Marie McInerney reported on the VMIAC – Our People, Our Voice Conference held in Melbourne from 1 – 2 November 2017 for the Croakey Conference News Service.

#VMIACCnf17

Croakey is a social journalism project for public health based in Australia. [http://croakey.org](http://croakey.org)
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Shouting out loud – hear the consumer voice in mental health policy and programs

(Intro by Marie McInerney)

Making sure that mental health consumers have a voice in their own care, in services and the broader workforce, and in big policy directions like the National Disability Insurance Scheme (NDIS) were key issues on the agenda for the 2017 Victorian Mental Health Illness Awareness Council (VMIAC) conference.

The two-day conference put lived experience at the core and showcased leadership and innovation from consumers and the consumer workforce and the importance of co-design and co-production.

It came amid major developments for the consumer mental health workforce in Victoria and with the NDIS, as well as concerns about a lack of consumer focus in the Fifth National Mental Health and Suicide Prevention Plan.

Policy experts were also disappointed there was barely a mention of mental health in the Productivity Commission’s recent landmark report, Shifting the Dial: 5 year productivity review, on priorities to enhance national welfare.

The theme for the VMIAC conference was Our People, Our Voice: an opportunity to yarn and forge our future.

It’s one that resonates personally for VMIAC CEO Maggie Toko, who lost and found her own voice during a traumatic childhood and adolescence, growing up in Aotearoa/New Zealand, dealing with disability, racism and grief, and through her own diagnosis of schizophrenia.
Croakey thanks her for permission to publish an edited version of a speech she gave soon after taking up the role at VMIAC in 2016, about her experiences growing up and what having a voice and choice means.

Keynote speakers at the conference included Victorian researcher and tertiary educator Cath Roper, who won the lifetime achievement award at the inaugural VMIAC 2016 Consumer Awards, and Fay Jackson, Deputy Commission with the New South Wales Mental Health Commission and general manager of inclusion at Flourish Australia.

Maggie Toko writes:

I know firsthand what it feels like not to have a voice.

I was born with a severe stammer. School was a nightmare for me, having to read out loud in class, I would count in my mind how many people were before me, I would get so anxious that by the time it got to me, I would have ripped the book, picked up the desk and thrown it across the room. Needless to say, I was forever in trouble. Had I been an adolescent today, I probably would have been diagnosed with oppositional defiance disorder.

I learnt embarrassment at a young age, I learnt what it was like to have my peers laugh at me, to have adults berate me, the classic line “speak slower, spit it out”.

Two profound things happened to me when I was a child. The first was I learnt to be silent. I did silence really well.

I didn’t get embarrassed anymore and neither did anyone else.

I gave up speaking at six years old. Most of the adults in my life just accepted that I didn’t speak.

This, however, brought different dilemmas. Being silent in society is unacceptable. If someone asks you a question, you are expected to answer it, if you don’t then you are considered to be hiding something, or you’re labeled stupid, rude, dumb.

If you can imagine, my childhood and adolescence were dark days. I had teachers say to me “If it wasn’t for the law, I would tell you to not bother coming here” and “you’ll never amount to much, I don’t know why we bother”.

The second profound thing that happened when I was young was that I heard a man call my mother a nigger. I watched her embarrassment, and his anger, it frustrated me because I couldn’t speak to defend her. That frustration would never leave me.

Those dark days would grow even darker when my mother died, when I was 12. My father had already died when I was a year old so this made my younger sister and I “wards of the state”.

For all those teachers saying I was dumb and stupid, I read profusely. Libraries were my friend, they were places of silence as there was no expectation for you to talk to anyone. I read books on civil rights, Dr Martin Luther King, the Black Panther movement.

I remember seeing the two athletes raise their fists in protest at the Olympics, watched them be stripped of their medals. I read about Dr King riding the freedom buses and wished that could have been me. I read that they believed in taking back freedom, not waiting for it to come to them.
Aotearoa had its own civil rights actions happening at the time. It resulted in a land march walk from one end of the island to the other, led by some of our elders. I joined the march when it came through our town, I had my first sense of what it meant to be proud to be a Maori. I spent less time at school, and more time hanging out on the street, it is where I met and started hanging out with a gang.

They were the first people to speak to me properly. I literally couldn’t string two words together when communicating with them. It didn’t matter, they listened until I was finished. Their response was “that must be one bad buzz for you sis”.

All of a sudden I had people who got me. People who didn’t care how I sounded, people who encouraged me to swear. Through swearing I was able to link my words together, I could say whole sentences without stuttering. For the first time in my life I was encouraged to believe that I just might do something. It took six months of being with the gang to find my voice, to recognise that outside of the books I had been reading, I had choice in my life.

I believe that choice is a hard thing to define. At that developmental stage where I learnt that I had a choice, I decided that I could accept everything that adults had told me over the years or I could make my own path, I decided to do just that – make my own path. I call it rowing my own waka or canoe.

Rowing my own waka encouraged me to continue using my voice, it provided freedom which I had never known before. It gave me confidence. It gave me the ability to say no. ‘No, I will not accept that judgement’, ‘No, I will not settle for second best’, ‘No, I will not be silenced anymore’. Embracing the meaning of having a voice would elevate my ability to advocate for myself when I was later diagnosed with schizophrenia.

Those earlier years would shape my passion for working with people, young people and mental health in particular. I don’t share my story much, I never wanted it to be a burden on anyone else. At the same time I made a decision not to hide it either.

I have worked with young people who have the most tragic stories but through all adversity they survive. They are encouraged to speak out, to empower themselves by dominating the space they consume, to stand proud about who they are.

Power to the universal voice, I say! Your voice matters – silence is NOT golden when it is used to suppress people. Freedom to express yourself in a way that is user friendly, in a way that achieves your goals, in a way that empowers you is paramount to having choice. The right to choose which path you want to take, without coercion, should be yours to make. Imagine what the world would be like if people focused on positive choices only.

Choice brings with it responsibility – that we make choices that are not harmful to ourselves or others, that we utilise decision making consensus. If it doesn’t feel like the right choice, then use our voice to question more.

