People diagnosed with 'mental illness' doing things for ourselves

OUR CONSUMER PLACE NEWSLETTER AUGUST 2012

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THUMBS UP/THUMBS DOWN

1. **THUMBS UP:** to our wonderful allies who understand their role in opening up more spaces for people with lived experience.
2. **THUMBS DOWN:** to "their recovery" – colonised versions of recovery where we fit into their boxes and programs and do what they think is "good for us"
3. **THUMBS UP:** to "the best life I can live as determined by me" (thanks Jon Kroeshel for that lovely turn of phrase!)
4. **THUMBS UP:** to community development approaches!
5. **THUMBS DOWN:** to non-consumers who listen to us briefly, but then stop listening altogether, believing they've "got it" and don't need to continue listening AND speak for us ... grrr!
6. **THUMBS DOWN:** to non-consumers who choose to focus their attention on criticising the word "consumer." Yes, it's a silly word, but there are many other silly words out there that have far graver social consequences. And anyway, it's *our* silly word!
7. **THUMBS UP:** to finding meaning in experiences that are difficult at first to understand, rather than just labelling them.
8. **THUMBS DOWN:** to the lack of trauma awareness in much of the mental health system. So much of what gets labelled as "mental illness" is understandable, adaptive responses to life trauma.
9. **THUMBS DOWN:** to having to say no to anyone who wants to come and do training (due to reaching capacity) :<
10. **THUMBS UP:** to the growth of so many beautiful approaches in our field. We are so proud to bear witness to this blossoming! It's a quiet revolution – as Arundhati Roy says, "Another world is not only possible, she is on her way. On a clear day I can hear her breathing."

Working towards genuine consumer participation: Why CAGs don't work

- A dialogue with Leah and Jacinta, project workers from Neami

Jacinta and Leah presented some of these ideas at the Victorian Mental Illness Awareness Council (VMIAC)'s Consumer Workforce Conference in late June. We asked them to submit this soapbox for the newsletter as we know many organisations have Consumer Advisory Groups (CAGs) embedded into their concepts and practices of consumer engagement and we wonder if this analysis resonates with other people's experiences of CAGs in action. We'd love to continue this conversation over subsequent newsletters ... let us know your thoughts!

Jacinta: When I started working at Neami (Neami is a national community mental health service, providing individual support to consumers in VIC, NSW, QLD, SA and WA), I was new to the mental health sector. I hadn't actually known that community mental health care existed; I certainly hadn't heard of a mental health consumer movement.

I was employed as a project officer to review the Consumer Advisory Groups (CAGs) at Neami – I only had a vague idea of what they were. I gathered that they had come from the mental health consumer movement, that their purpose was consumer participation, and that they were a way of gaining consumer input into how services are run.

Leah: While I didn't have the project skills or experience that Jacinta had when we started, I did have a lot of experience in consumer roles and the consumer movement. I had been a member of a number of CAGs in my time, and had had the privilege or running a couple as well. I had been working in a number of consumer roles, and I am employed as a Peer Support Worker at Neami, along with my role on the project.

We make a great team as Jacinta bought a lot of expertise around project work, whilst I was able to link our findings to external CAGs that I had been involved with.

Consumers often think they are there to represent all consumers, yet there are no mechanisms in place for them to do so.

J: Our project brief was simple – review how the CAGs at Neami were working and make recommendations for how they might be improved. When our project started, Neami ran a CAG in each state that Neami provides services, except WA. They met monthly, had approximately 12 members, and had a broad brief of reviewing policy and providing "advice" into Neami's initiatives. They were generally run by the state manager, or in some cases a delegate.

Our CAG review project team initially worked on the basis that the recommended changes to the CAG structure would be largely operational. The major finding in the first stage of the project, however, indicated to us that "fixing CAGs" would not be simple, or even desirable. Our key findings were that:

1. **The purpose of CAGs was ambiguous**. Simply put, people didn't know why they were there. Consumers, staff and managers across different states held varying views about the role of CAGs. *L: This is common in CAGs in other organisations. Consumers often think they are there to represent all consumers, yet there are no mechanisms in place for them to do so. In so many CAGs I have been a part of, the role of consumers is unclear.*

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2. J: **CAGs were not linked into any of the formal decision-making structures in the organisation**, operating in isolation. They were dependent on one person – usually the state manager - for agenda setting and in some cases did not have a sense of a broader purpose.
   L: In many services, CAGs are run by consumer consultants. This can often mean that the group is even further away from decision making bodies. We asked consumers in Neami's CAGs what they thought about management presence and they said it showed commitment from the organisation.

3. J: **Consumers often did not have the context needed to understand the documents they were advising on**, nor was there sufficient time for pre-reading. Some consumers we spoke to did not understand the difference between clinical and community mental health and so thought they were giving feedback on the whole system.

   L: Only one CAG I have been a part of provided some training for consumers. This was invaluable. How can a consumer be expected to participate meaningfully in a discussion if there is no context around what they are talking about? Sure, we want input on a policy, but what is a policy? What does all the jargon in it mean? What exactly does a policy do? One example is interview panels. How can a consumer participate meaningfully if they have not seen the position description, CVs of potential employees or understand the recruitment process?

J: CAGs had become routine: they were a way of "doing" consumer participation. But our project findings indicated that the purpose wasn't being met in a meaningful way. In an organisation that genuinely wants consumer participation, that has always paid consumers for their time on CAGs, that seeks consumer input into its activities – what was going wrong?

