in Melbourne recently, it's now you, the glorious Mornington Peninsula's turn!

An invitation to: *carers/family* *consumer advocates* *mental health workers*. Please come along to one of the most enjoyable MH conferences you'll ever attend! Talk about OUR mental health system, as real people without the titles and labels, then sit back and enjoy the heart warming fire and share a laugh and a good time with friends. Please do consider attending, it's a really nice event and one you will feel really a part of.

Date: SAT 15th October 2011 **Place:** "Crib Cottage" Campbell St. Crib Point... a gorgeous private property with lots of comfy seats and plenty of great shelter if the weather is goofy. Look for the RED lanterns out the front, just down from CRIB POINT station. Melways 164 J 12 **Time:** 6:30pm - about 9pm Free! And kids and families are MORE than welcome. Please bring dinner for yourself and nibblies to share. **RSVP** by 15/10/2011 for our numbers – Heidi 0404 128 307.

The Campfire is non-denominational, and a no judge and jury event, organised by people from all 3 perspectives of the MH system working toward a better spectrum of care for us and our kids. We really appreciate the generosity of the property owners for welcoming us and hosting the Campfire.

Introducing ... The Mountains are in my blood, with David Braniff

In 1997 whilst living in London and working as a civil engineer I was struck by a serious psychosis that came on very quickly. Lift off happened in the space of a few days and very quickly I had lost almost all touch with this reality. In my mind I was living in a bizarre and cosmic theatrical construct. God has many children and I believed I was one of them.

In the years to follow I was to gain insight and awareness into an experience that I wasn't really in control of but was also part of me, my mind, thoughts and feelings.

For four years my psychosis occupied 100% of my waking hours. I vividly chased my mind around with creative and meaningful thought process. It meant something to me - not easily interpreted by others. The internal dialogue of my mind followed a story that in the finish had really created its own mythology and developed a meaning in divinity that I could relate to.

> *I vividly chased my mind around with creative and meaningful thought process. It meant something to me - not easily interpreted by others.*

After a psychosis it is very common to get depression. I had years of the hard black cloud. It was as hard to endure as the psychosis. Years of the double edged sword of psychosis and depression had totally damaged my connection with the community and society in general. I was living on the fringe. I did not however, fall through the cracks in the system like many others do.

Many years of slow but rewarding recovery followed. I had to be diligent and patient with the process of re-establishing connection with my previous life. I wanted to be myself and live in the real world. I now love the idea of contributing to society and like my place within the community. This is the opposite of a term used in the mental health field “social isolation”.

My “lived experience” of mental illness has enabled me to work as a Recovery Mentor in PHaMs Programs in Mackay, Qld and Wodonga, Victoria.

I have been encouraged to articulate my experience through public presentations and guest speaker roles. I have also had the opportunity to teach Certificate IV in Mental Health at Wodonga TAFE.

The Mountains are in my Blood

The combination of life’s journey and the work I’ve done in psychosocial rehabilitation have developed insight and awareness into the issues that result from mental illness and importantly the essential ingredients of recovery.

My greatest passion, and what I’m currently putting my energy into, is raising the understanding and awareness of mental illness and recovery within the community. There are so many benefits for a better educated society, not least early intervention.

Australian society is currently very interested in mental health and will welcome the documentary style short film “The Mountains are in my Blood”. Film-maker Tom Broadhurst and I are telling a very relevant story through high quality cinema and a compelling script.

Film can be such a powerful way to educate. This project has the potential to develop into a contemporary mental health platform with good internet considerations. It's also a positive way to engage the younger generation and encourage education. There is a real interest in the community for this type of content - now more than ever.

Production is now at the stage where we can show people what we are doing and encourage participation. This is a link to our blog: http://themountainsareinmyblood.blogspot.com/

We are currently raising funds to resource the final stage of film production. Every amount of money raised will be used to increase cinema quality which leads to a greater impact on the audience. From 1st October we'll have a set time to raise the target amount. The sums of money are modest and will greatly assist production: www.pozible.com.au/index.php/archive/index/3703

Please contact me if you would like to discuss: dabraniff@yahoo.com.au; Mobile: 0412 879 341

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

Our Consumer Place staff are always engaged in a wide variety of activities – bringing some long-term projects to fruition, supporting consumer developed initiatives as they come to our attention, and participating in and responding to the ever-changing mental health environment in which we operate. It often feels like we are rather fancy jugglers (Merinda and Flick did actually meet at a circus, but that’s another story...)

Speaking of stories, see page 3 for details about our very exciting new publication, hot off the press – ***Speaking Our Minds: a guide to how we use our stories*** – soon to be released into the world.

Also, see page 3 for our upcoming conference – ***Consumers as Educators***. This has been many months (years) in the making and will be a brilliant opportunity to share the sophisticated thinking and educational resources that have been developed by this incredible consumer community.

In other news, Merinda and Flick both teach clinical workers (ie. psychiatric nurses, psychologists, occupational therapists, social workers and psychiatrists) in various contexts, including teaching tertiary students, being invited to give keynote presentations at conferences, giving smaller presentations at various events and facilitating discussions. Both of us have been writing sections of some collaboratively-written mental health textbooks. We also participated in the annual Mental Health Services Conference; this is always interesting because while consumer participation is structurally embedded, it’s still in many ways another “Other People’s Conference,” because the vast majority of the conference reflects priorities that are not ours and are often at odds with our priorities. But we at OCP believe in engaging with the existing system strategically, despite its profound limitations, while strengthening consumer work and consumer perspective both inside and outside of the system.