Collectively, we as a community need to do that. Too often, communities think that they are destined to accept the status quo of what society thinks – this is not so, the fact that we have lived experience consumers in the workforce is an example of that. Our collective voice is not about standing alone, it is about standing together, it is about sharing our stories, sharing our collective vision.

Our consumer voice is about acknowledging that those whose voices are silent or just a whisper have a right to be heard, have a right to be safe in this space so that they may one day shout out loud – this is ME, I am HERE.
Powerful call for action to stop human rights abuses of people with mental illness

Marie McInerney writes:

Leading mental health advocate Fay Jackson has urged fellow consumers to “use the language of the law” to hold people and governments to account on their failures to protect the rights of people with mental health issues.

Jackson, who has been diagnosed with bipolar disorder and is deputy commissioner of the NSW Mental Health Commission, delivered a powerful and emotional address on the opening day of the Victorian Mental Illness Awareness Council conference.

Jackson urged mental health consumers and advocates to focus on human rights rather than the role of stigma – which has been a target of many mental health campaigns over some years, and which she called a form of “soft discrimination”.

She described Australia’s commitment to key human rights protections as “a frigging joke” and urged more than 250 delegates, many of them mental health consumers and peer workers, to not just try to change services, but to change society.
“This world is too bloody hard, and we need to change it,’ she said. “It needs to be soft, it needs to be generous, it needs to be what we are, which is fragile and fierce”.

Jackson was speaking immediately after attending a memorial service near Melbourne for Jackie Crowe, a much loved and respected member of the National Mental Health Commission since its inception in 2012, who died suddenly recently (as previously reported at Croakey).

Explaining her “lithium tremor” for those at the conference who don’t know her, Jackson said it did not come from anxiety about public speaking, although she said she is always anxious when she speaks, mindful that she has to seize every opportunity to make a connection, to convey a message.

“All the moments we have are important, today of all days we should know that,” she said, holding back tears. “I acknowledge our sister Jackie. We bid you goodbye.”

Other speakers and delegates at the conference also paid deep tribute to Crowe publicly and privately, describing her as “high achieving, tireless, and hardworking” and a “champion, someone who held us bureaucrats to account in a very fair and genuine way”. (Read more tributes at the bottom of this post.)

**Focus on human rights**

Jackson urged mental health consumers and advocates to stop talking about the role of stigma, and to challenge on human rights grounds.

She said:

- *This is the language we need to be using, this is the language we need to speak.*

- *This is the language we need to hold each other and the government of this country to account.*

- *If you’re being intimidated, bullied, harassed, victimised, they are the words you should be using.*

- *We’ve allowed soft discrimination by using the word ‘stigma’. Reclaim the language of the law that will give us power.*

**Stop childhood trauma**

Jackson, whose conference biography describes her as a mother and grandmother who has also worked as a “Go Go dancer, teacher and comedian”, recounted being warned by doctors that she would never hold down work and “never be a valuable member of society”.

Now, as well as her role at the NSW Mental Health Commission, she is the General Manager of Inclusion at Flourish Australia, a large community managed organisation that supports people with mental health issues across New South Wales and south east Queensland.

And she’s a sought after public speaker and advocate for mental health rights, who has spoken across the country, including on programs like the ABC’s Q&A and One Plus One, calling out multiple abuses experienced by people with mental health issues, from child sexual abuse to forced medication and being confined to seclusion.
“Stop sexually abusing us as children and you’ve driven down most of the suicide rate,” she said, talking about the ongoing failure of health systems to invest in prevention instead of crisis interventions.

She also busts taboos and speaks out on the losses that people with mental health issues often experience from medication. Her tremors mean she can no longer do the fine brushwork that defined her painting.

Her message at the VMIAC conference for mental health consumers and advocates was to study the Universal Declaration of Human Rights, particularly Article 5, which states:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

“Australia is a signatory to that,” she said. “What a frigging joke”.

“What the hell have we been through (as mental health patients) if not that,” she said, pointing to patients with mental health issues being forcibly injected and suffering dramatically lower life expectancy.

Her slide said:

- What is being taken down and forcibly injected?
- What is being locked into seclusion and restraint and being forced to clean your own faeces?
- What is being forced to take medication that makes you obese, significantly negatively affects your quality of life and shortens your life expectancy?
- What is being placed on a CTO (community treatment orders)? This is not recovery focused!!

Jackson raised the shocking 2014 case of mother-of-two Miriam Merten at Lismore Base Hospital in New South Wales, who died after falling at least 20 times after she was locked naked in a seclusion room and chemically restrained.

“What happened to our sister Miriam is not unusual,” she said. “The only thing that was unusual in that situation was that it was recorded and (the footage) was released.”

Jackson also blasted Australia’s commitment to the International Convention on the Rights of Persons with Disabilities, which recognises the “right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”, when people with mental health issues have significantly lower life expectancy than other Australians.

Other failures for people with mental health, she said, were the International Covenant on Civil and Political Rights that “no one shall be subjected without his free consent to medical or scientific experimentation”, and rights to education, work, healthcare and social security, so often breached in Australia.

In Sweden, which she recently visited, 72 per cent of people with a schizophrenia diagnosis have a job. In Australia, only ten per cent do.

“Shame on us,” she said.
You can track Croakey's coverage of the conference here.

**Tweet reports**

*Flick Grey @flick_grey · 15h*

#VMIACConf17 Fragile and fierce. The wonderful Faye Jackson. Change will never come out of comfort.

*Indigo Daya @IndigoDaya · 15h*

@Faye_Jackson_MH: We need to stop using the language of stigma & use the language of law: discrimination, bullying, harassment #VMIACConf17

*Flick Grey @flick_grey · 16h*

#VMIACConf17 Faye Jackson: Australia is signatory to Universal Declaration of Human Rights. And yet we have forced mental health treatment.
You can track Croakey's coverage of the conference here.

Powerful call for action to stop human rights abuses of people with mental illness

#VMIACConf17 gets started

Our People, Our Voice Conference 2017
An Opportunity to Yarn and Forge Our Future

November 1st and 2nd
Northcote Town Hall
You can track Croakey's coverage of the conference here.