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L: In my experience, this is common. CAGs appear to be reactionary. They respond to what is going on in an organisation with little time for preparation, they aren't linked to higher decision making structures and there is no context. I had always thought it was because the organisations I was involved with didn't really care, and just saw CAG as the last box to tick before a new initiative was rolled out (if that). But I knew that Neami really did care about genuine consumer participation, maybe even consumer leadership. Why was it the same here as in the services I'd worked in that didn't care at all?

J: All the people our project team consulted with, both internal and external to Neami, expressed the need for a clear, nationally consistent CAG purpose. Why are we here? What are we trying to do? How do we know we're doing it?

L: Our consultations with external agencies found that others were struggling too. We spoke to several other PDRS organisations and community mental health services. We also had dialogue with peer support workers nationally who have experience in CAGS in a diverse array of services.

J: Organisations have an imperative to embed consumer participation in their practices because it's an organisational investment. It's vital to genuinely receiving input from consumers, which is what makes a responsive, relevant service. All the people we talked to during the course of our project, and literature from the consumer movement, emphasises the importance of consumer participation

beyond the tokenistic level. This means moving beyond "advice" and supporting the development of consumer leadership skills.

L: Speaking of tokenism; one service I was involved in "paid" their CAG members with supermarket vouchers that had the "not to be used to tobacco or alcohol products" disclaimer! This CAG spent the majority of their meetings doing "share time" so it was more of a support group. This was not consumer participation!

J: What if skill development was a new purpose for CAGs? What if we aim at consumer leadership and emphasise the importance of adequate support, training and resources to ensure this is possible.

It's also vital that consumers hear about the wider context of consumer participation and the consumer movement.

Our project team recommended phasing out the old CAG model, and instead embedding consumer participation in the organisation.

L: This meant that we could maintain the monthly groups, but give them a real purpose: capacity building and leadership development.

J: Consumer participation needs to be a shared responsibility, not the responsibility of one manager *(L:) or consumer consultant*. Consumer participation needs to happen at all levels of the organisation. Instead of CAGs, we want to run programs in each state that serve as "launching pads" for other consumer participation activities.

What will these "launching pad" programs do?

First, we want to create a safe environment where consumers learn, if they haven't already, about safe disclosure, their lived experience as a field of expertise, and how to apply this field of expertise to shaping Neami's services.

L: This is super important. So many consumers experience mental health system induced trauma. This trauma is usually what makes us as consumers so passionate, but it is often retold in CAGs in a way that can be re-traumatising for the person and the other consumers in the room. Often, when we ask for consumer perspective, consumers think that means they should talk about all the trauma, the denial of basic human rights and the abuse they have endured in the system. We wanted to make sure that no one thought they were expected to share those dark times.

J: Second, we want to teach context: about the mental health sector, models of care and Neami as an organisation. It's also vital that consumers hear about the wider context of consumer participation and the consumer movement.

Then we can get down to induction into specific areas: policy, or risk management, skills needed to be a consumer advisor on an interview panel or research so that consumers have a fundamental understanding of the area to which they are applying their lived experience expertise.

From here, consumers will be ready to apply their lived experience expertise to a given area: eg a policy or research committee. Consumers will have a safe space to return to where they can talk to other consumers and receive mentoring and further skills development.

L: By doing this first, we will then be able to have consumer advisors on internal working groups, have focus groups dedicated to specific purposes and have consumer input into the organisation's strategic directions. If we pull this off properly, it would mean that consumers would have a genuine, meaningful contribution to how the organisation moves forward.

INTERVIEW OF THE ISSUE – Rufus May!

Rufus May is a British clinical psychologist best known for using his own experiences of being a psychiatric patient to promote alternative recovery approaches for those experiencing psychotic symptoms. He was featured in a documentary called "the Doctor Who Hears Voices" (available here: http://www.channel4.com/programmes/the-doctor-who-hears-voices). He is a keynote speaker at the upcoming Mental Health Services (TheMHS) Conference in Cairns, and has been travelling around Australia, delivering training, workshops and consultations. Our Consumer Place was privileged to be able to co-host one of these workshops, on Healing from Emotional Trauma. Rufus brings together a wonderful, life-affirming combination of approaches, grounded in deep presence, compassion, respect and listening. He is also very playful – he wore a giraffe puppet on his hand during this interview (it's a reference to his engagement with non-violent communication approaches to compassionate communication). His website is: http://www.rufusmay.com/.

Our Consumer Place: How would you describe what consumers/survivors/mad folk are doing at the moment, in terms of changing systems and/or the world? And how does your work fit into this?

Rufus May: There is a growing movement of people telling their stories both of being on the receiving end of services and also of going through states of confusion and distress, and what's been helpful in that journey of empowerment, or emancipation, or recovery. That's a growing phenomenon – people encouraging each other to hear these stories. I guess what I try to do is elevate that wisdom that comes from experience, with my training. Everyone has personal wisdom, but clinicians defer to theories and don't listen to themselves enough, so I'm kind of promoting that elevation of wisdom from lived experience for everybody really.

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I'm interested in demonstrating that even the most mad experience has a kind of symbolism of meaning. I think if that's recognised, that might really challenge more medical, prescriptive approaches, because you can't then have a one-fits-all approach, you have to really help people find meaning in their experiences.

I think there's good stuff to be done around human rights, and it all comes from promoting the voice of lived experience, saying yep, I am someone to be listened to. Legislation often means people don't have the same rights, because they're "crazy people."

OCP: What would you pick out as some real gems, say three things that inspire you, or that you think are just brilliant?