We both have a special interest in issues around trauma and have been teaching on this issue. We have both also been integrally involved in organising the inaugural “***Borderline Personality Disorder Awareness Day***” on October 5th, in Melbourne (see Merinda’s article on page 8).

And finally, as always, we have been in contact with a large number of consumers and consumer-developed initiatives, projects, events and groups that are truly consumer-centric. As there is always more possible work than we are able to engage with, we strongly prioritise initiatives that are developed from a consumer perspective. While consumer participation is (usually) better than no participation, we have a much larger vision and a strong commitment to consumer perspective being fundamentally respected, and hence seek to nourish consumer leadership.

THUMBS UP/THUMBS DOWN

1. **THUMBS UP** to Jayashri Kulkarni and the team at The Alfred who have created Victoria's first women's only unit in 70 years. Before that there were many (but not like the ones we are now seeking!).
2. **THUMBS UP** to a wonderfully embracive definition of trauma we heard from a worker at Heal for Life: "an experience of more emotion than someone can handle in a given moment"
3. **THUMBS UP** to the Victorian Mental Health Carers' Network who have tried very hard to listen to consumer advice about arrangements for running the Borderline Personality Disorder (BPD) Awareness Day on 5th October.
4. **THUMBS UP** to Sathya Rau, Clinical Director of Spectrum (The Personality Disorder Service of Victoria), Jan Giffin and the other Spectrum staff involved in organising the BPD Awareness Day, for trying so hard to understand the consumer perspective despite all their training, directing them to think very differently.
5. **THUMBS UP** to Flick Grey (written by Merinda) for continuing, despite considerable hurdles, to maintain a political approach to organising the BPD Awareness Day in a way that fundamentally honoured the lived experience of the Critical Reference Group – consumers diagnosed with or recognising themselves as fitting the criteria of BPD.
6. **THUMBS DOWN** to the CAT Team that interpreted a consumer knowing the five criteria needed to be forcibly detained under the Mental Health Act as a symptom of illness.
7. **THUMBS UP** to the two nurses who ran fun and genuinely soothing activities at a public acute psych. unit and who were non-patronising, respectful, asked consumers for advice when no one turned up for the daily ward meeting (indeed, everyone quickly disappeared).
8. **THUMBS DOWN** to the staff on a High Dependency Unit (HDU) who used security guards to enforce their authority by picking on the youngest and most vulnerable person in the HDU to set an example to other older and potentially violent men.
9. **THUMBS UP** to staff on a HDU who tried to cope in a situation where there was extreme levels of underlying male violence and where vigilance and frustration were both obvious to other patients.
10. **THUMBS DOWN** to an HDU where there were five latently violent men and only one woman.
11. **THUMBS DOWN** to an acute unit where a person's personal belongings were put 'in trust' and then lost, including a mobile phone.
12. **THUMBS DOWN** to HDUs where staff fail to intervene in situations of unwanted sexual advances and where bedrooms are invaded, genitalia exposed and women terrified.
13. **THUMBS DOWN** to all acute psychiatric units where people urinate in public and urinate in other people's bedrooms and are not stopped or chastised by staff.
14. **THUMBS DOWN** to all staff in acute units who don't believe people when they complain about things like room invasion, people urinating in their rooms or other frightening transgressions.
15. **THUMBS UP** to the acute psychiatric unit that made a decision that it was just too dangerous to implement the no smoking directive.
16. **THUMBS DOWN** to the spruiking of "Emergency ECT" as if ECT is comparable to CPR. We acknowledge that there are consumers who have positive experiences with ECT, but the practice is very invasive and extremely controversial. Involuntary "emergency" ECT must not be conflated with honestly life saving emergency practices like CPR.

How to Live and Work with Non-Mad People

1. Sometimes Non-Mad people are hard to work with; sometimes they are not (just like everybody else).
2. Just because somebody has a tidy desk, do not assume they are Non-Mad, or vice versa.
3. When a Non-Mad person has taken sick leave, do not assume it was necessarily because they were physically ill.
4. Just because someone has a professional job, do not assume they are a Non-Mad person.
5. Non-Mad people sometimes suffer from delusions that Mad people are more likely to make lousy neighbours or employees. These delusions are treatable and should not be used as a basis for negative stereotyping of Non-Mad people.
6. Non-Mad people are safe to live with even if they commit most of the homicides.
7. Non-Mad people sometimes dribble or fall asleep or get muddled or forget, even though they are not on psych. drugs. They don't like it if you assume they are on psych. drugs.
8. Non-Mad people don't like to be told to keep taking their pills and pull themselves together any more than you do.
9. Be patient with Non-Mad people, they have to live longer (14 years male, 6 years female – even if suicide is taken out).
10. If you think that Non-Mad people can be a bit superficial, don't forget they are less likely to have life-priority-refining opportunities such as heart disease, cancer and diabetes.
11. Other life-priority-enhancing opportunities they are likely to miss out on are loss of income, occupation, employment and associated societal status; disrupted or curtailed education, relationship breakdown and housing problems.
12. Non-Mad people are also good artists, musicians and writers. Remember to be inclusive.
13. While being supportive, don't buy into cop-outs from Non-Mad people like "I don't need to take responsibility for my behaviour, because I am Non-Mad."
14. Remember at the heart of every Non-Mad person lies a human being, who needs to love and be loved just like you.

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