Powerful call for action to stop human rights abuses of people with mental illness

#VMIACConf17

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Powerful call for action to stop human rights abuses of people with mental illness

Tributes to Jackie Crowe

Jackie Crowe: “a champion, someone who held us as bureaucrats to account in a very fair and genuine way”. DHHS official #VMIACConf17
You can track Croakey's coverage of the conference here.

Powerful call for action to stop human rights abuses of people with mental illness

Statement by Minister Greg Hunt
Statement by SANE Australia
Statement by Brain and Mind Centre at University of Sydney
Statement by Mental Health Commission
Statement by Mental Health Australia
Statement by Connectica
Mental health services are causing trauma, rather than healing

I went mad because of horrific childhood trauma.

The system I turned to for help made everything worse.

My healing came from doing the opposite of what the doctors tried to force on me.

From powerpoint presentation by Indigo Daya

Marie McInerney reports:

The mental health system continues to inflict trauma, violence and harm because it regards those it sets out to help as the ‘problem’ to be fixed, not the ‘customer’ it serves.

That’s the assessment of leading Victorian mental health policy adviser Indigo Daya, a survivor of childhood trauma and a former compulsory patient of mental health services, after years of working in mental health consumer roles and in government.

Daya, who is Senior Consumer Advisor in the Office of the Chief Psychiatrist in Victoria and a long-time consumer and human rights advocate, was a keynote speaker at the VMIAC conference.

She said a big challenge for the consumer movement is that the system still sees the general public as its ‘customer’ and its aims to be about public safety and a sound economy, rather than the health and recovery of the people it treats. (See her slides below.)
Mental health services are causing trauma, rather than healing

“I thought…we’d been strong in delivering messages about what’s not okay, about the ways in which the system hurts us, fails to acknowledge trauma and abuse, the ways the system is violent and strips us of our rights, about those of us who end up worse off after experiencing services that are supposed to help us,” she later told Croakey.

“But what I’ve learnt in recent years is that those messages haven’t got through in the places they need to and that needs to inform our work, how we move forward.”

Seeing how the system works in terms of ‘customer’, ‘problem’ and ‘provider’ also helps to explain why consumers remain the least influential voice in the sector, way behind psychiatrists, the nursing union, and carer and family advocacy groups, she said.

“I think the ‘customer’ is the general public and we’re actually the problem that the system’s trying to fix,” she said.

“So that makes sense to me about why we’re not listened to: why would you listen to a problem, you’re just trying to fix it or get rid of it or contain it or control it.”
“We need a trauma system”

Like many other consumers, Daya prefers to talk about ‘madness’ rather than ‘mental illness’.

She was diagnosed with schizophrenia and borderline personality disorder, but she told the conference it was only after years of damaging interactions with the mental health system that she understood she “experienced madness” because of trauma and abuse in her childhood.

At her much-read blog and in other publications, she has written that there were so many lost opportunities for mental health clinicians to ask about her childhood trauma and offer counseling services and peer support that could have helped.

Instead, Daya said, she was subject to forced treatment that caused further harm.

“As a person living with madness”, she learnt that the system she turned to for help made things worse.

She only healed after peer support and trauma therapy helped to make sense of her experiences. This was despite a hospital psychiatrist who tried to prevent her from doing trauma therapy.

Daya acknowledged that this is not the story for everyone but said health professionals who talk about evidence-based treatments should recognise they don’t work for everyone.

Her experience, however, drives her focus on the impact of trauma on mental health.

Talking about evidence that between half and three-quarters of psychiatric inpatients had been either physically or sexually abused as children, Daya said she had been stunned to learn that experiencing multiple childhood traumas appears to give about the same risk of developing psychosis as smoking does for developing lung cancer.

Trauma was incredibly common and yet really not addressed or understood in the services that are there to help those affected by it, she said.

“I think we have to question the whole foundation of pathologising human experience and calling sadness and fear and shame and anger ‘illnesses’,” she said.

“For me we don’t need a mental illness system or a mental health system. We need a trauma system and we need a human system and an emotional system and a justice system that serves what people need, with no force whatsoever.”

She shared a quote from Professor Louise Newman, psychiatrist and Director of the Centre for Developmental Psychiatry and Psychology at Monash University that:

Failure to acknowledge the reality of trauma and abuse in the lives of children, and the long-term impact this can have in the lives of adults, is one of the most significant clinical and moral deficits of current mental health approaches.”
You can track Croakey’s coverage of the conference here.

Mental health services are causing trauma, rather than healing.

Experiencing multiple childhood traumas appears to give approximately the same risk of developing psychosis as smoking does for developing lung cancer. (Benton, cited in Slade & Longden, 2015)

Failure to acknowledge the reality of trauma and abuse in the lives of children, and the long-term impact this can have in the lives of adults, is one of the most significant clinical and moral deficits of current mental health approaches. (Prof Louise Newman cited in Kezelman & Stavropoulos, 2012)

I knew that Trauma was common for Consumers in the public MH System, but not just how much. 😢#VMIACCConf17

Trauma prevalence

Of people who use public clinical mental health services:

- Sexual or physical abuse as children
- Sexual or physical assault as adults
Silencing consumers at work

Daya also spoke about the big challenges facing mental health consumers in the workforce, not least that many often have to revisit trauma on a daily basis, in her case from her childhood and also from her compulsory treatment.

That came home graphically for her at a recent psychiatric conference in Europe where – right next to the morning tea and coffee each day – was a commercial display of restraints, complete with posters of them in action.

She was also dismayed by the approach of the conference itself.

Organised on the theme of ‘violence in clinical psychiatry’, she said it was focused “almost entirely about when people like myself might be violent, rather than… that the system itself is actually violent, a system that uses force, coercion, threats and restraints and treatments that have stripped away our cognitive ability and our memories…”

But she said there were many other barriers to consumer participation in the mental health workforce, on multiple levels:

- Sorry but that’s a minority view
- I’d love to, but we don’t have time
- That’s a subjective view
- But what about…/that’s like when...
- Is that representative of all consumers?
- Where’s your evidence?
- That’s not reasonable
- You don’t understand
- What current consumers say is more relevant
- The consumers I know don’t say that
- You can’t say that here
You can track Croakey’s coverage of the conference here.