RM: One I can think of is a project in London that is called Voice Collective. It's a project for children and young people who hear voices. I guess I think there's a real need to counter the growing pathologization of young people's experiences and children's experiences. That project works with parents and children around hearing voices, and educating them, and learning from them about

what's helpful – non-medical approaches to voice hearing. That seems to be a really good thing. They're using a lot of playful stuff, to engage children who hear voices, and going into schools and educating them, normalising the experience. I guess I'd like to see more of that, where we get into schools with non-medical ideas about distress and confusion being an understandable response to life's problems, and relationship problems and upsets and upsetting events. And really get that human understanding reignited in schools, so children are less afraid and more able to support friends. I think the kind of work that Voice Collective is doing – going into schools, working with that taboo experience, with that group of people – that's really brave and inspiring.

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[OCP: And do you see this kind of approach as fundamentally different to the kind of "mental health literacy" approaches that go into schools?]

RM: Yeah, from what I hear those approaches are much more about teaching people to recognise diagnostic criteria and things like that, and I think that just mystifies it and takes people's agency away. People think they are a victim of a diagnosable mental illness – I don't think that's very empowering, really. I'd rather see it as the mind's creative way of dealing with pain. We should be trying to create understanding, that this isn't something that is far removed from our own experiences, and be more accepting of grief, and pain, and when people are bullying themselves by self-harming, or something like that, well there's good reason for that – they will have been bullied in other ways. That's the way they're coping. Or understanding eating difficulties as a way to try to create some control. Just trying to get those ideas across to teachers and pupils, that it's something to be respectful towards and not be afraid of.

[OCP: and so the Voice Collective isn't just about people who hear voices specifically?]

RM: Oh, no, they are. But I'd be really excited about initiatives that did that in general. I'm not sure if there is one, but there should be! So that's my second one…

I really like some of the stuff that Rachel Perkins has done in mental health services. She's really tried to welcome people who have had mental health problems into the service as workers, and that's really positive. I'd like to see more of that. Often people who experience distress and confusion want to help others, and there aren't easy pathways of doing that. I'd like to see more of that.

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[OCP: And what is it about how Rachel Perkins does that?]

RM: Well, they have a whole department that is there to encourage the recruitment of people with lived experience. And I think they had a target to try to get a certain percentage of the workforce – like 20% or something – and they achieved that. Just seeing it as a valuable experience, rather than seeing it as something to be ashamed of. I'd like to see more employers doing that, like you would with other experiences of difference, you might see it as valuable for the job. I'd like to see that developed more. That's just one Trust in the UK – the majority don't adopt that approach. It would be a good model for other employers to be more inclusive.

And (well it's not a survivor-led thing) but I'm really interested in meditation and mindfulness. I do think it's really compatible with what survivors are trying to raise – the self-reflection that's really lacking in psychology and psychiatry. In mindfulness and meditation, you have to really understand yourself before you understand others. And also be humble about your own delusions – you know we've all got delusions! I really like that.

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We did these bed pushes – maybe we should do a few more! They were quite exciting, where we symbolically escaped psychiatric hospitals. The aim was to highlight that there is this other world going on where people don't have choices, there is no democracy. It is a totalitarian state and it's right within our own community, and people's experiences aren't respected, and they aren't listened to. And they're not seen as meaningful reactions to trauma, which they generally are. There's this archaic system operating right under our very noses and most people don't know about it. So we symbolically escaped from hospitals, dressed in pyjamas, and we pushed a bed on the road. We did 60 miles once, from Brighton to London! It raised awareness in a fun way. Things like that can be really good!

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OCP: What would you expect would be different if we lived in a community that embraced people who have mental health problems, or experienced madness, or as you say, distress and confusion?

RM: Well I live in a community a bit like that! I'm quite lucky to live in a community called Hebden Bridge, which is quite inclusive in many ways. It's quite an unusual, sort of artistic community.

I mean, really, it would be great if, like in Sweden, if some young people, when they're going through altered states of consciousness, were put into placements on farms. There's a film about it called *Healing Homes*, by Daniel Mackler. Therapists support the person and the family. If you've got families that are fairly healthy, that's a much better place to go than wards that are full of other people who are in states of disarray! The community would then be a resource. In Trieste, in Italy, they have a similar approach, really trying to base themselves much more in the community, and involve the community.

We had a retreat recently that we organised independently. We went from Hebden Bridge all the way up to the Lakes District, about 20 people, and we camped and we did scything and woodwork, running workshops and we did meditation. And it was really inclusive – we had someone there from a secure unit, we had people using mental health services, and we had their family members, and we had workers. Everyone just came together as a nice community. Everyone got some wellbeing from it, and from being close to nature. So I think having conversations, community meetings that

really squash those divides, and that teach wellbeing and communication skills that benefit everyone, and people with lived experience being seen as having a role in society, sharing their stories about what they've been through and what's been helpful. Breaking down the "otherisation" – there are lots of ways we need to do that, create community meetings so that can happen, where we embrace people rather than shun them.

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

RM: I think activism is important. It'd be nice on a legal front to have some successful cases against some of the damaging treatment approaches that are really harming people, like long-term consequences of drug-treatment, brain damage by ECT [Electroconvulsive Therapy]. It would be great to have people successfully take action against the hospital, because people would then be more careful about how they prescribed. There is increasing evidence about the health risks of medication. So that could be one area – trying to get more lawyers interested in the human rights abuses.

I'm very passionate about coercive treatment. The bed push was partly about that, about raising awareness about coercive treatment. You know, it's happening against children now, against adults, against older people – massive amounts. There are all kinds of areas to raise awareness about. I think using theatre is quite a good way to raise awareness. The bed push had a theatrical element to it. We had an ECT machine and we were offering the public free ECT.

[OCP: any takers?]

RM: No (laughs).