Mental health services are causing trauma, rather than healing

Hurtful oppression

Consumers also face a series of “emotional safety barriers” in their work, whether they work in policy, research or service delivery, she said.

These include isolation – often being the only consumer in a team or organisation, of having everyday work issues pathologised, and having to make impossible choices about what issue to take up or leave behind, for fear of being seen too ‘whingeing’.

It all adds up to a mental health consumer movement that, she says, remains “decades behind” other rights movements in being granted a strong voice.

That’s in part, perhaps, because people with mental health issues are still “perceived as mad… and potentially dangerous”, she said – illustrating her point with a range of media images, from the Teen Wolf TV series to health warnings about the dangers of ice.

But it is also because of a “profound lack of understanding about our experience”.

“People have to know that this system hurts at least as many people as it might help… that we violate people’s rights on a daily basis in thousands of different ways.”

That’s not done with malevolence by the people who work in the system, she said, but often by good people with good intent, which “makes it a bit harder for those people though to hear the message that their work is doing harm”.

“Some people struggle with the word ‘oppression’ but we have some of the greatest, most wide-reaching rights violations,” she said, showing a slide describing how more than half of the 20 rights spelt out in the Victorian Charter of Human Rights and Responsibilities are breached regularly in mental health treatment.
“We don’t just struggle for loss of liberty, we can potentially lose our thoughts, the ability to think, to feel emotions... potentially lose memories, our possessions, our friends,” she said.

“It is no small thing we struggle with.”

Watch this interview

See her slideshow here. And read her writing: The blog that shouldn’t be written.

More tweet reports
You can track Croakey's coverage of the conference here.

Mental health services are causing trauma, rather than healing.

@IndigoDaya talking about her experiences working to influence the system: how do things change when you're on the inside? #VMIACConf17

Important words from @IndigoDaya on how mental health consumers, others have to revisit trauma on daily basis in their work #VMIACConf17
You can track Croakey’s coverage of the conference here.

Mental health consumers so often have to ‘pick their battles’, not raise some issues so not seen as “whinging”, worse when solo.

#VMIACConf17

“If you don’t have a seat at the table, you’re probably on the menu”. But tensions too to being ‘on inside’: @IndigoDaya

#VMIACConf17

Mental health services are causing trauma, rather than healing.
“It is because I find some of my work upsetting that I am good at it” – and other reflections from a consumer peer support worker

Hamilton Kennedy has spent about three months in total as a patient in psychiatric hospitals, where he witnessed and experienced seclusion, forced medication, restraint and humiliation, including being crash-tackled to the floor by security and strapped into a wheelchair.

He now works as a consumer peer support worker in a youth psychiatric inpatient hospital in Melbourne, where he often has to relive his experiences of being an involuntary patient.

Seeing others in pain and distress has triggered significant re-trauma for him, and he told the recent Victorian Mental Illness Awareness Council (VMIAC) conference that for a while he thought he might have to shut down his emotions to cope or find a new job.

Kennedy’s standout presentation sparked quiet tears and deep discussions about how mental health consumers can channel the hurt and anger they feel in peer work – and that they often feel forced to disguise in order to present as “professional” – in a mental health system that uses practices like seclusion and restraint that he says are “tantamount to torture”.

Calling for more support for consumer peer support workers
Read an edited version of Kennedy’s presentation below, and watch his video interview with Croakey, in which he says:

- *We need more consumers in the workforce to create systemic change... I don’t think the Director of VicHealth is going to suddenly change everything.*
- *I think it’s going to be the ‘lowly’ consumers who are going to cause a ruckus, rattle the cages, or be mad or sad in the workplace that’s going to create a culture of change."

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**Hamilton Kennedy writes:**

I’m a 23-year-old dual diagnosis, consumer peer support worker in a youth psychiatric inpatient hospital.

I have a hell of a time at work, essentially reliving what it was like to be an involuntary mental health patient. I have spent approximately three months in and out of psychiatric hospitals. An experience where every day was almost the same. An experience where I was witness to and experienced seclusion, forced medication, restraint, and humiliation.

Today, I go to work and see it all over again.

Working in an inpatient unit is hard. Clinicians and consumers alike are aware of this.

Clinicians witness the struggles and despair of those who have been admitted and can be targets of frustration and misguided aggression. In fact, I have experienced extreme aggression and threats as a clinician. This is awful, and in no way do I wish to diminish the distress this can cause. But clinicians are positioned to create a certain amount of emotional distance by virtue of their training.

This is different as a peer worker on an inpatient unit. The emotional distance is hopefully and ought to be far less, and we have often been subject to the very same treatment we witness.

I recall, at 18, being strapped to a wheelchair in an inpatient unit, deemed to be at significant risk of absconding or aggression and violence to those who were transporting me. I remember the feel of the leather on my arms. It was humiliating. I don’t enjoy sitting in leather chairs anymore.

I recall being crash-tackled and carried out of the room by two brutes, holding me by each arm. I remember this specifically because, afterward, I felt my mental health significantly deteriorate. I thought I was supposed to be somewhere that helped with my mental health. This sure didn’t.

Something else that sticks in my mind is witnessing a woman, not that much older than me, being thrown to the floor as she screamed and cried about not being able to see her children. I’m not sure why this sticks with me, perhaps because it was so clear that her emotional distress was met with force.

I’ve seen some shit during my admissions.

**My work is retraumatising**

I work in Victoria, which has the **highest use of mechanical and physical restraint** in Australia. I also work in a ward which serves people aged 15-25, which, excluding forensic inpatient wards, have the highest rates of physical and mechanical restraint. I’ve seen some shit here too. More, in fact.
I watched a 17-year-old girl, who I cared about deeply, have six people pin her to the ground. The more attention that the situation drew, the more she tried to get out of it.

For some serendipitous reason, a childhood friend of mine from Sydney ended up at the ward I work in. I watched her dragged off by staff to a secluded area as she wailed in response to being told she was not to be discharged that day.

I don’t mention these examples for us to merely ogle at them but because they affected me in deep ways, triggering memories, physical sensations and flashbacks. However, dramatic it may be to say, they inspired terror. I was near mute for the rest of the day, playing over what I had just seen in my head. Remembering the entire time that this, in fact, had happened to me. It made me hyper-vigilant, I closed emotionally. I felt untrusting and unsafe around people. I felt re-traumatised.

My work is re-traumatising. It hurts. I see the misery I once felt and still sometimes feel. I see the lack of connection to consensus reality which I too know.

I essentially have a paid position to passively re-experience the darkest times in my life. I frequently have nightmares about being misidentified as a patient and being secluded. I tremble, get tunnel vision and dissociate at the mere presence of hospital security.

Use the trauma

I started to think this would cause me to ‘burn out’, become ineffective in my work or that my mental health would deteriorate. I was nearly convinced that I could not do this work any longer unless I suppressed and ignored the hurt I had experienced as an inpatient.

This was until I reflected upon previous traumas, and my initial experience of inpatient treatment. I thought, ‘Christ, surely there is a better way to treat me and those like me’.

I could not stand for this to be happening, but without the experience of it, I would not be so damn motivated to stand against it.

I decided I was going to utilise my trauma and the re-traumatising experiences I am subject to.

To some extent, I am allowing myself to have post-traumatic stress disorder, to re-experience trauma in a way that does not end. In the unit, people come and go, but largely it remains the same, a prison of those deemed too difficult for the broader community or for those whose emotional distress becomes too extreme.

Here, I occupy the unique position of straddling both sides of the fence.

It is odd to now say that I cherish the trauma I associate with the public mental health system, but in a way I do.

Firstly, it ensures a genuine emotional connection to people. Sometimes having a ‘mental illness’ isn’t sufficient to truly make me a peer to a person, we often have different belief systems, different backgrounds, and values. But one thing that we can relate on is our experience of how scary and strange an inpatient unit can be.

A constructive nuisance

Few clinicians will concede that having an admission sucks. People come up to me and say, ‘I hate it here, it’s a prison, I don’t feel comfortable’, to which I can say, ‘yeah... I know’. Sometimes I can physically see the change when they realise their emotions are being honoured by someone who also knows them. Walls come down and doors open, we lay our hurt bare with each other.
When this is done, the conversations we can have can be truly transformative. I learn of secrets, shame, wrongdoings, achievements and triumphs that clinicians could only dream of learning of.

I don't want to merely say to people 'oh yes, hospital is bad', I want it written on my face, I want to scream and bust down the doors too! My trauma and re-trauma means that I will try my best not to be a part of the medical industrial complex, nor endorse a system that exists for social control.

If I identify the work as re-traumatising, it means it brings up old emotions in me, including anger, which I can use. I always try to learn about the consumer's wishes for treatment and their future. My work means I can bring this consumer's voice to the clinical conversations from which they are usually excluded. If someone wants to be discharged, I'll do my damn best to make sure that it is known.

When I'm present as a consumer representative, I bring my anger, dressed up in a nice shirt and pants. Management needs someone nagging them, criticising them and being a constructive nuisance. As consumers, our voice needs to be heard, and if they aren't listening, well we've got to say it louder.

**Post-traumatic growth**

It was upsetting to see a childhood friend mistreated during their admission. Then it dawned on me. Everyone who is admitted to this ward is someone's friend or family member. That allowed me to deepen my empathy for those I work with. It exposed new possibilities for my practice. It made me better.

Re-traumatising experiences enable me to have what has been described as 'post-traumatic growth', a positive psychological change or higher level of functioning.

I truly believe that both my past and ongoing traumatic experiences benefit my life. This is not to discount the distress I feel, but I am lucky. I have good levels of social support, flexible life arrangements, an understanding of my spirituality, high levels of education and a lack of financial stress. I am privileged and lucky that these things have been afforded to me.

This raises the question though, how can we support other consumer workers who are not so lucky or privileged to grow from difficult experiences in their work?

**We bring a unique set of skills**

Our labour is emotionally intensive and as result deserves fair pay. Consumer workers ought to be paid at the appropriate award level, not employed under another award structure to minimise costs. It’s obvious but people work better when they are paid better.

And I’m sure as hell not getting out of bed to go expose myself to more difficult experiences for some garbage rate of pay. If I know my life will financially improve by my work, there is more likelihood of me doing it well.

There also needs to be more support for us in the workplace. Far too many consumer workers are not able to access lived experience supervision and many cannot access supervision at all.

Further, workplaces need to allow for and value our emotional expression. We bring a unique set of skills. Clinicians are often taught to minimise their emotional responses, I can understand why they may choose to but this does not mean we have to as well. If anything, I want to be able to let my emotions out more at work.
I am yet to meet a consumer worker who feels fully comfortable expressing their emotional responses to situations in their workplace. Maybe if more did, we would be able to achieve better outcomes for those we serve and develop better services.

This is why I believe we need more consumers employed. We are sensitive to others in a way that clinicians will not or cannot be. Let us use our unique connection to the space we work in to motivate us to be the best that we can.

Instead of you helping us, as has been the tale for so long, let us help you.

It is because I find some of my work upsetting that I am good at it.

It is because the work is triggering that I am able to connect with those I serve.

Because it re-traumatises me, I am good at it.

Follow on Twitter: @hamyltonkennedy

Watch this interview
When a mental health unit introduced a peer workforce, what happened next?

Peer worker Jesse Cross and family carer peer worker Melanie Ryan

Marie McInerney reports:

Peer worker supervisor Fiona Burton admits she was “taken aback” by the level of anxiety and hostility among some of her clinical colleagues at an adult mental health inpatient unit when plans were unveiled last year to introduce a peer workforce at Peninsula Health in Victoria.

Because the news came at a time of other changes at the health service, staff were worried that employing peer workers – workers with lived experience of mental illness, either as consumers or carers – might put their own jobs at risk or change existing roles.

But there were other issues that raised concerns about the way mental health professionals can end up thinking and talking about the people in their care, Burton told the recent Victorian Mental Illness Awareness Council (VMIAC) conference.

Some staff were worried about working alongside people who may not be fully “recovered” or that they might have to be “on their best behaviour” in the lunch room where they traditionally could joke or let off steam about patients.