And it was really interesting that children and old people really connected with the bed push. And they're two marginalised groups in our society who aren't really listened to as well. So I think I'd be interested in campaigning around children and old people, and some direct action about their needs being overlooked. They are beings who should be respected, rather than just being drugged up.

... there is this debate about whether, say psychosis is linked to trauma or not. And it would be good to have a list of all the psychiatrists who say it has nothing to do with trauma, and have this kind of hall of biological ... fundamentalists – like the top 100. Because I think it's kind of like holocaust denial.

And one more thing ... there is this debate about whether, say psychosis is linked to trauma or not. And it would be good to have a list of all the psychiatrists who say it has nothing to do with trauma, and have this kind of hall of biological ...

[OCP: fundamentalists?]

RM: Yeah, biological fundamentalists – like the top 100. Because I think it's kind of like holocaust denial. I think these people are really denying huge loss and huge violence in people's lives. And they need to be outed! You could review it each year and invite people to debate, but really put it out there and ask how they can justify this, when people are telling their stories, clearly making links and having that denied. It's really tough, all that denial that goes on. We somehow need to elevate that debate.

OCP: 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? And what about if you only had $10,000?

RM: $500 million? Well I really like Non-Violent Communication, so I would have teaching programs for Non-Violent Communication. It's really good at helping people be really respected and listened to compassionately. So I would like that to be rolled out across mental health services, and across schools, and if there's any money left over, employers too!

If I had only $10,000, I would like to make a short film, 10 minutes long, that would promote this kind of compassionate, optimistic approach to distress and confusion recovery, for young people.

OCP: 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?

I get really encouraged when people really connect with each other. I see that really happening in self-help groups.

There are three approaches that I really like as ways of working psychologically. I've already mentioned mindfulness and Non-Violent Communication, and the third is Voice Dialogue. It's another very inclusive, non-clinical approach, and it's about how we can become more aware of the different parts of ourselves and make peace with the different parts of ourselves. I get really excited when people are able to start making peace with themselves, or parts of themselves, or across relationships, find ways to really have difficult conversations and tune in to truths that need to be addressed and talked about, aired, reconciled with. When I see that happening with people – I sometimes talk to people with voices, and I see them finding ways to make peace with their voices – that's exciting. And when I see those people then helping other people – that's really exciting! When I witness people finding ways to empathise with aggressive communication, and that then turning to understanding and people being able to be really authentic and start to heal, start to feel their feelings and feel heard, that's really exciting. It's very moving to witness.

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There's someone that I help – and we're not out of the woods yet – but they used to have a very aggressive voice, we call Top Dog. And now he's changed. He says he's a changed voice! He used to be very aggressive and very destructive, but now he gives really good advice, and his main message is – tell people to listen to the voices. Deep down, they're hurting. They might be being really obnoxious and destructive, but deep down there's pain that needs to be honoured.

You can do positive rituals to honour pain, like the other day we did a ritual to honour somebody's loss of a baby, we floated some flowers on a river- things like that. Find a way to bring nature and beauty together with pain, instead of trying to push it away – we do that too much – that's exciting.

First Aid for Emotional Trauma

Information Sheet

Trauma (or post-traumatic stress) is the emotional "shock" after a life-threatening, violent event. Anything that makes our body panic and go into a fight/flight/freeze response can leave us traumatized. The effects may be immediate or take time to surface, and can be felt for the rest of our lives.

Being traumatized is a **normal response to an extreme situation**; even 'tough' people like firefighters or soldiers can be traumatized.

The causes of trauma include disaster, abuse, rape, witnessing violence, loss, or spending time with people who are traumatized ("vicarious traumatization"). Because **trauma happens when our bodies perceive our lives are in danger and we can't escape**, even medical surgeries, emotional abuse, or loss of a loved one or home can be traumatic.

Trauma means getting **stuck in the memory** of a life-threatening event. Our bodies and minds act like the event is still happening, right now, even though it is in the past.

We are on guard, defensive, and 'geared up,' or hopeless, paralyzed, and numb. We avoid things that remind us of the past and trigger painful memories, and we isolate ourselves from others and limit our freedom. We block out unpleasant memories and feelings, sometimes turning to drugs and alcohol. We repeat past situations. We have panic attacks or go into jumpy "fight-flight" mode, even when there is no real danger in the present. Our lives, health, and relationships with other people suffer, and **we live constrained and limited by our past**. Sometimes we take our pain out on others, or become self-destructive.

In the past these trauma responses were crucial to our survival, and in the present they protect us from being overwhelmed. When we value the usefulness of our trauma coping mechanisms, forgiveness and acceptance can invite gradual change.

Unfortunately **trauma is usually not a wound that heals just by waiting** for time to pass. Trauma can keep hold of our lives for many years. It is important to try to work with the trauma somehow -- in whatever way is best for you.

Making connections with others and honestly expressing our feelings is important, especially when we want to hide or avoid our problems. **Finding safety and trust is the first step to healing**.

Just talking, though, may not be enough to heal trauma. **Sometimes talking about what happened can mean *reliving* what happened** -- and not help. If the talking seems to go in circles or not lead to a sense of completion, it might be just stirring things up, not healing them.

It is also commonly believed that you can heal trauma by 'getting it out of your system,' punching pillows or venting strong emotions. This can be helpful, but sometimes it can end up making things worse, or even re-traumatize you. **Real trauma healing is usually slower and more gentle**.

Therapy, including EMDR, DBT, and cognitive-behavioral, can help many people. Others find these are not helpful. This sheet focuses on what we can do for each other as a community. Most importantly, **everyone is individual -- experiment and discover what works for you** and learn how to best help yourself and others.

Signs of a traumatized or 'triggered' state:

Repetitive thinking of worrying thoughts or memories related to the event; intrusive memories and feelings. Chronic fear.