The extent of the resistance could be seen in the roll-up by staff of the Peninsula Health Mental Health Service to education and training sessions prior to the peer workforce commencing.
The sessions were organised by Burton, the unit’s senior social worker, and occupational therapist Rohan De Mel, who were tasked to introduce and supervise the program. They had expected big interest in such a major philosophical and systemic shift to the way they worked.

“No-one came,” Burton said. She told Croakey:

- We’ve been in the service for a very long time, and we assumed that because of the relationships we had with people, they would be open to a new way of doing things.
- We were really quite surprised and taken aback by the level of anxiety and hostility by some people about this new workforce coming.”

Transformation in attitudes

The good news is that attitudes on the unit have completely turned around since, she said, with the peer workers now fully integrated in the team, recognized and respected as their own discipline and getting referrals from all staff.

How that happened was laid out in a joint presentation to the VMIAC conference by Burton and members of the team on the “challenges, learning and successes” of introducing six peer workers to the 29-bed unit at Peninsula Health on the Mornington Peninsula, south of Melbourne.

They described the pilot program, which has now secured ongoing state funding, as an “incredible journey”, with peer worker Jesse Cross detailing how they measure its impact by the heartfelt feedback to him and his colleagues from patients, families and carers:

- “You are only the second person in my life to actually get me”
- “You have changed my life”
- “I appreciate what you wrote in my file, it gave the doctor a better understanding of me”
- “It is inspiring to meet someone who has been through similar struggles and is now successfully employed”
- “It has been great to have support for the whole family.”

A family carer peer worker, Melanie Ryan, said: “We started with a lack of knowledge of peer work, a team that was concerned about how peer work was going to impact on their own roles and anxiety about integrating a new workforce into an inpatient unit.

“We (now) have an incredibly passionate workforce who are committed to providing the best for the people, family and carers they connect with.”

Changing landscape

The experience at Peninsula Health offers insights into the value of peer work in mental health, and also why Australia lags in this area compared to many other nations, the barriers to change, and the unsafe working environments that peer workers often face in mental health services.

As the recent TheMHS conference in Sydney also heard, employing peer workers in mental health is about much more than ensuring their voices are heard; it shakes up the old modes of mental health services that are based on medical management and clinician control.

Burton told the VMIAC conference, it’s not a change that can be introduced half-heartedly.
“It’s paramount that supervisors not only want to be part of the setting up of a peer program but are passionate about changing the mental health landscape and want to challenge the way we have done things in the past,” she said.

The team talked about the many issues that came up through the process, including the risk that peer workers become “inadvertently clinicalised” or that their supervisors “over-react” when a peer worker is facing challenges and think this may relate to a relapse in their mental illness rather than an everyday workplace response.

But the main challenges for Peninsula Health really came before the peer workers stepped onto the ward, Burton said.

In part, she says, this was because the program was announced while there were other unrelated reviews of positions underway.

That added to anxiety and created some resentment, with speculation that lost hours and positions were “funding the employment of the peer workforce”.

“I think you need to have a very stable organisation that’s very clear about what roles are prior to a peer workforce being implemented, so everyone feels very secure in their own positions and they don’t feel like they’re losing something,” she said.

But another big challenge was seeing that stereotypes and stigma about mental health in the general community were also evident in the unit itself, Burton said, showing a slide that declared: “We have forgotten what recovery looks like!”

The lunch room issue

In the early days, clinical staff expressed concerns about ‘ex patients’ being part of the treatment team and participating in clinical handover. “Why on earth would we have people who had been part of service now employed as peers?” was the complaint.

“One of the challenges for staff who work on an inpatient unit is that they support people when they are acutely unwell, and don’t have the opportunity to see a person change their life circumstances and progress further in their recovery,” Burton said.

And then there was the lunch room issue: what sharing it with peer workers might mean for the ways clinical staff have traditionally “debriefed”.

Burton said the unit’s lunch room, “like any lunch room”, is where staff talk about their difficult day, of their challenges on the ward.

Sometimes that involves black humour and language – she says delicately – that “isn’t as recovery and strengths-focused as you would want it”.

“People thought they would have to be on their best behaviour around the peer workers, that they might offend them with their language,” Burton said.

“My view is that if you’re even thinking that you might offend someone with your language, then you’re not using the right language.”
Focus on language

Language is a big focus for the peer program and in the unit, guided by the work of the Intentional Peer Support program in the US and Flourish Australia, that has seen them drop the word “consumer” to describe the people they care for.

Ryan explained the thinking to the conference:

We are individuals who have been brought together, some by choice, some not. We all come with our own stories, experiences that make us who we are. Some of us have had easier paths than others to get here.

We come together and we call each other different things – patient, inpatient, client, consumer, carer, borderline, schizophrenic, nurse, social worker – and we further add to the labels that we have collected along our journey.

Many in the consumer movement for some time have raised concerns about the use of the word “consumer” as it implies choice and suggests that there is a reciprocal contract between those who provide a service and those who use a service.”

Instead, those who use the Peninsula Health service are now simply referred to as “people”.

“By changing the language surrounding mental illness we can begin to promote hope, rather than defining a person, or group of people, by a diagnosis,” Burton said.

As its next step, the unit is looking at the language it uses in handover notes and how that adds to the labelling of people with mental health issues.

Burton showed a slide to illustrate the words and terms – like “helpless” and “hopeless” – that get used as shorthand by health professionals who are working under pressure but which are essentially unhelpful for practice and can be “inflammatory”.

Burton said:

Instead of saying that (someone) is ‘demanding’, we’re saying now to try to look behind the reason why they are being demanding – perhaps that they were distressed because they couldn’t get their phone charged.

We’ve got very good at doing shorthand: it’s in our notes, in our language, in our lunchroom. I think we need to look behind those words, to really understand why the person is acting the way they’re acting.”

Lessons learnt

But, despite all those challenges, Burton said the Peninsula Health team got a lot right with the program, to the point that resistance in the unit to the peer workers turned around very quickly – “after about three months it was like they’d always been there”.

When a mental health unit introduced a peer workforce, what happened next?

#VMIACConf17

Croakey

“Conference News Service”
Having the peer workers based in an office in the unit, rather than being community based, had turned out to be “fundamental” to success, helping them to forge an identity as a “unique discipline within the broader team”.

Another was having a Nursing Unit Manager, Liam Shaw, who backed the two supervisors “100 per cent” and made sure that resources were in place to support the commitment to peer work, including employing another social worker to free up Burton’s supervision time.

She also paid tribute to “some incredible peer workers who worked really hard to develop positive relationships with staff”.

“They are now completely integrated, they’re not seen as separate at all, there’s been no undermining, no negativity,” she said.

“I wouldn’t have thought this possible a year ago.”

See slides below: **What peer workers do**; and **What peer workers don’t do**
“Mad people have a lot to offer in the way we do business in the world” – #VMIACconf17

Marie McInerney reports:

The power of creativity, urge for revolution, rage about stigma and rights, pride that comes from a different way of knowing, and the joy and relief of sharing a safe space with peers.

They were among the key themes and feedback to emerge from the recent Victorian Mental Illness Awareness Council (VMIAC) conference.

This final wrap article features video interviews, snapshots and clips related to presentations, and powerful takeaway messages from a number of delegates/presenters in a VMIAC Vox Pop below, plus final tweets from the conference.

The calls for action include the need to understand the central role of trauma in mental ill-health, the terrible harms people continue to suffer in the name of psychiatric “help”, and the need to “find and honour the unique and diverse authentic voice in each of us.”
Different, larger ways of being

The discussions about freedom, revolution and rights were a standout feature of the conference, Victorian researcher and tertiary educator Cath Roper told Croakey, ahead of hosting a final reflection session.

There was also an emerging sense that there are “different (and) ... larger ways of being in the world” that are “freeing and energising” and counteract pressures to be “normal” or “recovered”, she said.

“I think mad people have a lot to offer in the way we do business in the world, the way we are in the world,” said Roper, who is a consumer academic at the Centre for Psychiatric Nursing at the University of Melbourne.

“Some of the monitoring and surveilling and self-surveilling kind of stuff we do in other areas of our lives, I think there’s too much of that in the world and a lot of people yearn for more freedom, more psychic freedom, more emotional freedom,” she said.

Roper said she was also inspired at the conference by a crest of new people, including peer worker presenter Hamilton Kennedy, who talk about purposefully using their experiences, in ways that are both truthful and courageous – “using hurts and strengths”.

On workforce issues, she told delegates she was struck by discussions about the need for “equity not equality” and to be recognised and paid for “expertise not representation”, and for greater strength of numbers.

“There is a fear of failure that many of us carry in this work, particularly if there are not enough of us,” she said. “We think ‘we’d better not do that or they’ll think we’re mad’. I want to liberate myself from that.”

Watch this interview with Cath Roper below, where she talks about the conference and her latest research into consumer perspectives.
“This stuff is about being human”

Roper opened up the final session of the conference to reflections from the delegates. Here is a selection:

- “I met a family I didn’t know I had. I’m astounded, exhausted, I’ve met amazing people who have been to such dark places and it’s given me hope.”
- “I feel re-energised, I’m so used to banging my head against institutional walls. Let’s get the bulldozers out.”
- “I wish all humans could come and hear and see this. This stuff is about being human.”
- “I feel I am among my brothers and sisters here. It’s truly an inspiration and a blessing.”
- “We pay such a huge price to be consumers. The ultimate price.”
- “Being a consumer and peer worker can be a very lonely journey.”

VMIAC Vox Pop

Q: What message did you most want to get across in your presentation/s?

Vrinda Edan, Consumer Workforce development officer, Mental Health Service, St Vincent’s Hospital

My message from the conference would be that consumers of mental health services are a community with unique perspectives and understandings of our experiences. We have a significant expertise to offer the sector and, if this expertise was taken up by the sector, we would have such a culture shift that our experiences of service use would be very different than what they are today.

Flick Grey, researcher and mental health consultant

There are parts of the human experience that are crucial resources for insight into human suffering, and the human condition, but that we currently tend to shut down or even pathologise – feeling suicidal, self-harm, shame, dissociation, sensitivity and inner voices that we might not be habitually tuned into. I’ve been learning to listen to these parts of myself and have found intense learning, joy, growth, insight and wisdom from this deep listening. And we also need collective listening – those of us who are “canaries in the mine” have much wisdom to share with our communities, but all-too-often, we are shamed and punished and people try to stop our behaviours. We need to listen, and then listen some more!

Heidi Everett, presenter ‘The art of the story’

My message in my presentation is to find and honour the unique and diverse authentic voice in each of us. We are all bonded by the abhorrent public psychiatric service, but our paths that led us there are from very different landscapes. We’re all mostly survivors of developmental-age trauma, not mentally ill people/people with mental illness. Let’s call it for what it is. Let’s demand attention for our strong and proud culture of survivorhood.

We need to feel empowered to think about and reveal our stories. We must expect our stories to be listened to and honoured. We deserve our stories to change things for others.
My message is also one of creative joy. The genuine creative spirit yearns for place to emerge and evolve. If we deny that spark in us, it will find ways to speak up through the miracle of mental illness.

Margaret Saunders, Deadly Thinking

I wanted to present Deadly Thinking so that everyone was aware of the program and what it is about and how it can help everyone with their social and emotional well being. (see snapshot of the program for Aboriginal and Torres Strait Islander people below).

Q: What was your main ‘takeaway’ message from the whole conference?

Vrinda Edan, Consumer Workforce development officer, Mental Health Service St Vincent’s Hospital

My personal takeaway message is that there is still harm being done to us even when we are on the ‘other side’ of the fence; however, I personally struggle with this. The message is not one of needing ‘protection’ but as needing to be included more in decisions and having more leadership opportunities. For instance, there are a number of senior positions in Victoria that have previously had consumers in them and they are now held by clinicians, some saying that they have lived experience even though they have never worked from that perspective, and others that openly say that they have no lived experience. This goes to a deep issue of culture of mental health sector and the credence given consumers and consumer workers.