Staring off into space, 'thousand yard stare.'

Flattened or frozen expression and body: freezing and numbing. "Emptiness."

Extreme defensiveness and rigid thinking, irritability, explosive overreaction.

Sexual preoccupation and constant interest

Discomfort, pain, stress, illness: "nervios."

Returning to traumatizing situations.

When someone has just been traumatized:

1. Help any bodily injury, medical issue, or physical need first.

2. Make sure to go to a safe place.

3. Don't get up and act like nothing happened. Stay dry, warm, and still. Trembling or being emotional is part of healing, and better than 'numbing out.'

4. If the person wants to talk, listen without interrupting or changing the subject.

5. Encourage them to feel the sensations in their body fully. (See below.)

Feeling Body Sensations: Key to Trauma First Aid
Trauma cuts us off from our bodies. When we are in overwhelming danger, we dissociate or 'leave our bodies' as a protective measure. Later this protective mechanism becomes stuck and counterproductive. The **key to healing trauma is to return to our bodies**, by feeling our physical sensations and making our bodies safe and alive again.

Ask, "*How do you know that you are sad? Is there tightness in your chest or throat? How do you know you are afraid? Is there a cold feeling, or a sinking feeling in your stomach? Feel it fully. How large is the feeling? Is it changing? What do you feel next?*" Listen without interruption and give plenty of time to feel and respond. Grounding and resourcing yourself will also help the other person.

Keeping eyes open usually is best for focusing on body sensations.

If the person can't feel their body at all, ask, "*Can you feel your feet on the ground? Your pelvis sitting on the chair?*" Grasp their hand or shoulder and say "*Can you feel my hand?*" **Always ask before touching**. If lying down, ask them to sit up. Ask to walk around slowly and feel their legs and feet. Or gently hold & press their feet to the ground.

If the person is staring off in the distance, talking in circles, withdrawn, or agitated, encourage them to put their attention to the world. Ask *"Look around. What colors do you see? Can you name them?* Ask them what sensations they feel in their bodies.

When someone is preoccupied with the traumatic memories, find distractions. Ask them *"When was a time that you felt safe and peaceful? Can you describe the sights, sounds, smells and colors of that time?"* Ask them to feel sensations in their body.

If the person is defensive, on-guard and uncooperative, just drop it. Change the subject, go for a walk, leave the discussion / work for later. When a traumatized and defensive person perceives you as a threat, it is very difficult to convince them to just 'snap out of it' or to see that they are experiencing a flashback. Wait until they are calm to discuss it.

If body sensations are too uncomfortable, try to find a sensation, even small, that is neutral or pleasant, and focus on it. Go back and forth between uncomfortable and pleasant senations. Notice any relaxation in breathing, warmth or trembling. This is normal; feel the sensations fully.

Accepting our feelings
Feelings of fear, guilt, loss, sadness or anger are normal when we are traumatized. Don't judge feelings in yourself or others. Listen with acceptance and care.

Triggers:
It can be helpful to make a list of situations and things that trigger traumatic memories and upset you. Anniversaries of events, people, places, and situations can all be triggers. Learn to avoid your triggers, expose yourself gradually, or prepare for them when they come. Ask friends to help you.

Resourcing:
Write down a list of things that make your body feel strong and safe. It can be anything, such as walking or taking baths, exercising or sports, listening to music or petting your dog. Add things you've done in the past and would like to do again. Keep the list and add to it with new resources you find.

Breathing:
Relaxed, deep breathing can often bring relief from trauma symptoms. Sit comfortably and gently fill your belly, chest, and shoulders on the in breath, and exhale your shoulders, chest, and belly. Breath comfortably -- don't push or use effort -- but allow yourself to take slow, deep breaths. A few minutes of breathing this way can help calm you down.

Physical Health
Trauma survivors have weakened immune systems and are more vulnerable to getting sick. Get adequate rest and fresh water, go to nature, exercise, and avoid junk food. Consider a good-quality multi-vitamin/multi-mineral supplement, with plenty of C and B.

Psychiatric Medications:
Anti-depressants, tranquilizers (benzodiazepines), and other psychiatric drugs may provide short term relief and can help with extreme anxiety and sleeplessness. These drugs have very risky side effects and are toxic to the body. Long-term use can lead to addiction, make sleeplessness and anxiety worse, interfere with the natural healing process, and overdose can be fatal. Avoid or use cautiously.

Alternative, Holistic, and Herbal Medicine
Herbs, traditional remedies, and holistic care can be very effective for trauma. After 9-11 and Katrina, acupuncturists gave immediate relief to trauma survivors, including firefighters and medical personnel.

Helping Children Who Have Been Traumatized

1. Attend to any physical medical needs first. Make sure the child is safe, warm, and dry.

2. Calm yourself -- this will help calm the child.

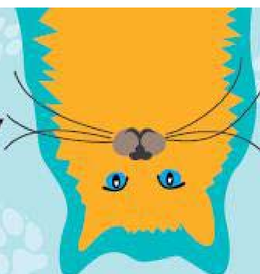
3. Tell the child it is OK to cry, to tremble or shake. Gently hold them and say "It's OK. It's all right to cry / feel angry. Just let the feelings happen."

4. Listen to the child and tell them their emotions are OK. Don't try to talk them out of their feelings or make them hush up.

5. Later, ask the child about what happened. Use toys or puppets. Go slowly so they are not overwhelmed. Ask what they are feeling in their body, where they feel it, what it's like. Stop and reassure them, then come back later when they are calm.

Written by Will Hall: wiltonhall@gmail.com.
Sources: Peter Levine, Judith Herman.
Thanks: Julie Diamond. 12-08 version.

INTRODUCING ...



Paws For Purrfect Patient Therapy

A consumer lead not-for-profit initiative

In this edition, we bring you an open letter from Naomi Fryers, the founder of Paws for Purrfect Patient Therapy, a practical, common-sense, growing consumer-developed initiative, based in Melbourne. Paws For Purrfect Patient Therapy (PFPPT) was founded in December 2011. Naomi Fryers currently works in housing and recovery in the mental health sector. She is a consumer and former foster carer for Save-A-Dog Scheme. Naomi is an animal lover with a passion for all things social justice. She believes how society treats their most vulnerable (including animals and consumers) is a reflection on society as a whole. She believes our pets are our best mates who deserve the unconditional love and loyalty they afford their owners.

"Dear Mental Health Consumers,
Here is an update on our consumer-run not for profit organisation Paws For Purrfect Patient Therapy (PFPPT- Melbourne).

PFPPT provides community and shelter based pet foster care services for people with mental illness. Our organisation was set up to allow patients to voluntarily surrender their pets during crisis periods (such as hospital stays).

To date sixteen pets of mental health consumers in crisis have been lovingly cared for by our organisation until such time as they are reunited with their owners.

In some potentially exciting news our organisation has just been nominated for a competition whereby we could win a $5,000 grant from Sun Super!!! This kind of funding would aid the organisations immensely and allow us to potentially expand our services!!

Do you think PFPPT is a good idea and want to get involved and help mental health consumers and their pets? Want to do more to help?? Voting is really easy!
http://sunsuperdreams.com.au/dream/view/paws-for-purrfect-patient-therapy
You just click on the link above and vote, then go to your email and click the link to make your vote count!!

Anyone requiring our services or wanting to volunteer with our organisation is also welcome to contact me. Please take a look around our website or get in touch!!

Many thanks,

Naomi Snell, Founder of Paws For Purrfect Patient Therapy (PFPPT)

http://www.pawsforpurrfectpatienttherapy.com/

Email: admin@pawsforpurrfectpatienttherapy.com; mobile: 0452 661 726

ourconsumerplace.com.au

RESOURCE CENTRE FOR MENTAL HEALTH CONSUMER DEVELOPED INITIATIVES

PSYCHOBABBLE COMPETITION AUSTRALIA

August 31st is your very last chance. We need more entries!!!

If you're going to the Mental Health Service's (TheMHS) conference in Cairns why don't you psychobabble on the plane? It's quite edifying to play with the language and the more you do the more you want to do… It's fun, useful, contagious and addictive! We are aiming for 1000 and we still need more! Below are a few more goodies to whet the appetite of all those who like word humour (puns are, of course, acceptable).

- **Manipulation:** Everyone manipulates. Those who get caught need training not castigation.
- **Manipulation:** There's nothing like the quite satisfaction of an excellent manipulation.
- **Manipulation:** A manipulation in the hand is worth two in the box.
- **Evidence Base:** Don't be confused about the difference between evidence base and the truth.
- **Severe and Enduring Mental Illness:** latest in a range of euphemisms for psychosis;
- **Severe and Enduring Mental Illness:** Blast! We have to change the letterhead from SMI to SEMI
- **SEMI:** semi colon!!
- **Sectioned:** Head, Arms, Legs, Torso thrown into the locked unit;
- **Recommended:** Your very good reference will enable you to be locked up against your will. Well done!
- **Scheduled**: Excuse me M'dear, the diary says it's time for your appointment with the locked unit
- **SOS:** Sectioned Or Scheduled
- **Recovery Plan:** Recovering from being Treated and Managed
- **Management Plan**: They talk about empowerment and then try to rule your life. Not very clever.
- **Treatment Plan**: I sign everything. No point in arguing if you'll just end up being thrown into the locked ward again.
- **Treatment Plan in Private Hospital**: I feel over-programmed already. There should be a programs limitation statute.

"PLEASE JOIN IN WITH US. WE NEED YOUR HELP NOT ONLY TO REACH 1000 ENTRIES BUT ALSO TO CHANGE THE THINKING AND ACTIONS OF THOSE WITH A LOT OF POWER IN OUR CULTURE: I'LL BE AT THE MENTAL HEALTH SERVICES CONFERENCE BUT WILL HAVE MY LAP TOP SO JUST KEEP SENDING THEM IN"

Merinda merindae@ourconsumerplace.com.au OR, by mail is fine: Merinda Epstein, Our Community, 51 Stanley Street, West Melbourne 3003

NEWS IN THE CONSUMER WORLD:

HACSU enterprise bargaining wins for consumer consultants

In an Australian first, Victorian Consumer/Carer Consultants have their wages and conditions properly identified and regulated, including regular pay rises. This is a significant first for Australia, to get Consumer and Carer Consultants covered by and recognised in an industrial instrument of any type. For more information, go to: http://hacsu.asn.au/images/docs/EP-outcomes-leaflet-fnl.pdf

Farewell Jon Kroschel

Jon Kroschel has recently resigned from his position as Consumer Consultant at Alfred Psychiatry. We don't normally report on every career move in the consumer workforce, but this one is a bit special – Jon was there for 15 years and he has made an enormous, thoughtful contribution to both the Alfred specifically, but also the consumer movement more generally. Jon was also one of the founding members of Our Consumer Place. His last day at the Alfred is 14th September 2012. We wish him well in whatever life holds next.