Flick Grey, researcher and mental health consultant

My main ‘takeaway’ message from the whole conference was that we are an incredibly diverse community, and that diversity can be enriching, if we honour and make space for complexity. In particular, it was beautiful to witness the honoring of elders and major thinkers in our movement, as well as the emerging voices, those working inside the system and those creating vibrant spaces outside the (damaged and damaging) system, those who can stand on stage shaking and vulnerable, and those who think to offer keynote speakers water, a warm shoulder and presence.

Heidi Everett, presenter ‘The art of the story’

My takeaway message from the afternoon I was there (including Cath Roper’s final address) was one of re-couragement.

The year saps advocates’ spirit and courage. I think we all felt a burst of love, and a regeneration of energy to keep going, keep chipping away at the systemic malpractice. Hope for redress, yet work for address.

I would expect that the voice of people with lived experience will have greater power in policy around our public psychiatric wards. We’re currently looking at a roll out of pseudo prisons based on the real fear of violence perpetrated by violent minority who are actually better placed in prisons. People with lived experience of trauma have to live in psych wards with these few people who take a big slice of the $40 million.

What about $40 million towards healing centres for non-violent patients?

Margaret Saunders, Deadly Thinking

The takeaway message for me was that not enough people know and understand the huge impact not addressing your mental health can do and how it affects everyone.
Q: What was the standout presentation/s for you?

**Vrinda Edan, Consumer Workforce development officer, Mental Health Service, St Vincent’s Hospital**

I didn’t get to many because of other commitments, but can’t really go past **Indigo’s**…

**Flick Grey, researcher and mental health consultant**

The standout presentation for me was **Fay Jackson’s keynote** – she spoke from a place of deep pain and strength and wisdom, having just come from the funeral of one of the leaders in our movement (Ed: read this earlier **tribute** at Croakey to Jackie Crowe). It was one of the most human, and humane presentations I’ve ever seen, coming not from any ego or power or defensiveness, but grounded in raw human passion and self-reflection and connection.

**Margaret Saunders, Deadly Thinking**

The presentation from Keir Saltmarsh (see below) at the beginning on the second day.

Q: Where would you most like consumers’ voices to have an impact over the next year or so?

**Vrinda Edan, Consumer Workforce development officer, Mental Health Service St Vincent’s Hospital**

How long is a piece of string?? There is so much work to do, we need more support for consumers to work in academia and research, more consumers working in government, more consumers in leadership roles. But the priority for me is for more understanding of the impact of compulsory treatments on consumers, their lives and health.

I would like the public to be more aware of the difference in life expectancy that is associated with mental health ‘treatments’, for the public to be aware of the impact of trauma, for the public to understand that as a person diagnosed with a mental illness, I am much more likely to be the victim of violence than the perpetrator.

**Flick Grey, researcher and mental health consultant**

I would most like consumer voices to be involved in laying the foundations for a Truth and Reconciliation process in psychiatry, as advocated by UK Professor Mike Slade in his book ‘Personal Recovery and Mental Illness’. So many talks at the conference spoke about the terrible harms people have suffered and continue to suffer in the name of psychiatric “help”.

For me, that has predominantly been being shunned, pathologised and rejected when I am struggling with suicidality – the very system that is meant to be there to support healing has inflicted incredible harms on so many of us. Consumer voices (and bodies and inner voices!) are needed to create the kind of spaces that would lay robust foundation for healing for trauma survivors, communal support and respect for spiritual emergence, a society that honors and respects diverse ways of being, redress for systemic oppression, and all the other things we are grappling with.

**Margaret Saunders, Deadly Thinking**

Having more opportunities for people to share their experiences and personal stories.
Snapshots from the conference

NDIS: The Musical

Not too many musicals feature terms like ‘psychosocial care’, ‘reasonable and permanent supports’ and ‘permanent and/or significant disability’.

But NDIS The Musical: The Elephant in the Room is, unsurprisingly, not your ordinary musical, but should be must-watch entertainment for politicians and policy makers.

Commissioned in 2016 by the Victorian Mental Illness Awareness Council (VMIAC) from Dave Barclay, one of its staffers at the time, it’s been getting rave reviews for its capacity to get across – with joy, humour and rage – major issues with the National Disability Insurance Scheme (NDIS) for people with mental health issues. Barclay told Croakey:

All the progress that has been made in the mental health world is to do with the recovery model and things being based on strengths and hopes and the idea that (mental ill health) is not permanent.

Yet all the legislation around the NDIS is the facts that it’s about functional impairment and permanency and significance and it’s pushing the mental health field back about 20 years ago to a time when asylums were around.”

Have a quick peek below at the opening song, performed at the VMIAC conference in Melbourne.

Watch this interview with Dave Barclay and fellow performer Kayla Hamil.

To book a performance, contact VMIAC.
Deadly thinking

Wiradjuri woman Margaret Saunders presented to the conference about Deadly Thinking: a social, emotional well-being and suicide prevention program specifically designed for Indigenous communities, confronting core social and mental well-being issues in a culturally appropriate, accessible and compelling way.

Watch the much-loved Mary G, Black Queen of the Kimberley, explain the program in this video:

And you can watch Saunders talk about her involvement in the program in this video.

Consumer Man

A video blast from the past from Keir Saltmarsh, one of the keynote speakers and Senior Education and Engagement Officer at Victoria’s Mental Health Complaints Commission.
You can track Croakey's coverage of the conference here.

“Mad people have a lot to offer in the way we do business in the world” – #VMIACconf17

Tweets

Dave Peters @Dpete1977 · Nov 2
Listening to the incredible Cath Roper and strongly relating to the ongoing struggle with Modern Technology... #VMIACConf17

liz dearn @lizdearn · Nov 2
‘The only way the system will improve is by flooding it with peer support workers’, Kier Saltmarsh #vmiacconf17

Flick Grey @flick_grey · Nov 1
NDIS the musical - comedy & song much needed to understand this crazy-making behemoth! Honestly this is a must-see! #NDIS #VMIACCConf17
Warm thanks to
... all who tweeted and shared the news from the conference. The Twitter transcript can be read here, and the analytics below show there were more than six million Twitter impressions, with 225 participants using the hashtag.

The #VMIACConf17 Influencers

The Numbers

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Croakey Conference News Service

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“Mad people have a lot to offer in the way we do business in the world” – #VMIACConf17