Guest editorial articulates vision for lived experience work

Louise Byrne (lived experience academic at Central Queensland University) and Brenda Happell (nursing educator) have co-written an editorial for the *International Journal of Mental Health Nursing* (2012) which articulates a vision for lived experience (ie. consumer) expertise. Here's an excerpt:

> *... At higher levels of employment or representation, it is essential that those employed in consumer roles have appropriate work experience in consumer roles and belong to relevant networks and affiliations. Just as a university would not employ a recently-graduated nurse for an academic position, a 'novice' consumer should not be employed for more sophisticated positions of representation. They must be trained in 'lived experience' work specifically, and understand the theoretical basis and the uniqueness of lived experience perspective. Consumer perspective and the consumer movement possess unique features and driving theories, like mental health nursing, albeit less established. Consumer employees must have a demonstrated understanding of and ability to work within service systems and the mental health sector from a consumer perspective, and to protect and promote the uniqueness of that position...*

The full article is published in the *International Journal of Mental Health Nursing* (2012) *21*, 299–300

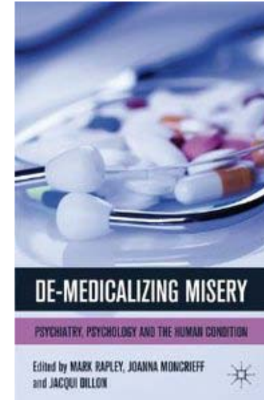
Australian Mental Health Outcomes and Classification Network (AMHOCN)

"The Australian Mental Health Outcomes and Classification Network (AMHOCN) has been tasked with developing a measure of carer experiences of care. AMHOCN has worked with a Carer Expert Advisory Panel and IPSOS Social Research Institute to develop a measure that captures information important to carers, is aligned with the National Standards for Mental Health Services, and has use across all age bands and service settings. The next phase of work involves undertaking a broader consultation to ensure relevance of the measure via focus group testing that will involve a small number of carers, consumers and clinicians. In total we expect no more than 15 - 20 participants.

AMHOCN is planning for this consultation / testing to take place in Melbourne from 10:00am – 1:00pm on Wednesday 12th September at the Crowne Plaza Hotel, 1 – 5 Spencer St, Melbourne. We are aiming to have carers, consumers and clinicians participate in this process and we are therefore seeking your assistance in contacting carers, consumers and clinicians to invite them to attend. If possible, we would appreciate this email being forwarded to people who you think can contribute to this process in a meaningful way.

Morning tea and lunch will be served and carers and consumers will receive a $50 payment for participation (paid via cheque or direct deposit following the consultation). Those interested in participating are asked to register online via the Latest News section of the homepage of the AMHOCN website http://amhocn.org or by emailing Josh Onikul: josh.onikul@nswiop.nsw.edu.au."

New book: De-Medicalizing Misery: Psychiatry, Psychology and the Human Condition, (2011) Edited by Mark Rapley, Joanna Moncrieff and Jacqui Dillon.



"Psychiatry and psychology have constructed a mental health system that does no justice to the problems it claims to understand and creates multiple problems for its users. Yet the myth of biologically-based mental illness defines our present. This book rethinks madness and distress reclaiming them as human, not medical, experiences." ... the table of contents alone is deeply exciting!

Readers may be familiar with Jacqui Dillon's work as a trainer, writer and voice hearer (www.jacquidillon.org); Joanna Moncrieff is a psychiatrist (who has been interviewed on madness radio: www.madnessradio.net/madness-radio-bipolar-medication-myths-joanna-moncrieff), and Mark Rapley was a key instigator of the critical psychology movement in Western Australia, before he moved back to the UK. Sadly, Mark died recently – we have lost a true ally.

2nd POWERS meeting

Below is an open letter from Heidi Everett about the recent POWERS meeting. Unfortunately, this newsletter didn't come out in time to publicise it, but we are assured these gatherings are wonderful and full of fabulous energy and there will be more.

"G'day all *Powerful* people,

This is an invitation to everyone, especially all mental health consumer advocates and carers, workers, anyone with an interest in generating real happiness and joy in people whose lives are affected by mental illness. The next Psych Ward Recovery and Support meeting is on Wednesday 15th August in North Melbourne. I'd love if you could please also share this invite with your MH advocate networks.

PWRS (aka POWERS) is a new concept in peer support. I'm really keen to hear from all people who are interested in running empowerment workshops using unique skills, passions and interests, or if you just have a great idea for a workshop, support group or other 'heart and soul' building activity. The psych ward 'recovery' bit is a bigger dream. One that will affect what goes on inside of hospital wards - some of us know how dire these places feel. A simple start could be the set up of a support group for people who've been left deeply affected by their experience, and involve those who can offer some kind of healing. POWERS is anything that gives people a sense of personal value and achievement, without relying on just traditional psychiatry, rehab and therapy. And it's not just people with mental illness that crave positivity and happiness, we all do!

Our first meeting was an excellent taste of things to come. Some initial concepts we hope to progress with are exploring creativity, honouring personal attributes like perseverance and spirituality, and more down to earth workshops like working with the environment and the natural world.

What has helped you in your own life? Want to share it? ... RSVP to skybeanz@gmail.com

Cheers all, Heidi"

Forgotten Australians

On August 8th, 2012, people from the Forgotten Australians conducted a rally on the steps of the Victorian Parliament House. The term Forgotten Australian was given by the Federal Government to the approximately 500,0000 children who were brought up in Orphanages/Homes including children brought up in and out of their family home.

"... We were locked behind doors alone and terrified. You did not hear our cries of pain and despair. ... It is difficult for many Forgotten Australians to attend rallies as many are living in poverty, are extremely ill, have physical and mental disabilities due to the severe trauma they experienced in institutions while under the care of the State. Many feel discriminated against, vulnerable and shamed in the general public. Despite this many are bravely attending this rally. This is the first time many have participated in a political protest calling for justice and redress."

Here is a link to a poignant song on this issue by Mark Torr (A Forgotten Australian) titled 'A Call For Justice': http://www.youtube.com/watch?v=rfXGNPuiOGM.

The group calls for:

1. A Redress Scheme to be implemented by the Victorian Government.
2. Reinstate funding to our service provider Open Place for life skills funding and medical.
3. A Royal Commission be established into the criminal abuse of children, sexual/ emotional /torture and criminal assaults into the children who were placed into State care.
4. The Victorian Government to pursue all offenders of sexual abuse, criminal assault and torture of the children who resided in Children's Homes and Orphanages. The sexual abuse of many children also happened when the children in these homes were placed with holiday hosts over school holidays.
5. The Victorian government change the existing laws to make all Church denominations criminally accountable for not reporting sexual abuse of children to the police.
6. That all Health and Community Services including: Medical Practices, Mental Health and Aged Care be provided with education from Forgotten Australians and given information regarding Forgotten Australians so that services can be specifically implemented to meet their needs and wants.
7. All Churches/Organizations to provide funding to our service providers Open Place so that programs can be once again fully funded.

The Fire Within: *A very special invitation to all mental health consumer support services.*

The Fire Within - 'I am not a victim of my illness, I am a master of my wellness'

A contemporary presentation on the experience of mental illness and wellness by indie mental health jillaroo Heidi Everett. Great for mental health consumer services, social services and community groups looking for something different to add to their calendar.

'I take mental illness by the horns and wrangle it into a purring little kitten. Using thought provoking original music, artwork and surprising audience participation, I invite you to create your own braver, more vibrant set of perspectives. Because mental illness isn't the experience, it's the way we deal with it.'

Some informative stuff...

Heidi has over ten years experience presenting to a variety of audiences and communities around Australia. Prior talks include; the Big Issue Street Soccer program, Port Phillip Prison, Lord Somers Young Leaders project; Peninsula Health, Alfred Health, Carers Council of Australia, the Women & Domestic Violence campaigns and Tasmanian Mental Health Week official launch. Heidi has also featured on many local media outlets, Channel 31 and ABC television (Enough Rope 'Angels & Demons'). Heidi also has directed many exciting community events and projects including the Mimosa Arts Festival, Schizy Week events, the Campfire Conferences and runs the new concept in peer support POWERS.

One hour presentation (plus Q&A, cuppa with audience). Fee can be negotiable. Smiles assured.

Email: skybeanz@gmail.com; Text message: 0404 128 307; ESP: not available yet; www.heidieverett.com.au

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

Intentional Peer Support Training

We have begun delivering Intentional Peer Support training After a trip to QLD to hone our skills, OCP is running a course in early Sept (all places are filled, but there will be more in the future)!

Consumer Perspective Supervision

Flick is working on a project to examine best practice in consumer supervision (in the sense of reflective space/practice supervision, not line management). If you have experience or thoughts on this topic that you'd like to share, please drop Flick a line: flickg@ourconsumerplace.com.au.

Advance Directives

Our Consumer Place recognises the value of advance directives in mental health. Merinda gave a talk on this topic at a forum run by the Centre for Excellence in Peer Support on the topic of Employing and Supporting peer workers. See also VMIAC's workshop on Advance Statements on page 20.

The Mental Health Services Conference

We will be at the Mental Health Services Conference in Cairns (August 21st -24th)- running a workshop on using story, and another with Emma Ladd (from the Mental Illness Fellowship) on Allies in Mental Health. Flick is also speaking on the Consumer Day. Do come and say hello!

Dax Centre: To Live is to Fight

The Dax Centre currently has a great exhibition by Donna Lawrence, a beautiful artist from QLD, with lived experience of 'mental illness.' We were involved in opening the exhibition and as part of a forum on Human Rights in Mental Health.

Newsletter feedback –

Thank you to everyone who gave us feedback on the newsletter - it was really valuable to us. The hardest part now is knowing that we cannot possibly please everyone! But there will be some changes over the next few months, in response to the feedback.

Psychobabble

Keep those entries coming in! See pages 14-15 for more information about Psychobabble, but keep spreading the work, and bear in mind the closing date is August 31st. And rest assured names will only be attached to the winning entries, and anonymity is always possible! Enjoy!

Neil Turton Lane: A Consumer Workshop on Advance Statements

VMIAC's CONSUMER WORKFORCE EDUCATION AND MUTUAL SUPPORT DAY

11 am-3 pm Thursday 06th September 2012

Guest Speakers:
Neil Turton Lane: Team Leader, Consumer Participation Mental Health, Western Region Health Centre
With David Pedlar, Wing Ho, Josephine Maria and Gizem Acaroglu

Join us for a one hour interactive workshop on Advance Statements developed by Consumers and the Consumer Consultant team at Western Region Health Centre. Incorporating actors, storytelling and information learn how a written Advance Statement can provide extra support in a time of crisis with regards to: psychiatric admissions, home and living arrangements, family & friends, finances, workplace and more

AGENDA

11:00 to 12:00 Guest Speaker:
(This session is open to the entire Consumer Workforce, Consumers & Consumers who are looking at becoming a Consumer Consultant and PHAMS Workers).
12:00 to 13:00 Lunch …..All Welcome
(This afternoon's session is open to the Consumer Workforce ONLY)
13:00 to 15:00 Mutual Support

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

WWW.VMIAC.ORG.AU

VMIAC Bldg 1, 22 Aintree Street, Brunswick East Tel 03 9380 3900 Fax 03 9388 1445